HANDBOOK

For Teenagers with ASD/Aspergers, and their Parents

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- Introduction

In this handbook, where I refer to procedures, systems and assistance that is available relating to health, mental health, school/education and government funding, I am referring to the procedures, systems and assistance that is available in Australia, and in some cases, particularly in South Australia.

INTRODUCTION

Note to Teenagers Who Are Reading This Handbook

If your parents have given this handbook to you to read by yourself, OR, if you have decided to read this handbook by yourself, then I ask you to please read this page first.

No two people with Autism Spectrum Disorder (ASD or Autism for short), or what some people call Aspergers, are the same. Therefore:

1. a. If you find that you can relate to most things in this handbook, there is a good chance that you have ASD/Aspergers;

   b. If you find that you can relate to only some things in this handbook, but not others, that is okay. That does not mean that you don’t have ASD/Aspergers;

2. a. You might feel that most things in this handbook are relevant to you;

   b. You might feel that only some things in this handbook are relevant to you, but not others. That is okay. That does not mean that you don’t have ASD/Aspergers.

If you come across anything in this handbook that you find confusing, that you disagree with, or that makes you feel bad in any way (e.g., hurt, angry, worried, upset), please talk to your parents and/or your psychologist (if you have a psychologist) about it. Your parents and/or your psychologist can discuss things with you and explain to you anything that you don’t understand, or need reassurance about.

If you don't have a psychologist, or if your psychologist is not helpful, and if your parents are not helpful, please talk to another adult whom you know and trust, whom you feel safe and comfortable with, and who has been kind and helpful to you before.

If there are any parts of this handbook that you like and/or find helpful, I recommend that you tell your parents. It might help your parents to better understand you.

If you have decided to read this handbook by yourself, and if reading it makes you think that you might have ASD/Aspergers, please tell your parents and/or your psychologist (if you have a psychologist) that you think you might have ASD/Aspergers, and tell them about this handbook and this website.

If you don't have a psychologist, or your psychologist is not helpful, and if your parents are not helpful, please tell another adult whom you know and trust, whom you feel safe and comfortable with, and who has been kind and helpful to you before.

If you come across any words or phrases in this handbook that you don't understand, check the section called "Explanation of Terms", which is at the end of this handbook. That section contains explanations or definitions for many of the words and phrases that are used in this handbook that a teenager with ASD/Aspergers might not understand.

There is no need for you to read the next section of this handbook, which is called “Note to the Parents of Teenagers with ASD/Aspergers”. You can go straight to the section of this handbook called “What is Autism Spectrum Disorder?” and continue reading from there.

Note to the Parents of Teenagers with ASD/Aspergers

I have written this handbook for teenagers who have Autism Spectrum Disorder (ASD or Autism for short), or what some people call Aspergers, and their parents.

Some people with ASD have a combination of ASD traits/symptoms that are less obvious, or not obvious at all, to most people. Many of these sorts of people with ASD often experience particular types of issues that are not very well recognised or understood by many educators, medical professionals, or mental health professionals, let alone the general public.

I personally sometimes like to use the term Aspergers to refer to people with ASD who have a combination of ASD traits/symptoms that are less obvious, or not obvious at all, to most people.

The term ASD covers a very broad a range of issues, difficulties and abilities. Even the term Aspergers covers a broad range of issues, difficulties and abilities. No two people with ASD/Aspergers are the same.

This handbook contains information that is particularly relevant to teenagers who have what I sometimes like to call Aspergers, and their parents. That is why I have chosen to use the term Aspergers, as well as ASD, in this handbook.

I am aware that using the term Aspergers nowadays is somewhat controversial. I explain my use of the term 'Aspergers' in more detail under the section on my website called, "What Do I Mean by "Autism Spectrum Disorder, or What Some People Call Aspergers?"" I hope people will not be offended, or put off from reading my website or Handbook, due to my personal choice to sometimes use the term Aspergers.

Apart from this introduction, I have written this handbook as though I am talking directly to a teenager with ASD/Aspergers. However, I strongly recommend that the parents of teenagers with ASD/Aspergers read this handbook themselves before deciding whether or not to give it to their teenagers. Each person with ASD/Aspergers is different - their parents will know them best, and what they are likely to be able to understand and/or cope with, or not. That way, the parents can decide whether to use this handbook as a guide for themselves to help their teenagers with ASD/Aspergers, or to give it directly to their teenagers, for them to read and work through themselves, seeking guidance from their parents if/when they feel it necessary.

Some parents might feel that only certain sections of this handbook are relevant/appropriate for their teenagers with ASD/Aspergers, and that other sections are not. Parents can choose to only use, and/or give to their teenagers with ASD/Aspergers, those sections of this handbook that they feel are relevant/appropriate for their particular child.

If parents decide to give this handbook directly to their teenagers with ASD/Aspergers to read themselves, I strongly recommend that the parents do the following:

- Before giving this handbook to their teenagers with ASD/Aspergers:
    - Explain to their teenagers that no two people with ASD/Aspergers are the same. Therefore;
        - They might find that they relate to most things in this handbook, OR, only some things, but not others;
        - They might feel that most things in this handbook are relevant to them, OR, only some things, but not others;

    - Tell their teenagers to tell them if they come across anything in this handbook that they find confusing, that they disagree with, or that makes them feel bad in any way (e.g., hurt, angry, worried, upset).
- After their teenagers with ASD/Aspergers have finished reading this handbook, OR, if it takes their teenagers longer than a week to read, at regular intervals during the reading process:
    - Initiate discussion with their teenagers about this handbook, at a time when neither the parents nor the teenagers are busy, distracted, or in a rush, and;
        - Specifically ask their teenagers if they came across anything in this handbook that they found confusing, that they disagreed with, or that made them feel bad in any way (e.g., hurt, angry, worried, upset);
        - Specifically ask their teenagers with ASD/Aspergers if there were any parts of this handbook that they liked and/or found helpful.

That way, the parents can discuss and explain anything that their teenagers with ASD/Aspergers don't understand, or need reassurance about. Such discussions can also help parents to better understand their teenagers with ASD/Aspergers.

I have written this handbook for a number of reasons. One reason is that a lot of people with ASD/Aspergers either do not display symptoms that are obvious to most people, or they display symptoms that suggest there is an issue, but it is not clear to most people what the issue actually is. Unfortunately, a lot of people in these categories go undiagnosed until they are teenagers or older, when they experience such high levels of stress due to the life changes they are going through, that they react in ways that cause people to notice that they are struggling. Even then, it still might not be clear to most people that they are struggling, or that the issue might be ASD/Aspergers, and it can be difficult to obtain the correct diagnosis.

Even once a teenager with ASD/Aspergers is diagnosed, it can be very difficult to work out what sort of support and/or treatment would be most appropriate for that particular teenager with ASD/Aspergers, and then it can also be very difficult to obtain such support and/or treatment. That is another reason why I have written this handbook.

One main type of support/treatment that teenagers with ASD/Aspergers will likely need is regular ongoing psychotherapy with a psychologist who specialises in ASD/Aspergers, to help them to cope with the changes they are going through as they are growing up, to help them understand the world and themselves, and to help them with issues of their sense of identity. They might need ongoing psychotherapy throughout their lives.

For a teenager with ASD/Aspergers to benefit from psychotherapy, they need their parents to find them a good psychologist who specialises in ASD/Aspergers, and whom they feel comfortable with, and they need to be able to continue to see this same psychologist for the long term, as they cannot cope with having to get used to new people on a regular basis. They also might struggle with/hate having to go over the same things with a new psychologist. The psychologist will likely recommend other support and/or treatment options on top of their one-on-one psychotherapy sessions, depending on their patient's individual needs. For example, many teenagers with ASD/Aspergers benefit from attending a social skills group, and/or having an adjusted learning plan for their schooling.

Unfortunately, the sorts of psychologists I have described above tend to be 'private', there are too few of them, and they are in high demand. This means that some people will find it difficult to afford their fees, even with the assistance of a Mental Health Care Plan (MHCP for short). It is not that these psychologists charge unreasonable fees for their expertise. It is just that the Mental Health Care Plan does not cover the full amount of a standard consult, and you will have to pay a gap fee. It also means that these sorts of psychologists have very long waiting lists. Even if you are able to obtain NDIS (which stands for National Disability Insurance Scheme) funding for your child, which should cover the full cost of psychotherapy consults (among other things), you will still have to wait many months for a first appointment with a 'good' psychologist who specialises in ASD/Aspergers.

In the meantime, it is the parents who must support their teenagers with ASD/Aspergers. Even once a teenager with ASD/Aspergers has started seeing an appropriate psychologist, it is still their parents, who they live with, who are helping them on a day-to-day basis. Teenagers with ASD/Aspergers tend to need a lot of emotional and organisational support on a day-to-day basis, together with more explanation and guidance than most teenagers need on how to do many day-to-day tasks. Therefore, the parents of teenagers with ASD/Aspergers need to be able to understand their teenagers, their specific needs, and how best to support them. That is another reason why I have written this handbook, as a starting point, to help parents of teenagers with ASD/Aspergers to be better able to do this.

If you are a parent who has noticed that your teenager is having difficulties, and you are wondering if they might have ASD/Aspergers, reading this handbook can give you an idea of what sorts of symptoms a teenager with ASD/Aspergers might have. However, remember that no two people with ASD/Aspergers are the same, so even if, after reading this handbook, you feel that it does not describe your child, it does not necessarily mean that your child does not have ASD/Aspergers. Depending on the gender of your child, it is a good idea to start by googling either "girls with Aspergers", or "boys with Aspergers". If you do this, and still feel unsure, it is worth googling the opposite gender. You might have a boy with ASD/Aspergers whose traits/symptoms are more like those described under “girls with Aspergers”, or vice versa.

If you think there’s a chance that your child might have ASD/Aspergers, I highly recommend that you seek a diagnosis (*see my website for how to do this)*. If they do have ASD/Aspergers, it is not something that they are going to grow out of. Rather, their difficulties with coping in life are likely to get worse, as they head towards adulthood, and life becomes more and more complicated and stressful for them. The earlier you can get them diagnosed and set up with the appropriate support and/or treatment, the better. With the right support and/or treatment, people with ASD/Aspergers can grow up to be happy in life, and, over time, symptoms that bother them might improve a lot. However, they have to survive adolescence first.

If you seek a diagnosis when your child is younger, but ASD is not diagnosed, do not be afraid to seek a diagnosis again, when your child is a bit older, if you still feel that they are having difficulties. Sometimes it is difficult to obtain a clear diagnosis of ASD when a child is too young, for a variety of reasons *(I mention many of these reasons throughout this handbook)*.

If you have noticed that your child seems a bit ‘odd’ OR ‘unique’, and you suspect that they might have ASD/Aspergers, but they are perfectly happy and coping with life, you might prefer not to seek a diagnosis. However, if your ‘odd’ OR ‘unique’ child is clearly struggling (with learning/schoolwork, and/or social interaction, and/or anxiety or depression, and/or signs of emotional distress), and/OR if they repeatedly say things to you along the lines of, “I don’t understand people,” “I don’t understand things like other people do,” “I don’t understand anything,” (even if this does not fit with your own observations of your child) “I’m not human,” “I’m an alien/magical being,” “I’m not from this world,” (even if you think your child is just joking or speaking figuratively) then please do not hesitate to seek a diagnosis. The sooner your child is diagnosed, the sooner you will be able to obtain the appropriate support/treatment for them, and support for yourselves as parents.

If you think your child might have ASD/Aspergers, and you take them to see a psychologist and/or psychiatrist, and are told that they think your child might be suffering from symptoms of psychosis, please insist that your child is tested for ASD first, before exploring anything else. If you have to take your child to a different psychologist and/or psychiatrist, please do so. Having ASD/Aspergers CAN cause some people to experience symptoms of psychosis. Unfortunately, ASD/Aspergers can sometimes be misdiagnosed as schizophrenia or bi-polar disorder (and probably other serious mental health disorders). If your child goes down the treatment path for these serious mental health disorders, when in actual fact they have undiagnosed ASD/Aspergers, it will be very harmful for your child's mental health.

If you come across a psychologist and/or psychiatrist who is keen to prescribe mood affecting medication to your child (such as antipsychotic and/or antidepressant medication), without first trying non-pharmaceutical support/treatment (such as talking psychotherapy with a psychologist who specialises in ASD/Aspergers), please run for the hills. People with ASD/Aspergers are very sensitive to a lot of things, including medication. If they are given the wrong medication, too high a dose, or are given any medication that they don't actually need, it can be very harmful for their physical and/or mental health.

Some people with ASD/Aspergers do benefit from medication, such as antipsychotic and/or antidepressant medication. However, this should only be prescribed by a psychiatrist who specialises in ASD/Aspergers, and only if non-pharmaceutical support/treatment (such as talking psychotherapy with a psychologist who specialises in ASD/Aspergers) has not been sufficient, and if their symptoms are still very severe.

Further, if a teenager with ASD/Aspergers is prescribed with antipsychotic and/or antidepressant medication, it is vital that they continue to have regular, ongoing sessions with their own psychologist who specialises in ASD/Aspergers, who knows them, and can monitor the effects of the medication upon their mood and thoughts. It can take months before a patient will experience the full effects of such medication. These effects could improve the mood and thoughts of a teenager with ASD/Aspergers, OR could make them feel much worse, and could cause them to be at high risk of attempting suicide.

A person with ASD/Aspergers should not even be referred to a psychiatrist unless extensive psychotherapy with a good psychologist who specialises in ASD/Aspergers has already been tried, and has not been sufficient, and if their symptoms are still very severe. Good psychologists and/or psychiatrists should be very cautious about prescribing antipsychotic and/or antidepressant medication, even to adults, but especially to anyone under the age of 25, as young brains are still developing and react differently to such medication.

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Upon reading this handbook, you might recognise a lot of the traits, symptoms, behaviours and difficulties associated with ASD/Aspergers that I have described, as being traits, symptoms, behaviours and difficulties that you have experienced and/or still do experience yourself.

This might cause you to think, "*I have these traits, symptoms, behaviours and difficulties, but I don't have ASD/Aspergers. Therefore, this handbook must be incorrect. My child/teenager has these traits, symptoms, behaviours and difficulties, but since I have determined that this handbook is incorrect, then my child/teenager must not have ASD/Aspergers*."

If this is the case, I would suggest to you that you probably DO have ASD/Aspergers, but that it has just never been noticed or recognised in you, by yourself, or others, and, therefore, you have never been diagnosed. Many people with ASD/Aspergers have parents who have ASD/Aspergers. However, their parents might never have been diagnosed, because at the time when their parents were growing up, ASD/Aspergers was not as well understood and recognised as it is today.

Your own traits, symptoms, behaviours and difficulties associated with your ASD/Aspergers might affect you differently to how ASD/Aspergers affects your child/teenager. If you have reached this stage of life without being diagnosed, you have no doubt figured out ways to cope in life. The type of environment you grew up in, and the experiences and relationships that you had whilst growing up, might have enabled you to cope. However, current times, i.e., the times in which your child/teenager is growing up, are very different to the times in which you grew up.

You might not need a diagnosis of ASD, nor help to cope with your ASD/Aspergers. **However, your child/teenager might very well need a diagnosis of ASD and help to cope with their ASD/Aspergers**.

WHAT IS AUTISM SPECTRUM DISORDER?

So, you have been diagnosed with Autism Spectrum Disorder (ASD or Autism for short), or are wondering if you might have ASD/Aspergers.

What does that mean? I found the following definition online:

> "**Autism spectrum disorder (ASD) is a complex developmental condition** involving persistent challenges with social communication, restricted interests, and repetitive behavior. While autism is considered a lifelong disorder, **the degree of impairment in functioning because of these challenges varies between individuals with autism**."[i]

Hmm, that is very broad and general. What does it actually mean for you?

The term ASD covers a very wide range of symptoms and abilities/disabilities.

Someone with **very severe ASD** traits/symptoms would likely have some, or all, of the following sorts of problems:

- Need constant support and supervision, even when they are teenagers or adults;
- Be unable to use spoken language. Appear to take no notice of people around them;
- Have a low IQ. *(However, this is controversial. Personally, I wonder how someone's IQ can be measured if they have severe difficulty with communication)*;

- Have motor abnormalities, such as poor timing and coordination of balance, which causes difficulty with running, jumping, and ball throwing. They are usually clumsy, walk slowly or have an unusual way of walking, and have poor handwriting;
- Have repetitive behaviours* which are extreme and uncontrollable. A few examples are violent rocking, head banging, door slamming, moaning; *(*Repetitive behaviour is also called 'stimming'. This handbook contains a section called "Stimming", which explains this topic).*
- Their sensory issues are extreme and they will feel totally overwhelmed when in crowds, amongst noise and bright lights, causing them to react in ways that are very noticeable to other people;
- Suffer from sleeplessness and/or epilepsy and/or gastrointestinal issues;
- They might sometimes try to eat non-food items;
- They might sometimes hit, bite or kick other people (even if the other people are not harming them);
- They might sometimes run away from other people (even if the other people are not harming them).[ii]

The good news is, **you do not have severe ASD** traits/symptoms, otherwise it would have been noticeable from an early age, and you would have been diagnosed much earlier.

If you have ASD, you have a combination of ASD traits/symptoms that are less obvious, or not obvious at all, to most people. I personally sometimes like to use the term Aspergers to refer to people with ASD who are like this.

People with what I sometimes like to call Aspergers might have some of the traits/symptoms that affect people with ‘severe ASD’, but their traits/symptoms will **not be as severe**. For example:

- They usually DO NOT need constant support and supervision once they are teenagers or adults;
- They CAN use spoken language, and might even be able to speak perfectly well (they might just find it extremely difficult to speak in certain situations, when they feel overwhelmed). They DO appear to notice the people around them, but they might find it overwhelming to spend a lot of time interacting with other people;
- They will NOT necessarily have a low IQ. They might even have a very high IQ. However, **the way they process information will usually be different to the way most people process information**;
- They might have motor abnormalities, but these might NOT be severe or obvious (for example, their handwriting might be okay, or even very good, they might be okay at drawing, or even very good at drawing, they might walk normally, and even be a good dancer, and/or be good at certain sports, and/or they might be able to play a musical instrument);
- They DO have repetitive behaviours, but they are not as extreme as someone with severe ASD traits/symptoms, and they can control them for periods of time;
- **They DO have sensory issues, which can cause them significant problems**, but they are not as severe as someone with severe ASD traits/symptoms;
- They DO tend to suffer from sleeplessness and gastrointestinal issues;
- They are less likely to try to eat non-food items than someone with severe ASD traits/symptoms;

- Some might sometimes hit, kick, or push other people, when they feel very distressed, angry or frustrated, and/or feel cornered, but they are less likely than someone with severe ASD traits/symptoms to do this when the other people are not harming them;
- They are less likely than someone with severe ASD traits/symptoms to run away from other people when the other people are not harming them.

Although you do not have severe ASD traits/symptoms, if you have what I sometimes like to call Aspergers, it does cause you significant difficulty and should not be made light of. **People with Aspergers DO have to deal with extra difficulties that not everyone has to deal with**. In some ways, having Aspergers is trickier than having severe ASD traits/symptoms, because it is not as obvious, and other people often don't understand just how difficult it can be. Also, people with Aspergers might not be diagnosed until they are teenagers, or even older, and it can take time for them, their parents and their support people to understand all the ways it affects them, and what sorts of things can be helpful for them, because each person with Aspergers is different.

So let's move on from the broader term of "ASD" and look at what I sometimes like to call Aspergers in more detail, which is more relevant and helpful to you.

WHAT IS ASPERGERS?

‘Autism’ and ‘Aspergers’ both refer to the one same condition, which is now called ‘Autism Spectrum Disorder’ (ASD or Autism for short). I explain this in more detail under the section on my website called, “What Do I Mean by “Autism Spectrum Disorder, or What Some People Call Aspergers?””

I personally sometimes like to use the term Aspergers to refer to people with ASD who have a combination of ASD traits/symptoms that are <u>less</u> obvious, or <u>not</u> obvious at all, to most people.

Aspergers is sometimes mistaken for, or treated as, a psychological condition, but it is NOT a psychological condition. Aspergers is a form of ASD. Therefore, **Aspergers is a neurological condition (some people call it ‘neurobiological’)**.

What is the difference between a psychological condition and a neurological condition?

I googled and found the following:

<u>Psychological condition/disorder:</u>

> “A psychological disorder is a condition characterised by abnormal thoughts, feelings, and behaviors.”[iii]
>
> “Mental disorders (or mental illnesses) are conditions that affect your thinking, feeling, mood, and behaviour. They may be occasional or long-lasting (chronic). They can affect your ability to relate to others and function each day.”[iv]

This does seem to describe some ASD/Aspergers symptoms. However, it DOES NOT describe all ASD/Aspergers symptoms.

Neurological condition/disorder*:

> "The term "neurologic disorder" applies to any condition that is caused by a **dysfunction* in part of the brain** or nervous system, resulting in **physical and/or psychological symptoms**…
>
> …The brain is self-organizing. It selects information to forward its growth and development. It also adapts to the environment. **Experience of the environment through the senses of touch, smell, sight, taste and hearing produces connections in the brain**…
>
> …**Areas that control movement, communication, vision, hearing or thinking can be affected**…
>
> ….Symptoms of neurologic disorders vary. **Physical, cognitive (or thinking), emotional and behavioral symptoms may be present**, with specific disorders having combinations or clusters of these symptoms."[v]

This is quite general, because there are a lot of different neurological conditions. ASD, and therefore, Aspergers, is only one type of neurological condition. However, this DOES account for all ASD/Aspergers symptoms.

ASD is classified as a type of disability*. People with severe ASD traits/symptoms appear to be obviously disabled.

However, **people with what I sometimes like to call Aspergers do not seem to be obviously disabled. The term ‘disabled’ might not seem appropriate for them.**

*(*Some people with ASD/Aspergers do not like the terms ‘disorder’, ‘dysfunction’ or ‘disability’ to describe their ‘condition’. However, the term ‘disability’ needs to be used in order to obtain NDIS funding. Many people with ASD/Aspergers will need to obtain NDIS funding in order to pay for support and/or treatment to help them cope with life).*

These days, having ASD/Aspergers is often described as being ‘neurodivergent’.

Being neurodivergent does not mean that you are any less intelligent than most people. It just means that your brain processes things differently from most people.

People with ASD/Aspergers need to be taught in a way that suits them, so that their brain can process things. However, each person with ASD/Aspergers is different.

People with ASD/Aspergers tend to have their own specific ways of learning, which might not always be provided by ‘mainstream’ teaching methods.

Because of the way their brains process things, people with ASD/Aspergers tend to have the following general symptoms:

- Difficulty with change;
- Sensory issues;
- Stimming (also known as repetitive behaviour);
- Intense interests;
- Social issues (& communication issues);
- Emotional issues (& communication issues);
    - Temper meltdowns;
    - Depression meltdowns;
- Different learning needs(& thought processing & communication issues);
- Eating and stomach issues.

I will go into each of these general symptoms in more detail in the following sections of this handbook.

Because of the stress that having ASD/Aspergers can cause, people with ASD/Aspergers are likely to experience anxiety and/or depression at some point(s) in their lives. Anxiety and depression are psychological conditions, which can be caused by many different things. ASD/Aspergers is a neurological condition, but the difficulties experienced by people who have ASD/Aspergers can cause a great deal of stress, which in turn can cause them to experience the psychological conditions of anxiety and/or depression.

