

THE TEENAGE YEARS: AS WE ARE



Foundation
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As I Am

IRELAND'S AUTISM CHARITY

FOREWORD

The Community Support Team at AsIAm, Ireland's National Autism Charity, are delighted to present to you in conjunction with the St. John of God Foundation, the third of three resource packs for autistic children, young people and families.

AsIAm provides opportunities for autistic teenagers to connect through special interests and shared experiences by running a range of clubs such as history, Dungeon and Dragons, and Lego. We also provide support to parents and other family members who seek to learn more about autism and advocacy; so they can better support their child. For more information on this work, please see our website AsIAm.ie.

Lucena Child and Adolescent Mental Health Services (CAMHS) provides services for young people under 18 with moderate/ severe mental health concerns. We were delighted to partner with AsIAm to support the development and publication of this much needed resource, which is the final of a three-part series. The aim of Lucena CAMHS's involvement in these publications is to promote autism acceptance and widen public understanding of autism. As a CAMHS, we recognise the negative impact that late identification, stigmatisation, and environmental demands (e.g. school) can have on the mental health of autistic individuals.

The publication of this resource has been supported by the Saint John of God (SJOG) Foundation and the Hospital Saturday Fund. The St John of God Foundation fundraises on behalf of a range of Community Services who provide support to children and adolescents experiencing mental health challenges and to adults and children living with a range of intellectual disabilities. We thank the foundation, and the psychologists, occupational therapists and speech and language therapists on Team A Lucena CAMHS for their input into the development of this resource.

For more information about the work of Saint John of God Foundation see sjogfoundation.ie. For more information about Lucena CAMHS please see www.lucenaclinic.ie.



IRELAND'S AUTISM CHARITY

A-Z GLOSSARY

A-Z Glossary

As you learn more about being autistic, and the cultural aspects that come with being a part of the autistic community in Ireland, you may come across many new words and terms that the community often uses but you may not be familiar with. It can feel like a new language. Like any new language, nobody expects you to learn all of the terms right away, or to get them 'right' each time. There are many of these words and terms in this book. We hope by including an A-Z glossary, you have a useful reference to look back upon.

Term	What it means
AAC (Augmentative and Alternative Communication)	<p>AAC means all of the ways that someone communicates besides talking. Augmentative means to add to someone's speech. Alternative means to be used instead of speech. When people hear about AAC, they can think of fancy tech devices. However, No-tech and low-tech options include examples such as writing down or drawing your request or pointing to something. More high tech options include examples such as using an app on a tablet to communicate or using a computer with a "voice".</p> <p>AAC is NOT just for those who are non-speaking. You may use AAC to support the spoken communication you want to make, or to replace spoken communication when you feel overwhelmed.</p>
Alexithymia	<p>Alexithymia broadly describes a difficulty in processing your own emotions and understanding the emotions expressed by others. You might need more time to process your emotions and you might experience difficulties 'reading faces'.</p>
Alternative Education	<p>An alternative education is anything other than mainstream, special and homeschool which can include things like online learning through programmes like iScoil.</p>
Autism Class	<p>An autism class is a class group within a mainstream school that caters to autistic students by having a smaller amount of students. Some students may be in the autism class for the whole day and some may also attend some classes with more students. You may also hear it called a 'unit'.</p>
Autistic burnout	<p>This is a state of intense physical, mental or emotional exhaustion that an autistic person can experience because of the additional load of having to navigate a world that is not built with autistic people in mind. This can often arise from consistently masking or prolonged periods of sensory overload.</p>

Asynchronous communication	Asynchronous communication is used to describe any type of communication where one person provides information, and then there is a delay period before the recipients take in the information and respond accordingly.
Disclosure	Disclosure is the process of deciding to share information about your difference or disability or some aspects of your disability, difference or condition to others, such as at school, or with friends or family.
(Diagnostic and Statistical Manual of Mental Disorders - 5th edition) DSM-V	The handbook used by healthcare professionals as a guide to the diagnosis of various differences, disability, and mental health conditions.
Echolalia	Echolalia is an immediate or delayed copying of words or phrases that you have heard, either for scripting to explain something with words you heard somewhere else, or as a vocal stim with repeating words that feel good in your mouth or sound good to you.
Home Schooling	Homeschooling is a practice where a child is educated at home by a parent or tutor instead of attending a typical school.
Special interest / hyperfixation	<p>Whilst it does share some similarities with a special interest, a hyperfixation is not always enjoyable and can potentially consume the person's life where we may lose track of time or have little energy to focus on other things.</p> <p>Hyperfixation is an interest that an autistic person may be completely engrossed with; be it a hobby, movie, book, or special interest and so on.</p>
Identity-first language	When talking about autism, this means we say 'autistic person' as opposed to 'person with autism' (this way of speaking is called 'person-first language'). The reason we use 'identity-first language' is because autism is seen as a core part of a person. You would not be who you are if you were not autistic. You are of course able to choose whatever language you want to describe yourself and your relationship to autism. Language use might not even be important to you at all, and that is okay.
Info-dumping	Info-dumping is a term often used for when an autistic person talks extensively about their special interest. This can also be a way of showing affection as it shows that you trust the person with something you care as much about as your special interest.

Interoception	Interoception is your brain's ability to understand the signals or sensations that your body is having such as reactions to hunger, temperature, tiredness and even pain. You might find you often don't notice when you are feeling hungry, or where a body part might hurt. This might happen when you are particularly focused on something else, and your brain decides feelings such as hunger or pain aren't a priority right now.
Monotropism	The theory of autism developed by autistic researchers, <i>Dinah Murray</i> and <i>Wenn Lawson</i> . Monotropic minds can focus very intently on one thing at a time with very intense interests, though they can struggle with shifting their attention. This is sometimes described as 'flashlight' focus due to not only its intensity, but how other areas fade into 'darkness' when you are focused on a particular interest or task.
Neurodiversity-affirmative	Neurodiversity-affirming with the understanding that autism, attention deficit/hyperactivity disorder (ADHD), dyslexia, among other neurodivergence aren't problems to be cured or solved, but individual neurotypes with unique strengths, needs, and challenges.
Neurodivergent	This is how we refer to a person who identifies as having a brain that is a different neurotype to the 'typical', Examples include being autistic, dyspraxic, dyslexic, having ADHD or Tourettes.
Proprioception	Proprioception is the brain's ability to understand where the body is in space, this can be a sense that autistic people struggle with. If you struggle with proprioception you might feel like you're clumsy or be told that you have "bad posture" or "a funny walk".
Self-advocacy	This means communicating your thoughts, feelings and needs so that you can feel comfortable and included in all settings, including at school. It can also mean being open about being autistic and sharing your experience of being autistic and speaking about issues which impact the community.

Self-diagnosis (in context of autism)	This is when you self-identify as an autistic person, but without going through a formal assessment for an autism diagnosis with a professional.
Shutdown	A shutdown, much like a meltdown, can happen when you're overstimulated but is usually expressed internally, you might lose your language or seek out quiet or dark space.
Special school	Special schools are those that provide an education for children with disability who might not thrive in a mainstream school.
Spoons	The Spoon Theory has been used to explain why everyday life can be so overwhelming and draining for autistic people. In spoon theory the spoons are a physical manifestation of energy. Everyone wakes up with a certain amount of spoons in the drawer and each activity takes a certain amount of spoons away or gives a certain amount back.
Stimming	Stimming (short for self-stimulatory behaviour) is a repetitive series of actions which an autistic person may do when they are excited, anxious or stimulated.
Unmasking	Unmasking is often described as taking acceptance and pride for being autistic, where an autistic person feels confident and safe to be fully open about themselves. This also includes where neurotypical people make adjustments or accommodations to include and accept an autistic person. For many autistic people, it is a process of unlearning the feelings of guilt or shame that can be associated with autistic traits if they are not accepted by wider society.

INTRODUCTION

Hello there,

Welcome to the "The Teenage Years... As We Are". We are delighted you have decided to read some or all of this book. You might be reading this book as a person who identifies as being autistic, or a person who wants to learn more about what it is to be autistic.

In the past decade, we have seen a significant change in society's attitudes towards autism. More people know about autism and we are becoming more diverse as a community. Famous autistic people have become more comfortable to talk about being autistic publicly, from Daryl Hannah - an actor and environmentalist so groundbreaking in her acceptance of herself that she disclosed her autism in the 1990s - to Sir Anthony Hopkins - the first openly autistic person to win an Oscar - to Aoife Dooley and Blindboy - bringing discussion of autistic artists to Ireland.

This change means we are advocating for ourselves, after decades of being spoken for - we are doctors and engineers, authors and artists, lawyers and teachers, dancers and comedians, partners and parents, among many other professions and vocations. There are autistic people in all walks of life, and one of the most groundbreaking changes is that we have moved through our isolation to find support in each other.

The autism community can feel like an unusual community to be born into, as your family might not be autistic. Culture can be hard to understand if you haven't been part of that community. For example, a person certainly wouldn't be able to learn how to be Irish or any other nationality all by themselves - they learned by being immersed within the culture. So like many other groups, both ourselves and our families start to learn our culture from each other.

In this book we will share many peoples' thoughts, poetry, pictures and stories about being an autistic teenager. We don't have all the answers, but with the help of other autistic teenagers and autistic adults - as well as some friends who work in psychology, occupational therapy, speech language therapy and autism advocacy, we hope to have some of them. However as are most things with autism, this is a continuing conversation where language, terminology and understanding continuously grows.

So, let's ask more questions and seek out more answers so that when the next generation comes along, we can be there to welcome them.

Team Teenage Years As We Are

W E L C O M E



**AUTISM:
THE PROFESSIONAL
ASSESSMENT BIT**

In a book that hopes to talk to you about autism in a way that is not medicalised, it feels kind of strange for us to begin by talking about the diagnosis process, which typically takes place in some form of healthcare setting and is carried out by medical or healthcare professionals.