DIFFICULTY WITH CHANGE (& UNCERTAINTY):

People with ASD/Aspergers have great difficulty with change and uncertainty. It causes them to experience a high level of distress and confusion.

Everyone has to go through change and uncertainty at times throughout their lives. It is impossible to completely avoid all change and uncertainty.

Therefore, **people with ASD/Aspergers will have to go through change and uncertainty at times throughout their lives, which will cause them to experience high levels of distress and confusion.**

Currently, and/or recently, you have been going through the following changes and/or uncertainty that everyone goes through:

- Entering puberty is a time of change;
- Starting high school is a time of change;
- Becoming an older adolescent/adult is a time of change and uncertainty.

All of the above stages of life are stressful for most people.

If a teenager with ASD/Aspergers has not been diagnosed, when they express or exhibit signs of stress, other people often assume that they are simply experiencing a level of stress that is normal for most teenagers to experience.

This is one of many reasons why ASD/Aspergers is often not diagnosed earlier.

However, **for someone with ASD/Aspergers, the level of stress caused by change and uncertainty is much more severe, confusing and complex than it is for most people. Even a change or level of uncertainty that is considered minor by most people, can cause a person with ASD/Aspergers to experience a high level of distress and confusion.**

Suggestions for How to Cope with Change and/or Uncertainty:

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents and school understand your difficulty with change and uncertainty. For this reason, it is important that your parents inform your school if you have a diagnosis of ASD.

- People with ASD/Aspergers need time to prepare when changes are about to happen. They need to be forewarned and have the changes explained to them clearly, so that they know what to expect.

- Ideally, people with ASD/Aspergers should avoid trying to go through too many changes at once.

- When people with ASD/Aspergers need to go through a change in their life, they might need to do so gradually,* OR, once they are prepared and ready for the change, they might need to do it without delay, so that they are not spending a long time in an in-between stage, because being in an in-between stage equates to being in a state of uncertainty.

You will most likely need your parents, and/or a psychologist who specialises in ASD/Aspergers, and/or a support person to help you to carry out the above suggestions for how to cope with change and/or uncertainty.

Your parents and your school could help to minimise change and uncertainty in your life. Your parents, and/or psychologist, and/or a support person, could hopefully help you to cope when you do have to go through change and uncertainty.

When you are going through changes and/or uncertainty in your life, it can help to talk about them with your parents, and/or psychologist, and/or a support person. For example, you can:

- Ask them any questions you have about the changes and/or uncertainty;
- Tell them what's worrying you about the changes and/or uncertainty;
- Tell them how you are feeling about the changes and/or uncertainty.

*Although people with ASD/Aspergers tend to have difficulty with change and uncertainty, sometimes, a person with ASD/Aspergers might seem to suddenly decide that they want to do something new. When a person with ASD/Aspergers feels a strong urge to do something, it can be difficult for them to think about anything else, and they might feel very impatient. They might feel the need to start doing it without delay, or they will lose the urge, or the motivation, or the confidence to do it.

In these situations, sometimes a teenager with ASD/Aspergers needs help and guidance (from their parents, and/or psychologist, and/or a support person) to be patient, and to make sure they are ready for, and capable of, undertaking the new thing or change that they want.

However, sometimes they actually ARE ready for, and capable of, undertaking the new thing or change that they want, and it is best to let them do it without delay. Otherwise, they will become very frustrated, and might be put off from doing it at all, even if it is something that would be very positive for them to do. The difference is that they are in control of the change. It is something they have chosen. They might well have been mentally preparing for it for some time, even if they haven't previously mentioned it to other people.

If, on multiple separate occasions, a teenager with ASD/Aspergers finds that they can't, or aren't allowed, to undertake a new thing or change that they want to try, they might start to think that there's no point in trying to undertake <u>any</u> new thing or change that they want to try. They will likely need to be reminded that just because they couldn't, or weren't allowed to, undertake some new things or changes that they wanted to try in the past, doesn't mean that they won't be able, or allowed, to undertake other new things or changes that they want to try in the future.

SENSORY ISSUES:

‘Sensory’ means sights, sounds, smells, tastes and textures/touch.

It is normal for people to have certain sights, sounds, smells, tastes and textures that they either like or dislike, and others that they neither like nor dislike.

However, **people with ASD/Aspergers are more sensitive to certain things than most people**. (But they can also be less sensitive to certain things than most people).

Also, most people have an awareness of their own body in space. This is called proprioception. **Some people with ASD/Aspergers have less awareness of their body in space than most people do**. This might cause them do things like trip, bump into things (including other people) and stand in inappropriate places, more often than most people do. When a person with ASD/Aspergers does these sorts of things, other people often think that the person with ASD/Apsergers is simply clumsy. However, such ‘clumsiness’ is actually due to their sensory issues.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

Sensory Triggers:

People with ASD/Aspergers will have certain sights, sounds, smells, tastes and textures that they absolutely CANNOT STAND. These are called sensory triggers. When a person with ASD/Aspergers experiences a sensory trigger, it can make them feel one, some, or all, of the following sorts of symptoms:

- Physical pain;
- Nausea;
- Dizziness;
- Confusion;
- Extreme irritation/anger. They might lose control of their reactions, causing them to shout and swear at other people, or even hit, kick or throw things at other people, or damage property;
- OR they might withdraw into themselves. They might find it very difficult to speak;
- They might be unable to concentrate on anything whilst experiencing the negative sensory trigger, OR find it very difficult to concentrate;
- They might just want to get away from the sensory trigger as fast as they can;
- They might need to stim *(this handbook contains a section called "Stimming", which explains this topic)*.

When a person with ASD/Aspergers reacts to experiencing a sensory trigger, sometimes their reaction is noticeable to other people. However, if the other people don't know that the person has ASD/Aspergers, they often don't understand WHY the person with ASD/Aspergers is acting in that way. This can cause other people to misinterpret the behaviour of the person with ASD/Aspergers. For example:

- If a person with ASD/Aspergers reacts to experiencing a sensory trigger by shouting and swearing at other people, or hitting, kicking or throwing things at other people, or damaging property, other people might think that the person with ASD/Aspergers is simply behaving badly for no good reason;

- If a person with ASD/Aspergers reacts to experiencing a sensory trigger by not being able to speak when spoken to, or by suddenly running or walking away from someone who is talking to them, other people might think that the person with ASD/Aspergers is simply being rude for no good reason;

- If a person with ASD/Aspergers reacts to experiencing a sensory trigger by being unable to concentrate on a conversation, or on their schoolwork, other people might think that the person with ASD/Aspergers is less intelligent than they actually are, or that they are not even trying to concentrate.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

However, when some people with ASD/Aspergers react to experiencing sensory triggers, their reactions are NOT very noticeable to other people.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

What are your negative sensory triggers?

I have listed some examples of sensory triggers below. It might be that some, or all, of these are sensory triggers for you. It might be that none of these are sensory triggers for you. Your sensory triggers might be different to those listed below.

Start your own list of sensory triggers on the lines below. If you are unsure, ask your parents to help you, based on what they have observed, or on what they remember you telling them in the past. Over time, some negative sensory triggers might not bother you so much, but you also might develop new ones. If this happens, you can add to your list or amend it.

SIGHTS

<u>Examples of Sensory Triggers (SIGHTS):</u>

- Bright lights, and/or flickering lights, and/or particular colours of lights (e.g., you might cope with yellow lights, but not white lights);
- Seeing too many objects all at once (e.g., at a supermarket or department store, or at a busy shopping centre);
- Seeing too much motion around you (e.g., at school, at a busy shopping centre, or at a big social gathering);
- The visual appearance of certain movies, or scenes in certain movies;
- Oversized objects;
- Miniature objects;
- Certain colours;
- Certain people's faces.

<u>Your Sensory Triggers List (SIGHTS):</u>

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SOUNDS

<u>Examples of Sensory Triggers (SOUNDS):</u>

- Noisy crowds;
- Live audience cheering on TV, especially if they whoop or whistle;
- Rustling noises (like plastic bags);
- Wind or rain;
- Traffic;
- Sirens/alarms;
- Power tools;
- Fireworks;
- Certain music;
- Yelling/arguing;
- Certain people’s voices;
- Babies crying.

<u>Your Sensory Triggers List (SOUNDS):</u>

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SMELLS

Examples of Sensory Triggers (SMELLS):

- It can be any sort of smell.

Your Sensory Triggers List (SMELLS):

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TASTES

Examples of Sensory Triggers (TASTES):

- It can be any sort of taste.

Your Sensory Triggers List (TASTES):

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TEXTURES/TOUCH

<u>Examples of Sensory Triggers (TEXTURES/TOUCH):</u>

- The feel of certain food in your mouth;
- Uncomfortable clothing (including clothing labels), certain fabrics;
- Heat OR cold;
- Wind;
- Fan blowing right in your face;
- Certain surfaces, e.g., sand;
- Having dirty or sticky hands;
- People standing too close to you/feeling cornered;
- Physical affection (you might like certain types of physical affection, but not others).

<u>Your Sensory Triggers List (TEXTURES/TOUCH):</u>

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Sensory Buzzers:

However, being extra sensitive is not all bad. **People with ASD/Aspergers will have certain sights, sounds, smells, tastes and textures that they REALLY SUPER ENJOY**. I will call these ‘sensory buzzers’. When a person with ASD/Aspergers experiences a sensory buzzer, it can make them feel:

- Excited;
- Happy;
- Calm;
- Relaxed;
- Blissful.

What are your positive sensory buzzers?

I have listed some examples of sensory buzzers below. It might be that some, or all, of these are sensory buzzers for you. It might be that none of these are sensory buzzers for you. Your sensory buzzers might be different to those listed below.

Start your own list of sensory buzzers on the lines below. If you are unsure, ask your parents to help you, based on what they have observed, or on what they remember you telling them in the past. Over time, some of your sensory buzzers might change. If this happens, you can add to your list or amend it.

SIGHTS

<u>Examples of Sensory Buzzers (SIGHTS):</u>

- Certain colours, including only eating food that is a certain colour;
- Certain shapes or patterns (or lack of pattern);
- Animals/natural environment (or just certain animals, or certain aspects of the natural environment);
- Certain types of light, including the light at certain times of day;
- Fairy lights;
- Certain movies/TV shows (maybe cute and/or dramatic, visually);
- Certain fashion (maybe cute and/or dramatic, visually);
- Certain hairstyles;
- Certain people, or facial features.

<u>Your Sensory Buzzers List (SIGHTS):</u>

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SOUNDS

Examples of Sensory Buzzers (SOUNDS):

- Background noise (e.g., TV or fan);
- Certain sounds in nature, such as birdsong, rain, wind, water;
- Certain music;
- Certain rhythms;
- Drumming finger nails on a hard surface;
- Tapping or sliding feet on certain surfaces;
- 'Swishy' sounds;
- Certain people's voices;
- The sound of certain words;
- OR silence.

Your Sensory Buzzers List (SOUNDS):

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SMELLS

__Examples of Sensory Buzzers (SMELLS):__

- It can be any sort of smell.

__Your Sensory Buzzers List (SMELLS):__

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TASTES

__Examples of Sensory Buzzers (TASTES):__

- It can be any sort of taste.

__Your Sensory Buzzers List (TASTES):__

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TEXTURES/TOUCH

<u>Examples of Sensory Buzzers (TEXTURES/TOUCH):</u>

- The feel of soft food/certain food in your mouth;
- Comfortable clothing, certain fabrics;
- Heat OR cold;
- Hot water bottle;
- Having a bath;
- Swimming;
- Patting pets’ fur;
- Brushing or playing with someone’s hair, or having your own hair brushed or played with;
- Play dough;
- Going for drives (i.e., the motion);
- Being in a small space (e.g., under a bed).

<u>Your Sensory Buzzers List (TEXTURES/TOUCH):</u>

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Each person with ASD/Aspergers is different. **What might be a sensory buzzer for one person, might be a sensory trigger for another.**

Suggestions for How to Cope with Sensory Triggers:

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents and school understand your sensory needs. For this reason, it is important that your parents inform your school if you have a diagnosis of ASD.

It can be helpful to make lists of your own specific sensory triggers and buzzers, like the ones on the preceding pages, so that both you and your parents can use them to help you to work out what sorts of things to avoid (sensory triggers), and what sorts of things can help you to feel calm and/or happy (sensory buzzers). It can also be helpful for your parents to inform your school and teachers of your specific sensory needs.

You can use your sensory buzzers to help you cope with your sensory triggers.

Try to avoid sensory triggers where possible. In your own home, and especially in your own bedroom, you can eliminate a lot of sensory triggers, and surround yourself with sensory buzzers.

If you have been diagnosed with ASD, your school might be able to make some adjustments to your schooling experience to lessen sensory triggers, to help you to cope.

If you experience a sensory trigger when you are with friends or family members who know you have ASD/Aspergers, it is okay to say to them something like:

> "I'm sorry, but I just can't cope with that noise (or sight, or smell, etc). Can you please stop making that noise (or sight, or smell, etc). Otherwise, I will have to leave."
>
> OR
>
> "I'm sorry, but I just can't cope with that taste (or texture, or smell, etc). I cannot eat that."
>
> OR
>
> "I'm sorry, but I just can't cope with the noise (or sight, or smell, or texture) in this place. I will have to leave."

You might not always feel comfortable to say the above sorts of phrases out loud, even to family and friends. It can help if you have someone with you, whom you trust and feel comfortable with, who you can say these things to, and they can say them to other people on your behalf.

If you experience a sensory trigger at school (and if you have been diagnosed with ASD, and your school has been informed), you can say the above sorts of phrases to teachers at your school.

You can also say the above sorts of phrases to strangers, if necessary, and explain that you have ASD/Aspergers. However, you might not always feel comfortable to do so, or to even have someone whom you trust and feel comfortable with, say them to strangers for you.

Even if you or someone whom you trust and feel comfortable with, say the above sorts of phrases when you experience a sensory trigger, some people just won't understand and won't adjust their behaviour to enable you to cope. In those situations, OR if you just don't feel comfortable saying the above sorts of phrases, or to even have someone whom you trust and feel comfortable with, say them for you, <u>it is okay for you to simply leave the situation</u> without any explanation.

Don't worry about <u>appearing</u> rude. You are NOT <u>actually</u> being rude.

If you have been diagnosed with ASD, and your school has been informed, your teachers at school should understand. If you get told off at school for walking away from a sensory trigger, tell your parent(s). The teachers at your school should <u>not</u> tell you off for this. However, sometimes teachers might forget about one, or some, of your sensory triggers, and your parents might need to remind them.

If you find yourself in a situation that you can't cope with, and you feel that other people are pressuring you to stay in that situation, <u>you don't have to give in to them</u>. They don't understand how difficult it is for you, or how long it will take you to recover from experiencing an overload of sensory triggers.

If you need or want to do something, but you know it will involve your sensory triggers (like going to the shops, going out for a walk, going to school, or some other activity where there might be a lot of people, and therefore a lot of sights, sounds, smells and movement), find ways to lessen the effect of the sensory triggers. For example:

- Wear comfortable clothing and shoes, which are suitable for the particular activity and/or environment;

- Wear sunglasses to lessen the effects of what you see;

- Wear earplugs to lessen the noise;

- Try to go at a time when there will be less people around (if possible);

- Go to smaller shops rather than large ones;

- Take some ‘sensory buzzers’ with you, such as:
    - A nice smelling perfume or soap in your bag;
    - A nice feeling bit of fabric in your bag, or a stress ball if you like the feel of it;
    - Music on your phone and headphones to listen to it.

    If you are feeling overwhelmed whilst out and about, take a moment to smell your nice perfume or soap, feel the nice fabric in your bag, squeeze your stress ball, or listen to your nice music. You can do one, some, or all of these things, or you might have a different sensory buzzer that you prefer to use.

- Go for walks at dusk if you find it too bright during the day (but don’t go for walks alone once it gets completely dark at night);

- Plan to not spend too long doing an activity that will involve sensory triggers, or else take breaks during the activity. If you are doing an activity in an environment that involves sensory triggers, leave the activity early, if necessary.

After experiencing a sensory trigger, or sensory overload, even if the trigger or overload was only for a short period of time, you will usually need some down time to recover. You might need to relax by yourself in a safe, private, quiet space, where you feel safe and comfortable.

If you are at home when you experience the sensory trigger or overload, this might be your bedroom.

If you are at school when you experience the sensory trigger or overload, this might be a special room that your school has allocated for this purpose. Most schools should have such a space, but if they don't, if you have been diagnosed with ASD, and your school has been informed, your parents can ask your school to provide such a space.

If you are not at home, or at school, when you experience the sensory trigger or overload, you might have to look for a suitable space nearby.

Once you are in a safe, private, quiet space, you might need, or want, to use one, or some, of your sensory buzzers, and/or to stim, and/or to engage in one, or some, of your intense interests, to help you to relax. *(This handbook contains sections called "Stimming" and "Intense Interests", which explain these topics)*.

If you have been out and about amongst sensory triggers for an extended period of time, such as being at school for the day, or even spending a day out doing something you enjoy, you might need a longer period of down time to recover. When you get home, it might take you the rest of the day to recover. That is okay. After an event that involves a particularly intense, and/or long exposure to sensory triggers, you might need a whole day or two of down time to recover. Again, that is okay.

If you are feeling negative emotions (e.g., irritated, angry or teary) as a result of a sensory trigger, you might need to release your emotions by doing something like:

- Punching a punching bag;
- Screaming into a pillow;
- Ripping up paper;
- Hugging a teddy bear.

I have done a separate section in this handbook called “Emotional Issues”, as it is a complex issue, where I list more suggestions of how to express/release negative emotions in a healthy way.

Eating & Stomach Sensations:

If you have ASD/Aspergers, it can get tricky when it comes to food, because you do need to eat nutritious food to stay healthy, feel well and have energy. **Due to sensory issues, it can be difficult for people with ASD/Aspergers to find a balance of foods that they like/can cope with, and that also provide adequate nutrition.**

It is normal to feel full or even a bit bloated after eating. This is the body's way of letting you know when you have eaten enough. It is normal for your stomach to feel empty/hungry when you haven't eaten for a while. This is the body's way of letting you know when you need to eat.

Due to sensory issues, some people with ASD/Aspergers might sometimes (or often) find that the sensations of feeling either full (or bloated) or empty (or hungry) bother them more than they bother most people.

OR some people with ASD/Aspergers might not always notice such symptoms as much as other people do, so they might not immediately realise when they need to eat or stop eating.

If you have ASD/Aspergers, you might need to create a suitable eating schedule, which you can follow, to make sure you eat enough foods that provide adequate nutrition, and to avoid getting too full or too hungry. You might need help from your parents and/or a support person to do this. Or, you might need your parents and/or a support person to remind you to eat (and to eat enough foods that provide adequate nutrition), or to stop eating.

Many people with ASD/Aspergers like using schedules. However, some people with ASD/Aspergers find the idea of having a timetable/schedule to be stressful (like my daughter), because it can make them feel that there is a lot of pressure on them to do certain tasks/activities at certain times, and within a certain timeframe.

Please don’t be put off by this. If you, and/or your parents, and/or a support person create a schedule to make sure you eat enough foods that provide adequate nutrition, and to avoid getting too full or too hungry, you don’t have to strictly follow it all the time. It has been created as a guide only, to help you.

I have done a separate section in this handbook called “Eating and Stomach Issues”, as it is a complex issue.

Body Sensations When Sick:

It is normal for people to feel well most of the time.

However, it is also normal for people to get sick occasionally.

Everyone will catch a cold, flu virus, or stomach virus occasionally. When that happens, sometimes people just need to rest at home and they will recover in a few days, or a couple of weeks. If they are feeling particularly unwell, or it is taking them more than a couple of weeks to recover, they might need to see a doctor and get some medication to help them recover.

It is also normal for people to sometimes not feel 100% well for very short periods of time (a few hours, or a day or two), without it meaning that they are actually sick. By this I mean that it is normal to experience minor irritations, such as:

- A minor headache (this might just mean you need to drink more water and less caffeine, and to get more sleep);
- Muscle aches and pains (this might just mean your muscles are tired from exercising, or you might have been sitting or sleeping for too long in an odd position);
- Feeling a bit bloated or nauseous (this might just mean you have eaten too much, or eaten something that is difficult for your body to digest).

The above sorts of symptoms should come and go quickly. If they persist for more than a couple of days, then you might actually be sick.

Some people with ASD/Aspergers might find it more difficult than most people to cope with some of the symptoms of sickness, or even minor irritations, due to their sensory issues.

AND/OR some people with ASD/Aspergers might not always notice some such symptoms as much as other people do, so they might not immediately realise when they are actually sick.

AND/OR many people with ASD/Aspergers sometimes, or often, experience symptoms of sickness in response to a sensory trigger, overload, or stress, and what they really need is down time, rest, and calming sensory buzzers to help them recover.

AND/OR many people with ASD/Aspergers might sometimes, or often, find it difficult to ‘verbally express’ (i.e., say out loud) their symptoms in a way that enables other people to easily understand just how sick they actually are. **They might not be using the tone of voice, or showing the facial expression or body language that most people would expect of someone who is feeling very ill.**

It can be very difficult to distinguish between each of these different scenarios, for the person with ASD/Aspergers themselves, for their parents, and even for their medical support people.

Young children are expected to have difficulty expressing their symptoms of sickness, so parents and medical support people automatically take these sorts of things into consideration when dealing with young children. Teenagers are usually expected to be able to express their symptoms of sickness. However, teenagers with ASD/Aspergers often have difficulty with this, for the reasons I’ve just explained above.

People with ASD/Aspergers, and especially teenagers with ASD/Aspergers, need their parents, doctors, and support people to be aware of these issues.

When a teenager with ASD/Aspergers complains of feeling unwell or in pain, they need their parents, and/or doctors, and/or support people to talk through their symptoms with them, to try to work out if they are sick with an illness or injury, if they are experiencing a heightened reaction to what would be a minor irritation for most people, or if they are feeling sick or in pain due to sensory triggers, overload or stress. They then need support and/or advice on how to treat and/or cope with whatever it is they are experiencing.

People with ASD/Aspergers can also be extra sensitive to medication.

> "Autistic people need lower doses of drugs and supplements as our bodies are too sensitive. Some cannot even take a multivitamin without becoming sick."[vi]

When prescribing medication to a patient who has ASD/Aspergers, doctors should consider how that medication could affect their patient with ASD/Aspergers, and bear in mind that they might need a smaller dose than most people.

STIMMING (ALSO KNOWN AS REPETITIVE BEHAVIOUR):

People with ASD/Aspergers do something called stimming. **Stimming is also called 'repetitive behaviour'**.

Not all people with ASD/Aspergers have the same stimming behaviours. Each person with ASD/Aspergers might have one, or a few, or many different stimming behaviours, which they do/use from time to time.

It is called 'repetitive behaviour', because each time they feel the need/urge to stim, people with ASD/Aspergers tend to use one or more of their particular repertoire of stimming behaviours, i.e., it is a repeat of the same stimming behaviour they have done/used before. On each occasion that they stim, they tend to do that particular behaviour repetitively, i.e., over and over. They might like to do the stimming behaviour a certain number of times, each time they do it.

So what is stimming?

> "Stimming is short for self-stimulatory behavior, but that's not exactly what it is. Stimming is simply something we do to soothe ourselves when we are upset, anxious, overloaded, or in pain; to release unpleasant feelings or energy."[vii]

However, people with ASD/Aspergers also often stim in relation to positive feelings, not just negative ones. In fact, people with ASD/Aspergers stim in response to various things, such as:

- **Sensory issues:**
  - To soothe or distract themselves if they are experiencing a sensory trigger, or if their senses are overloaded;
  - To express joy/release energy, if they are experiencing a sensory buzzer and feel very excited.
- **Social and emotional issues:**
  - To soothe or distract themselves if they're feeling anxious or overwhelmed, because, for example:
    - They're at an appointment, or are taking part in some other form of social interaction that makes them feel stressed;
    - They're taking a test, or they have homework due;
    - They know any of these activities are coming up soon.
  - If they're feeling excited. Sometimes when my daughter was reading on her phone, and got to a part that she was excited about, she had to run up and down the hall listening to music on her headphones.
  - They might also stim in response to other emotions, such as anger, sadness, loneliness, or happiness.

- **Different learning needs/thought processing issues:**
    - To help them to focus and recall something. If I've forgotten why I came into the kitchen, sometimes I click my fingers repetitively. At the same time, I might also say to myself, "Now, what was I going to do?"
    - To help them to tear their mind away from distracting thoughts, and to focus on what they need, or want, to focus on. Although I like writing certain kinds of lists, I HATE writing my weekly shopping list, partly because I find it incredibly boring, and partly because it involves me having to make lots of little decisions, i.e., I have to make a decision about each item I am going to put on the list. Sometimes I find it very hard to get started.

      Firstly, I use a routine to make it easier. I always write my shopping list in the same order, starting with what items I need for breakfast.

      Secondly, I use visual cues. I always start by looking in the cupboard where my breakfast cereal is kept.

      Thirdly, if I'm still having trouble starting my list, I use some of my stims. I will open the cupboard where I keep my breakfast cereal, and I will sing a little song to myself, which goes, "Special K, boom, boom, boom ba dee boom." I might repeat this a few times. I might even click my fingers or clap my hands as well. This will help me to get started on writing my shopping list.
    - To distract themselves from unpleasant thoughts.
- **Boredom.**

What are your stims?

I have listed some examples of stims below. It might be that some, or all, of these are stims for you. It might be that none of these are stims for you. Your stims might be different to those listed below.

Start your own list of stims on the lines below. If you are unsure, ask your parents to help you, based on what they have observed, or on what they remember you telling them in the past. Over time, some of your stims might change. If this happens, you can add to your list or amend it.

Examples of Stims:

- Rocking, swaying, twirling, spinning (yourself or objects), flapping your hands or arms, clapping;
- Pacing, running, walking on your tip toes, tapping your feet, twitching your muscles, dancing, jumping (on ground, or on trampoline), jiggling leg when sitting down, skipping;
- Twiddling thumbs, playing with fingers and/or nails, biting nails, flicking fingers, clicking fingers, drumming fingers on a surface, hand scratching;
- Watching ‘eye floaters’ in your eyes *(I explain what eye floaters are under the section called “Explanation of Terms”, at the end of this handbook)*;
- Blurring your eyes, blinking, twitching your eyebrows;
- Singing;
- Speaking in funny voice;
- Repeating words or phrases;
- Talking to yourself;
- Making certain noises, like humming, whistling, animal noises, grunting, or anything, really;

- Watching your favourite movie or TV show over and over;
- Self-harming CAN be a type of stim. Usually people with ASD/Aspergers only do this if they are on the wrong medication, OR if they are discouraged from doing safe, non-harmful stimming, causing their stress levels build up without release, OR if they are experiencing abuse or bullying, OR some other type of ongoing stress that they feel is never going to end.

<u>Your Stims List:</u>

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When a person with ASD/Aspergers stims, sometimes it looks a bit odd to other people. If the other people don’t know that the person has ASD/Aspergers, they often don’t understand WHY the person with ASD/Aspergers is acting in that way. This can cause other people to misinterpret the behaviour of the person with ASD/Aspergers. For example, when other people see a person with ASD/Aspergers stimming, they might think that the person with ASD/Aspergers is simply being silly, or funny, or fidgety.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

However, some stimming behaviours that are done by some people with ASD/Aspergers are not very noticeable to most other people, or do not look very odd to most other people.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

Suggestions Regarding Stimming:

First of all, do your stimming as much as you need or want (BUT NOT self-harming). It's better to release that emotion/energy, than to let it all build up inside you and cause you to feel unwell or distressed.

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents and school understand your need to stim. For this reason, it is important that your parents inform your school if you have a diagnosis of ASD.

It can be helpful to make a list of your own specific stims, like the one on the preceding page, so that your parents can recognise and understand your stimming behaviours. It can also be helpful for your parents to inform your school of your specific stims list, so that your teachers can recognise and understand your stimming behaviours.

If you feel that your stimming behaviour might look a bit odd to other people, and if you feel self-conscious about that, OR if people make fun of you when you stim in public, and if that makes you feel bad, make sure that you have plenty of time each day when you can go to a safe, private space and stim.

You should be allowed to feel comfortable to stim as much as you need or want in your own home (BUT NOT self-harming), as long as you are not bothering the other members of your household too much.

It can be helpful if your school can provide a safe, private space at school, such as a particular room, where you can go to relax and/or stim for a short period of time in between lessons, and/or at recess or lunch. Most schools should have such a space, but if they don't, if you have been diagnosed with ASD, and your school has been informed, your parents can ask your school to provide such a space.

If you feel a need to stim whilst at school, and if you feel self-conscious about stimming in front of other students, but for some reason you don't feel you can go to the space/room that your school has provided for this purpose, you might need to find a safe, private space at your school where you can go to stim privately at recess and/or lunch, such as:

- A toilet cubicle;

- A space in the school yard or on the school oval, where you are far away from other students, so that other students cannot hear you, and cannot clearly see what you are doing.

If you feel you can't, or don't want to stim at school, some other ways you could try to release emotion/energy at school are:

- Running or walking around the school oval at recess and/or lunch (you could listen to music on your headphones whilst you run or walk, if you like);

- Walking around the school yard at recess and/or lunch (you could listen to music on your headphones whilst you walk, if you like).

  (Running and/or walking, and/or listening to music on headphones are actually stims for some people with ASD/Aspergers. However, these behaviours don't look odd to other people).

You could also try to release some of that emotion/energy before and/or after school, so that you don't feel such a strong need to stim whilst at school. For example, you could try:

- Running or walking on a local public oval (you could listen to music on your headphones whilst you run or walk, if you like);

- Going for a long walk around your local neighbourhood (you could listen to music on your headphones whilst you walk, if you like).

  Some people with ASD/Aspergers have difficulty with directions and easily get lost. If you are like this, you might need to take someone with you, who is good with directions, if you go for a long walk. If you do go for a long walk by yourself, it's a good idea to take your mobile phone, so you can phone your parent(s) if you get lost, or have any other difficulties;

- Going for a bike ride (if you are able to ride a bike safely) around your local neighbourhood;

- Swimming, or some other sport or exercise that you enjoy. If you can only do this sort of activity at a location that is away from your home, you might need your parents to take you there.

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Repeating words or phrases is a form of stimming. Repeating positive phrases can help drive out unpleasant thoughts.

If you are having unpleasant thoughts, try choosing something pleasant to think about and say it out loud, repetitively, such as, “puppies”, or “ice-cream”. Maybe click your fingers or clap your hands as you say it. If you can, and if you want to, try to visualise the puppies or ice-cream as you say the words; try to imagine the feel of the puppies’ fur, and their warmth, or the taste and texture of the ice-cream, and its coolness; try to imagine the sounds and smells associated with the puppies or ice-cream. It doesn’t have to be puppies or ice-cream, just something that you find pleasant.

If you are feeling anxious about something you have to do, or a situation you are in, try repeating to yourself phrases like, “I can do this,” or, “Everything is going to be okay,” even if you don’t really believe it at first. Maybe click your fingers or clap your hands as you are saying these phrases.

If you are in public, and if you feel self-conscious about doing the above sorts of things in front of other people, you could say the above sorts of phrases to yourself, in your mind only (i.e., not out loud). Instead of clicking your fingers or clapping your hands, you could tap your foot/feet, jiggle your leg(s), or tap your hand(s) against your leg. This will not look very odd to most other people

Stimming can help you to do things that you find difficult, or don’t want to do, but that you have to do.

Usually parents and teachers tell children that they must/should do the activities they HAVE to do first, such as chores or homework, then their reward will be to do activities they enjoy, AFTER they have finished, e.g., their chores or homework.

However, teenagers with ASD/Aspergers might have to do the opposite, because if they are constantly thinking of the activity they WANT to do, they will never be able to focus on the activity they HAVE to do. Parents and teachers might have to let them, or even encourage them, to do a stim or activity that they enjoy first, to get their mind focused and happy, and empty of other thoughts. Then they can focus on their homework or chores for short periods, with breaks in between when they can do stims or activities that they enjoy. The sorts of activities I am talking about need to be what some people call ‘mindfulness’ activities, but that I call ‘mindlessness’ activities.

For example, colouring in a picture that has already been drawn, is not very creative. Colouring in following a code of numbers (i.e., painting by numbers), is even less creative. I am not trying to malign these activities. I know that many people enjoy these sorts of activities, and they can be done as ‘mindfulness’ activities. However, I think the more appropriate term would be ‘mindlessness’, because these sorts of activities are done to calm the mind. They are done to help people ‘switch off’ their mind when their thoughts are causing them to feel stressed and/or distracted.

Some of these ‘mindlessness’ activities can be stims for some people with ASD, or they can have a similar effect.

Examples of 'mindlessness' activities:

1. Sudoku puzzles *(I do this myself)*.
2. Crosswords, or other word puzzles *(I do this myself)*.
3. Games on your phone, like Candy Crush (i.e., where you have to match, say, three icons in a row, and each game does not take very long) *(I do this myself).* NOT an in depth, interactive game, where you become an avatar and interact with other avatars, and could be on there for hours, and there is no end to it. NOT a game where you have to create, like Minecraft, where you could be on there for hours, and there is no end to it.
4. Knitting *(I have done this myself in the past)*.
5. Other craft activities, where you are following someone else's pattern. NOT creating your own pattern/design.
6. Colouring in. NOT drawing your own picture.
7. Tipping out a pile of Lego, then sorting the pieces into colour, then size. *(I don't set out to do this myself, but if Lego is tipped out in front of me, I automatically start doing this)*. NOT creating something out of the Lego.
8. Listening to music that you have heard before and know very well, and that you know makes you feel calm and/or happy *(I do this myself)*.
9. Watching movies or TV shows that you have seen before and know very well, and that you know make you feel calm and/or happy *(I do this myself)*.

If you are needing to focus your mind, and empty it of upsetting or distracting thoughts, before doing an activity that you might find stressful, or that requires you to focus and concentrate, spend some time stimming, or doing one or more of the above sorts of ‘mindlessness’ activities FIRST. However, don’t spend all day stimming, or doing the above activities. Do ONE Sudoku puzzle, or ONE crossword, or word puzzle, or ONE game on your phone, or knit, say, five rows, or colour in ONE simple picture. Then spend a short time doing the activity that you might find stressful, or that requires you to focus and concentrate. Then spend some more time stimming, or doing one or more of the above sorts of ‘mindlessness’ activities.

I am not saying that you should never do activities like creating your own craft pattern/design, drawing your own picture, or creating something out of Lego, or that you should never play an in depth, interactive or creative game on your phone, or other electronic device. You definitely <u>should</u> set aside plenty of time on a regular basis to do these sorts of activities, if you enjoy them. Doing these sorts of activities can certainly help you to feel happier, less stressed, and to distract your mind from upsetting thoughts.

However, these sorts of activities will <u>not</u> help you to focus your mind and concentrate on doing something that you HAVE to do, but don’t WANT to do. Rather, you are likely to get completely caught up in doing these sorts of activities for hours, and totally forget about the activity that you HAVE to do, but don’t WANT to do. Therefore, you simply won’t get it done, which could result in negative consequences for you.

If you have difficulty falling asleep at night, just before going to bed, try stimming, or doing some of your ‘mindlessness’ activities. Then, when you get into bed, do activity number 8 and/or 9 in bed, before you try to fall asleep. Or, you might already have some other bedtime routine that works for you.

INTENSE INTERESTS:

Everybody has certain interests, pastimes or hobbies that they enjoy.

People with ASD/Aspergers tend to become very intense about their favourite interests, pastimes or hobbies. **They can become obsessed** with doing their favourite things, learning about their favourite things, thinking about their favourite things, talking about their favourite things, and collecting their favourite things.

Some people with ASD/Aspergers have unusual interests, pastimes or hobbies, especially males with ASD/Aspergers. However, when it comes to females with ASD/Aspergers:

> "…our obsessions do usually fall under the heading of "normal" girlhood things, like books, music, art, and animals. It is the rapacity with which we enjoy them and the passion they inspire in us which is taken to a new level."[viii]

This is another reason why ASD/Aspergers is often not diagnosed earlier (especially in females).

However, males with ASD/Aspergers can have intense interests that are not considered 'unusual' in themselves, and females with ASD/Aspergers can have intense interests that are considered 'unusual' by most people.

What are your intense interests?

I have listed some examples of my daughter's intense interests below, to show that intense interests are not necessarily 'unusual' in themselves. You might have completely different intense interests – they can be anything.

Start your own list of intense interests on the lines below. If you are unsure, ask your parents to help you, based on what they have observed, or on what they remember you telling them in the past. Over time, some of your intense interests might change. If this happens, you can add to your list or amend it. You might only ever have one intense interest, or a small number of intense interests, which stay with you for your whole life.

Examples of Intense Interests:

When my daughter was a young child, some of her intense interests were:

- **Disney princesses, Bratz, and Littlest Pet Shop:**

  She was quite obsessed with collecting and playing with the dolls/toys and watching the movies related to these dolls/toys/characters.

  She talked about them a lot, drew many pictures of them, and wrote stories about them. She was very good at drawing and writing stories.

When my daughter was an older child, some of her intense interests were:

- **Certain Youtube shows and hosts, such as:**
    - Make-up tutorials:

      She collected make-up, and liked to try make-up styles that she had learnt from Youtube, on herself and on me. She was very good at it. She had certain favourite make-up tutorial hosts whom she absolutely loved, and would talk about them a lot.

    - Stampy Longnose:

      He had a Youtube show where viewers could watch him playing Minecraft, whilst he chatted about what he was doing on Minecraft, and also made random, funny, silly, quirky comments about all sorts of things. My daughter played Minecraft herself, but she really loved watching Stampy Longnose play Minecraft, and listening to his commentary. She absolutely loved him, and would talk about him a lot.

    - Ryan Higa;

      He had a Youtube show where he would do all sorts of funny skits, by himself, and with other people. She thought he was incredibly funny.

I think she felt quite ‘attached’ to these Youtube hosts.

- **Clothes:**

  Even when my daughter was a young child, she liked to choose her own clothes, and loved to dress up. Her interest in clothes increased as she became an older child.

  She would spend hours at the shops choosing her clothes. She had to get clothes that looked and felt just right to her. **I believe she was a lot more particular about choosing her clothes than an average child would be**. This was probably partly due to sensory issues, but I believe she was also expressing herself, and trying out different identities. I also think that, in a way, she was collecting clothes.

- Animals.
- Outer space.

When my daughter was a teenager, some of her intense interests were:

- **Movies and TV shows:**

  The genres she especially liked were fantasy, supernatural, science fiction and dystopian. Some of these were quite dark, but she also loved cute and sweet movies and TV shows. She also liked unusual, quirky and rare ones.

  She became very attached to the characters in her favourite movies and TV shows, and talked about them a lot. She liked to collect the DVDs of her favourite movies.

- **Listening to certain music, and watching music videos:**

  Her favourite artists included Lindsay Stirling and certain K-Pop groups, especially EXID and Stray Kids. She talked about them a lot, and **I believe she felt very attached to them**.

- Playing violin.
- Animals.
- The environment.
- Outer space.
- World War 2.

My daughter would watch her favourite movies, TV shows, Youtube shows and music videos over and over. **She liked to research facts** about her favourite actors, Youtube hosts, musical artists and topics on the internet. **She liked to tell me these facts**.

Your Intense Interests List:

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Downside to Intense Interests:

Being obsessed with certain things might not sound very positive, and it can cause some difficulties. When people with ASD/Aspergers are focused on their intense interests, it can be very difficult for them to drag themselves away from what they are doing, and to focus on the more mundane, but necessary, activities of day-to-day life, like eating, sleeping, grooming and household chores. It can also make it hard for them to focus on schoolwork, if the school subject does not fall within an area that interests them.

When a person with ASD/Aspergers finds it very difficult to drag themselves away from engaging in their intense interests to focus on something else, such as chores or schoolwork, or what someone else is saying to them, if other people don't know that the person has ASD/Aspergers, they often don't understand WHY the person with ASD/Aspergers is acting in that way.

This can cause other people to misinterpret the behaviour of the person with ASD/Aspergers. For example, the other people might think that the person with ASD/Aspergers is purposely trying to avoid doing chores or schoolwork, or purposely ignoring what is being said to them. They might not realise just how difficult it can be for the person with ASD/Aspergers to drag themselves away from engaging in their intense interests, and to focus on something else.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

If people with ASD/Aspergers don't get to spend time engaging in their intense interests, they can become stressed and/or depressed.

When a person with ASD/Aspergers becomes stressed and/or depressed due to not being able, or allowed, to engage in their intense interests often enough, for a long enough period of time, or at all, if other people don’t know that the person has ASD/Aspergers, they often don’t understand WHY the person with ASD/Aspergers is stressed and/or depressed.

The intense interests of a person with ASD/Aspergers might not be activities that most other people consider to be useful. Therefore, **other people might not understand just how important it is for the person with ASD/Aspergers to be able to engage in those activities**.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

Upside to Intense Interests:

Having intense interests can give you a sense of purpose and a sense of identity, especially if you have ASD/Aspergers. Engaging in your intense interests is usually very fulfilling, and can give you feelings of great joy and excitement, especially if you have ASD/Aspergers.

Finding, and spending time with other people who have one, some, or all of the same intense interests as you, and engaging in your intense interests together, can be very enjoyable. This can be a good way to make friends.

Also, having intense interests in certain things can enable you to have great focus on those things, and to potentially become very good at, or knowledgeable about, those things. You could use your knowledge and abilities in your areas of intense interest to help or entertain other people, which can be very fulfilling.

Down the track, one of your intense interests could develop into a career path for you, so that, hopefully, you can end up doing a job that you enjoy. You might find a job that you enjoy so much that you want to keep doing that same job forever.

However, you don’t have to stay stuck working in the same job forever, if you don’t want to. You could end up trying different jobs as your interests change over time, if that is what you want to do. **However, it is quite okay to simply enjoy your intense interests, without having to figure out how to turn one or more of them into a job.**

Suggestions Regarding Intense Interests:

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents and school understand your need to engage in your intense interests, how it affects your ability to focus and learn, and how it can affect your mood. For this reason, it is important that your parents inform your school if you have a diagnosis of ASD.

You can use your intense interests to your advantage. If you are feeling bad, spend some time focusing on one or more of your intense interests, and, hopefully, it will cheer you up, and take your mind off whatever was making you feel bad.

You do need to have time each day to let your mind wander and think about whatever you like, and to engage in your intense interests. However, it is a part of life that you do have to spend some time each day focusing on other necessary activities of day-to-day life that you might find mundane, such as eating, sleeping, grooming, chores and schoolwork.

It’s a good idea to set aside small amounts of time each day to do the necessary activities of day-to-day life that you might find mundane, and to also make sure you set aside plenty of time each day to do the things you really enjoy and want to do.

You might need to create a schedule, which you can follow, to remind yourself to do the necessary activities of day-to-day life, but that also allows you plenty of time each day to do the things you really enjoy and want to do. You might need help from your parents and/or a support person to create and follow such a schedule. OR, you might need your parents to remind you to do the necessary activities of day-to-day life, and/or to remind you to spend time doing things that you really enjoy and want to do.

Many people with ASD/Aspergers like using schedules. However, some people with ASD/Aspergers find the idea of having a timetable/schedule to be stressful (like my daughter), because it can make them feel that there is a lot of pressure on them to do certain tasks/activities at certain times, and within a certain timeframe.

Please don’t be put off by this. If you, and/or your parents, and/or a support person create a schedule to remind you to do the necessary activities of day-to-day life, and also to allow time for you to do things that you really enjoy and want to do, you don’t have to strictly follow it all the time. It has been created as a guide only, to help you.

Some people with ASD/Aspergers might never be very good at, or be able to cope with spending much time doing the mundane, but necessary, activities of day-to-day life. They might always need help with these activities from their parents and/or a support person, so they can spend their time doing the things that they enjoy, are good at, and give them purpose, or they can become very stressed and/or depressed.

Intense Interests and Paid Employment:

Most people need and/or want to have a paid job. Anyone who seeks a paid job wants to be able to do a job that they enjoy and are interested in. **However, it is particularly important for people with ASD/Aspergers to work in an area that interests them, otherwise they could find it very difficult, stressful and depressing**.

> "Obsessive activity is an illustration of the incredible focus that we possess…we have to work with our strengths not our deficits…"[ix]

Teenagers and/or young adults with ASD/Aspergers might have great difficulty in figuring out how they can turn one of their intense interests into a paid job. They might not be able to figure out what steps they'd have to take in order to obtain a paid job of any sort.

Many of them will need the assistance of their parents and/or a career counsellor who understands their ASD/Aspergers needs. Many of them will need clear step-by-step instructions on what to do, and they might need a support person to do some of the steps for them, or at least with them. They might take longer than most people to reach a stage where they are ready to undertake a paid job.

They need their parents and support people to encourage them, but to also be patient, and not to push them. They need to do it in their own time, or it can set them back. If a person with ASD/Aspergers is pushed to do something before they are ready, it can cause them to feel a very high level of anxiety. They might not be able to do it well, and/or they might not be able to cope, which can make them feel like a failure, and cause them to completely lose confidence. This will be a bad experience for them, and could put them off ever trying again. If they are able to eventually build up the confidence to try again, it will most likely take them a very long time to get to that point, and they might feel an even greater level of anxiety than they did the first time they tried.

Some people with ASD/Aspergers find it very difficult to obtain a paid job, or to cope with having a paid job. **Many people place great importance on having a paid job and making money,** and they express this attitude very often. **Constantly hearing this sort of attitude expressed by people around them can cause a person with ASD/Aspergers to feel painfully inadequate, if they are unable to obtain or cope with having a paid job.** If this is the case **for a person with ASD/Aspergers, it is EXTREMELY IMPORTANT that they are reassured that they are valuable whether or not they ever have a paid job.**

Intense Interests and Unpaid, but Fulfilling Activities:

There are other activities that a person with ASD/Aspergers can do, besides having a paid job, to use their intense interests, knowledge and/or abilities to feel useful and valuable, either within their family or within the community.

They might need assistance from their parents and/or a support person to figure out what such activities, in particular, would be suitable for them. They might also need assistance from their parents and/or a support person in order to be able to take part in such activities. For example:

- They might need step-by-step instructions and/or supervision to be able to undertake such activities;

- They might need a parent or support person to drive them to and from any such activities, if it is outside of their home;

- They might need a parent or support person to stay with them for moral support during the activity, especially if it is outside of their home;

- They might need psychotherapy with a psychologist who specialises in ASD/Aspergers to help them work up to being able to cope in a social situation, before taking part in an activity outside of their home and/or involving other people who they are not familiar with.

A person with ASD/Aspergers might always need this sort of assistance, OR they might only need it when they first start doing a new activity, until they become familiar and confident with the activity itself, the environment in which the activity takes place, and the other people who are present during the activity.