On top of this, the day you are diagnosed as autistic is by no means the beginning of your autism 'journey' either - if you are autistic, you have been so since you were born. So, why are we telling you about the professional assessment and diagnosis of autism?

- ▶ Many of you may be waiting for your autism assessment, or you may have just completed it.
- ▶ You might not want to talk about your assessment, but you'd like to read more.
- ▶ Historically a lot of information about autism assessment has been hidden from teenagers and families, which has in turn led to anxiety, confusion, guilt and self-doubt.

What is medicalisation?

It sees the problem as the person's disability or difference and places the responsibility on the person to address these issues to fit into society's standards and expectations.

There are many different feelings people experience when waiting for an autism assessment. You might feel excited or nervous. You might feel upset that your parent(s) think you need to be 'assessed'. You might feel anxious at the thought of healthcare professionals 'observing' you. There is absolutely no 'set' feeling you should have. It is also very common to not be sure what you feel about having an autism assessment.

So, what is an 'autism assessment'?

In Ireland, a professional assessment of autism is usually given either by a psychiatrist, clinical psychologist or educational psychologist who specialises in autism. The professional will use the Diagnostic Statistical Manual of Mental Disorders (DSM) to make an assessment on whether or not, in their professional opinion, you are autistic. The DSM-V describes criteria for the assessment and diagnosis of a variety of differences, disabilities, and mental health conditions.

Many people may know about autism and see autistic features in themselves. After learning about autism, many teenagers might self-identify as autistic. Some might be happy with this self-diagnosis and decide against a professional assessment to confirm this diagnosis. Others might want to seek a professional assessment with the help of their family.

Self-diagnosis

Self-diagnosis while school or college aged may impact your ability to access certain education supports. For example, if you wish to access an autism classroom, you are required to have a professional diagnosis.

Why does my autism assessment feel like a negative thing that is happening to me?

If autism has been explained to you as a disorder, it is logical to feel negatively about going to an assessment to find out if you are 'disordered'. The criteria also presume that every autistic person has to have a certain list of traits to get a diagnosis of autism, but does not take into account that wider societal factors can also shape a person's experience of being autistic, such as whether they are able to be open about whether they might be autistic in the first place. The criteria also do not take into account the bias that may be held against different minority groups e.g., children of colour, Travellers, which means your autistic traits may be misunderstood. In short, we cannot stress enough that how a professional feels or judges your autistic experience could be hugely different to how your experience of daily life feels.

How can an autism assessment benefit me?

We think there are several benefits to getting an assessment. However, there is no exhaustive list of what you get out of going through the process. It is completely individual to the person and depends on what you wanted to find out by going through the process.

Here's how some members of the AsIAm community feel about the autism diagnosis criteria:

"The word 'deficit' I think is negatively describing my autism, my communication style and my behaviours, I would much prefer to use the description of my autism as being a difference and a feeling of uniqueness."

"I don't "fail" to make eye contact, I just prefer not to do it because it's distracting and uncomfortable."

"While I have very specific interests and engage with these with intensity, and often struggle in social situations and struggle with eye contact, I feel the criteria makes autism sound like something limiting. It isn't."

"Being autistic is what makes me see the world differently and by having a diagnosis I can be kinder to myself, accept things I find difficult and care for myself to avoid burnout."

A professional assessment can:

- ▶ Allow you to look at yourself through a different lens. What we mean here is it may give you answers to questions you have had about why you find certain things more challenging than others, and why you find other things easier. It can also give you answers on how you react and respond to situations.
- ▶ Help those around you understand that your actions are not “difficult” or “challenging”, but may in fact indicate a need for support.
- ▶ Reduce the judgement you place on yourself when you don't enjoy something that is important or fun to those around you, through improved understanding of your autistic experience. Where in the past, you may have forced yourself through an occasion, you might now say to yourself 'I am being reasonable in leaving early'.
- ▶ Provide access to autism-specific supports and services in school or within healthcare. Knowing you are autistic also allows you, and your family, to intentionally choose schools, doctors and therapists who are neurodiversity-affirmative. It can also give you a better idea of what supports to ask for in these environments.

What does it mean to be neurodiversity-affirmative?

A professional who is neurodiversity-affirmative has a good understanding of autism and autistic culture, and will work with you as their patient or client to ensure their service is adapted to how you prefer to communicate.

So, what does an assessment involve exactly?

We asked a psychologist who regularly makes autism diagnoses how they put the information together. This is what they said:

You will meet with at least one healthcare professional. This professional could be a psychiatrist, psychologist, speech and language therapist, and/or occupational therapist. Some people will see one professional for their assessment, other people will see a team of professionals (called a 'multi-disciplinary team'). Seeing a team of professionals means they can combine their skills to give you more thorough recommendations of support.

Spending time with you:

The professional should always want to spend time with the person being assessed and get to know them. To understand how you experience being autistic, they will observe how you might react to different situations. They will likely use a standardised set of questions or tasks to help with this. What standardised means here is that the set of questions/tasks were developed and researched with large groups of autistic people to show whether these questions/tasks can help to identify autistic features. Standardised also means that the tasks/questions come with scores to determine if someone is autistic or not compared to others of the same age and assigned gender. However, these tests have mainly been tested with large groups of boys whose gender aligns with the sex they were assigned at birth (i.e., cisgender). They also assume that the person being assessed is being authentically true to themselves during the assessment. This means these questions/tasks are likely to miss autistic people if a professional is just relying on the scores. The healthcare professional should also ask questions about your own experience of the world and your own understanding of self.

Overall, during your assessment, the healthcare professionals are looking to see:

- ▶ How do you like to communicate and be communicated with?
- ▶ How do you use body movements for example, stimming and sounds to cope or communicate in situations?
- ▶ Is routine important to you?
- ▶ What is it like for you to experience the world?

Spending time with your parent/caregiver:

As being autistic is throughout life, not just as a teenager, the healthcare professionals will want to speak with those who know or who knew you extremely well when you were younger. This is usually a person's parent or another family member or caregiver.

Most healthcare professionals ask your parents/caregiver about what you were like when you were a toddler, or when you started school. They might also ask them about your life at home, how you find school, and about important life events.

Putting the information together to make a diagnosis:

When making a diagnosis, the healthcare professional uses their judgement based on what they have been told by you, the people who know you well, and what they have seen first-hand when they have met with you.

You should be invited to meet with the healthcare professionals who did the assessment to hear about what led them to agree or disagree with you about being autistic. In this meeting, you may also talk about the barriers that are making life challenging in some areas, as well as the strengths and talents you have. You may also talk about how you can find and access support.

However, if you don't want to go to the meeting, you can give your parent(s) questions to ask on your behalf.

Can I choose to wait until I am over 18 before I get assessed?

You can wait until you are over 18 to be assessed. At this time, you will be considered an adult. However, at the moment in Ireland, there are no public assessment teams dedicated to diagnosing autistic adults. Currently, the vast majority of adults who think they might be autistic can only get an assessment privately. A private adult assessment is often quite a lot cheaper than a private child assessment, but is still costly. This is one reason many adults in Ireland choose to self-identify as autistic.

"To me stimming is repetitive movements or noises. Stimming helps Autistic people to cope with emotions and overwhelming situations. I know for me I flap my hands and bang my knees and roll my lips when I am excited and nervous. Don't judge us for stimming as this is our way of self regulating ourselves when we are overwhelmed, nervous and excited. "

Emily, aged 17

Telling people that you are autistic

One of the choices that you can have is the decision of whether you wish to be open with different people about being autistic, or sharing some aspects of being autistic. This is sometimes known as a **disclosure**.

Every autistic person has different experiences of disclosure. Some may be comfortable and safe to inform and educate classmates, teachers or friends about their experience, whereas some may feel more reluctant or hesitant to do so. You might feel anxious or reluctant to tell others if you fear being bullied or being treated differently at school.

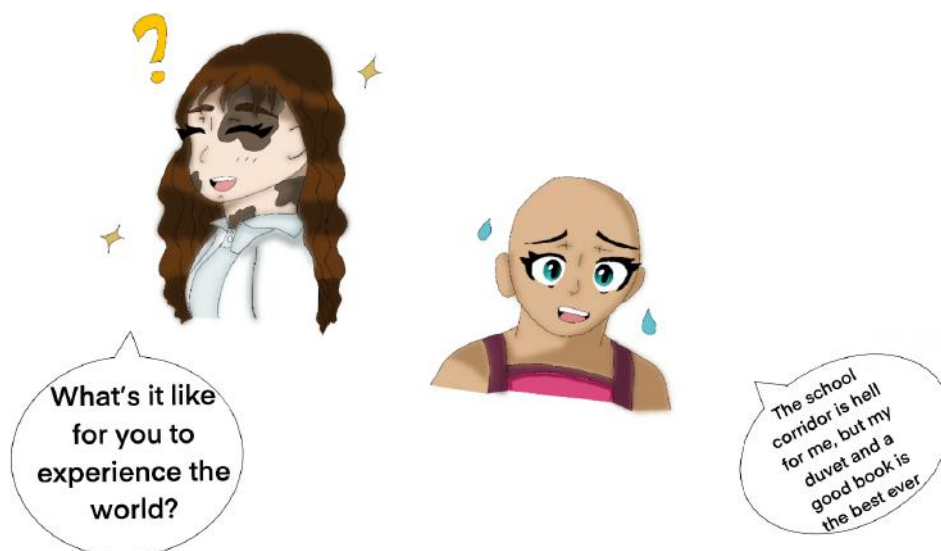
Whilst this does not always happen, any decision to be open about being autistic should be treated with sensitivity and respect. People who know about you being autistic, such as Principals or Coaches, should only tell others with you or your parents' or guardians' permission. Up until you turn 18, there are sometimes situations where your parents or guardians may decide to disclose that you are autistic on your behalf, for example if you need support or accommodations at school.

It can be hard to tell whether it is safe or a good idea to tell others about being autistic. It often depends on the type of environment or situation you are in.

There are some things that you can think about before making a decision:

In the situation in question:

- ▶ What if the environment is not safe for me to be open about being autistic? Would my differences be taken into account or would my differences or support needs be used against me?
- ▶ Is it a situation where it will help me if I can follow rules differently? For example, what if I need to wear a different uniform in school?
- ▶ What is the environment like? Does it have a lot of stressful parts that I need to manage, especially during busy times? Could I get support if I find it overwhelming?



Autism spectrum

I'm part of the autism spectrum

I am told at least you aren't fully autistic

You don't look autistic

I am autistic its a spectrum and there is no specific way an autistic person looks

I'd rather hear acceptance than ignorance

But I am proud of my autistic identity

Jaymie Lycaon
Aleister Doyle

- ▶ How much of my physical and emotional energy will it take to try and fit in and not disclose?
- ▶ Will disclosing make me feel more understood by my friends and family?

Like most things in life, no two autistic people feel exactly the same about their experience of diagnosis, and no two autistic people had the exact same experience.

Here are some stories and words about autism diagnosis that were shared with us:

Emily, 17 years old

"From a young age I knew I was different. I tried so hard to fit in which resulted in me being exhausted. I did not know the correct term for this until I received my Autism diagnosis, I then found out it was 'masking' - **in simple terms, this is basically hiding our autistic selves and all the things that make us 'us' and learning to behave like Neurotypicals to fit into the world with Neurotypicals.**

Before I got my Autism diagnosis I spent endless amounts of time on Google searching about Autism. I love researching, so this special interest comes in handy especially after my diagnosis to understand me more. When I got my Autism diagnosis it was the best day of my life because my mam and I had been searching for answers for my differences and struggles since early primary school and now I have a label that describes my struggles and strengths but also my uniqueness.

It took a few months for me to really process that I was Autistic, I kind of felt and still do feel like I was and am grieving for all the years I didn't understand or know who I was and why was I different.

From seeing other Autistics on Twitter and Instagram I am starting to understand myself much more. Following Autistics provides me

with better, more realistic and much more detailed information that makes me understood and less alone as they are Autistic like me. Autistics I like to follow are ItsEmilyKaty, Stefanie Preissner, autistic_callum_, thespectrumgirl, neurodivergent_lou and autieselfcare. "

Parmjit, 28 years old

"I was diagnosed as autistic when I was seven. My only memory of the assessment is throwing the toys around the room and my Dad's shirt having sweaty arm patches from trying to stop me breaking things. **Nobody told me I was autistic.** I heard it said quietly by my Mum in appointments over the years, and another time when my teacher brought me to A&E when I broke my toe kicking a wall. My girlfriend recently asked me if I was angry with my parents for not telling me I was autistic. No. I am not. Twenty years ago, most of the dialogue about being autistic was negative, so my parents were trying to keep me safe by not telling me. I was already bullied about the colour of my skin.

If I had known I was autistic as a child, with it then being seen as this sad and tragic thing, it's hard to know how that might have affected me. **My parents had to make decisions differently to Irish parents, knowing I was already vulnerable just because of our heritage. It is totally different now.** If my children are autistic, I want them to know and celebrate that"

Sorcha, 26 years old

"The idea that I was Autistic was first brought to me when I was twelve - to me it was out of the blue - and when I asked what it meant standing around the kitchen island with my parents, they told me it meant that I didn't have feelings. Instantly I knew it couldn't be true - for one thing because I was furious - I had huge feelings that I couldn't always control. We went to my doctor about it... this woman who I trusted implicitly told me that I definitely had "Asperger's Syndrome" because I was just like Sheldon Cooper. I could only assume that it was true.

The day of the test I was pulled from my history class - the only class where I ever felt like my head was above water. My lunch hour came and went, and I said nothing, it can be hard to say anything when you know you are being watched. When the results came back, I was told I had Autistic traits. I thought I was Autistic, and I thought that the people who counted thought I was Autistic, but I felt I couldn't own it and I couldn't ask for help.

A decade later, it was my husband who came to me first with the idea - we need to get you a diagnosis. The assessor smiled when she told me. "It seems clear to me that you are an autistic woman who has worked very hard and struggled very greatly to get where you are today."

I cried. It was like I'd been living in a dark room all my life, and years of struggling later someone turned on the light. My husband got us ice cream on the way home - I got a scoop of honeycomb and one of pistachio, I'll remember that.

Nothing around me changed very much after my diagnosis but I changed. For a solid decade I had thought that when I wasn't smart enough to solve an obstacle I was broken. After my diagnosis I allowed myself to find other things out about myself: I am kind and loving and loyal and creative and I can be smart about the things that I love but it's not the key to my value and not being smart enough was never my weakness.

I don't need to prove myself over and over and over again to be of value. **I am of value; I was of value the whole time."**

You Will Wonder Why

By Isabelle Blum

You will wonder why
You find noisy classrooms unbearable,
You will wonder why
Change is unendurable.
You will wonder why
You were alone in the playground as a child,
You will wonder why
the lights in the supermarket are painfully luminous.
You will wonder why
Trying to make friends is like trying to interpret an unknown dialect of an unknown
language.
You will wonder why
Socialising can be as exhausting as a ten mile run,
You will wonder why
Eye contact feels so unnatural and beyond endurance.
You will wonder why
Loud noise feels so painfully insufferable.
You will wonder what is wrong with you.
But stop putting yourself down.
Lock up that voice inside your
Head that tells you you
Aren't good enough and throw
Away the key.
You are not flawed.
You are a magnificent human being.
You are phenomenal.
You are worthy and deserving of respect.
You are brave.
You are enough.
Welcome to the community, you are safe now.
You are not alone

FRIENDSHIPS AND BELONGING

In this section, we talk about experiences of making and keeping friends.

If you find **reading about friendship uncomfortable**, we suggest you skip this section.



From when we are in playschool right up to when we grow old, it can feel like friends and friendship are always something people worry about. Do I have enough friends? Do my friends actually like me? Do I treat my friends well? Will I lose my friends? These very valid worries can be particularly magnified as a teenager, when it can feel like the adults in our lives have a lot of opinions and advice on our friends and friendships too.

Although you may have heard many views on friendships, we want to share a few things you may not hear so often:

- ▶ You do not NEED to have friends. If you feel happy and fulfilled without friends, that experience is completely right for you.
- ▶ Likewise, wanting to have friends when you do not have friends does not make you 'weird' or 'desperate'.
- ▶ Keeping friends that you do not feel you have much in common with to avoid the alternative of having no friends at all, is something lots of people experience, both autistic and non-autistic.
- ▶ Lots of non-autistic people also have trouble making friends, but this doesn't mean that the barriers you face are any less valid.
- ▶ You may have had less opportunities to make friends due to not meeting people who are similar to you or because you are too busy trying to cope in overwhelming environments to be 'sociable and chatty'.
- ▶ You may feel that you may not relate to what other people your age might be interested in. Again, this is more common than you think. Often, both autistic and non-autistic people will find certain stages of their life easier to make friends - some may find it easier in secondary school, others may find it easier in college.
- ▶ If your experience of 'making friends' has been changing yourself, tolerating being treated poorly or being bullied, it can feel frustrating to be asked to continue to 'try and make friends'.
- ▶ As an autistic person, it is not inevitable that you 'have difficulty making friends'. It may in fact be a strength you are proud of.

Does being autistic mean I experience friendship differently?

This is a hard question to answer. All humans, autistic and non-autistic, generally want a broadly similar range of things from different friendships - safety, acceptance, energy, enjoyment and mutual respect and support.

We also know that non-autistic people can also have difficulty in making and keeping friends, and may also struggle with the norms and expectations that can often come with friendship.

Ultimately, everyone experiences friendship differently, however there are some common joys and frustrations shared by many autistic people when it comes to friendship.

Here are three of these common experiences:

1. *Feeling the need to mask, and getting to unmask in different social situations*

If your mask is how you feel or have felt you need to hide being autistic, then unmasking is learning in what situations you are comfortable to not hide yourself. Unmasking can be a slow and gradual process, which happens in small parts. For example, allowing yourself to stim during a stressful exam if this helps soothe you, and the alternative is unbearable anxiety.

You might find that you mask and unmask differently in different situations. Maybe your mask is very high at school, lower while doing activities you like and maybe gone completely when you're alone with family.

Previously, autistic teenagers were often taught to mask and hide being autistic in all social situations. Many autistic adults say that this kind of teaching, often described as 'social skills training', led to them feeling unworthy, anxious and deeply insecure. The autistic community speaking up more and more, and amplifying the '**double empathy problem**' has led to great criticism of 'social skills training'.

What is the double empathy problem?

The 'double empathy problem' suggests that autistic people experience the world, communicate, form relationships, and express emotions differently to non-autistic people. Non-autistic people may not always understand or know how to connect with autistic culture and communication and autistic people may not always understand or know how to connect with non-autistic culture or communication. The gaps in both our perspectives can create problems in understanding each other.

Julia (23) shared her thoughts on masking:

"I masked a lot in school, and obsessively observed non-autistic communication. Of course I did, it looked easier and the people I was observing seemed a lot happier than me. I would hate any teenager reading this to feel embarrassed if they do the same, or that they aren't being true to themselves. I have learned that being true to myself, for me personally, doesn't mean bearing my soul and being an open book. For me now, an example of being myself is not staying in the work lunch room to chat, and instead freeing myself of that pressure and going for a walk at lunch, where I can enjoy stimming. Other people mightn't see this as being myself, but they aren't me, so of course 'being myself' means something different.

Also, learning how non-autistic people communicate differently has in some ways been helpful to me. My parents are not autistic, nor is my boss, and it helps me to understand how they communicate, or what I can expect from them.