SOCIAL ISSUES (& COMMUNICATION ISSUES):

Many people with ASD/Aspergers have difficulty with ‘social situations’, for a variety of reasons, such as:

- Being in a public place with a group of people can cause them to experience sensory overload.

- Many people with ASD/Aspergers become stressed* when other people come too close to them, and are ‘in their space’.

- Many people with ASD/Aspergers might ‘freeze’ in social situations, because the situation makes them feel stressed*. They might not know what to say, or because they are feeling so stressed*, they might find it difficult to speak, which they might find embarrassing.

  *(*When I use the word ‘stressed’ here, I do not only, or necessarily, mean ‘anxious’, but, also, or rather, ‘confused’, ‘overwhelmed’, or ‘experiencing sensory overload’).*

- Many people with ASD/Aspergers find it difficult to process information when it is only given verbally, i.e., spoken. Therefore, many people with ASD/Aspergers might find it difficult to take in and process what everyone is saying in a social situation. They can find it overwhelming and exhausting.

- When in a social situation with a group of people, a person with ASD/Aspergers cannot really control their environment. They cannot always predict what the other people are going to do or say. That can be very confusing and stressful for someone with ASD/Aspergers.

This sort of situation can make a person with ASD/Aspergers feel afraid that something out of their control might cause them to experience a sensory trigger or overload, causing them to have a public ‘meltdown’ and embarrass themselves. *(This handbook contains a section called “Emotional Issues [& Communication Issues]”), which explains what a ‘meltdown’ is)*.

A person with ASD/Aspergers might be afraid that they will find themselves in a social situation that they cannot cope with, but that they will feel too embarrassed to get up and leave, because that would draw attention to themselves. That would make them feel trapped. This sort of situation can be incredibly stressful for a person with ASD/Aspergers. I believe that if a person with ASD/Aspergers is constantly forced to be in such situations, they can develop PTSD in relation to this sort of situation.

- People with ASD/Aspergers tend to think differently to most people. People with ASD/Aspergers can find it difficult to understand what other people really mean when they say something. Also, other people can find it difficult to understand what people with ASD/Aspergers really mean when they say something. This can lead to confusion, frustration and even hurt feelings.

  Children or teenagers with ASD/Aspergers might even say to their parents, “I don’t understand people,” but their parents might not fully understand just how confused their children or teenagers actually are.

For these reasons, many people with ASD/Aspergers cope better in social situations with small groups of people (especially people they know), and for short periods of time, rather than with large groups of people (especially people they don’t know), and/or for long periods of time. Many people with ASD/Aspergers become stressed, and/or irritated, and/or exhausted when they have to engage with other people all day, even if it is with people they know.

Many people with ASD/Aspergers find it difficult to ‘fit in’ socially, due to:

- People with ASD/Aspergers tend to think very logically and literally, OR their logic is different to that of most other people. Therefore, they might not always realise when someone is making a joke or being sarcastic. Sometimes other people might think that some people with ASD/Aspergers seem to be naïve and/or gullible. Unfortunately, this can lead to some people with ASD/Aspergers being teased and/or taken advantage of by some people.

- When a child reaches adolescence, they start to learn and use more intricate levels of social etiquette, such as ‘white lies’, and being nice to a person when they’re ‘face-to-face’ with them, even though they ‘vent’ about that person ‘behind their back’ (i.e., say all the things they don’t like about that person to other people, when that person is not present).

  Many people with ASD/Aspergers find it very difficult to understand and navigate these intricacies of social etiquette.

  Certain levels of these behaviours are considered by most people to be acceptable, and even polite. However, if you go too far with telling white lies, you might be deemed to be ‘fake’. If you go too far when ‘venting’ about someone behind their back, you might be deemed to be ‘bitchy’, or ‘two-faced’. If you share a certain amount of personal information about yourself, you are considered to be open and honest, which is a positive thing. However, if you go too far with sharing personal information, this is sometimes considered to be ‘oversharing’.

  All of this can be very confusing to a person with ASD/Aspergers!

When teenagers start to try to navigate these more intricate levels of social etiquette, it is normal for most teenagers to experience some level of difficulty, and to make some mistakes as they learn. Most teenagers will feel embarrassed and/or foolish from time to time when they make such mistakes, but they will be able to get over it quickly and move on.

However, **for a teenager with ASD/Aspergers, the level of difficulty they experience with this sort of thing is much greater than it is for most teenagers, and it can cause them to experience a <u>much higher level of distress and confusion</u> than most teenagers would experience.** Also, many people with ASD/Aspergers tend to HATE making mistakes. When they make a mistake, they tend to find it <u>much more difficult than most people</u> to get over it and move on.

This can cause people with ASD/Aspergers to feel very unsure of themselves. They tend to need, want or expect there to be clear, concise ‘black and white’ rules to everything in life, which they can easily follow (and get ‘right’), when in actual fact, many ‘rules of life’ have exceptions, and/or are a bit ‘grey’.

People are usually only expected to start to understand and behave according to these more intricate levels of social etiquette when they become teenagers. For this reason, some people with ASD/Aspergers might have many friends when they are young children, and their social development might <u>seem</u> to be ‘normal’ until they reach adolescence or adulthood.

Then, once they reach an age where they are faced with more intricate levels of social etiquette, they might start to show signs of social awkwardness, and difficulty in finding friends they can relate to.

Many teenagers find this stage of life awkward and difficult to navigate to some degree. **However, for a teenager with ASD/Aspergers, it is much more than just an 'awkward phase' that they will figure out for themselves and/or will soon grow out of.** Teenagers with ASD/Aspergers usually need to be given a lot more patience, guidance and support to navigate this stage of life than most teenagers do. Some people with ASD/Aspergers might always have difficulty with social etiquette.

- Some people with ASD/Aspergers find it hard to 'read the room', which causes them to behave in ways that other people might sometimes think are insensitive. For example, some people with ASD/Aspergers might talk endlessly about their favourite topic(s), without pausing to allow or invite anyone else to talk about something different. Some people with ASD/Aspergers might not realise when other people are not as interested as they are in listening to them talk about their favourite topic(s). They might be self-absorbed in their own interests, and not seem* to care about other people.

- Some people with ASD/Aspergers have unusual interests or odd habits (such as odd and obvious stims).

All of these issues can make some people with ASD/Aspergers seem* odd and/or unlikeable to other people. This can cause some other people to not want to be friends with some people with ASD/Aspergers, which can make some people with ASD/Aspergers feel left out.

*(*Note I say 'seem'. You are NOT actually unlikeable. Unfortunately, some people are just not very tolerant or understanding of people with ASD/Aspergers, because people with ASD/Aspergers are different to themselves).*

It can also cause some children/teenagers to bully some children/teenagers with ASD/Aspergers. A lot of people with ASD/Aspergers were bullied at school and have PTSD as a result.

All of the issues outlined so far in this section of this handbook can cause some people with ASD/Aspergers to avoid social situations.

However, people with ASD/Aspergers CAN have a great sense of humour. Some people with ASD/Aspergers, especially females, can usually tell when someone is a nice person, even when it isn't obvious to other people. They know what it's like to be 'different' and that doesn't put them off. In fact, some people with ASD/Aspergers might be more drawn to other people who are 'different', because they find them interesting.

Some people with ASD/Aspergers, especially females, can usually tell when someone is not a very kind or caring person, even if that person is considered 'popular' by most other people. However, even if a person with ASD/Aspergers has these abilities, they can still sometimes be misled by other people.

Some people with ASD/Aspergers, especially females, can be very empathetic and very good at 'reading' people's emotions. In fact, once they reach adolescence, they can become overly concerned about hurting other people's feelings, and being thought badly of by other people. They can have a very high standard of what is 'good' social behaviour, for themselves, and for others. However, there might still be times when they feel they can't totally understand other people.

Some people with ASD/Aspergers, especially females, have stims that are not obvious, or don't seem overly odd to other people. However, some of their interests and the way they react to some things might be different to most people. Other people might find them interesting because they are different and unique.

People with ASD/Aspergers can be very likeable. They can be very funny, intelligent and interesting. They can be very talkative and fun to be around, and/or gentle and kind, and/or like to be led. If they are lucky enough to find the right friend, or group of friends, who are accepting of, and even enjoy, their unique traits, **they can be very popular**.

Some people with ASD/Aspergers really enjoy social interaction. Some would, if they could find the right friends and environment.

For these reasons, some people with ASD/Aspergers, especially females, are not diagnosed until they are older.

Some further reasons why some people with ASD/Aspergers, especially females, are not diagnosed until they are older, are:

- Most people tend to gravitate towards other people who are similar to them. If there are teenagers at a high school who have ASD/Aspergers, who also happen to be similar to each other, there's a good chance that they will find each other and become friends. If you are a teenager with ASD/Aspergers, and have a group of friends who are teenagers with ASD/Aspergers, and you are all similar, you might assume that you all just have a similar personality type, rather than having some kind of ‘condition’, like ASD/Aspergers. Your teachers and parents might assume the same thing.

You might be the most socially adept person with ASD/Aspergers in your group of friends with ASD/Aspergers. You might even be able to explain social intricacies to your friends, to some degree. This might cause you to assume that you couldn’t have a ‘condition’ like ASD/Aspergers.

Your parents might have undiagnosed ASD/Aspergers themselves, and therefore they might assume that you just have a similar personality type to them, because you ‘take after’ them, rather than having some kind of ‘condition’, like ASD/Aspergers.

- When people with ASD/Aspergers experience stressful situations (such as social situations, which can also involve sensory triggers), they might feel intense emotions such as confusion, frustration, embarrassment and rage. This might cause them to lose control and behave in a physically aggressive way. Boys with ASD/Aspergers are more likely to behave aggressively than girls with ASD/Aspergers.

  Aggressive behaviour is not socially acceptable. So when a child with ASD/Aspergers behaves aggressively, adults (like parents or teachers) notice, and usually something is done about it. This can lead to the child with ASD/Aspergers being diagnosed with ASD at a young age. Because boys with ASD/Aspergers are more likely than girls with ASD/Aspergers to behave aggressively, boys with ASD/Aspergers are also more likely than girls with ASD/Aspergers to be diagnosed at a young age.

  Many girls with ASD/Aspergers do not tend to behave in a physically aggressive way. However, they might occasionally find themselves in situations where they feel trapped by people doing things that they cannot cope with. This can cause a person with ASD/Aspergers to panic, and to hit or kick out at the people who are upsetting them, even if the person with ASD/Aspergers, for example, is a girl who is normally quiet and gentle.

Losing control like that can be very upsetting for the person with ASD/Aspergers. They can feel very embarrassed about it, and/or they can feel ashamed that they behaved badly, even if other people thought that their behaviour was understandable in the circumstances, and that it wasn't even that bad.

Girls with ASD/Aspergers are more likely than boys with ASD/Aspergers to 'verbalise' (i.e., say out loud to other people) their emotions, rather than express their negative emotions by being physically aggressive towards other people. However, they are also more likely to withdraw into themselves and not express negative emotions in a way that is obvious to other people at all (i.e., not even 'verbally'). **They might be feeling very distressed, but it is not obvious to most other people**. For this reason, girls with ASD/Aspergers **are often just seen as quiet and/or shy**, and are not diagnosed at an earlier age.

- At school, a child/teenager with ASD/Aspergers, especially a girl, can often rely on their friends to help them when they don't understand things. Therefore, their ASD/Aspergers symptoms might go unnoticed by their teachers and parents.

  Girls are most likely to hang out with other girls, and:

  > "…girls with Asperger's Syndrome are often "mothered' by other girls. They may prompt the child when she is unsure what to do or say in social situations and comfort her when she is distressed."[x]

- Some people with ASD/Aspergers, especially females, are very good at something called 'masking'. Some examples of masking behaviours are:

    - Many people with ASD/Aspergers often don't want to speak in social situations, but they might still almost always respond when asked a question, because otherwise they would draw too much attention to themselves. **Many people with ASD/Aspergers often find that they can't put their thoughts into words when they are in a social situation. However, they might be able to give standard, acceptable responses to questions, or say standard, acceptable phrases that they have learnt are the expected responses or phrases to say in particular situations.**

      This helps the person with ASD/Aspergers to appear 'normal', and not draw embarrassing attention to themselves. **However, these standard responses and phrases might not reflect what the person with ASD/Aspergers actually thinks or feels.**

    - Some people with ASD/Aspergers, especially females, can be very good at observing social behaviour and at **mimicking appropriate social behaviour and speech**.

      It might be that they have been teased or scolded for some of their own ASD/Aspergers behaviours/speech in the past, or they have seen other people being teased or scolded for certain behaviours/speech. In order to avoid being teased or scolded, they might make a conscious effort not to behave or speak in that manner when in public, and to mimic the types of behaviours/speech that they have observed to be socially acceptable. This can take a lot of effort for a person with ASD/Aspergers, and can leave them feeling exhausted.

However, some people with ASD/Aspergers might not even be aware that they are mimicking other people's social behaviour and/or speech.

If the mimicking is obvious, other people might notice it. However, it might be done so expertly that it is <u>not</u> recognised by other people as mimicking.

The person with ASD/Aspergers might seem to be behaving in a completely 'normal' way, but they might not necessarily fully understand all that they are doing or saying, or all that others are doing and saying (even if they pretend to understand), and they might not be expressing what they really think, or how they really feel.

Mimicking is quite a natural thing for young children to do. It is one of the ways in which they learn, practice and develop. Usually by the time they are teenagers, children are developing a sense of their own identity. However, **teenagers with ASD/Aspergers might still feel a need to mimic, and still find it natural**, to a greater degree than most teenagers do.

Most teenagers are still developing their identity, and will likely 'try out' different 'identities', to some degree. However, teenagers with ASD/Aspergers might do this to a much greater degree than most teenagers do. **They might not even know what they actually really think or feel. They might not have a strong sense of their own identity, and end up 'mirroring' the identity of other people who they interact with, and thinking that is their own identity at that time**.

A teenager with ASD/Aspergers might act differently when they are around different people, because they can't help but 'mirror' whatever people they are interacting with. Some people with ASD/Aspergers still

> do this when they are adults. If other people notice this sort of behaviour, they might wonder what the true character of the person with ASD/Aspergers is. However, they might simply think that the person with ASD/Aspergers is good at getting along with lots of different people.
>
> Some people with ASD/Aspergers are so good at mimicking, that they decide to take up acting or comedy as a career or hobby.

***

Some people with ASD/Aspergers are very sociable, have friends and <u>do</u> take part in social activities.

Some people with ASD/Aspergers want to have friends and take part in social activities, but they are afraid to because of some, or all, of the issues that I have already outlined in this section of this handbook.

Some people with ASD/Aspergers prefer to spend time on their own, engaging in their own interests, and do not care to socialise much. Some people with ASD/Aspergers would never socialise if they had their way.

Most people need to be able to interact with other people to some degree in order to be able to live an independent life, and to do the things they need and/or want to do, such as going to the shops, attending school or university, having a job, travelling, and/or doing any other activity they enjoy, if it involves being around other people.

Also, it is good to have at least one or two friends. Spending time with friends who you like, trust and feel comfortable with can make you feel very happy. It is also good practice for when you need and/or want to take part in other necessary social interaction.

Suggestions for How to Cope with Social Issues:

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents and school understand your social issues and communication issues. For this reason, it is important that your parents inform your school if you have a diagnosis of ASD.

How to cope with the stress of social interaction:

A psychologist who specialises in ASD/Aspergers can help you to take steps towards being able to cope with going out in public and in social situations, so that you can do all the things you need and/or want to do.

Many teenagers with ASD/Aspergers benefit from attending a social skills group. If you want to attend a social skills group, you might need the help of a psychologist first, before you feel ready to attend a social skills group.

Most likely, you will need your parents to arrange any appointments with an appropriate psychologist.

Some people with ASD/Aspergers need to have a lot of time alone each day, and only be in social situations for short periods, with breaks in between, so that they do not become overwhelmed and distressed.

You might need to:

- Limit your social interactions, so that you mainly engage in social situations with people you know, and with small groups of people, rather than with large groups of people (especially with too many people you don't know);
- Plan your activities so that you are not engaging with other people:
    - for the whole day, but only for a few hours on any one day; or
    - more often than you can cope with;
- Prepare an 'escape plan' in advance, for how you can easily remove yourself from the social situation at any time, if you need to, without drawing attention to yourself;
- Plan to have down time after social activity.

You might need your parents and/or a support person to help you to plan your social activities according to the above suggestions.

It is perfectly okay to leave a social event early, if you feel that you are not coping. Don't worry about <u>appearing</u> rude. You are NOT <u>actually</u> being rude. If you feel that other people are pressuring you to stay at a social event when you are not coping, <u>you don't have to give in to them</u>. They don't understand how difficult it is for you.

Some people with ASD/Aspergers might always, or almost always, need to have someone they trust and feel comfortable with accompany them when they are in social situations, to help them cope.

Many people with ASD/Aspergers find that social situations can cause them to experience a great deal of stress, expend a lot of energy, and to feel exhausted afterwards. After spending time in a social situation, you might need down time to recover. You might need to relax by yourself in a safe, private, quiet space, where you can rest, surround yourself with/use your sensory buzzers (if possible), and/or stim, and/or engage in your intense interests.

If you are at home, this might be your bedroom. If you are at school, this might be a special room that your school has allocated for this purpose. Most schools should have such a space, but if they don't, if you have been diagnosed with ASD, and your school has been informed, your parents can ask your school to provide such a space. If you are not at home, or at school, you might have to look for a suitable space nearby, OR you might have to wait until you get home (you might have to leave the situation early to go home).

If you do want to have friends and/or interact more with other people:

1. If you are truly happy spending most of your time alone, then that is fine. But if you want to make more friends and/or interact more with other people, a good idea would be to find clubs or groups that do activities that centre around your interests. That way you'll hopefully be able to enjoy doing the activities, and you might get to meet like-minded people with similar interests, who could potentially become your friends. At the very least, you'll get practice with being around other people.

2. Many teenagers with ASD/Aspergers benefit from attending a social skills group. You might need to attend a social skills group first, before you feel ready to attend clubs or groups that do activities that centre around your interests.

If you want to try attending a social skills group and/or clubs or groups that do activities that centre around your interests, you will most likely need your parents and/or a support person to arrange, or help you to arrange this.

If you find it hard to tell when someone is treating you badly:

If there is someone in your life who you think you like, and if interacting with them sometimes makes you feel happy, but at other times makes you feel bad, and you're unsure if they are a nice person or not, a good idea would be to talk through the situation, in private, with someone who you trust, and feel comfortable with*. You could describe to them what this other person does that sometimes makes you feel bad, and ask them for their opinion on whether they think that the other person is a nice person or not. For example, they might be able to help you figure out if this other person is being 'fake', or 'two-faced'.

If you think you have difficulty understanding social etiquette:

If you find it difficult to understand and/or use intricate levels of social etiquette, such as 'white lies' and/or 'venting', try not to overthink things. More often than not, honesty is the best policy. If you like to be honest and don't like to lie, that is a good thing.

If someone gets upset with you for saying something that is true, and you don't understand why, it might be best, in that moment, to simply say something like, "I'm sorry, I didn't mean to offend you." Then later, in private, you could talk through the situation with someone who you trust, and feel comfortable with*. You could describe to them what happened, and ask them for their opinion on why they think the other person might have gotten upset with you.

It might be that the other person was <u>not</u> justified in getting upset with you, or it might be that what you said <u>was</u> something that many people might take offence at, even though that was not your intention. There is no need for you to feel bad about this, but seeking advice like this might help you to learn how to avoid having too many conflicts with other people, which can be upsetting for both you and the other people.

*(*e.g., a good friend whom you trust, and/or your parents, and/or <u>your own specialised psychologist</u>).*

If your friends are constantly getting upset with you, they might not be the best sort of friends for you. You might need to find friends who are more patient and understanding of you, that is, friends who:

- do not easily get offended by you, but when they do, they don't get overly upset with you, but, rather, they kindly explain to you why they feel offended, so you can learn from your mistakes;

- are usually quick to accept your apologies.

If you are in a social situation with people who you don’t know very well, and if you are unsure whether they are likely to appreciate your honesty, or be offended by it, <u>you don’t need to lie to them</u>. However, it might be best to keep your opinions to yourself, until you have had a chance to listen to, and observe them, and to decide whether or not you feel confident that they will be understanding of you.

EMOTIONAL ISSUES (& COMMUNICATION ISSUES):

Whilst some people with ASD/Aspergers might seem to be unemotional, most people with ASD/Aspergers tend to experience extreme emotions (both positive and negative), usually in response to their:

- Difficulty with change (& uncertainty) - (*negative emotions*);
- Sensory issues - (*positive emotions for sensory buzzers, negative emotions for sensory triggers*);
- Intense interests - (*positive emotions when engaging in intense interests, negative emotions when prevented from engaging in intense interests*);
- Social issues (& communication issues) - (*negative emotions if experiencing social problems*);
- Different learning needs (& thought processing & communication issues) - (*negative emotions if experiencing learning problems*).

People with ASD/Aspergers often have difficulty with understanding, and/or processing, and/or expressing their emotions.

When a person with ASD/Aspergers feels emotions, they might sometimes, or often, find it difficult to pinpoint what caused them to feel those emotions.

Because people with ASD/Aspergers process information differently to most people, when a person with ASD/Aspergers experiences something, they might not feel emotions in response to what they're experiencing straight away. Instead, there might be a delay between the time when the person with ASD/Aspergers experiences something that causes them to feel emotions, and the time when they actually start to feel the resulting emotions.

Many people with ASD/Aspergers find it very difficult to speak about their emotions, because:

- Their emotions are causing them to feel overwhelmed, making it difficult for them to speak; and/or

- They find it very difficult to describe their emotions with words.

A person with ASD/Aspergers might say to someone, "I don't feel well," or, "I don't feel good," but when the other person asks follow up questions, the person with ASD/Aspergers might be unable, or find it very difficult, to elaborate. That can make it difficult for most people to be able to pinpoint what is making the person with ASD/Aspergers to not feel 'well', or 'good', or to even be able to determine whether the problem is emotional or physical.

When a person with ASD/Aspergers ‘verbally expresses’ to someone the emotions they are feeling in response to something, sometimes, or often, the person with ASD/Aspergers uses a tone of voice and/or facial expression that most people wouldn’t use when verbally expressing to someone that they are feeling those particular emotions. In other words, **the tone of voice and/or facial expression of the person with ASD/Aspergers doesn’t always match the emotions that they are feeling, and that they are trying to verbally express**.

This often causes other people to misunderstand what emotions the person with ASD/Aspergers is trying to communicate, or to not fully grasp the depth of the emotions that the person with ASD/Aspergers is trying to communicate. For example:

- A person with ASD/Aspergers might be deeply bothered by something, so they might say something like, “I feel terrible about this.” However, when they say it, they might have a smile on their face and then let out a little giggle. Most people would interpret the smile and the giggle to mean that when the person said, “I feel terrible about this,” they weren’t being serious, i.e., that they might just be joking, or that they might feel a little bit bad about it, but that they don’t actually feel <u>terrible</u> about it.

- A person with ASD/Aspergers might be feeling fine, when someone asks them how they are feeling. However, the person with ASD/Aspergers might, at that moment, be intently focused on something (like a particular train of thought, an intense interest, or simply enjoying a sensory buzzer). So when the other person asks them how they are feeling, the person with ASD/Aspergers might feel grumpy or impatient, because they have been interrupted, and they now have to make an effort to concentrate on verbally responding to a question.