However, what I have learned is that it is a two way street... if I am making an effort to understand how someone communicates, I also want them to make an effort to understand how I communicate."

Did you know?

Many cohorts within the autistic community, particularly those from marginalised communities, argue that unmasking is much riskier for them due to a lack of recognition for how autistic traits are interpreted by others. As the predominant public perception of autism can often be based on a white, male, cisgender idea of being autistic, this means many autistic people can feel that unmasking might impact their safety. Unfortunately, whilst these conversations are happening more often within the autistic community, it is not really discussed much outside of these spaces

2. Valuing different ways of being friends

Often, when friendship is discussed, a lot of people seem to place an emphasis on two people connecting by talking to each other regularly. In the autism community, a lot of teenagers and adults express a preference for **'parallel play'**.

Lots of autistic people also really enjoy **'asynchronous communication'**. This is when you send a message without expecting an instant response. Examples of this could be a friend texting you during the week, and you replying at the weekend, or a friend sending you a DM and you waiting until you are next online to reply.

If parallel play and asynchronous communication is more energising and meaningful for you, you are completely right to seek them out.

3. The Joy of Info-Dumping

Info-dumping is a term for when an autistic person talks extensively about their special interest. When it comes to friendship, this can often be a way an autistic person shows affection as it shows that you trust the person with something you care as much about as your special interest.



What is Parallel Play?

Parallel play is a very common way of socialising among autistic people, maybe when your friend comes over they play a video game and you scroll through social media and show them funny posts.

You aren't doing the same thing, but you're spending time together and that's what's important. This doesn't just include humans. One of the most popular types of parallel play could be having your dog sit by you as you watch TV.

Autistic people, like any other group of people, often have incredible qualities to bring to a friendship.

These include:

- Being direct and honest
- Having a strong sense of integrity
- Having a strong sense of loyalty
- Being less likely to judge others
- Being passionate about interests
- Showing kindness, sensitivity and empathy towards others
- Being accepting of other peoples' differences
- Not expecting others to live up to social expectations they may feel uncomfortable with
- Providing a different perspective on things

So, how do I know if I'm a good friend, or if I have good friends?

Teenagers are often told by adults whether the people they consider friends are 'good friends' or 'bad influences'. **We could write a checklist of what a 'good friend does' but we know the reality of making and keeping friends is not that simple.** For example, 'being kind'. That depends on what kindness means to you. Is kindness being invited to the party? How about being invited to the party but being expected to be the one to pay for everyone's taxi there? If a person is unkind on one occasion (e.g., perhaps if they were feeling hormonal and cranky), are they then not a good friend anymore? Like most experiences in life, there is no one right answer. Additionally, if your style of thinking is highly ordered and logical, receiving advice that must be adapted for different situations can be an overwhelming experience to navigate.

You might be advised to measure friendship by how the person you are friends with makes you 'feel', but what about if you have trouble identifying how something has made you feel until way after the situation finishes? It can feel really complicated.

In navigating being and having a good friend(s), one skill worth learning can be figuring out what boundaries, or personal rules you are comfortable with. Boundaries are often even more important for autistic people as it may not always be obvious to find out what the person's intentions might be just from talking to them, or what to do if people do or say things that you might not be comfortable with.

Boundaries can look different from person to person, as most of the time they are based on what individually people need or want. You can use the below suggestions to help figure out what boundaries that you would be comfortable with a friend:

Boundary 1: How you treat each other's time

An important boundary to create in a friendship is how you treat each other's time.

? Do you just want to meet in one usual situation (e.g., school) or would you also like to hang out over the weekend or in other places?

? How often do you want to meet in real life and/or talk online?

? Do you want to talk outside of when you meet up? Some people would like to constantly text or call, but that might be something you find overwhelming. It can be helpful to figure out with your friend how much contact that you both feel comfortable with.

You could do this by saying:

"I appreciate your time and value your friendship, but I find having to instantly reply to your messages a little overwhelming. Could you give me some time so I can process your message and give a fuller response?"

Boundary 2: Knowing what you need and can expect from friendships

When you are friends with someone, it can be important that they know what you need to feel safe and comfortable. For example, in order to say 'yes' to an invite to the cinema, you might need your friend to text in advance when they are going to arrive so you are reassured that they are on their way. Being able to express and advocate for yourself and your needs is really important to ensure that your friendship is healthy, mutual and genuine.

Spend some time thinking about what you think you reasonably need from a friend to feel their understanding and respect.

To get you thinking more about this, some examples might be:

- ▶ If you are hanging out and they want to change something in the environment that might seem small to them, can they help prepare you by asking, "Is it alright if I....turn some music on, turn the light off, open the crisps etc?"
- ▶ If they have been mad at you about something, can they let you know they are no longer mad rather than assume it is 'forgotten' about?
- ▶ If a plan for a meet up changes, can they let you know before you get there even if it seems a minor change to them?
- ▶ If you tell them something about being autistic, can they try and avoid saying "but everyone does that" if it makes you feel unheard?
- ▶ If you find it hard to know when they are joking over text, can they make this clearer by saying things like 'joking with you!'?
- ▶ If they feel you have not been understanding or respecting them, can they tell you directly rather than dropping hints as you don't want to miss out on when they are upset?
- ▶ If you are quiet after meeting with them, can they try and remember that this is probably because you want some quiet time after something sociable?
- ▶ If they notice you haven't been turning up to social events, can they still send you a message to let you know about the plan, even if they doubt you'll come?

Everything in this list is reasonable, and does not 'expect too much'.



Boundary 3: Reciprocity

One boundary that can be harder to look after is if the relationship is not reciprocal. This means that one person may be listening and attending to the needs of the other person, but the other person is not doing this back.

Whilst friendships are often not an exact give-and-take, what you are giving and what you are getting out of your friendships should balance out over the long run.

If you feel drained after spending time with a friend or if you think that you are always the one who is giving without being supported, it might be a good idea to think about whether the friendship adds to your life, and whether you feel that communicating a boundary is needed for the friendship to continue.

This can look like asking somebody to check in every so often or to be invited to hang out.

For example:

“Hey! I care about you and enjoy your friendship, but it does not feel good if I only hear from you if you want something from me - I’d appreciate it if you were to check in or invite me to things, and give some more of your time to support me.”

Boundary 4: How much you tell them about your life

It is OK to have friends who know a lot about you and friends who know a little less about you. This includes telling someone that you are autistic. If a friend tries to push you into revealing more about yourself that you feel comfortable with, honesty is the best policy, and you can say something like **"Thanks for asking, I actually don't enjoy talking about that"**.

This also works in reverse - just because a friend does not tell you something private about themselves, does not make them any less of a friend. Try to be respectful if friends prefer to keep something to themselves, and not to push them into revealing things that they would prefer not to.

Boundary 5: Others unhappiness is not your unhappiness:

Whilst being able to sympathise with and support friends are fantastic qualities to have, it can be hard to express these feelings while at the same time looking after ourselves. It can start to feel like we can only feel happy if our friends are happy too, but showing too much empathy or support can have a drain on our own ability to look after ourselves. This can be particularly so if you feel very intense emotions, or if you feel very emotionally attached to the friend. If this happens, it doesn't mean you need to stop checking in with your friend but you might want to take breaks from constant contact.

You might say to the friend,:

"I have been feeling quite exhausted and drained lately, so if you are hearing from me less that is why".

Important!

You might implement all the reasonable boundaries we have mentioned, and still, the person may decide they do not want to be friends. This can really hurt. It can also create panic if it feels the loss of the friendship will mean a major change to your routine (e.g., who you sit with in class). If you notice that someone is no longer acting like your friend, it is reasonable to ask them if everything is okay, as you have noticed a change in the friendship.

They then have a number of options in how they respond:

- 1. Ignore your message or ignore your attempt:** This hurts. It can also be frustrating as you may feel you have unanswered questions, and lack of information on why the situation happened like it did.
- 2. Tell you everything is fine: This can go two ways.** After the person tells you this, the friendship can feel like it's reverted back to normal. OR the person can tell you this, but it doesn't feel like they were truthful as they still don't appear to be acting like a friend.
- 3. Explain to you how they feel:** This could be that they want to work on the friendship or could be that they feel the friendship has come to an end.

What 1, 2 and 3 have in common is that **you cannot control the person's response**, even though at times we would all love to have the power to do so. You have control over your responses, and they have control over theirs. You have control over who you want to be friends with, and they have control over who they want to be friends with. If a friendship ends that you didn't want to end, it is so understandable that it can make you feel extremely sad.

If it is a school or activity based friendship, it might be worth thinking about how your routine will be different now and what you can do instead. For example, if the person is who you ate your lunch with, what is your plan for lunchtime now? Planning ahead of these scenarios can help feelings of panic when going through them.

Emily (17)

"I have always struggled to make and keep friends. In primary school I tried so hard to blend in with the rest of my peers but I couldn't. I was exhausted from desperately trying with numerous failed attempts, which then resulted in me just sitting on my own in the school yard. Non-autistic students tend to love their lunch breaks but for me they are a source of dread as they involve several forced social interactions and no real structure and many unknowns.

A lot of the time I don't understand whether someone is being serious or joking. For example, a boy in my class does tell me stories about his friends and I don't understand whether he is being serious. I always think he is being serious and then I get laughed at for not knowing it's a joke. This is because I struggle with reading people's faces and also I am a literal processor. I am also a very honest person, sometimes too honest!! If someone is talking to me I may say things without thinking and I may come across as mean or hurtful when really I am trying to express myself and my points and get straight to the point.

I often feel others got a script about life that I did not. **Talking exhausts me.** It requires so much thinking for me and I have to try so hard to understand the other person's views on what they're telling me, process what they're saying and I over analyse everything . When I come home from school most days I'm so exhausted. I can be upset from not being understood and having to mask, which is so exhausting and probably the reason why I was diagnosed later in my life."

Julian (15)

"When it comes to my diagnosis and how it affected me, I have to say that yes it affected me socially. Some might feel sad for me after finding that I lost friends after being diagnosed, but I find it a positive, because they were never my friends. I deserve the real friends I have now, and so what if I knocked on a few bad doors?

Now, whenever I do shut bad doors, I find myself going to one of the first right doors I've ever found, and finding consolation with them. That's a true friend, someone who cares, but above all else, is someone you can have fun with and leave the rest of the world behind.

I've found the closest friends to me have always been autistic by pure coincidence, so having autism in common with all of them is something I'm very proud of. When making friends the goal for me personally is to not mask, but I never thought I'd find such wonderful people along the way.

In my view, the best way to make friends is to do something you both enjoy, and in turn enjoy each other's company. Whether in real life or online, there will be people out there that suit you and what you prefer.

A useful tip though is knowing their birthday, I also recommend getting them a card to show you care or even a thoughtful gift on special occasions.

People who have something in common with you, who are fun to be around, but most importantly accept you for who you are, diagnosis and all, is who I want to be friends with."

Luke (22)

"What I would say to those who are autistic and dyspraxic (like me!) who are struggling with socialising and making friends is...

- ▶ There are loads of people without friends or in bad friendships, so none of that makes you unusual if you feel like you are the only one. Now I've gotten that out of the way!
- ▶ **My processing makes it really hard to keep up with conversations.** It is ok to let the people you are talking to know about this, don't be afraid to speak about it.
- ▶ If you have a special interest in something and have been able to learn a lot about it, then you might find it easiest to have conversations with people who also know about this stuff. I am really into certain games like: Ratchet and Clank, Banjo-Kazooie and I know lots about these. But if people are talking about TV shows I do not watch, then I will not be able to engage.
- ▶ Don't feel bad if you cannot find the right friends for you, there is no time limit to make your forever friends. You cannot go from acquaintances to good friends in a day or even a month. One of my good friends now is someone I just saw regularly at my English class. It was just really slow and casual how we got to know each other.
- ▶ If you take part in an activity together, that tends to mean that you have that in common. I take part in Special Olympics and I have made a lot of friends there. So, when you do find someone who also knows and is interested in the same stuff, then you will find it a lot easier to socialise. For example: I met one of my friends because he was into Halo (an Xbox video game series). I was more of a casual fan of it, but was interested enough to talk about it with him. He would just keep talking to me about it. 7 years after he left school, we are still playing video games with each other online every night.
- ▶ I have learned it doesn't work for me to focus in on one person or a group of people who I want to be friends with, and then ignore everyone else. I've done that a few times. It really brings down your self-esteem if you are focusing on people who do not want to be friends with you.
- ▶ **I don't think we should have to feel like you have to be friends with everyone or have loads of friends.** A lot of people are 'gang friends', so only hang out in a massive, loud group - but actually don't know the other people well or talk to them one on one. From school, I have around two friends and from college the same. That just goes to show that after 10 years, I have come away with four friends and I think that is doing pretty well."

The uncanny concept of eye contact

By Isabella Blum

It hurts. It burns.

Why must we implement this action

just to communicate with the world

and be perceived as "normal"?

We are scalded if we refuse to.

"Look at me when I'm talking to you!"- the phrase

plays a traumatising role in all our childhood memories.

We try but no; it hurts, it burns.

We aren't lying to you, or being rude, or ungrateful;

But we simply cannot look at your eyes;

It hurts, it burns.

And by the way you are perfectly

Capable of being able to hear and understand

Us when we are not looking at you.

Julia (23)

"The world of making friends was one of the scariest experiences growing up. For somebody who liked to be alone and only enjoyed the company of my family who were safe and understood me, why should I even bother trying to make friends? Outside of school it was okay, my mum knew me so well she didn't pressure me to make friends or try and force relationships, she knew I would be drawn to the people who made me feel safe and got how my mind worked.

In school there are so many pressures and expectations! I was a loud child, I liked to make people laugh and joke around. I also became hyper and didn't know when to stop. I did not follow fashion trends, or like to sit and chat about going out with friends, or who the latest person who everyone fancied. My focus was so much on having some friends that I didn't think about whether they were good friends or what does a good friend look like?

Everyone had friends so that was what I felt I needed to do. I managed to make a few friends who seemed to like me but they did things which I didn't like. I was so desperate to keep them as my friends that it didn't matter. I would pretend to like what they were talking about. I would make as many excuses as possible to not see them outside of school but occasionally would have to and join in with things I hated! But that was okay because they were still my friends. I remember the idea of a date and wearing a dress and make up was my worst nightmare, but I did it because that was what I felt I needed to do to fit in.

When I left school, I never spoke to those people again, I was free of having to pretend with them. I made a couple of new friends after school. They were older and I thought they were amazing. I would always try and hide the fact I was Autistic as I didn't think they would want to be my friend if they knew. These guys very quickly found their uses for me. I would pay for everything I could as I thought that would make them like me more. When I passed my driving test it was only me who drove. I was made to feel guilty if I didn't provide lifts on nights out even when I was scared at times.

I would finish work and refuse to do anything else just in case they text me and invited me out. Sometimes I would sit up until the early hours of the morning waiting for a message. My mum would try and tell me that these were not things that good friends did but it didn't matter to me. I felt like I would do anything I could to keep them as friends. I finally built up the courage to start thinking for myself and they didn't like that, so one day they just never spoke to me again. I felt sick with relief in the end that all the pressure of trying to fit in with them had gone.

Fast forward to me now being an adult in my twenties. I have quite a few friends. And they're so good to me. **My favourites are genuinely the ones who know I'm Autistic and accept it.** I don't hide it anymore. They buy ME gifts and always remind me that they're there for me. They understand a problem I might be having from my perspective and I try to see it from their perspective, but no longer feel that I have to. And a couple of really special ones know there's something wrong just from the look on my face."

Claire (16)

"My Mam and Dad respect that I do not socialise like my two brothers and don't pressure me. There are certain 'social' (read: stressful) things I do when I know it is very important to them (like talking to my cousin when my auntie and her visit). Likewise, they know that pushing me beyond those compromises really upsets me and they must not do it.

To get through these 'compromise' situations, here are some of my hacks:

Saying "*that's interesting*" (in your head you can complete the sentence 'to you' -. I finish off sentences silently ALL the day long!)

When I've gotten totally lost in a conversation or it has stopped 'making sense', redirection can work really well. I think about something that person seemed happy to tell me about previously and I seem to get away with blurting out, "*oh do you remember that time when...*" - this helps the conversation to become more predictable for me.

Non-autistic people seem to love compliments that are general. Safe, go-to ones of mine include; "*Oh I like those runners/glasses/top etc*". I find non-autistic people also love to say 'Do you?' like they haven't heard you yet, so I save energy and just repeat the compliment again.

I do want to emphasise that I do not do the above with people I feel like I have a genuine connection with. **And if I have to do the above, it's usually a signal to me that this is a superficial connection**, rather than friendship. I do the above when I want to go easy on myself, get through a situation and forget about it. Sometimes, I choose to mask my way to safety."

Aaron (26)

"For me, Transition Year was a major turning point. I found the stress and pressure of school very difficult. TY gave me space to relax, to get to know a smaller group of people better and to make friends through my interests. Ultimately it was using my interests, such as debating and TY mini company, which enabled me to overcome my anxiety and unease at making friends. When I made the group of friends I have today when I was in TY, then things became really positive."

Here are some ways you can reduce that awkwardness:

- Send them a text or message to say that you understand what they've said, and while it has made you feel sad, you know nobody is to blame.
- Explain in the text that you might be acting differently but this is because you are trying to process what they have told you.
- If you do value the friendship, tell them that in simple terms - it is enough just to say 'I really value you'.
- If you would like to have a little time and space to get over your feelings before talking to them again or resuming your friendship, then it's absolutely the right thing for you to ask for this.

A note on the 'friend zone'...

Being put in the 'friend zone' is not the insult it might feel like. Friend zone means that the person communicates to you that they see you as a friend rather than someone they are physically attracted to or somebody that they want to 'date' or 'go out with'. Being physically attracted to someone is often called 'fancying' someone.

Nearly everyone on this planet will at some stage have fancied someone who doesn't fancy them. This can feel like you weren't 'worthy' of the person fancying you, or finding you attractive. This feeling can be even more intense as nearly everywhere you look (social media, Netflix, influencers) 'romantic' or physical relationships can seem much more coveted or desirable than a friendship.

It can be incredibly hard not to feel hurt by the other person in this situation, but regardless of how kind and supportive either person in the friendship has been, this does not entitle either person within the friendship to develop into a physical relationship. You cannot make yourself physically attracted to someone, and someone cannot make themselves physically attracted to you. In short, **nobody owes you, and you owe nobody physical attraction.**

A person's friendship, rather than their physical attraction, is not a consolation prize. When people say, 'be careful, you're going to be friendzoned!', what they might not realise they are inferring is, 'be careful, that person will use their own autonomy to think they value you as a friend and do not want to enter into a physical relationship with you'. If a person is offering you their genuine friendship, and you want it, this is something wonderful and of value in its own right. They are saying 'I choose to have you as a friend because of the qualities you have'.

Of course, all we have said does not take away from that horrible feeling when you decide to put yourself out there and tell someone you fancy them, and they say they don't fancy you. It can also feel unpredictable as to what is then going to happen next. Usually, what happens next is the vibe or familiarity between you both can feel 'out of sorts' or awkward for a while.

Peer Pressure

When people look back on the experience of making friends as teenagers, they often bemoan the things they did to 'fit in'. **We do not know one adult who does not regret something they did as a teenager in order to fit in with the people around them.** This pressure from other people to do things we would not normally do is often referred to as peer pressure, and seems to be mostly used when speaking about teenagers.

This feeling of pressure can feel more intense when you are autistic. As well as worrying about the reaction you saying 'no' will result in, you may also feel that if you say 'yes', then you will find the thing unenjoyable. Lots of you might also feel a weird doubt about why you can't seem to enjoy the thing others are enjoying.