The person with ASD/Aspergers might say, “I’m fine.” However, when they say it, they might have a frown on their face, speak with a terse tone of voice, and turn away from the other person. Many people would interpret the frown, terse tone of voice, and the fact that they turned away, to mean that the person with ASD/Aspergers is not fine, but angry or upset about something.

- Sometimes, when talking about something that they are very interested and excited about, a person with ASD/Aspergers might use a tone of voice, and/or facial expression, and/or gestures that are very animated, and most people would recognise that the person with ASD/Aspergers is very interested and excited. However, sometimes a person with ASD/Aspergers might use a tone of voice, and/or a facial expression, and/or gestures that most people would interpret as meaning that the person with ASD/Aspergers is not at all interested or excited about what they are saying, when, in fact, they are.

When a person with ASD/Aspergers wants or needs to tell someone about something that is deeply personal and important to them, such as their deepest fears or concerns, or their secret wishes or aspirations about the things they are most passionate about, sometimes, or often, the person with ASD/Aspergers can find it extremely difficult, if not impossible, to say out loud.

They might try to tell someone by talking about things related to what they really want to say, trying to lead the other person to say it out loud for them. They might say everything else related to the issue, without being able to say the one thing they actually really want to say. Some people might be able to guess what the person with ASD/Aspergers is really trying to say, but others will not. People cannot read minds.

This can make psychotherapy especially tricky for a teenager with ASD/Aspergers. Psychologists don't tend to like to lead their patients too much, and for good reason. They want their patients to tell them what they are really thinking and feeling. They don't want to make guesses or suggestions that some patients might simply agree with, even if they are not correct. Some patients with ASD/Aspergers might be especially prone to doing this.

However, some patients with ASD/Aspergers might try to lead their psychologists to voice what it is they really want to say, but without success, because even psychologists cannot read minds. That is, some patients with ASD/Aspergers might say something to their psychologist like:

> *"I thought, maybe, I might be experiencing XXXX, but then I thought, maybe it's just XXXX, or XXXX. I don't know,"*

and smile or laugh as if it's really not important, when what they really might be trying to say is:

> *"I definitely think I am experiencing XXXX, and this is really important, but I cannot say that out loud. I am giving you options to choose from, and I need you, as my psychologist, to pick the correct option and say it out loud. I need you to confirm that I might be experiencing XXXX, that you don't think I'm silly for thinking that I'm experiencing XXXX, and to start off the conversation about XXXX, so that I can talk about it."*

I think this is probably because when people with ASD/Aspergers try to express themselves, they are often misunderstood, their thoughts and feelings are often dismissed, minimised, or made fun of, or they are often told off for expressing their true thoughts and feelings, without understanding why. It's confusing and upsetting when people react this way when you simply express your true thoughts and feelings, but it is especially painful when people react this way to your deepest fears or concerns, or your secret wishes or aspirations about the things you are most passionate about.

Because of this, it can take a lot more sessions for a teenager with ASD/Aspergers to become comfortable with their psychologist, than it would for most people. It can also take a lot longer for a psychologist to get to know a teenage patient with ASD/Aspergers, than it would it would take them to get to know most patients, and to learn how to correctly interpret the way <u>that particular teenager with ASD/Aspergers</u> verbally expresses themselves.

This is one of the reasons why, when undergoing psychotherapy, teenagers with ASD/Aspergers need a good psychologist who <u>specialises in ASD/Aspergers,</u> and whom they feel comfortable with, and they need to be able to continue to see this same psychologist for the long term, on a regular, ongoing basis in order to benefit from the psychotherapy sessions.

Some people with ASD/Aspergers who find it very difficult, if not impossible, to explain or express ‘verbally’ something that is deeply personal and important to them, <u>can</u> express themselves perfectly well in writing. In fact, they might be able to write very eloquently. If this is the case, in certain scenarios, where people are usually expected to speak out loud, a person with ASD/Aspergers might need to be given the option of expressing themselves in writing instead.

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Emotional Issues & Changes Associated with Growing Up:

When a child reaches adolescence, they start to go through a new stage of development. Most teenagers will find that their thoughts, feelings and some, or many, or even all, of their interests will start to change during adolescence. When a person with ASD/Aspergers goes through adolescence, they too will likely find that their thoughts and feelings will change, and some, or many, or even all, of their intense interests might change. People with ASD/Aspergers have great difficulty with change.

Therefore, they might experience a level of distress, which is much more severe, confusing and complex than most teenagers experience, when they reach adolescence and start to go through changes in their thoughts, feelings and intense interests (not to mention their bodies)**.** Also, for a person with ASD/Aspergers, their thoughts, feelings and intense interests are such a big part of their identity, that when these start to change during adolescence, they might start to experience an identity crisis.

Some young children with ASD/Aspergers might feel comfortable with, and used to, their thoughts and feelings, and greatly enjoy their intense interests, and therefore feel quite happy most of the time. Therefore, **some young children with ASD/Aspergers might not exhibit emotional issues that are obvious to most other people**.

However, **when such children with ASD/Aspergers start to go through adolescence**, and experience severe, confusing and complex levels of distress, due to their changing thoughts, feelings and intense interests, **they will likely start to exhibit signs of distress that are noticeable to other people**.

This is another reason why ASD/Aspergers is often not diagnosed until adolescence.

Emotional Issues & Impatience, Perfectionism & an ‘All or Nothing’ Attitude:

When a person with ASD/Aspergers feels a strong urge to do something, it can be difficult for them to think about anything else, and they might feel very impatient. They might feel the need to start doing it without delay, or they will lose the urge, or the motivation, or the confidence to do it, and might be put off from doing it at all, even if it is something that would be very positive for them to do.

Many people with ASD/Aspergers are perfectionists. If someone with ASD/Aspergers wants to try doing something, or starts doing something, and even the slightest little thing goes wrong, in their perception (even if the thing that goes ‘wrong’, is something that most people wouldn’t be bothered by), it can put the person with ASD/Aspergers off it forever, and they won’t want to try it again. If a person with ASD/Aspergers can’t understand or do something easily straight away, they might quickly give up and not stick at it, or try it again.

If any of these things happen, they might feel as though the thing has been ‘ruined’ for them.

Many people with ASD/Aspergers often have difficulty coping with constructive criticism. They can’t always tell the difference between constructive criticism, which is intended to help them, and nasty criticism, which is intended to scold them, or put them down.

Because many people with ASD/Aspergers tend to have an ‘all or nothing’ attitude, and interpret things in a very ‘black and white’ manner, when they are given constructive criticism, and are told something like:

> *“You haven’t quite got the hang of it yet, or reached the level that I know you can achieve, but if you keep trying and/or practising, or if you try it this way, you will improve. I am confident that you will get the hang of it, and/or be able to achieve an even better level than what you have already achieved, which is already good,”*

they might interpret it as meaning something like:

> *“You have not done it right, or are not doing it right. It is not perfect. Therefore, it is not good enough. Therefore, you are a failure. You will never be able to do it properly, well, or at all.”*

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Because of their emotional issues, people with ASD/Aspergers often experience what are referred to as ‘emotional meltdowns’ (‘meltdowns’ for short).

There are two types of ASD/Aspergers meltdown - a temper meltdown and a depression meltdown.[xi]

Temper Meltdowns:

People with ASD/Aspergers often experience a build-up of extreme emotions, due to the fact that they are very sensitive to a lot of things, and due to the fact that they process information differently to most people, which often causes them to experience confusion. This build-up of extreme emotions can result in a person with ASD/Aspergers feeling emotionally out of control, and feeling rage, frustration or despair. **When people with ASD/Aspergers express or feel this built-up rage, frustration or despair, it is called a temper meltdown.**

The sorts of things that can trigger a person with ASD/Aspergers to have a temper meltdown are:

- An overload of sensory triggers;
- An overload of social activity;
- Trying to do too much, without a break;
- An overload of negative emotion;
- Making a mistake;
- A change of plans;
- Not being able to understand things;
- Feeling misunderstood;
- Experiencing a situation that they feel is unjust;
- Being falsely accused;
- Being taken unfair advantage of;
- Being in a situation where they feel trapped.

The effects of a temper meltdown usually only last a few hours or a day.

Some women with Aspergers have given the following descriptions of what a temper meltdown feels like:

> “These meltdowns are an outpouring of rage, and when you scratch beneath the surface of rage even a tiny bit, you find pain. Pain which builds up in cumulative, often combative, frustration.”
>
> “When a temper meltdown is building, the feeling is…more like an extreme tension; an electricity. In my case I feel angry, agitated, sometimes dizzy; I’m not breathing right. When I speak, if I can speak, I may be sarcastic and scornful.”
>
> “A temper meltdown can mean public tears and outrage; yelling, swearing, and being vicious.”[xii]

When a person with ASD/Aspergers experiences a temper meltdown they might react in one or more of the following ways*:*

- Stimming vigorously;
- Bursting into tears and sobbing uncontrollably;
- Storming off;
- They might lose control of their reactions, causing them to shout and swear at other people, or say nasty things to other people, or even to hit, kick or throw things at other people, or damage property;
- OR they might withdraw into themselves. They might find it very difficult to speak;

- They might be unable to concentrate on anything whilst experiencing the temper meltdown, OR find it very difficult to concentrate.

When a person with ASD/Aspergers has a temper meltdown, sometimes their reaction is noticeable to other people. However, if the other people don't know that the person has ASD/Aspergers, they often don't understand WHY the person with ASD/Aspergers is acting in that way, or having such an extreme emotional reaction. This can cause other people to misinterpret the behaviour of the person with ASD/Aspergers. For example:

- People with ASD/Aspergers can have an extreme emotional reaction to things that wouldn't cause most people to have an extreme emotional reaction. Therefore, other people might:
    - be unable to see any reason why the person with ASD/Aspergers suddenly started acting in that way; and/or
    - think that the person with ASD/Aspergers is overreacting to something that most people would consider to be only a minor irritation;
- If a person with ASD/Aspergers storms off, or is unable to speak when spoken to, other people might think the person with ASD/Aspergers is simply being rude for no good reason.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

However, when some people with ASD/Aspergers have a temper meltdown, their reactions are NOT very noticeable to other people. For example, **if they withdraw into themselves, and/or bottle up their emotions, and/or are unable to speak about their emotions, other people might just think that they are quiet and shy, and not realise that they are experiencing extreme distress**. OR, if a person with ASD/Aspergers goes to a safe, private space by themselves when they have a temper meltdown, other people will not notice their emotional reaction, because they won't be able to see or hear it.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

Even if you don't tend to express these sorts of emotions in a manner that is obvious to other people, when you have a temper meltdown, **having these sorts of emotions** bottled up inside **must be very distressing**.

Depression Meltdowns:

People with ASD/Aspergers are prone to anxiety and depression, because of the difficulties they experience due to their ASD/Aspergers.

Depression often tends to develop due to feeling powerless to do the things you want to do in life. You might feel 'stuck' in an unhappy situation and not know how to move forward and improve your life.

Many people with ASD/Aspergers often have trouble letting go of emotions. When people don't let go of their negative emotions, it can turn into depression.

The sorts of things that can trigger a person with ASD/Aspergers to have a depression meltdown are:

- The same sorts of things that can trigger a temper meltdown;
- Experiencing these sorts of triggers on a regular, ongoing basis, without relief;
- Not being able to express/release negative emotions in a healthy way;
- Too much change all at once, or in a short period of time;
- Unrealistic expectations of themselves, such as perfectionism, which can lead them to feel bad about themselves when they don’t, or can’t, achieve perfection;
- Feeling bad about themselves due to:
    - A hurtful comment;
    - Constructive criticism;
    - Having a temper meltdown;
- Low self-esteem due to constantly feeling bad about themselves;
- Unrealistic expectations of other people, and/or the world, such as perfectionism, which can lead them to feel bitterly disappointed, or that there is no point in life, when other people and/or the world don’t, or can’t, achieve perfection;
- Not being able to change their attitude, or the way they do things, or their path in life, when things don’t go as they want or expect;
- Obsessing about negative things;
- Anything that sets them on a negative train of thought, when they follow that train of thought to the extreme;
- Loneliness;
- Not being able to let go of negative emotions.

Being prone to these sorts of triggers and difficulties is a typical trait of having ASD/Aspergers. People with ASD/Aspergers can't help being that way. They need other people to be patient and understanding. Many people with ASD/Aspergers need a psychologist who specialises in ASD/Aspergers to help them to cope.

When the focus of a person with ASD/Aspergers is taken over with these sorts of negative thoughts and feelings, and they don't go away, but spiral into depression, it's called a depression meltdown.

An ASD/Aspergers depression meltdown can last for days or even weeks.

These types of meltdown are:

> "…incredibly crippling, intense, and debilitating…can result in stomach pain, nausea, vomiting, exhaustion, dizziness, headaches, diarrhea…"[xiii]

They can cause a person with ASD/Aspergers to experience nightmares.

Some women with Aspergers have described how their depression meltdowns feel:

> "I will feel like I've been hit with a baseball bat. I'll feel it in my belly and my head. Immediately, I'm dizzy, like the world has shifted off its axis. It's that swooning feeling right before you faint. It's the feeling you have when you receive terrible news; now freeze that and stay there for hours,

> days even. Once this happens, it's very hard to stop ourselves "going down the rabbit hole." We go down quickly and we go down hard...We will despair of anything ever being right again. We are paralyzed with grief."
>
> "Depression meltdowns are like being in solitary confinement, in a dark, damp basement, full of filth and spiders. They are like death, the loneliest place on earth, the worst nightmare you've ever had come to life. They make me wonder if I'm possessed, if I am insane, if I am cursed and if I will ever be happy again."
>
> "During the really terrible depressions, day after day I lie in bed; anguish has taken my body and my thoughts are not my own."
>
> "We can't even read or watch a film in such a state, the usual sanctuaries for minor meltdowns or minor depressions. When such a meltdown sets in, the world is a black and evil place."
>
> "I spent the entire summer in my bed."[xiv]

Sometimes, a person with ASD/Aspergers has a depression meltdown when they have not yet been diagnosed with ASD/Aspergers. That might result in them being diagnosed with depression, but not with ASD/Aspergers.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

Suggestions for How to Cope with Emotional Issues:

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents and school understand your emotional issues. For this reason, it is important that your parents inform your school if you have a diagnosis of ASD.

A psychologist who specialises in ASD/Aspergers can help you to learn how to cope with your emotional issues, by helping you to:

- Better understand, process and verbalise your emotions;
- Learn how to express/release your negative emotions in a healthy way;
- Better understand the changes you are going through as you are growing up;
- Talk through issues in relation to your sense of identity.

Most likely, you will need your parents to arrange any appointments with an appropriate psychologist.

Many people with ASD/Aspergers, and especially teenagers with ASD/Aspergers, need to be reminded often that just because they tried something and it failed, or didn’t go how they wanted or expected, or wasn’t ‘perfect’, doesn’t mean that they shouldn’t try the same thing again. They need to be reminded that many things don’t go ‘right’, or turn out ‘perfectly’, the first time, but that they might go ‘right’, or turn out much better the next time. They need to be reminded that most people need to practise doing something before they become good at it.

Many people with ASD/Aspergers, and especially teenagers with ASD/Aspergers, need a lot of reassurance and positive reinforcement.

Suggestions for How to Cope with Temper Meltdowns:

It is a good idea to know what sorts of things can trigger you to experience a temper meltdown. Some suggestions for how to avoid temper meltdowns, or to have them less often, and/or to a less severe degree, are:

- Don't overload yourself with too many activities, or too many things that you know you find stressful.

- Talk to your parents, and/or your own specialised psychologist, and/or a support person when:
  - Something's bothering you;
  - You are going through a big change, or are about to;
  - Someone has hurt your feelings;
  - You don't understand something.

  Hopefully, they will be able to talk these issues through with you, or help you to talk them through, and 'break them down', in order to help you to feel better about these issues, and to be able to cope.

- Refer to the sections in this handbook which I have listed below, and especially to the suggestions in each of those sections:

  - Difficulty with Change (& Uncertainty);
  - Sensory Issues;
  - Stimming;
  - Intense Interests*;*
  - Social Issues (& Communication Issues);
  - Different Learning Needs (& Thought Processing Issues & Communication Issues.

However, you won't always be able to avoid having temper meltdowns, and that is okay.

It is important to learn to be able to express/release your negative emotions in a healthy way, for when you do have a temper meltdown, or can feel one coming on. People who constantly bottle up (i.e., don't express/release) their negative emotions tend to develop other psychological or health issues, such as:

- Stomach issues;
- An eating disorder;
- Self-harming behaviours;
- Depression.

Some suggestions for how to express/release your negative emotions (i.e., when having a temper meltdown) in a healthy way, are:

- Go to a safe space, and:
    - Stim;
    - Punch a punching bag (if available);
    - Scream into a pillow (if available);
    - Rip up paper;
    - Cry;
    - Use a fidget toy (if available);
    - Count to ten;
    - Take three deep breaths, or pretend to blow up a balloon;
    - Hug a family member or friend, or your favourite soft toy;
    - Write down your feelings, or draw a picture;
    - Talk about your negative emotions with your parents, your own specialised psychologist, or a support person (if available);

- Jump on a trampoline, or swing on a swing (if available);
- Run on an oval (if available).

You might find it helpful to ask your parents, and/or your own specialised psychologist, and/or a support person to help you to think of some other ways to express/release your negative emotions in a healthy way, and to write these down on the lines below.

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After you have a temper meltdown, if you've expressed/released your negative emotions in a healthy way, there is no need for you to feel bad or embarrassed about losing control of your emotions. It is perfectly okay. Everybody loses control of their emotions sometimes. You've done the right thing by expressing/releasing your negative emotions in a healthy way.

If, during a temper meltdown, you behave in a way that's not appropriate, such as shouting and/or swearing at other people, or saying nasty things to other people, or even hitting, kicking or throwing things at other people, or damaging property, OR if you behave in a way you don't like, or feel embarrassed about, try not to be too hard on yourself afterwards.

Don’t judge yourself too harshly, or feel too guilty. NOBODY is perfect. EVERYBODY has moments when they behave in a way that they are not proud of, even people who <u>don’t</u> have ASD/Aspergers. <u>No-one expects you to behave perfectly all the time</u>.

If, when you have a temper meltdown, you do or say some things that are hurtful to other people, simply apologise to the people or person you have hurt. You might want to do this straight away after your temper meltdown, or you might need to give yourself some time to calm down.

When you apologise to someone, they might accept your apology straight away, or they might need some time to calm down. If the person you apologise to is not ready to accept your apology and forgive you straight away, try apologising to them again, maybe a few hours later, or the next day, or a few days later. Most people really appreciate an apology, and are very happy to accept a genuine apology, and to ‘forgive and forget’.

If you apologise to someone, but they are not prepared to accept your apology, even after you’ve tried to apologise on a few separate occasions, and after a few weeks have passed, then you might have to simply leave them alone, and accept that they are not going to be your friend anymore. You have done all that you can. You need friends who are understanding and forgiving. You don’t have to continue to feel guilty about having upset someone who won’t accept your apology. **Try to let go of any guilt or hurt feelings you have about the situation. If you continue to hold onto such feelings for too long, they can turn into depression**.

Suggestions for How to Cope with Depression Meltdowns:

It is a good idea to know what sorts of things can trigger you to experience a depression meltdown. The suggestions that I have given for how to cope with emotional issues, and for how to avoid temper meltdowns, or to have them less often, and/or to a less severe degree, can also be helpful in relation to depression meltdowns.

However, you will probably still experience a depression meltdown at some point(s) in your life.

Some suggestions for how to deal with a depression meltdown when you are experiencing one, are:

- If you need to spend a lot of time in bed, doing nothing, or sleeping, that is okay. Your brain needs down time. During, or after, experiencing an intense emotional upset, you will likely need a lot of down time to process your emotions.
- Go easy on yourself. Do the bare minimum. Avoid things that cause you further stress. Try to do things that make you feel comforted. Use your sensory buzzers.
- Cry.
- Hug a family member or friend, or your favourite soft toy.
- Stim.
- Do some gentle exercise that you enjoy.
- Write down your feelings, if/when you are able to.
- Talk about your negative emotions with your parents, and/or your own specialised psychologist, and/or a support person, if/when you are able to.

- Do some easy activities that you enjoy, and that distract you from your depression, even if they only distract you a little bit and/or for a short time. I especially recommend doing 'mindlessness' activities, and will explain this in more detail on the following pages. *(In the section of this handbook called "Stimming", I explain what I call 'mindlessness' activities, at pages 60-63).*
- Try to engage in your intense interests, but don't push yourself.
- Try to remember that just because you are feeling depressed at a particular time, does not mean that you will feel that way forever.

You can use 'mindlessness' activities to help you to cope with emotional issues, especially depression meltdowns.

If your mind is in severe distress, or if you are suffering a bout of ongoing depression, and you are in no state to even try to do an activity that you might find stressful, or that requires you to focus and concentrate, then spend as much time as you need or want doing 'mindlessness' activities. Spend all day doing these sorts of activities, if you need or want. If you are in a state of deep depression, you might not be able to do much at all. At most, you might be able to spend a little time doing some 'mindlessness' activities.

If you are suffering a bout of ongoing depression:

Start off by trying to spend a little time each day doing some 'mindlessness' activities. You might build up to spending quite a lot of time each day doing 'mindlessness' activities.

Then, on days when you feel up to it, try spending some time doing activities that you usually enjoy, where you are actually creating something, such as:

- Drawing;
- Writing a story or song lyrics;
- A more complex craft activity that involves your own creativity;
- Set yourself a research project on a topic of interest that you can research on the internet. Write an essay, or your opinion on what you've researched, or a book you've read, or a movie you've watched.

It does not have to be your best work. You don't have to finish it in one sitting, or at all, and you don't have to show your work to anyone.

Alternatively, you could try spending some time doing the following types of activities, if these are activities that you usually enjoy. These sorts of activities are not necessarily you creating (unless you are creating a new song or dance), but they are also not 'mindless', because they do require a higher level of focus and concentration, even though you are doing something that you usually enjoy.

- Read a new book/watch a new movie or TV show;
- Play an instrument (if you know how to play an instrument);
- Sing;
- Dance.

It doesn't need to be your best performance, and you don't have to perform in front of anyone.

You need to learn how to be okay with doing a less than perfect job. Your ability to work/perform will improve as your mental health improves.

Even though you will be doing activities that you usually enjoy, you might still need to do some 'mindlessness' activities beforehand, to help you to psyche yourself up and focus, and afterwards, to help you to wind down.

When you feel up to it, use your ‘mindlessness’ activities to help you to do one challenging, but positive, activity per fortnight, such as going for a short walk in your neighbourhood, or at the beach, or on a nature trail, or attending a small social gathering/activity, with people who you know, and who you usually like. Go with someone who you feel safe and comfortable with, e.g., your parents, or a close friend, or a support worker.

Yes, you will be outside in the world, where you might come across other people, and you cannot control your environment. However, before doing it, you will spend time doing your ‘mindlessness’ activities, then go out for the challenging, but positive, activity with someone who you feel safe and comfortable with, then come home and rest and do more ‘mindlessness’ activities.

You will probably still find it tiring and stressful going out for the challenging, but positive, activity, but I promise you will also enjoy it. It will get a bit easier each time.

Over time, you might feel up to trying to do one challenging, but positive, activity every week, or even more than once a week. However, don’t overdo it.