That's a lot to process!

Another complication when it comes to pressure from peers might happen if you have a **monotropic** style of thinking. Your brain might not help you out with spotlighting possible consequences in the moment, even though you are 'aware of the existence' of these consequences. This can lead to that 'oh I don't feel good about this' thought being delayed until a while after the situation takes place - maybe later than day or even days or weeks later.

Emily (17) told us where she can feel peer pressure in her life:

"My name is Emily and I am 17 years old. I experience lots of peer pressure as I am sure other Autistic teenagers do also. Especially as teens in Secondary School when discos, nights out and drinking are seen as the 'norm' and these events create extreme sensory overload for us and extreme stress because I don't know what to expect and nothing about these events are predictable or structured. These events include people that I may not know which stresses me out."

Monotropism

Monotropism is a theory of autism developed by autistic researchers, Dinah Murray and Wenn Lawson. Monotropic minds can focus very intently on one thing at a time with very intense interest. A monotropic mind can also easily connect various topics into the topic they are focusing upon. This is sometimes described as 'flashlight' focus due to not only its intensity, but how other areas pale into 'darkness' when you are focused. This can make you a very determined problem solver and passionate about your work.

"Everyone vapes, what's wrong with you?"

"Oh my god, you're not a virgin, are you?"



A lot of autistic and non-autistic teenagers and adults can feel that alcohol is needed to make a social situation less awkward. You can feel under pressure to drink alcohol especially if everyone around you is doing the same. You might also want to try vaping. Vaping contains nicotine and is an addictive substance, just like smoking. We actually do not understand the long-term side effects of vaping yet.

If you are similar to Emily, who is finding it hard to have a socialising option that doesn't involve alcohol, **NoName Clubs** are clubs set up all over Ireland for young people for ages 15 and upwards. These clubs focus on a social life for young people in which the use of alcohol and other drugs is seen as unnecessary. If this interests you, you can find out more information about these clubs here on this website: www.nonameclub.ie

If you are asked to be part of a social situation you don't want to be in, you have some options:

Option 1: Say No

This is the one we hear the most. It can be hugely difficult to consciously decide you are going to say 'no' to something, when you feel that saying 'no' will result in ridicule, exclusion, being seen as 'judgey' or just drawing attention to yourself. This can be even more difficult when you feel you are already judged negatively because of being autistic or being part of another minority group. It is also something that is a skill requiring practice. If you do feel safe to say 'no' however, this can be the quickest way to shut a situation down.

We asked Emily (17) how she copes with peer pressure:

"I have been seen as 'odd', 'weird' and 'different' because these events are not for me, I do not go to them because they don't suit me or my needs. This experience has been intimidating because neurotypicals don't understand that I require so much preparation, routine, predictability and structure which these events don't involve.

When people ask "Oh Emily why will you not come out for the night", I reply with "I cannot tolerate noise, or touch, or bright lights, or unknowns. Like not knowing who's going to be there, how long we will be out for, what is going to happen and not going to happen". This usually gives the non-autistic person an insight into why these events are not for me."

Option 2: Getting yourself away from the situation

We described how a monotropic style of thinking may mean you do not process how you feel about something until after it has taken place, and your brain is free to pay attention to the consequences.

You cannot force your brain to work things out more quickly in a difficult situation. So what can you do instead?

Bernadette (17) shared her thoughts with us on this:

"My Mum is autistic herself and has taught me some ways to get myself out of a situation in a non-confrontational way. Yes, of course she taught me about the importance of standing up for myself but she also knew there are times where if I can't 'stand up and say no', then I need another option apart from 'do it'.

These are our hacks:

- ▶ *Text her to call me and then I roll my eyes and say she's making me go home.*
- ▶ *Say I have a headache.*
- ▶ *Go to the toilet. I could not cope in social situations without the toilet. I go in and sit in a cubicle when I am feeling overwhelmed, or when I don't want to join in on what people are doing. I actually carry a bottle of water (that I don't even drink from much) so I can say something like, "Ah I need to go again, I drink way too much."*
- ▶ *When I know I need to leave a situation, but can't seem to move myself, I have a rhyme in my head to get me going - 'Lift one foot a little, kick out a leg, put the foot down again' - I find that one step then lets my body take over.*
- ▶ *Knowing what the 'things' are I might be offered and having an answer ready to say 'no' that doesn't show I haven't done the 'thing' before' - so, I have often said "No thanks, had a bad experience with spirits" when offered vodka.*

I know my auntie said to my Mum before that she shouldn't be teaching me to pretend, but she says if someone had taught her how to pretend in certain situations when she was a teenager, that would have really helped her and at times, kept her safe."

MEETING PEOPLE AND HANGING OUT ONLINE

For a lot of teenagers and adults, chatting to friends and family online can be much more fun than chatting to people offline/face or face. **This is a completely valid way of socialising.** After all, isn't socialising about having fun? Some people in your life may not understand this, or view these chats as not as important to chatting to people in real life (IRL). It can be extremely frustrating explaining to someone why hanging out online is your preference.

Here are some examples you could use to explain your preference:

- ▶ When we write to somebody online, it gives us more time to process what the person has said and come up with a response than when someone speaks out loud and expects a response
- ▶ Using our phone/laptop/tablet generally means we have much more control over our environment and can socialise without the competing pressures of sensory overload (e.g., you are able to talk to someone while lying in your cosy bed feeling relaxed)
- ▶ Emojis and GIFS can feel a 'safe' response when we aren't too sure what the other person meant/if they're joking or if we can't think exactly what to say
- ▶ We can focus all our attention on the words being exchanged and not feel our body language, eye contact, stimming or how we look is being judged
- ▶ Info dumping can work well over online messaging

In the next section, we talk about the positives and negatives of social media.

If you find reading about topics such as **online bullying or pornography** uncomfortable, we suggest you skip this section.

Online talk - terms and acronyms:

People sometimes use a different style of communication online. They may shorten a phrase or a word. For example, Wbu - What about you? IRL - In real life. You can use websites such as **netlingo.com** to see what many internet terms and acronyms mean.

Adapting our friendship and relationship boundaries from IRL to online

Much like IRL friendships and socialising, there are times that socialising online or using social media, can feel uncomfortable or upsetting. We have talked about using boundaries to figure out how you feel comfortable with a friend.

These boundaries can also be adapted for when socialising online. In fact, a lot of people have even MORE social boundaries online for the following reasons:

It's difficult to 'figure someone out' online

When we meet someone IRL, we always see what they look like and we often get to see how they act with other people too, and not just you. For example, a new boy in school: is he rude to the 1st years but really nice to the 6th years? Does he tell one friend one thing and you another thing? Online however, it may take us a much longer time to trust someone because we have no way of knowing if what they say is true.

Not only do we not know if what they SAY is true, we don't know if how they LOOK is true.

So, what boundary could I use?

Remind yourself that it takes us longer to know a person's character online than it does IRL. We can still get to know their interests, sense of humour, talents etc all the while knowing we are only able to see what they want us to see.

It's difficult to know are you making a new friend or connecting with an influencer

When we meet someone, we generally know if they want to talk to us personally or professionally. If they are a doctor, teacher or therapist for example, we learn that part of their job is to talk to us and that they should not try to be our friend or speak to us outside of their work. They want to talk to us professionally.

On social media, there are also people we can speak to personally and professionally. The professionals on social media are called 'influencers'.

What is an 'influencer'?

An influencer is someone who has built an online reputation about their knowledge of certain subject, i.e., gaming, make-up brands, music, baking or vlogging. Influencers tend to use blog posts, YouTube, social media or platforms such as Twitter, YouTube, Instagram or TikTok to share content. They are called influencers as they have the power to 'influence' their followers' decisions. Influencers are generally over the age of 18.

Speaking with their followers is the job of the influencer, just like part of a waiter's job is talking to his customers. They might vlog about their experiences, or put on live streams, connecting with their followers in the process.

A 'relationship' with an influencer is designed to be professional. We are the customers who are consuming their content and they are working as an influencer producing content. This can be confusing as we may see their posts saying "I love you guys so much" and they may like or reply to our comments and DMs, just like friends and family do. **The difference is this interaction with their followers is part of the influencers' job.** This is not generally dishonest or unkind of them, just like your waiter might be very friendly to you but does not suggest your families meet up at the weekend.

How do I know someone is an 'influencer'?

- ▶ They may have lots of followers, from thousands to millions.
- ▶ They will have a lot more followers than people they follow.
- ▶ They might have a 'blue tick' beside their name to show they are a 'verified' account.
- ▶ They may be very active on a lot of platforms,
- ▶ They may encourage people to support them by asking them to donate or to subscribe to their profile on a platform like Patreon.

A question you might find silly to ask:

What is social media?

This is the collective word given to websites and apps that you might use to communicate with other people. We mainly use these websites and apps to keep in touch with friends and family and to share content such as pictures and videos.

Did you know?

TikTok – If you are age 13-15, your account is automatically set to private. From ages 16 to 17, your account is set to public. You can change this in your settings

Instagram – If you are under 16, you automatically have a private account

Facebook – If you are under 18, you automatically have a private account

So, what boundary could I use?

- ▶ **Have the same expectation of an influencer online as you would of other 'professionals' in your life.** You can like them, be entertained by them, have favourites, while knowing that they do not see you as a friend. Often people know a lot more about influencers than influencers know about their followers, and therefore influencers may not always be aware of the effect that what they say or what they promote has on their followers.

For example, imagine you are feeling upset that your family cannot afford to go on holidays, and your favourite influencer posts photos of their holiday. If a friend did this, you might find it insensitive. However, the influencer doesn't know anything about your situation, because they don't know you. An influencer will not always act in the way you would hope a family member or friend to you would. This can feel jarring when it is someone you spend a lot of time looking at and listening to, and you feel you know them so well.