I’m not saying that doing the above things will immediately make you feel fine and make life easy. However, I think that trying to do the above things will help you to feel a bit less awful, and make life feel slightly easier. I encourage you to persevere with trying to do the above things each day. Gradually, over time, hopefully, you will start to feel a bit better each day, and you will find life a bit easier each day. There will be times when you will feel like you are slipping backwards into your depression. That is normal and okay. Keep persevering. Each day is a new day. In fact, each hour is a new hour, and each minute is a new minute. If something goes wrong to ruin your vibe, let go of the last day, or hour, or minute, and start afresh with a new minute, hour, or day.

Do not compare yourself to other people, and do not judge yourself by anyone else's standards. Other people are not dealing with what you are dealing with.

***

If you are a teenager who has ASD/Aspergers, you will most likely need your parents, and/or a psychologist who specialises in ASD/Aspergers, and/or a support person to help you to carry out the above suggestions for how to cope with emotional issues.

All of the **emotional issues** I have mentioned in this section can affect people of any age who have ASD/Aspergers, but they **especially affect teenagers with ASD/Aspergers**. However, with the right help, teenagers with ASD/Aspergers can learn how to better verbalise, and/or otherwise express/release, and cope with their emotional issues, and these issues can greatly improve once they have settled into adulthood.

DIFFERENT LEARNING NEEDS (& THOUGHT PROCESSING & COMMUNICATION ISSUES):

People with ASD/Aspergers process information differently to most people, and so they tend to have their own ways of learning. This does not mean that they are any less intelligent than most people. In fact, many people with ASD/Aspergers are very clever at certain things, especially when they are young children:

> "…early ability to read and comprehend above our years (hyperlexia) gives some young Aspergirls an air of intellectual maturity that tricks people into thinking we possess emotional maturity as well." (*I have added underlining)*.

However:

> "This skill levels off as we get older."[xv]

Some people with ASD/Aspergers are very clever at certain things throughout their whole lives.

The environment at 'mainstream schools', and the way things are taught in mainstream schools, might not always be an ideal way of learning for people with ASD/Aspergers. Often people with ASD/Aspergers find their own ways of learning:

> "We like to teach ourselves just about anything we're interested in, not only because of impatience but also because we have our own methods for ingesting and comprehending. We might not "get it" from other's instructions, particularly verbal ones, and we take information in, in our own way."[xvi]

Some things that can affect a teenager with ASD/Aspergers' ability to learn are:

- They are usually attending a mainstream school, where they have to cope with:
    - Sensory issues;
    - Not always feeling that they are able to stim when they want/need;
    - Lessons that don't always fall within an area of their intense interests;
    - Social issues;
    - Not being taught in a way that suits the way they process information.
- "…sensory processing difficulties; shutting down under pressure or around others."[xvii] (e.g., at school).
- "AS* makes it difficult to learn from where you have been. It makes it difficult to generalize and problem solve."[xviii]
  *(*AS stands for Asperger's Syndrome).*
- "…children with Asperger's have a higher rate of fluid intelligence…ability to see order in confusion, to…understand the relationships of seemingly unrelated things…not have higher crystallised intelligence (the ability to use acquired knowledge and skills)…"[xix]
- Short term memory issues.

No two people with ASD/Aspergers are exactly the same. They don't all have the same learning strengths and weaknesses. Some general suggestions that might help some students with ASD/Aspergers to cope with their schoolwork are:

- Minimising stress factors in the learning environment, such as:
    - Change;
    - Sensory triggers;
    - Social triggers;

  and providing emotional support when needed.
- Spending short periods focusing on set work, followed by relaxation.
- Breaking down information into smaller sections, presenting only the relevant information, and using a larger font.
- Allowing extra time to process information and to complete work.
- When teaching abstract based tasks, using clear 'building block' steps, examples, and visual demonstrations, and generally providing extra support.

Some children with ASD/Aspergers do not seem to have any obvious problems with their schoolwork when they are in primary school. That is probably because, in primary school, the teaching methods tend to follow the above guidelines.

This is another reason why ASD/Aspergers is often not diagnosed earlier.

A lot of students with ASD/Aspergers do have difficulty with schoolwork, whether this difficulty starts at primary school, or not until high school.

Once a child reaches high school, the amount and complexity of schoolwork increases greatly, and there is pressure to do a lot more, even outside of school. This is combined with the unfamiliar environment and social aspects of high school, and the changes of going through the new developmental stage of adolescence. All of these factors are stressful for most teenagers. However, **for a teenager with ASD/Aspergers, the level of stress caused by these factors is much more severe, confusing and complex than it is for most teenagers.**

Once a child/teenager with ASD/Aspergers gets settled into high school, ideally with appropriate measures in place to help them cope, OR if they are able to do their schooling in a less stressful learning environment than a mainstream school, they might be able to again do well with their schoolwork.

For students in Year 11 and 12, the amount, complexity and pressure of schoolwork tends to become even more intense, as does the pressure of working out what they're going to do once they finish high school. Some students with ASD/Aspergers will cope up until this point, and then start to have difficulties.

Many children/teenagers with ASD/Aspergers need a lot of help to adjust to the change of going from primary school to high school. They might then reach a further 'crisis' point in Year 11 and 12, and need further help to adjust. *(This handbook contains a section called "Difficulty with Change", which explains this topic).*

However, <u>some</u> people with ASD/Aspergers might <u>never</u> be very good at mainstream schoolwork, OR they might do well with their schoolwork at primary school, but <u>never</u> be very good at mainstream high school work. It's important to let them know that mainstream schoolwork and/or testing is not the only measure of a person's intelligence and/or abilities, and that some qualities just can't be measured. **They need to be reassured that they are valuable whether or not they are good at mainstream schoolwork.**

Once a student with ASD/Aspergers finishes high school, the next stage in their life might be another 'crisis' point for them, as it is yet another <u>big change</u> in their life. Whether they are starting university, TAFE, or some other educational course, or trying to get straight into the workforce, or whatever else they might be doing with their life, again, they will likely need further help to adjust. *(This handbook contains a section called "Difficulty with Change", which explains this topic)*.

<u>Some</u> students with ASD/Aspergers <u>are very good</u> at academic learning, and don't tend to have difficulty with their schoolwork, even once they reach high school. It might mainly be the sensory and/or social aspects of high school that cause them difficulty and/or distress. They might even go on to university and do very well with university studies.

Different Learning Needs & Thought Processing & Communication Issues:

Because people with ASD/Aspergers process information differently to most people, and often have difficulty expressing themselves ‘verbally’, it affects their ability to communicate. This can cause social issues, and can also impact their ability to participate in the mainstream school environment.

Some people seem to have a notion that when someone asks you a question, and you have to answer immediately, without thinking, that the first thing you say, i.e., the first thing that comes to your mind, reflects what you truly think. This is usually not the case for someone with ASD/Aspergers.

When a person with ASD/Aspergers is asked a question, they usually need plenty of time to answer. It helps if they do not feel pressure to answer quickly, or that there is a right or wrong answer. It also helps if the question is asked in a calm and gentle tone of voice, but phrased in a direct, unambiguous manner.

If it is a very simple question, or a question about something that they know very well and have already thought about a lot, especially recently, a person with ASD/Aspergers might be able to answer straight away. However, if this is not the case, they will usually need to take a bit of time to answer. Sometimes, even a question that might seem very simple to most people, requires a lot of thought for a person with ASD/Aspergers.

Sometimes, a person with ASD/Aspergers will simply not be able to answer a question ‘on the spot’, in a meaningful way. They might have to consider the question at another time, when they are feeling relaxed, and able to focus, in an environment without distractions, such as in a quiet spot in the school library, or alone in their bedroom, and come back with their answer at a later time, or even the next day.

Apart from sensory issues, or emotional issues, there are some ‘thought processing’ reasons why people with ASD/Aspergers often need more time than most people to be able to provide a verbal response to a question asked verbally.

Firstly, some people with ASD/Aspergers think in very unique ways. Temple Grandin, who is a well-known scientist, animal behaviorist and author, who happens to have ASD/Aspergers, has written about how she thinks in pictures. This means that in order to speak or write, she has to first translate her thoughts into words.

Secondly, when faced with a lot of information all at once, a lot of people with ASD/Aspergers find it difficult to discern which points are important, and/or valid, and/or relevant. When a person is asked a question, they have to retrieve the relevant information from their brain, in order to provide a response. This process tends to take longer for people with ASD/Aspergers. They might know which set of information in their brain will likely contain the answer, but they still might find it difficult to discern, from that set of information in their own brain, which points are important, and/or valid, and/or relevant to the question.

An example of how this can affect how well, or how quickly, a person with ASD/Aspergers can provide a meaningful verbal response to a question asked verbally, from my own experience, is:

> If someone asks me a question and I don’t answer straight away, it does not necessarily mean that I have not heard, or do not understand the question, and it usually doesn’t mean that I am ignoring the question. If I don’t understand a question, I usually ask for clarification, and I don’t tend to ignore questions. Rather, it usually means that I am processing the question, and searching through the information in my brain to be able to provide a true and meaningful answer. It might take me a little bit longer than most people to focus, pinpoint the relevant information in my

brain, assess whether it is accurate, and/or whether it reflects what I genuinely think or feel, and then for the words to come out of my mouth in an intelligible manner.

Sometimes, I am pretty sure that I know what my answer is likely to be, but I still feel the need to scan through all the other possibilities, from the relevant set of information in my brain. I think that when I do this, it's because I want to make sure that my answer reflects what I actually think or feel, as opposed to being just a standard, acceptable response that I feel is the response that the other person wants or expects.

If, whilst I am doing this, the other person repeats the question, because they think I haven't heard, they are interrupting my thought process, and I'll have to go back to the beginning and start again. If the other person rephrases the question because they think I haven't understood, or if they tell me to hurry up and answer, again, they are interrupting my thought process, and I'll have to go back to the beginning and start again. This sort of scenario becomes frustrating for both of us, and I will realise that the other person is getting impatient with me, so I will just give a standard, acceptable response that I feel is the response that they want or expect, even though it might not reflect what I actually think or feel. Or, I might simply agree with them, even if I don't know if I actually agree with them. Or, I might simply say, "I don't know," when what I really mean is, "I need time to retrieve the relevant information from my brain."

Sometimes, when responding to a question, I speak out loud my thought process. When I do this, the first thing that I say is not necessarily going to be my final answer. However, because I will probably pause whilst speaking out loud my thought process, the other person might think that I am finished speaking, and that I have already said my final answer. The

> other person might start speaking, and the conversation will move on. Therefore, the other person might think that they know how I think or feel in response to that question, when they really don't, because I haven't yet been able to provide my final response.

Some people with ASD/Aspergers who find it very difficult, if not impossible, to explain or express 'verbally' something that is complex, can express themselves perfectly well in writing. In fact, they might be able to write very eloquently. This is because writing gives them time and a method to order their thoughts.

Personally, when I start writing about something, I tend to want to list all the information that comes to my mind, i.e., usually too much information for the specific question I am trying to answer. However, once I write it down and see it on paper (or on the computer screen), I can rearrange it into a sensible order, assess whether it is accurate, and/or whether it reflects what I genuinely think or feel, pinpoint which information is relevant, and delete the unnecessary information. I can also edit what I've written, to pick the most appropriate words and phrasing, to make it clearer for the reader, and avoid misinterpretation.

Some people might say that the preceding paragraph is simply the definition of writing, as an art form. I agree. The point is, you can't do that when you are taking part in a 'real time' verbal conversation. This is not a problem for most people, but it is often a problem for people with ASD/Aspergers.

If this is the case for a student with ASD/Aspergers, in certain scenarios, where students are usually expected to speak out loud, and 'on the spot', a student with ASD/Aspergers might need to be given the option of expressing themselves in writing instead, and not be expected to provide their answer(s) 'on the spot'.

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Thinking in unique ways, and thought processing issues, can make psychotherapy especially tricky for a teenager with ASD/Aspergers. Sometimes, psychologists ask questions that are not obviously related to why their patient is undertaking psychotherapy, but are designed to gauge their patient's response to certain things. However, a person with ASD/Aspergers might not interpret, or respond to these sorts of questions in the way that most people would. If they feel that the question is unrelated to why they are undertaking psychotherapy, but is just meaningless small talk, they might just give a standard, acceptable response, without thinking about what they actually think or feel in response to the question, so that they can get on with discussing things that are related to why they are undertaking psychotherapy. OR, they might overthink the question, trying to figure out what the psychologist is trying to find out from them, but they might not interpret this correctly. Either way, the psychologist might not actually be getting the information they are seeking, even though they might think that they are.

Different people with ASD/Aspergers have different language abilities. Personally, I love figurative language, and find analogies helpful. In fact, sometimes I find it easier to use analogies, when I am trying to 'verbalise' what I am trying to express, than to speak in plain, literal, language. However, many people with ASD/Aspergers simply cannot understand figurative language.

Because of these issues, it can take a lot longer for a psychologist to get to know a teenage patient with ASD/Aspergers, than it would it would take them to get to know most patients. In any of the above scenarios, a person with ASD/Aspergers needs a psychologist who will get to the point and speak to them in a direct, unambiguous manner, and give them plenty of time to respond, without interrupting. However, it will still take time for the psychologist to learn the best way to speak to that particular teenager with ASD/Aspergers, and to correctly interpret the way that particular teenager with ASD/Aspergers verbally expresses themselves.

This is one of the reasons why, when undergoing psychotherapy, teenagers with ASD/Aspergers need a good psychologist who specialises in ASD/Aspergers, and whom they feel comfortable with, and they need to be able to continue to see this same psychologist for the long term, on a regular, ongoing basis, in order to benefit from the psychotherapy sessions.

Different Learning Needs & Emotional Issues:

Due to the extreme levels of stress and confusion experienced by teenagers with ASD/Aspergers, many teenagers with ASD/Aspergers develop depression. **Depression affects people emotionally, mentally and physically, which, understandably, makes it very difficult to focus on schoolwork.**

Teenagers with ASD/Aspergers who are experiencing depression, and who are having difficulty with their schoolwork as a result, need to be reassured that they need not be concerned about their schoolwork. Their mental wellness must come first! Once their mental health improves, they might be able to focus on things like schoolwork again. If they are keen to continue with schoolwork, there is no time limit. They can always come back to it at a later date and do it at a pace that suits them. They might just have to do it through TAFE, rather than at a high school, depending on their age.

However, teenagers with ASD/Aspergers and their parents need to be aware that **some teenagers with ASD/Aspergers might never be able to cope with schoolwork or academic work past a certain point**. This might be due to their mental ability OR their mental health. Some people with ASD/Aspergers are very intelligent, but are unable to achieve a high level of 'certified' education, due to the stress they experience when constantly trying to focus on schoolwork or academic work, and/or dealing with change, sensory, social and emotional issues.

To keep pushing a teenager with ASD/Aspergers to continue with their schooling, when they are not coping (either due to mental ability OR mental health), can be extremely detrimental to their mental health. This can be difficult for a teenager with ASD/Aspergers and/or their parents to accept, because society tends to place a high importance on mainstream schooling and academia. However, they might need to learn to accept that they have to let it go, and focus on doing things that they can achieve without too much stress, and that make them feel happy.

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In an ideal world, all students with ASD/Aspergers would be able to attend schools/ have teachers who could, and would, tailor their teaching methods to suit the needs of their students with ASD/Aspergers. Unfortunately, it is not an ideal world.

People with **very severe ASD traits/symptoms** would likely be diagnosed at an early age. They might then be put into a special class or school for children with special learning needs, where the teachers would have training in this area, and would be able to tailor their teaching methods to suit the children's needs (although, in reality, there are not enough of these school settings, and they are extremely difficult to get into). **However, these types of special classes or schools tend to be for children with a 'lower learning ability'*.**

*(*By 'lower learning ability' I do not necessarily mean 'less intelligent'. I simply mean that their particular combination and severity of ASD traits/symptoms are such that they are unlikely to be able to process, retain and express the information taught in the mainstream school curriculum, to the extent that they would be able to reach a level of 'certified' education that is equal to the mainstream school curriculum).*

One of the reasons why some people with ASD/Aspergers are not diagnosed with ASD at an early age is because **they have a 'normal'** level of intelligence and **ability to learn**, and do well (or at least okay) with their schoolwork when their mental health is good, when their sensory and social issues are not too severe, or are not being overly tested, and when they are not overloaded with too much schoolwork or change at once. That is, they have a **combination of ASD traits/symptoms that are <u>less</u> obvious, or <u>not</u> obvious at all, to most people (or what I sometimes like to call Aspergers)**. Therefore, the types of classes or schools described in the preceding paragraphs would not be suitable for them.

That means that **children/teenagers with what I sometimes like to call Aspergers are <u>usually</u> attending mainstream schools and 'normal' classes, where the teachers do not always have a great level of knowledge or understanding of ASD/Aspergers**.

Once a child/teenager is diagnosed with ASD, their parents can obtain assistance for them with their different learning needs from ASD support people, such as a psychologist, and/or occupational therapist, and/or speech therapist, and/or someone to provide one-on-one tutoring sessions, if necessary. These ASD support people can make recommendations to their school of measures for their school to implement, to help the child/teenager with ASD/Aspergers to be better able to cope and learn at school. However, the process for obtaining, and putting in place, such specialised ASD support is neither quick, nor easy, as I will explain later on in this section of this handbook, at pages 140-145.

Further, some children with ASD/Aspergers are not diagnosed until they are teenagers. Without a diagnosis, they will NOT be able to obtain the sort of specialised support with their learning that is described in the preceding paragraph. Many teenagers with undiagnosed ASD cannot cope at high school, and leave school early, before they can receive such specialised support.

If a child/teenager is diagnosed with ASD, it is important that their parents inform their school and speak to their teachers about their child/teenager's particular needs. If a school student has a diagnosis of ASD, and their school has been informed, the school is required by law to allow/cater for the needs of the student with ASD. This might involve creating an adjusted learning plan. Currently, the official name for an adjusted learning plan is a One Plan, or a Negotiated Education Plan (NEP for short), or a Personalised Plan for Learning (PPL for short), depending on the school.

There are some fantastic mainstream schools, and some fantastic mainstream teachers, who cater very well for students who have a diagnosis of ASD, with the help of the sorts of specialised ASD support people mentioned above.

However, some schools, and some teachers are better than others. If parents are not satisfied that their child/teenager's teacher(s) are adequately catering to their learning needs, then they need to speak to someone higher up at their child/teenager's school. By this I mean, firstly, the Inclusive Education Co-ordinator (or equivalent person), and if this does not result in an improvement, then parents might need to speak to the middle school co-ordinator (or senior school co-ordinator, depending on their teenager's year level), or even the principal of their teenager's school. I do NOT mean the student counsellor.

There is also a big difference between public and private schools, and the way they are able to cater to students with a diagnosis of ASD.

Each school in South Australia is allocated a bulk amount of funding from the Government to cater for the needs of their students with disabilities. This funding is used by each school to pay for Inclusive Education support staff, and to provide a small budget for the Inclusive Education team at each school to use to purchase resources for assisting their students with disabilities.

For some students with a diagnosis of ASD, certain public schools might be better able to cater to their needs. However, due to many factors, the Inclusive Education support staff and resources available at many public schools are simply not enough to adequately meet the needs of all their diagnosed students, especially teenagers with what I sometimes like to call Aspergers.

For some students with a diagnosis of ASD, a private school setting would suit them much better. Of course, for many parents, a private school is simply not an option, for financial reasons.

Suggestions for How to Cope with Different Learning Needs:

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents and school understand your different learning needs. For this reason, it is important that your parents inform your school if you have a diagnosis of ASD.

To do this, parents should contact the Inclusive Education Co-ordinator (or equivalent person) at their teenager's school, advise them of their teenager's diagnosis of ASD, and provide them with a copy of their teenager's ASD diagnosis/assessment report (and any other relevant reports that they might have). The school should then organise for a copy of the report(s) to be given to their teenager's teachers. If parents don't know who the Inclusive Education Co-ordinator at their teenager's school is, or how to contact them, they should ask the staff at the school Office.

Reading this handbook, and using some, or all, of the suggestions in all the different sections can help (especially if you use the suggestions when you are at school, and/or when you are doing schoolwork and/or homework).

In the section of this handbook called "Stimming", at pages 53, and 60-62, I have given some suggestions of how to use stimming and what I call 'mindlessness' activities, to help you to focus, recall information and concentrate, which you might find particularly helpful when doing schoolwork.

The above might be all you need, especially if you have good family support. However, many people with ASD/Aspergers need much more help/support with their different learning needs.

Each teenager with ASD/Aspergers is different, but many will need:

1. Shorter lessons and/or fewer lessons each day, with breaks during lessons and/or in between lessons. **Mainstream schools should be able to cater to this, for students who have a diagnosis of ASD.**

2. Lighter schoolwork load. **Mainstream schools should be able to cater to this, for students who have a diagnosis of ASD. This might be achieved by what is called a 'modified program'.**

3. A safe, private, quiet space, such as a designated room at the school, where they can go during their breaks to rest, and/or use their sensory buzzers, and/or stim, and/or engage in their intense interests. They need this to recover from/cope with the stress that being at school causes them, due to, among other things, sensory overload, social issues, and having to try to understand and learn the information that is being presented to them in class in a way that they might find difficult to process. **Mainstream schools should be able to provide such a space for students who have a diagnosis of ASD.**

4. A 'special tutor' who is <u>trained in ASD/Aspergers</u> to provide one-on-one teaching sessions to help break down and explain the homework from 'in class' lessons, to ensure that the teenager with ASD/Aspergers understands what they are being asked to do. If the teenager with ASD/Aspergers doesn't understand something from their 'in class' lessons, the tutor can explain/present the information in a way that the teenager with ASD/Aspergers is better able to understand. **<u>Some</u> mainstream schools might be able to provide an Education Support Officer (ESO for short), or a School Services Officer (SSO for short) to act as a 'special tutor' on campus, for students who have a diagnosis of ASD.**

However, if a teenager with ASD/Aspergers needs a 'special tutor', their parents might need to find them a private tutor outside of school.

5. A psychologist who <u>specialises in ASD/Aspergers</u>, who the teenager with ASD/Aspergers can meet with regularly (ideally weekly), to talk about any problems they are experiencing, including confusion about their sense of identity. **Mainstream schools do not have such a person on campus.**

   Most teenagers with ASD/Aspergers WILL need a psychologist who <u>specialises in ASD/Aspergers</u>. Their parents will need to find them a private psychologist outside of school.

Ideally, I think it would be fantastic if all mainstream schools could have special ASD/Aspergers trained tutors and psychologists on campus, as outlined above. In reality, this is not the case. **There are some <u>special</u> schools in South Australia that have ASD trained teachers, psychologists, occupational therapists and speech therapists on campus. However, these schools are designed to cater for students with 'more severe' ASD traits/symptoms.**

This is why it is so important for children/teenagers with ASD/Aspergers to be able to obtain a diagnosis of ASD as early as possible. The sooner they can obtain a diagnosis of ASD, the sooner they can be set up with appropriate ASD support people, and an appropriate One Plan, NEP or PPL can be put in place for them. **This should hopefully improve not only their ability to learn, but their <u>whole schooling experience</u>, including the social and emotional aspects of school, all of which can greatly impact the mental health of a child/teenager with ASD/Aspergers.**

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A Further Note to Teenagers Who Are Reading This Handbook:

There is no need for you to read the rest of this section of this handbook. It is designed for your parents’ information. You can go straight to the next section of this handbook, which is called “Eating and Stomach Issues”, and continue reading from there.