- ▶ **Be mindful of the message the person is trying to communicate by their posts.** Often there is a strategy to how influencers use social media - they might be promoting something, like a product, a TV series they are in or music they have created. Even the vlogs that they post may be constructed in a way to portray a more positive or glamorous image of themselves and their lives to followers than what their life actually looks like.

For example, celebrities, influencers and prominent people in public often have other people, like a public relations(PR) agency, a Communications Manager or Social Media Manager that they hire to look after their accounts, and they may not be on their account themselves. So when a celebrity or influencer posts on their account, it is often filtered through this person first - there may be a very intentional strategy behind what they say.

- ▶ **When looking at someone's social media, remind yourself that you are seeing the very best moments of their 24 hour day.** The social media feeds of many influencers may only show the best parts of their life. The photos and videos they share can have filters or be touched up by apps to remove blemishes or imperfections. You may not see them having bad days or feeling the same anxieties or stresses as everybody else.

What is a DM?

Direct Messaging is a form of online communication only visible to you and the sender.

It's difficult to control who sees what you say and do

In our school, we might tell one person in our class about what we did every night on holiday. We might then tell a few people in our year where we went on holiday, but not what we did every night as that means explaining more about our family and lives. We probably wouldn't tell someone in a different year group, who we only know by name, anything about our holiday. You might be more or less private than what we have just explained. **In life, we will come across thousands of people, and we will constantly make decisions about how much we want them to know about us.** Similarly, online, we will come across thousands of people, and we are able to make decisions about how much we want them to know about us.



So, what boundary could I use?

- ▶ Decide what different people online will be able to see of what you post and interact with. A profile page on private-mode means only your 'friends' or 'followers' can see what you post. You must approve other profiles before they can see your profile.
- ▶ If you want to have a conversation online with someone, this can be posted publicly (all of your friends and followers can see it) or via DM. If you would not have the conversation standing at the top of your classroom with your whole class watching and listening, then this is likely to be a conversation that takes place over DM.
- ▶ Before accepting someone as a friend or follower, decide if you are okay with that person having the power to show what you post to their friends or family that you don't know (by screenshotting).
- ▶ If you change your mind about a friend or follower having the power to see, react to, or share what you post, you have some choices. You can 'block', 'unfollow' or 'mute' them. If you 'block' a person, they may be able to check if they can still see your profile. If you 'unfollow' a person, they may be able to check if they are still in your 'followers' list. On Instagram you have the option to 'mute' stories and posts from followers, which means you will not see their posts or stories. They will not know if you have done so.
- ▶ If you receive comments, photos or messages that distress you, before deleting them, you could take screenshots or photographs of their messages and posts as evidence of what has happened. These can be helpful when seeking help or if you choose to report them.

Wait, why would someone who isn't an influencer want a public social media account?

The main reason is usually to build follower counts. Logically, if strangers can follow you as well as family and friends, you are likely to have more followers. However, anybody looking at someone's social media count with thousands of followers can tell that the account owner doesn't know all of those people. It would not be possible.

It's difficult to 'take back' what we say or do online

Day to day, our conversations and interactions are not recorded and played out loud to a crowd. Imagine if an argument with our Dad in the car or a confession to a friend that you fancy another friend was played out loud! We talk with people safe in the knowledge that it is only the person we are speaking to who hears and sees us. So, if we say a hurtful comment to a friend or family member, they are the only person we need to apologise to and that usually resolves it.

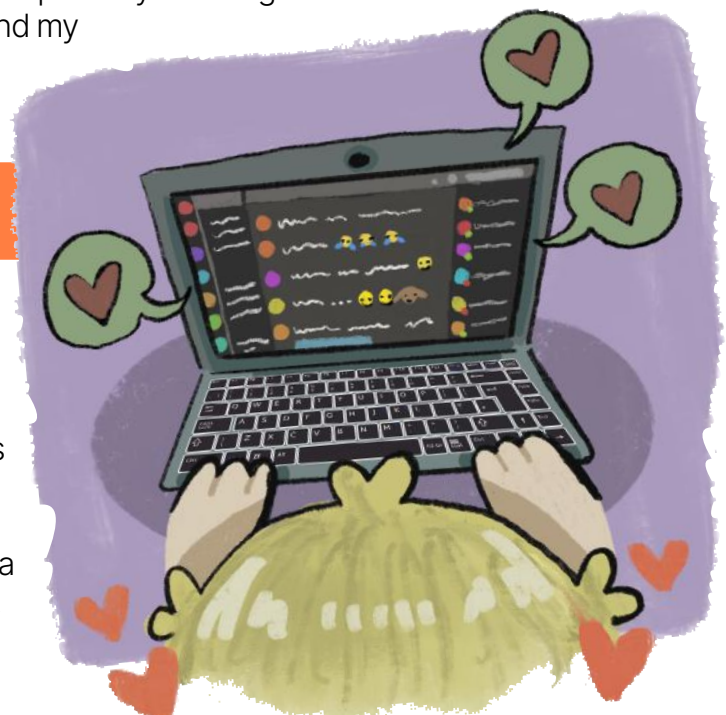
It sounds obvious but social media is the complete opposite of this. Every opinion, argument, interaction, joke and comment we put on social media is heard and seen by everyone we have as followers or friends. Not only this, they can share this 'record' of what we say and do with anyone they want to. **Even if we choose to delete a post, there is a possibility someone might have taken a copy, or a screenshot of it.**

So, what boundary could I use?

Keep our social media in our control. Everything we share publicly on our page, we are deciding, "Yes, I am comfortable with everyone possibly knowing this about me; everyone in my year, everyone on my road and my parent(s) too".

It's difficult to take a break online

When we want to socialise in person, there usually needs to be a plan in advance. When we want to use social media, we generally just need to grab our phone or tablet. That definitely has its advantages, but also means we can find it hard to escape or take a break. Just like socialising in person, you can know yourself when social media starts to make you feel anxious or in a bad mood, but you can find it completely unavoidable.



Social media sites are also built by their owners to make you want to use them as much as possible. Algorithms, which is the way that social media platforms find content that you are likely to engage with, play a big part of what you see online. For example, if you liked, reshared, searched or watched something for a long time on these platforms, then they will use these algorithms to to give you more of the content that you enjoy.

This can be very helpful but also makes it more likely that you may:

- ▶ Doomscroll; where each negative post you read links to another so you find it hard to stop reading.
- ▶ See posts or imagery you don't want to see again. Say you look at a certain hashtag, and the pictures or posts you see make you feel upset. The social media site doesn't register your emotion, only your interest, and therefore will continue to show you pictures of the same thing even when you don't search for it.

So, what boundary could I use?

- ▶ On Instagram, you can limit posts from public pages you don't follow.
- ▶ You can mute your notifications.
- ▶ You can hide posts with certain keywords or hashtags and they will be removed from your feed.
- ▶ Use the 'Do not disturb' function, or a productivity app, to reduce distractions and to hide any notifications that are not important to you.
- ▶ Talk to someone who you find listens to your point of view about this. Nearly everyone who uses social media experiences overwhelm, and will have suggestions on how to manage.
- ▶ On Instagram, mute posts or stories from people you follow when needed to reduce the content you see.

Pornography

Aside from social media, we all use the internet to find out information about things we want to know more about. This could be a route to a destination, the name of an actor or how to do something. **As teenagers, sex is something you start to hear discussed more and more, but is also something you mightn't know a lot about.**

Have you heard the term '**sexting**' and wondered what people are talking about?

Sexting is when you exchange messages and images of a sexual nature with another person. A person or people might ask you to send naked images or 'nudes' of yourself.

You might feel comfortable with this person. However, all of us can benefit from knowing that once you send a photo, the person who receives it can send it to others. A general guide can be 'I will only send a photo on my phone that I would be happy for that person to print and have stuck on their bedroom wall that other people can see'.

Did you know?

Often, you aren't told that sending nude images of yourself is illegal if you are under the age of 18. It is also illegal to have images of other nude under 18 year olds on your own phone, or to send them to others. This is classified as child pornography possession and distribution in Ireland.

Often, we do not want to show we have not heard of a 'sex word'. When asked if you have done something or would do something, it can feel easier to say 'yes' than explain you do not know what that word or terms means. The internet is therefore a logical place you might go to answer your questions about sex.

We do not have space in this book to go through all of terms you might hear in relation to sex, but sexetc.org is somewhere you can look online to read information about sex that is accurate and respectful to you and others.

Another way teenagers may find out about sex is by watching pornography or 'porn'. Porn is media where sexual activity of a person or people is recorded. This curiosity to see what having sex looks like does not at all make you strange or weird. The drawback however to using porn to learn about sex is that you are watching 'fake' sex - or sex that is being performed by actors. This is different to the sex people have in everyday life.

So, when you watch porn, it can cause you to think the following:

Thought: That's what it should look and sound like when I have sex.

Reality: Porn is a type of performance. Sounds of enjoyment, positions of bodies and words the actors use to each other are part of this performance. They are there for the viewer's pleasure more so than the actors. Whilst that does not necessarily mean that they don't enjoy it, like any performance (e.g, a film or a musical), this does not really represent 'real life' or 'real sex' because real people will not have a script to follow when they have sex and will not have particular acts they are expected to do.

Thought: My body is very different to the person I am watching.

Reality: The people you are watching are often chosen for having a certain body shape. This is not a body shape that the majority of men or women have.

Thought: Doing that looks painful

Reality: A lot of the content in porn is there for the enjoyment of heterosexual men and does not focus on the woman's enjoyment or safety. There may be acts that the woman does not enjoy or consent. This is a global problem that is unfortunately growing.

Thought: That person looks and sounds like they are really enjoying doing that. Should I try that?