<u>Steps for How to Obtain and Put in Place Specialised ASD Support to Help Your Teenager to Cope with their Different Learning Needs at School:</u>

What actually needs to happen, in the order set out below, is:

1. The parents of the teenager with ASD/Aspergers need to obtain a diagnosis of ASD for their teenager (*see my website for how to do this)*. The diagnosing psychologist will prepare an ASD assessment report that will include recommendations for the specific learning needs of the teenager with ASD/Aspergers.

2. The parents of the teenager with ASD/Aspergers can provide the psychologist's ASD assessment report to their teenager's mainstream school, **and the school <u>should</u> do it's best to implement the relevant recommendations contained in the report**. If recommended in the report, the teenager's teacher(s) are required by law to develop a One Plan, NEP or PPL based on those recommendations. However, the teacher(s) will not likely be 'specialists in ASD/Aspergers'.

   Most schools should have ESOs and/or SSOs employed to support students with One Plans, NEPs or PPLs. An ESO or SSO <u>might</u> be able to spend <u>some</u> time acting as a 'special tutor' for the teenager with ASD/Aspergers, but in many cases, they won't be able to spend as much time helping the teenager with ASD/Aspergers as they actually require. Further, ESOs or SSOs employed by the school will not necessarily be specialists in ASD/Aspergers.

3. The parents of the teenager with ASD/Aspergers need to apply for, be approved for, and obtain NDIS funding (*see my website for how to do this)* for, among other things, regular ongoing sessions with a <u>psychologist who specialises in ASD/Aspergers</u>, and/or assistance from other ASD support

people, if necessary (unless they are wealthy enough to be able to afford this out of their own pocket, which few people are).

4. If necessary, the parents of the teenager with ASD/Aspergers can then engage an ASD trained occupational therapist (OT for short) to attend and observe the teenager with ASD/Aspergers at their school. The OT can then prepare a report setting out recommendations for adjustments to be made to the schooling experience of the teenager with ASD/Aspergers, to help them to cope. This report can be provided to the school, **and the school <u>should</u> do its best to implement any recommendations contained in it**.

5. If a teenager with ASD/Aspergers needs an occupational therapist, they might have sessions with the OT at school (for which they will leave their classroom), and/or they might have sessions with the OT outside of school to help them to learn how to cope with mainstream school, among other things.

6. If necessary, the parents can also engage an ASD trained speech therapist. If a teenager with ASD/Aspergers needs a speech therapist, they might have sessions with them at school (for which they will leave their classroom), and/or they might have sessions with them outside of school.

7. The speech therapist might also provide a report, which can be provided to the school, **and the school <u>should</u> do it's best to implement any recommendations contained in it**.

In reality, even with the above measures, mainstream schools still aren't always able to implement all of the recommendations of the psychologist, and/or occupational therapist, and/or speech therapist to an adequate level.

It’s also important to note the following:

- NDIS funding cannot be used to support anything related to education. This might sound confusing, given what I’ve mentioned above. NDIS can be used to fund occupational therapists, and/or speech therapists, and/or psychologists. However, these sorts of ASD support people will be helping students who have ASD/Aspergers with things like their sensory needs, communication needs, emotional needs and thought processing needs, in order to help them to be better able to cope with attending school, and to be better able to complete their schoolwork. They will not be teaching them the school curriculum;

- Schools are not required to allow allied health professionals* to provide therapy sessions during the school day (*i.e., occupational therapists, and/or speech therapists, and/or psychologists).

  This is because schools are legislated to teach students for a minimum of 5.5 hours per day, up to a maximum of 5.75 hours per day. If students need to attend therapy sessions, this needs to done outside of school, to allow students access to the maximum school time, because many students with special needs miss vital lesson time, and there’s no provision for them to catch up.

Many teenagers with ASD/Aspergers will need regular ongoing sessions with a psychologist who specialises in ASD/Aspergers to help them to cope with the changes they are going through as they are growing up, to help them understand the world, and themselves, to help them with issues of their sense of identity, and to talk through any problems they are experiencing, especially problems that they are experiencing due to issues related to their ASD/Aspergers.

If a child/teenager with ASD/Aspergers is very good at academic learning, they might not need a special tutor (they might not even need a One Plan, NEP or PPL, or a 'modified program'). If they do need a special tutor, and the person provided at their school to perform this role is not adequate, or if their school does not provide such a person, then the parents of the teenager with ASD/Aspergers might need to find them a private tutor outside of school.

If a child has not been diagnosed with ASD until they are a teenager, due to the fact that they have a combination of ASD traits/symptoms that are <u>less</u> obvious, or <u>not</u> obvious at all, to most people, they might not need an occupational therapist or speech therapist. OR it might not <u>seem</u> like they need an occupational therapist or speech therapist.

However, even a teenager with what I sometimes like to call Aspergers might still benefit greatly from having an occupational therapist walk and talk them through specific activities that they find difficult, teaching them what to do, on site, and repeating this process on a regular basis, until the teenager with ASD/Aspergers becomes comfortable with these activities.

The sorts of activities I am thinking of are things like catching a bus, going shopping, or cooking <u>by themselves</u>. These are activities that a neurotypical (i.e., 'normal') teenager would be able to do by themselves without difficulty. However, a teenager with ASD/Aspergers, even if they are good at their schoolwork, and even if their ASD traits/symptoms seem to be 'less severe', might have great difficulty with such day-to-day activities. They might also need 'refresher' courses from time to time. **(I am not 100% sure that this is the sort of thing an occupational therapist would actually do)**.

Even if a teenager with ASD/Aspergers can speak perfectly well in situations where they feel comfortable, they might still benefit from sessions with a speech therapist to help them learn ways to cope with speaking in certain social situations, where they don't feel comfortable, and how to say what they really mean, which some people with ASD/Aspergers find incredibly difficult to do. A speech therapist might also be able to help a teenager with ASD/Aspergers to better understand/interpret some of the different ways in which neurotypical people speak, which people with ASD/Aspergers often find confusing. **(I am not 100 % sure that this is the sort of thing a speech therapist would actually do).**

Many people with ASD/Aspergers cannot cope with having an overly busy schedule, where they have to attend a lot of formal activities, and/or engage with other people, especially if it involves a lot of different people for each activity. They often need a lot of down time at their home to rest and recover between activities.

However, as I've described in this section so far, the child/teenager with ASD/Aspergers might be expected to attend, on an ongoing, regular basis, possibly a psychologist, and/or possibly an occupational therapist, and/or possibly a speech therapist, and/or possibly a private 'special tutor', possibly all outside of school, in order to help them to cope at a mainstream school, on top of attending school, rather than having all the support they need actually at their school. Their parents will need NDIS funding to pay for all of this specialised support/treatment, unless they are wealthy enough to be able to afford it out of their own pocket.

A diagnosis of ASD can be difficult to obtain, and can take a long time to obtain. For someone with what I sometimes like to call Aspergers, it can take years of misdiagnosis before getting the correct and much needed diagnosis, in order to be able to obtain the correct and much needed support/treatment.

NDIS funding can only be applied for and obtained after a person has been diagnosed with a recognised ‘disability’, such as ASD. Once applied for, it can take months to be approved for, and to obtain the NDIS funding ready to use, and it can be difficult to obtain an adequate level of NDIS funding.

Once NDIS funding is obtained, it can be difficult for parents to work out exactly what sort of support/treatment will best suit the specific needs of their teenager with ASD/Aspergers. Not all ASD support people are equal, and it can be very difficult for parents to find ‘good’ ASD support people who will best suit the specific needs of their teenager with ASD/Aspergers. By ‘good’, I mean ASD support people who their teenagers feel comfortable with, and who are well trained in the most up-to-date knowledge and understanding of the issues and needs of people with ASD/Aspergers, and how different the issues and needs of each person with ASD/Aspergers can be.

Although it is often unavoidable, it is not ideal for parents to take their teenagers with ASD/Aspergers to see one support person after another, or to try one treatment/therapy activity after another, in a sort of trial and error approach, to see what works. People with ASD/Aspergers (and especially teenagers with ASD/Aspergers) tend to not be able to cope with trying one thing after another that doesn’t work. It will likely put them off trying any further new support people or treatment/therapy activities. And who can blame them? Therefore, parents need to take care to do their research and find 'good’ ASD support people to start with, which is much easier said than done.

(My website contains a section called “Therapists, Clinics and Services That I Recommend, or Have Been Recommended to Me, for Teenagers with ASD/Aspergers, In South Australia”, which could help you to find good therapists and clinics that specialise in ASD/Aspergers).

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I am not saying all of this to discourage teenagers with ASD/Aspergers, or their parents, but, rather, to prepare them for what to expect. I believe that obtaining the appropriate support/treatment/therapy for a teenager with ASD/Aspergers is well worth it, and in fact, can be life-changing (for the better).

It can take many months, even years, to obtain a diagnosis of ASD, AND the NDIS funding needed, AND get the correct and much needed support/treatment/ therapy in place, but you will never reach that point unless the process is started. Therefore, **if parents suspect that their child might have ASD/Aspergers, I strongly recommend that they start the process, by seeking a diagnosis as soon as possible.**

If their child does not receive a diagnosis of ASD the first time they are assessed, but their parents still feel that their child is having difficulties, I strongly recommend that they seek a diagnosis again, either with a different ASD assessor, or at a later date.

In the meantime, if they are able, parents of teenagers with ASD/Aspergers might find themselves trying to perform the roles of special tutor, psychologist, occupational therapist, and speech therapist to their teenagers with ASD/Aspergers, to the best of their untrained ability. This is on top of their other 'normal' parenting, family and domestic duties.

In reality, many parents of teenagers with ASD/Aspergers are not able to do this to a great degree. It might be beyond their ability, or they might not have the time, because most parents have to work in a paid job to provide food and shelter for themselves and their children. If a teenager with ASD/Aspergers has two parents who are together, then one parent might be able to stay at home and provide their teenager with ASD/Aspergers with the extra support that they need, whilst the other parent works in a paid job to provide food and shelter for their family.

However, if a teenager with ASD/Aspergers is living with a single parent who is their sole, or main financial provider (by means of a paid job), then it is very difficult for that parent to provide their child with the level of 'non-financial support' they need, due to their lack of time. Many single parents are their child's sole, or main providers of 'actual parenting' (i.e., non-financial support), as well as their child's sole, or main financial providers.

Some parents of teenagers with ASD/Aspergers apply for, and are able to, obtain a Carer Payment to live on (as opposed to a paid job, or only a paid job), so they can stay at home to provide their child with the level of non-financial support that their child needs (*see my website for how to apply for Carer Payment)*.

However, for a parent to be eligible for Carer Payment to care for their child, they need to meet the means test, and their child needs to have substantial medical needs, which, in the case of ASD/Aspergers, usually refers to mental health or mental ability issues (though not lack of intelligence). Not all parents of teenagers with ASD/Aspergers will be eligible for Carer Payment, due to either their financial situation, or their child's mental health and abilities. If a parent is eligible for Carer Payment to care for their child with ASD/Aspergers, their child will definitely have needs that require specialised professional support/treatment.

Carer Payment does not provide enough money to pay for such specialised professional support/treatment**.** As I've already mentioned, most parents of teenagers with ASD/Aspergers (and especially those on Carer Payment) will need NDIS funding for this, and the amount of NDIS funding is not always enough.

Without the appropriate specialised ASD support/treatment, some teenagers with ASD/Aspergers might develop such severe anxiety regarding attending school that they can no longer cope with attending a ‘face-to-face’ school. Once they leave face-to-face school, it can be very difficult to get them to go back, because once a person with ASD/Aspergers has a bad experience with something, it can put them off it forever, and they won’t want to try it ever again. Also, they might be suffering from PTSD in relation to attending face-to-face school.

There are other schooling options, such as online learning. Some teenagers with ASD/Aspergers like, and can cope with, online learning. However, online learning does not provide the teenager with ASD/Aspergers with much needed opportunities to practise social skills. They will need to attend some other form of face-to-face socialisation, likely organised and facilitated by their parents. Some teenagers with ASD/Asperger do <u>not</u> like, and <u>cannot</u> cope with online learning. They might find it to be too abstract and confusing, with too many ‘IT tools and processes’ they have to learn how to use, on top of doing the actual learning and schoolwork.

Further, if a teenager with ASD/Aspergers is doing their schooling via online learning, they will need to be supervised by their parents (yet another thing that their parents have to find time to do!)

These are all more reasons why it is so important for parents of children/teenagers with ASD/Aspergers to be able obtain a diagnosis of ASD for their children/teenagers as soon as possible - to try to avoid their teenagers getting to the point where they leave face-to-face school early in the first place!

Even if a teenager with ASD/Aspergers does leave face-to-face school early (and this is the best option for some teenagers with ASD/Aspergers), if they have already obtained a diagnosis of ASD before they get to that point, they will hopefully already have ASD support people in place to help them with this transition, as opposed to their parents having to provide all of the support that their teenager needs.

Leaving school is a big life change. People with ASD/Aspergers have great difficulty with change, even if it is a change that they want. **When a teenager with ASD/Aspergers leaves school, they will likely need a lot of emotional support, help figuring out what to do with their life and how to do it, and help to actually do it**.

I am sorry if a lot of the information in the ‘Suggestions for How to Cope With Different Learning Needs’ section of this handbook sounds negative and/or disheartening. I hope that in time, the mental health system, education system and government funding system will improve greatly with regards to providing adequate, appropriate assistance for teenagers with ASD/Aspergers that is more streamlined and is quicker and easier to obtain. However, it wouldn’t be very helpful if I was not truthful about the difficulties involved with the systems that are currently in place.

That is indeed why I have written this handbook, and created my website, to empower parents to be able to help their teenagers with ASD/Aspergers to receive the support/treatment that they need, by informing parents about what sorts of support/treatment their teenagers with ASD/Aspergers are likely to need, and the process for obtaining it. I also hope to empower teenagers with ASD/Aspergers to be better able to help themselves, and their parents to be better able to help/support their teenagers with ASD/Aspergers themselves, whilst they are going through the often long and difficult process of getting appropriate, specialised professional support/treatment in place.

EATING & STOMACH ISSUES:

Many people with ASD/Aspergers have eating and/or stomach issues, for many reasons, such as:

1. Sensory issues:

- Many people with ASD/Aspergers find it difficult to cope with the taste, texture or smell of certain foods, or how certain foods look (such as the colour), or how certain foods sound when eaten, so they might avoid those foods.

  If other people don't know that a person has ASD/Aspergers, and they notice that the person with ASD/Aspergers avoids many foods, often the other people misinterpret this behaviour, and simply think of the person with ASD/Aspergers as being a 'fussy eater'. However, **sensory issues are more severe and complex than the term 'fussy eater' suggests**.

  This is another reason why ASD/Aspergers is often not diagnosed earlier.

- Some people with ASD/Aspergers might find it difficult to cope with the sensation of bloating in their stomach when they are full, which might make them avoid eating.

- Some people with ASD/Aspergers might find it difficult to cope with the sensation of emptiness in their stomach when they are hungry, which might make them constantly want to eat to feel full.

- Some people with ASD/Aspergers might be less sensitive than most people to the sensations of hunger and/or bloating, and therefore either not eat enough food, or not know when to stop eating.

- Most people have certain foods that they enjoy eating, not just due to hunger, but for sensory pleasure. However, some people with ASD/Aspergers might find that eating in general, or eating certain foods, is a like a sensory buzzer or a stim for them. They might feel the urge to eat in general, OR to eat certain foods, not just due to hunger, but for sensory pleasure, more than most people do. This, in turn, might make them feel bloated, which they might find difficult to cope with.

- Some people can eat any type of food, and it won't upset their stomach. However, a lot of people will find that certain foods upset their stomach, at least a little bit. People with ASD/Aspergers tend to be more sensitive to a lot of things, including food, so they might have more foods that upset their stomach than most people do, or have foods that upset their stomach more than they would upset most people's stomachs.

Not eating enough of a variety of nutritious foods, OR not eating enough food in general, OR eating too much food, can make any person feel a bit nauseous, and/or bloated, and/or headachy, and/or tired. **Some people with ASD/Aspergers might not associate these sensations with the cause**.

2. **People with ASD/Aspergers tend to develop intense interests in certain things:**

   - They might become so engrossed in an intense interest that they forget to eat.

   - Some people with ASD/Aspergers might form an intense interest in diet, causing them to constantly think about, research and try different diets. This might not always be ideal, physically, and/or emotionally. Not all diets are ideal for all people. A person with ASD/Aspergers who develops an intense interest in diet might become fixated on their eating habits, and how these will affect them. **It might become a source of anxiety for them**.

3. **People with ASD/Aspergers are prone to experiencing anxiety and/or depression:**

   - Anxiety and/or depression can cause some people to lose their appetite and not eat enough, but it can cause some people to overeat (called comfort eating).

   - Depression causes people to lose motivation to do things, including eating, and/or obtaining, and/or preparing healthy food.

   - Experiencing high levels of anxiety, especially on a regular basis, or for a long period of time, is known to cause stomach issues.

- When people with ASD/Aspergers experience anxiety and/or depression, they are sometimes prescribed with antidepressant medication and/or antipsychotic medication (a person with ASD/Aspergers might also be prescribed with this sort of medication to treat other severe issues associated with ASD/Aspergers). Both of these types of medication can cause stomach upset, and can affect appetite.

4. Many people with ASD/Aspergers have one or more ‘physical gastrointestinal conditions’:

By ‘physical gastrointestinal condition’, I mean a condition that affects the way a person’s digestive system copes with food, that is not simply caused by the ASD/Aspergers symptoms of sensory issues, eating habits/behavioural issues, or anxiety or depression.

In her book, *Aspergirls (Empowering Females with Asperger Syndrome),* Rudy Simone refers to the fact that many people with ASD/Aspergers have a compromised intestinal tract.

Women with Aspergers who she interviewed reported experiencing one or more of the following gastrointestinal (or related) issues:

> “Chronic nausea, mild to severe food allergies (mostly wheat, dairy), migraines, guttate psoriasis, hypothyroidism, “malaise and fogginess from eating processed food,” irritable bowel syndrome (IBS), hiatal hernia, constipation, ulcers, heartburn; sensitive, irritated skin; chronic fatigue syndrome, fibromyalgia, food feels like glass in stomach, diagnosed leaky gut, strong sugar and salt cravings, complete lack of appetite, no interest in food.”[xx]

There are various diets that some people have recommended for people with ASD/Aspergers, to help with their physical gastrointestinal issues, and other ASD/Aspergers issues. However:

> "Because of taste, habit, budget, and time, most of us will never try these diets even if we had absolute proof that they worked, and so far that has largely been anecdotal."[xxi] (*I have added underlining).*

Suggestions for How to Cope with Eating & Stomach Issues:

If you have ASD/Aspergers, it can help if you have been diagnosed with ASD, and your parents, GP, and other support people understand your eating and stomach issues.

If your eating habits are not bothering you at all, and your parents and/or medical support people are not worried about your eating habits, then please ignore this section. Just continue with your current eating habits, and please do not focus on your eating habits.

1. Sensory issues:

If you have difficulty eating enough food, due to sensory issues, or just don't have much of an appetite, it is best to eat small amounts of food regularly throughout the day to keep your energy levels up, even if you don't feel hungry.

If you want to try to eat more food in general, and/or more healthy foods, for the sake or your health, this will probably involve trying to eat some food that you don’t particularly like, or that is new to you. To help yourself cope with the sensory difficulties or anxiety you might experience when doing this, you could try using one, or some, of your sensory buzzers and/or stims***** before, during and after you try the food that you don’t particularly like, or that is new to you.

*(*This handbook contains sections called “Sensory Issues” and “Stimming”, which explain sensory buzzers and stims).*

Because people with ASD/Aspergers tend to have difficulty with change*****, which includes trying to eat foods that they are not used to eating, it’s a good idea not to try eating too many foods that you don’t particularly like, or that are new to you, all at once. Try eating a little bit of one new food that you want to try, perhaps once a day, or only once a week, to start with, and build up from there.

*(*This handbook contains a section called “Difficulty with Change”, which explains this topic).*

Whilst it’s good for parents or other caregivers to encourage and provide opportunities for children/teenagers with ASD/Aspergers to try new food, it’s important that they do not force a child/teenager with ASD/Aspergers to eat food that they don’t want to eat. This can be incredibly traumatic for a person with ASD/Aspergers, and could put them off ever trying that particular food, or any new food, again, or at least not for a very long time.

Many people with ASD/Aspergers are never able to eat a great variety of different foods, and that is okay. However, if, due to your sensory issues, you are really struggling to find a balance of foods that you like/can cope with, and that also provide adequate nutrition, you might need the help of a nutritionist, and/or psychologist, and/or a food/eating therapist.

A nutritionist can help you to work out a balance of foods that you like/can cope with, and that also provide adequate nutrition. A psychologist who specialises in ASD/Aspergers, or a food/eating therapist can help you to learn ways to cope with eating food that you have sensory issues with, but that you need to eat in order to obtain adequate nutrition.

If you think you are eating too much food, and if this worries you, talk to your parents, and/or psychologist, and/or GP about it. You might not actually be eating too much food, after all.

If you are eating too much food, OR not enough food, an eating schedule might be helpful. To prepare and follow a suitable eating schedule, you will most likely need help from your parents. You might also need help from a nutritionist, and/or psychologist, and/or a food/eating therapist, ideally ones who specialise in ASD/Aspergers.

Many people with ASD/Aspergers like using schedules. However, some people with ASD/Aspergers find the idea of having a timetable/schedule to be stressful (like my daughter), because it can make them feel that there is a lot of pressure on them to do certain tasks/activities at certain times, and within a certain timeframe.

Please don't be put off by this. If you, and/or your parents, and/or a support person create a schedule to make sure you eat an appropriate amount of food, you don't have to strictly follow it all the time. It has been created as a guide only, to help you.

2. If you develop an intense interest in diet:

There are a lot of different diets out there. Some are good, but most of them are fad diets, and are not sustainable. Some might have adverse effects.

Generally, the best sort of diet for most people is a balanced diet of food from all of the five food groups, as per the food pyramid, a list of which is on the next page. It is also best for most people to limit the amount of processed food, fatty/oily food, and sugary food that they eat, to drink plenty of water, and to do regular exercise.

However, **if you find it too difficult to follow what most people would consider to be a 'good, balanced diet', please, just eat whatever you can. Many people with ASD/Aspergers might have certain foods that they cannot bring themselves to eat, due to sensory issues. If they are also avoiding certain foods because they have been told they are 'bad' for them, or unhealthy, then there might not be a lot of foods left for them to eat. This might cause them to not eat enough food to sustain themselves**.

You need to eat to live. It's better to eat enough quantity of food, even if it's not all food that is considered to be especially 'good', or healthy, than to not eat enough quantity, or you'll feel very unwell, and could get very sick. If you have great difficulty with this, you might need the help of a psychologist, and/or a food/eating therapist, and/or a nutritionist, ideally ones who specialise in ASD/Aspergers.

List of foods from the five food groups, as per the food pyramid:

Fats & Sugars

Fried foods, potato chips, chocolate, lollies, & desserts.

It's okay to eat some of these each day, but try not to eat heaps & heaps of these each day, as it might give you a headache and/or a stomach ache. If you do get a headache and/or a stomach ache, I recommend drinking a glass of water.

Milk & Dairy Foods

Milk (including flavoured milk), yoghurt, & cheese.

Try to eat/drink some of these each day. Eat/drink whichever forms you like/can cope with, & in whatever forms you prefer.

Meat & Other Proteins

Fish, chicken, beef, lamb, pork/bacon/ham, any other kind of meat, eggs, nuts, seeds, & legumes (like chick peas, beans & tofu).

Try to eat some of these each day. Eat whichever forms you like/can cope with, & in whatever forms you prefer.

Breads, Cereals & Potatoes

Bread or toast with or without any topping of your choice, any breakfast cereal with or without milk, rice or pasta with or without sauce or flavouring, crackers with or without any topping of your choice, & potatoes (boiled, baked, roasted or mashed).

Try to eat plenty of these each day, as they will give you energy. Eat whichever forms you like/can cope with, & in whatever forms you prefer.

Fruits & Vegetables

If you like fruits & vegetables, & can eat plenty of these each day, that's great. If you can't stand fruits & vegetables, try to eat some of these each day, whichever ones you can cope with, & in whatever forms you can cope with, whether it's fresh or canned, raw or cooked, or mashed or disguised in some way. It's okay if there are only a few types of fruits & vegetables that you can cope with.

Also, please do not ‘overdo it’ with exercise. Many people with ASD/Aspergers get tired more easily than most people do. **If a person with ASD/Aspergers uses up too much energy all at once, they are more likely than most people to feel quite unwell, OR very unwell, and to need more time to recover. Using up too much energy all at once can also cause a person with ASD/Aspergers to experience <u>unpleasant emotional side effects</u>**.

Many people with ASD/Aspergers are prone to an ‘all or nothing’ approach, and to overdoing things. However, when it comes to diet and exercise, <u>moderation is a much healthier approach</u>.

If you have difficulty working out what amount of exercise would be suitable for you, or have a tendency to overdo it with exercise, you might need advice from your GP, and/or help from a psychologist who <u>specialises in ASD/Aspergers</u>.

3. <u>If you experience eating and/or stomach issues due to anxiety and/or depression:</u>

A psychologist who <u>specialises in ASD/Aspergers</u> can help you to deal with your anxiety and/or depression, and to learn ways to be able to eat enough food. A nutritionist, and/or a food/eating therapist might also be helpful.

4. If you have physical gastrointestinal issues:

If you feel nauseous, have pains in your abdomen, or have diarrhoea or constipation, tell your parents about it. Hopefully, they can help you to work out if it is certain food that is causing your discomfort, or something else, and whether you need to see a doctor about it. If it is certain foods that are causing your discomfort, you might have to avoid those foods.

If a teenager with ASD/Aspergers complains of gastrointestinal issues to their parents, and/or any of their support people, they need to be taken seriously. Their parents, and/or support people, and especially their GP, need to bear in mind that although people with ASD/Aspergers are prone to eating and/or stomach issues as a result of sensory issues, anxiety and/or depression, they are also prone to physical gastrointestinal issues**. In some cases, constantly feeling unwell due to physical gastrointestinal issues is what causes a person with ASD/Aspergers to experience anxiety and/or depression** (and/or exacerbates existing feelings of anxiety and/or depression)**, as opposed to the other way around**.

In many cases, teenagers with ASD/Aspergers need their GPs to explore physical gastrointestinal issues, including referring them to a gastroenterologist, if necessary. Parents of teenagers with ASD/Aspergers might need to specifically request this of their teenagers' GP, in order for this to occur.

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Sometimes people with ASD/Aspergers need to take dietary supplements, if they have difficulty eating enough nutritious foods.

However:

> “Autistic people need lower doses of drugs and supplements as our bodies are too sensitive. Some cannot even take a multivitamin without becoming sick.”[xxii]

If a person with ASD/Aspergers is prone to eating and/or stomach issues, any doctor who prescribes medication for them (including vitamin supplements) should consider how that medication could affect their eating and/or stomach issues. Doctors should bear in mind that people with ASD/Aspergers can be extra sensitive to medication, and might need a smaller dose than most people.

***

If a young child with ASD/Aspergers is a fussy eater, they may well be able to be encouraged to eat a wider variety of healthy foods as they get older. However, once they reach adolescence, they might develop eating and/or stomach issues again, which might be even worse than when they were a young child.

I believe this is due to:

- The stress caused by the changes involved in going through the new developmental stage of adolescence, such as:
    - more complex social issues;
    - changes in their thoughts, feelings and intense interests;

  - more complex schoolwork;
  - thinking about what will happen when they finish school, i.e., figuring out what to do with their life and how to do it;
  - changes in their bodies.
- Hormonal changes in their bodies, which I believe affect sensory issues.

***

If you need professional medical help with your eating and/or stomach issues, you will most likely need your parents to arrange any appointments with the appropriate medical professionals, such as:

- Your GP; and/or
- A psychologist who specialises in ASD/Apsergers; and/or
- A nutritionist; and/or
- A food/eating therapist; and/or
- A gastroenterologist.

Eating disorders:

Some teenagers with ASD/Aspergers develop an eating disorder as a result of one or more of the sorts of eating and/or stomach issues mentioned in this section of this handbook, OR as a result of social and/or emotional issues. If you develop an eating disorder, you will most likely need the help of a psychologist who specialises in ASD/Aspergers to help you to deal with this, and you might also need the help of a nutritionist, and/or a food/eating therapist.

Please tell your parents, and/or your own specialised psychologist, and/or a support person, if you are feeling concerned about your eating, in any way, such as:

- If you think you're eating too much or too little, and if this worries you;
- If you are worried about how you will be affected by eating certain foods;
- If you can't think about anything else besides eating and/or food, and if this causes you distress;
- If you feel guilty or depressed about eating.

Please tell/talk to your parents, and/or your own specialised psychologist, and/or a support person, if you are feeling concerned or distressed about anything, such as:

- Someone has hurt your feelings;
- You don't understand something;
- When you are going through changes and/or uncertainty in your life, or are about to, including the changes associated with growing up. It can help to:

  - Ask them any questions you have about the changes and/or uncertainty;
  - Tell them what’s worrying you about the changes and/or uncertainty;
  - Tell them how you are feeling about the changes and/or uncertainty.

Hopefully, they will be able to talk these issues through with you, or help you to talk them through, and break them down, in order to help you to feel better about these issues, and to be able to cope.

EXPLANATION OF TERMS:

Term (word or phrase)	**Explanation** (or Definition)
Specialises in ASD/Aspergers OR Trained in ASD/Aspergers OR 'Specialist in ASD/Aspergers'	I mean someone who has done extensive, specialised study and/or training in the area of ASD, in the most up-to-date knowledge and understanding of the issues and needs of people with ASD/Aspergers, and how different the issues and needs of each person with ASD/Aspergers can be, including in relation to people who have a combination of ASD traits/symptoms that are less obvious, or not obvious at all, to most people and in relation to the differences between males and females with ASD/Aspergers. I do NOT mean someone who has done a short, cursory course, or broad, general training in counselling or general psychology. I do NOT mean someone who has done a short, cursory course, or broad, general training in the very broad area of ASD.
IQ	IQ stands for intelligence quotient. An IQ test is a special type of standardised test, or set of tests, designed to assess human intelligence. If a person does an IQ test, their total score from the test is called their IQ.

	It's important not to place too much importance on IQ scores, because, although an IQ test can be a useful tool to measure some types of intelligence, and in particular, the type of intelligence necessary to do well in academic work, it cannot measure creativity, social intelligence, or emotional intelligence. Also, some people find that the pressure of doing a test causes them to feel very distressed, and/or overwhelmed, which can make it very difficult for them to concentrate. For this reason, some people who are very intelligent will not always get a very high score on a test.
Communication issues	This does not just mean difficulty in speaking/listening or writing/reading, but also, for example, difficulty expressing what you really mean, and/or understanding what other people really mean, and/or feeling too overwhelmed to speak out loud, or to put your thoughts into words.
Support person	A support person is someone who helps you to do things, and/or deal with things. For example, your support people could be your parents, support workers, a special teacher or counsellor at your school, your psychologist, and/or other ASD support people.
'Condition'	A person's 'condition' is their state of fitness and/or health, including mental health.

	To 'have a condition' means to have some kind of illness, disease, disorder, disability or other medical problem, including mental health issues and/or mental ability. ASD/Aspergers, could be described as a 'condition'.
'Mainstream' teaching methods 'Mainstream school'	'Mainstream' teaching methods are the teaching methods used at mainstream schools. A 'mainstream school' is a normal school. Most schools are mainstream schools, and most children/teenagers go to mainstream schools.
Medical support people	A medical support person is a support person who has medical training, and who provides you with medical treatment. For example, your medical support people could be your doctor (GP or other specialist), psychologist, psychiatrist, occupational therapist, and/or speech therapist.
Social interaction	Social interaction is any interaction with other people, but especially face-to face interaction with other people. This does not just mean at a party or hanging out with friends, but also, for example, attending school or work, going to the shops, using public transport, attending an appointment with a doctor, psychologist or ASD support person.

‘Face-to-face’	‘Face-to-face’ means you are physically there in person with another person or people.
‘Face-to-face’ school	‘Face-to-face’ school is normal school, where you attend physically in person with other students and teachers.
‘Eye floaters’	‘Eye floaters’ are small clumps of protein inside your eye that cause you to see black or grey spots, transparent blobs or tiny string-like shapes drifting through your vision. Eye floaters are very common and harmless. In fact, most people will experience eye floaters at some time in their life.
In public	In public means where there are other people present. However, it usually does not mean when you are at home with just your close family members, or with one or two close friends.
‘Attached’ to someone (e.g., a Youtube host or TV presenter, an actor or character in a movie or TV show, or a musician or other artist)	In this instance, feeling ‘attached’ to a person means feeling an emotional connection to that person. This means that you feel you can relate to that person, and that you have feelings of care and concern for that person. If you were unable to see or hear that person again for a long time, you would miss them. Feeling ‘attached’ to a person is a normal part of a human relationship. People with ASD/Aspergers often feel ‘attached’ to, e.g., their favourite actors and/or musicians, even though they’ve never met them in person, and are

	never likely to meet them in person, and don't have an actual relationship with them. This is okay. Although it's important for people with ASD/Aspergers to be able to interact with other people, and to have relationships with other people, to the extent that they need and want to, they might have great difficulty with social interaction and relationships. They might need a lot of help in this area. They might not be able, or want, to engage in social interaction and/or relationships very often, or to a great degree. Watching and/or listening to, e.g., their favourite actors and/or musicians perform, and/or researching facts about them can make a person with ASD/Aspergers feel very happy, and is good for their mental health.
Down the track	Down the track means later in time, when you are at a different stage of your life. For example, it could mean in a few months, or in a few years, when you are older. If you are a school student, it could mean after you finish high school or university.
Social situation	A social situation is any situation that involves social interaction.
'In their space'	This means when someone stands or leans too close to them, so that they feel uncomfortable.

‘Freeze’	In this instance, to ‘freeze’ means to experience a ‘freeze response’. When a person feels threatened, they might experience what is called a ‘fight, flight or freeze response’. This is a natural type of stress response that instantly causes involuntary hormonal and physiological changes in a person’s body. This response is nature’s way of preparing a person to face, escape, or hide from danger, in order to keep themselves safe. When a person experiences a ‘fight, flight or freeze’ response, their ability to organise their thoughts is temporarily suspended, leaving them flustered. They might fight the person who they feel is threatening them, or flee the situation, or they might ‘freeze’. When a person ‘freezes’, they find themselves unable to move or act against the threat. This isn’t a conscious decision, but rather, an automatic reaction, which means the person can’t control it. Many people with ASD/Aspergers experience a ‘fight, flight or freeze response’ in anxiety-inducing situations, where there is no real danger.

PTSD	PTSD stands for post-traumatic stress disorder. PTSD is a mental health condition which is triggered by experiencing (or witnessing) a terrifying/traumatic event. The effects can last months or even years. It can cause a person to experience severe anxiety and/or depression. It can cause a person to become easily startled or frightened, and to always be on guard for danger. Triggers that bring back memories of the trauma can cause a person to experience intense emotional and physical reactions, which can cause them to try to avoid thinking or talking about the traumatic event, and to avoid places, activities or people that remind them of the traumatic event. People with ASD/Aspergers are very sensitive to a lot of things, more so than most people. They also tend to experience extreme emotions in response to a lot of things, and have difficulty dealing with their emotions, more so than most people. Because of this, sometimes an event or situation that would not be terrifying or traumatic for most people, is terrifying or traumatic for a person with ASD/Aspergers. Such an event or situation could cause a person with ASD/Aspergers to experience PTSD, even though it would not cause most people to experience PTSD.

'Fit in'	To 'fit in' means to be socially compatible with other members of a group. It often means trying to be like everyone else. Traditionally, a lot of people have placed great importance on 'fitting in'. However, nowadays, a lot of people feel that it is much more important to feel that you 'belong', with people who appreciate you, than to try to 'fit in' with people who don't. Belonging means finding friends who you feel you can be yourself with, because they like you for who you really are, and for all that is unique about you.
Social etiquette	Social etiquette is the set of rules or customs that most people consider to be acceptable and/or polite behaviour in particular social groups or social situations. Different societies or social groups can have different social etiquette.
'White lies'	A 'white lie' is a lie that is thought to be harmless, and is told to avoid hurting someone's feelings, or to avoid trouble. For <u>example</u>, if your friend asks you if you like their new hair style, it is usually best to say something like, "Yes," or, "I think it suits you," even if you <u>don't</u> actually like it, otherwise you might hurt your friend's feelings.

	Some people with ASD/Aspergers have difficulty with telling the difference between a white lie, which is harmless, and the other type of lie, which is bad, and can be harmful. For example, if someone tells you that they are in love with you, but you are not in love with them, it is NOT a good idea to tell them that you are in love with them, in order to avoid hurting their feelings. Eventually, they will realise that you are not actually in love with them, and this will hurt their feelings even more than if you told them from the start that you were not in love with them. To someone with ASD/Aspergers, the two different scenarios in the above examples could seem like two very similar scenarios. This could be very confusing for someone with ASD/Aspergers. Generally speaking, telling the truth is considered to be good, and telling lies is considered to be bad. For someone with ASD/Aspergers, it can be very difficult to understand how it can sometimes not be very good to tell the truth, and sometimes be okay to tell a lie.
‘Vent’	In this instance, to ‘vent’ means to say all the things you don’t like about a particular person, or how they’ve annoyed or upset you, to another person or people, when that particular person is not present.

When you talk about a particular person with other people, when that particular person is not present, it is often referred to as talking about that particular person ‘behind their back’, even though you might not literally be located behind their back.

Why do people vent about other people behind their back?

Sometimes people vent about one of their teachers, or their boss, behind their back, because if they said all the things they don’t like about their teacher or boss to their face, they might get in trouble, or fired from their job.

Sometimes people vent to their friend(s) about a person who is not their friend, and who they don’t like, perhaps because that person is not very nice. They might vent about that person to their friends, behind that person’s back, rather than say directly to that person all the things they don’t like about them, in order to avoid getting into a verbal or physical fight with that person.

<u>Sometimes</u> people vent about one of their friends behind that friend’s back, in order to avoid hurting that friend’s feelings.

<u>Here is an example of why someone might vent about one of their friends behind their back:</u>

Imagine there is a girl called Jane. Let’s say that Jane has a friend called Mary. Let’s say that Jane likes Mary overall, and knows that Mary is a nice person, but that sometimes, Mary really annoys Jane.

Jane realises that the things that Mary does, that annoy her, are not really bad things. Therefore, Jane might not want to complain to Mary about the things that she does, that annoy her, because that might hurt Mary’s feelings. However, Jane might feel that if she keeps those negative feelings of annoyance inside, and never says them out loud to anyone, she might one day really lose her temper with Mary, and really hurt Mary’s feelings.

Therefore, sometimes, Jane might vent about Mary behind her back to let out those negative feelings of annoyance, without hurting Mary’s feelings. Then, when Jane sees Mary again, she does not have pent up feelings of annoyance for Mary, and can be patient with her, and can be nice to her when she is face-to-face with her.

	However, Jane would have to choose a very trustworthy person to vent to about Mary behind her back. That is, Jane would have to choose someone who she could trust not to tell Mary what she said about her, when she was venting about Mary behind her back, because, if that person did tell Mary, Mary would get upset with Jane, and Jane would look like a bad person. To someone with ASD/Aspergers, the concept of venting about a friend behind their back can be very confusing. To use the above example, imagine that you are friends with both Jane and Mary. If Jane complains to you about Mary, when Mary is not present, is Jane being mean about Mary? Does Jane no longer like Mary? Should you tell Mary that Jane was saying mean things about her? Or is Jane simply venting about Mary to an acceptable degree? Generally speaking, saying negative things about your friend behind their back is considered to be bad. For someone with ASD/Aspergers, it can be very difficult to understand how it can sometimes be okay to do this.
‘Fake’	If a person is described as being ‘fake’ it means they are acting in a way that does not reflect their true personality, and/or saying things that do not reflect what they truly think, or how they truly feel.

	Being ‘fake’ is usually considered to be bad. To someone with ASD/Aspergers, this could be confusing, because, by this definition, telling a ‘white lie’, which is supposed to be okay, could be described as being ‘fake’. Being ‘fake’ is similar to being ‘two-faced’.
‘Two-faced’	**If a person is described as being ‘two-faced’, it means they say or do certain things in certain situations, but then say or do the opposite in other situations.** For example, they might say nasty things about you to other people behind your back, but then act nicely towards you when they are with you. This makes it hard to know what their true character is, or what they truly think and/or feel. Being ‘two-faced’ is usually considered to be bad. To someone with ASD/Aspergers, this could be confusing, because, by this definition, ‘venting’, which is supposed to be okay, to a certain extent, could be described as being ‘two-faced’ Also, to a certain extent, it is normal and acceptable to act differently in different situations. People with ASD/Aspergers often do this, because they often do something called ‘mirroring’.

	I explain the term ‘mirroring’ at page 184 of this section of this handbook. I have also written about the term ‘mirroring’ under the section of this handbook called “Social Issues (& Communication Issues)”, at pages 87-88.

I have written some suggestions for how to cope if you find it difficult to understand things like ‘white lies’, ‘venting’, and people being ‘fake’ and/or ‘two-faced’ under the section of this handbook called “Social Issues (& Communication Issues)”, at pages 92-94.

‘Black and white’ rules	A subject or situation that is ‘black and white’ is one that is clear and distinct, and cannot be confused with anything else. It is easy to understand, and usually involves a simple choice between two opposite things, such as good and bad, or right and wrong.
‘Grey’	A subject or situation that is ‘grey’ is one that is not clear and distinct, but is open to interpretation. It is not easy to understand, and does not involve a simple choice between two opposite things. The answer usually lies somewhere in between two opposite things, and there is not one clear answer that is ‘right’.
‘Normal’	When someone is described as being ‘normal’, it usually means that they have no serious physical or mental health problems, or ‘conditions’, and/or that they are ‘mainstream’

	'Mainstream' means the ideas, attitudes and views that most people have, the activities that most people do, and the ways in which most people do things. Mainstream ideas, attitudes, views, activities and ways of doing things are considered by most people to be 'normal'. For example, a mainstream lifestyle is to go to school, then maybe go to TAFE or university, then get a job, then get married, buy a house in the suburbs, and have children. Most people want this lifestyle, and most people pursue this lifestyle. However, a mainstream lifestyle is NOT for everyone. Great scientists, inventors, artists and performers usually do NOT live mainstream lifestyles. It is perfectly okay to NOT want to live a mainstream lifestyle.
'Read the room'	This means to assess and determine the general mood and attitudes of the people in a particular setting, by listening, and observing. When a person can 'read the room', they can then avoid saying things, or acting in a way that might offend the other people who are present. They can also adjust their behaviour, in order to 'fit in'.
'Different'	In this instance I mean different to what is considered to be 'normal', or 'mainstream'.

‘Reading’ emotions	This means being able to tell how someone else is feeling, from their facial expressions, gestures (body language), and tone of voice, even if they don’t verbally express their feelings in a clear, concise way.
Socially adept	This means having the skills and ability to understand, and take part in, various social situations, and to interact with various other people. People who are very socially adept tend to be able to get along easily with other people, engage in small talk, and keep conversations going. Many socially adept people enjoy interacting with other people, have many friends and enjoy maintaining their friendships.
‘Take after’ parents	To ‘take after’ someone, means to resemble them, in appearance, temperament, or character. You can usually only take after an older family member, like your parents, or grandparents.
‘Mirroring’ identity of others	‘Mirroring’ means to imitate or copy another person's characteristics, behaviours or traits, such as their speech patterns, gestures or attitudes. Many people do this, to some degree, without realising it. Some people with ASD/Aspergers do it to an even greater degree than most people, either on purpose, or without realising it, because they might not have a strong sense of their own identity. In a way, they are borrowing the other person’s self-image.

Socialise	This means to take part in social interaction.
Social skills group	A social skills group is like a class. It is usually taught/led by a psychologist. The sorts of people who attend social skills groups are usually children, or teenagers, or young adults, who have difficulty with social interaction. There are usually only up to about 10 people in a social skills group, and they are usually all about the same age. Social skills groups are designed to teach people (usually children, or teenagers, or young adults) how to interact with other people appropriately, and/or how to cope in social situations. Simply by being present at a social skills group, a person is getting practice with being around other people, in an environment that is designed to be safe, non-threatening, and to not involve too much pressure or stress.
Social event	This means an event that involves social interaction. It usually means something like a party, or a concert. It could mean a gathering of family and/or friends, who you don't live with, for a meal, including a barbeque. It could mean a sleepover party with a few friends. It could mean an organised outing with a group of people.

‘Verbally express’	I mean say out loud to other people.
TAFE	TAFE stands for Technical and Further Education. TAFE is a learning institute where people can undertake courses and/or classes, in order to train and/or learn how to be able to do one particular type of job, or another. TAFE offers many different courses and classes for different types of jobs. People usually only attend TAFE after they have finished high school.
‘On the spot’	In this instance, ‘on the spot’ means immediately, at this current place and time.
‘Certified’ education	I mean any form of education where you receive a certificate at the end of it that states that you have completed the education. School, university and TAFE are ‘certified’ education. It usually involves completing assignments, and/or tests, and/or exams, and/or other assessment tasks to a satisfactory level, to show that you have understood what has been taught.
ASD support person	An ASD support person is a support person who helps you to do things, and/or deal with things, and/or provides you with medical treatment, specifically in relation to your ASD difficulties, issues and needs.

	For example, your ASD support people could be your psychologist, occupational therapist, speech therapist, private 'special tutor', or a special teacher/tutor or counsellor at your school, and/or some other support worker, who helps you with your ASD/Aspergers issues.
Adjusted learning plan	When a child has a disability (which includes ASD/Aspergers), they might be attending a mainstream school, but they might have difficulty coping with the 'normal' mainstream school environment and curriculum. Therefore, their school experience might need to be adjusted to suit their needs. The 'plan' for how to adjust the school experience of a child with a disability in order to suit their particular needs, is often referred to as an 'adjusted learning plan'. The official title for an adjusted learning plan has changed over the years. For example, it used to be called a Negotiated Learning Plan. Currently, it is called a One Plan, or a Negotiated Education Plan (NEP for short), or a Personalised Plan for Learning (PPL for short), depending on the school. However, most people who work in the area of childhood education and/or development, will know what is meant by the term 'adjusted learning plan'.

Stomach issues	I mean any issues to do with your stomach and/or bowels.
Upset stomach	This means when you feel nauseous, and/or vomit, and/or have pain in your stomach and/or bowels, and/or have diarrhoea or constipation.

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