Reality: Whilst there are videos where actors are genuinely enjoying the experience, in a lot of porn content, the woman in particular may be told to act as if she enjoys the experience, as part of the role. This is even if she is finding it painful. In most videos, the actors may not necessarily be physically or sexually attracted to each other. Not all porn you watch is consensual, meaning a person may not have given consent to the sex act. **What you rarely see in porn is one person asking the other person 'are you enjoying this?' or when someone isn't enjoying it or wanting to do it, they say or communicate 'stop' and this is respected.** This goes against the very basis of what enjoyable, consensual sex should be.

When you have boundaries on social media and internet use and still have a negative experience

Because online safety laws have not been developed as well as in person laws, this means we are not as protected by the law online as we are in person. We have all seen images, headlines and content that upsets us or makes us feel 'strange'. That is not your fault.

David (14) shared his view on navigating social media:

"I hate when my Dad says if I see anything weird on social media to tell him. What's weird? And I am always called weird so I am probably looking at weird stuff. I try instead to ask him a question about something I see online if I don't understand it. That can be a joke a friend makes, a TikTok, whatever. He then explains it but also will tell me if it's alright the person posted that. I did it one day by accident and I liked how he explained but didn't go mad that someone I knew had posted about that topic (I won't say what it was). The question thing works okay because it doesn't turn it into a massive deal. BUT there's a big BUT. My Dad actually works really hard at not freaking out at small things and giving me an answer when I ask a question. I think because we don't live with my Mam, he tries not to get us into fights. My friend tried it and his Mam went mad and banned him on social media for a week. I think that's so unfair! So if your Mam is like that, maybe say to her you're going to try this question thing so she's warned."

Consent

Consent is full agreement by all participants that they 100% are comfortable engaging in sex or any type of sexual act. Consent must be **clear and continuous** throughout the interaction, meaning you or the other person can change their mind at any time. You must be 17 years of age before you can legally give consent.

If you can't talk to someone you know

If you are seeing distressing content online, or receiving comments, photos or messages that upset you, but you do not want to tell someone you know, there are also free helplines available where you can speak to a safe adult anonymously.

Childline 1800 666 666 any time, day or night.

Teen Line 1800 833 634 any time, day or night.

Samaritans - 116 123 any time, day or night

Reporting to the Gardaí

Some forms of bullying are against the law. Sexual harassment, sharing of intimate images (i.e., nude or semi nude photos or content where you are performing a sex act) without consent, racism, and persistent bullying/harassment are all illegal. If any of these incidents happen to you, you can report these incidents to the Gardaí.

MINDING YOUR MENTAL HEALTH



Many of you reading this may have experienced a mental health problem, or be experiencing one now. People often equate having a mental health problem with being permanently unhappy. That is not true. We do not feel happy nor unhappy all of the time. Throughout our days, we actually usually dip and slide from different emotions. Feeling flashes of unhappiness in difficult situations does not mean you have a mental health problem. Having a mental health problem is in fact often described as finding it very difficult, or even impossible, to cope with how you are thinking, feeling and reacting to different aspects of your life.

For those of you who were recognised as autistic later in your life, sometimes having problems with your mental health can come before a diagnosis. Being an undiagnosed autistic person trying to exist 'normally' in a world that wasn't designed for you can have a hugely negative impact on your mood and/or level of anxiety. Then when mental health is supported without regard to autism, support can be ineffective, e.g., some medications, cognitive behavioural therapy (CBT) without adaptations, or focusing on the person changing and not the environment the person is struggling to navigate.

Understanding and Caring for Your Mental Health:

Does being autistic mean I experience mental health problems differently?

Every person in the world has the potential to develop and recover from mental health problems depending on their biology, and what happens to them over their lives. There are therefore numerous mental health conditions that are recognised internationally. While there is lots of information available about these mental health conditions, there is much less information available on how autistic people experience them. In the following section, we will introduce some of the more common mental health problems autistic people experience.

Trauma

It has only recently begun to be recognised that as a community, many autistic people experience trauma because of living in a world where the majority of society are not autistic, and where your needs are not always understood or accommodated for. This can be for various reasons, and an autistic person's trauma is often unique to the person.

Living a life where your autistic experience may be misunderstood and having to hide who you are can be exhausting and incredibly distressing. 'Re-traumatisation' can happen when you have to go through similarly negative experiences in different settings. If you would like to learn more about autistic trauma, @littlepuddins.ie on Instagram uses their character Auti to share their experiences of autistic trauma.

In this section, we talk about **mental health**.

If you find reading about different mental health conditions uncomfortable, we have labelled each section so you can skip out on topics where you wish.

We have listed supports you may want to avail of in the Resources section at the end of the book.

Examples of autistic trauma include, but are not limited to:

- ▶ Being taught to see your autistic traits as “deficits” that need to be “fixed” or “cured”
- ▶ Being told not to put a “label” on your differences or that you shouldn’t want a ‘label’
- ▶ Being judged negatively due to not being understood
- ▶ Feeling pressure to mask or having to repress your stims or autistic characteristics, or to make eye contact
- ▶ Feeling hypersensitive or putting yourself through overwhelming sensory situations
- ▶ Having to force yourself through uncomfortable social situations
- ▶ Being bullied or feeling isolated because of your differences or needs
- ▶ Having your need for accommodations or supports not understood or ignored
- ▶ Feeling ignored or belittled when you try to communicate with others
- ▶ Having “interventions” or therapies used on you without your knowledge or consent
- ▶ Having your experience of being autistic not validated or acknowledged

Anxiety

It is very common for autistic people to experience anxiety. However, there is a myth that part of being autistic is being anxious. This is not true. Researchers in the area of autism have shown anxiety itself is NOT part of being autistic but can come from the stress and trauma of being a neurodivergent person in a world that is often built with non-autistic people in mind. This means you can feel like you must constantly be hypervigilant or on ‘high alert’ for threats in your environment. Added to this, you may have a brain that is very skilled at hyperfocusing on things, and is therefore very skilled at focusing on what’s worrying you.



What is Anxiety?

By itself anxiety is a **feeling of worry and unease**, this is a completely normal feeling to have.

An excessive amount of anxiety could be due to living in highly stressful conditions or part of a larger anxiety condition.

Emily (17) shared her experiences of anxiety:

"I feel very anxious in uncertain and new situations. I need a plan going into every situation and if the situation is unexpected I cannot plan! I actually constantly worry about things that to others may seem small but to me they are very big. Like for example I would be sick with worry with lots of "what ifs"; What if a teacher that I have isn't in? What if my mom gets delayed when picking me up from my bus stop? What if one of my loved ones gets sick? What if I get sick? What if our car breaks down? The list goes on and on, constantly worrying about the unknown. "

What might help?

Know how your body and mind acts when you are anxious

Anxiety can feel similar in your body to other emotions (e.g., excitement, anger). It can therefore be annoyingly hard to recognise early signs of it, especially if anxiety is new to you. If you know you are anxious, focus in on what exactly your body does when it is anxious to help you recognise it (e.g., your face might get hot or your mouth might dry up).

Know your triggers and soothers

Write down, or record, what you notice triggers your anxiety and what soothes your anxiety. Triggers could be 'not knowing how you are getting home from school' or 'having to eat at someone else's house'. Soothers could be stimming to release anxiety or distractions like we described above.

Know that avoidance is not failure

Particularly when it comes to sensory change or novelty such as a new food or uniform, people might often say, 'the more you do it, the more you like it'. This is not always true. Your brain might continue to recognise the difference as a threat and become more stressed by it. We do not say this to stop you trying new things, we say it to let you know that avoidance can be very logical and protective for you.

When you can't avoid a trigger (e.g., if you are on the bus and a baby is crying, and noise is a trigger for anxiety), know what practical things help you in that situation (e.g., earplugs, playing music etc).

Meltdown and Shutdown

Despite the resilience autistic people often develop by living in a world where you are masking or constantly anticipating 'threats', distress can build and build until you meltdown or shutdown.

What is the difference between shutdown and meltdown?

Did you know that until recent years, much of the autistic experience was described by non-autistic people with autistic peoples' voices sidelined? This means experiences such as meltdowns and shutdowns were often described using medical language, and suggestions for managing these experiences came from those who had not experienced them.

More and more autistic people have documented their experiences of autistic meltdown, shutdown and burnout. While both meltdown and shutdown indicate you are overwhelmed, generally speaking, **meltdown** is described as a loss of your control which shows itself externally (e.g., crying) and **shutdown** is described as a more internal experience where it can feel like you are shutting down.

We asked the AsIAm community to share their descriptions of meltdown and shutdown.

Do any of these feel familiar to you?

"I feel like I need to climb out of my skin"

"A sudden inability to filter out the outside world"

"Crying and shaking"

"Feeling sick"

"An overload that causes you to say and do things you normally wouldn't"

"Feels like every word is an electric shock"

"Total loss of control"

"A need to escape whichever way I can"



Shutdown

"If meltdown is fight or flight then shutdown is freeze"

"Self-preservation"

"Dead battery"

"Frozen in a bubble"

"Like a trapdoor closing"

"All the air out of the balloon"

We also asked what helps when experiencing meltdown or shutdown:

"Tell people who are important to me that I may have meltdowns or shutdown sometimes"

"Write down what I feel like saying and delete it"

"Tell family to leave me be when I am in it, and not try to teach me something new"

"Tell family not to touch me"

"Tell family to offer me a chat afterwards not during"

Burnout

You might have heard the word burnout before, but autistic burnout is different to general burnout. General burnout is usually associated with working too hard. Autistic burnout can in fact look like depression (loss of appetite, inability to concentrate, trouble sleeping, lack of interest in things, isolation). It can happen when you become completely fatigued by masking and by social interactions that cause you stress.

We asked the AsIAm community to describe what autistic burnout felt like:

- "I just need to retreat from the world to recover"
- "Too much external stimulus combined with too much internal pressure to mask"
- "Dog tired and deflated"
- "A tiredness sleep cannot help"

We also asked what helps when experiencing burnout:

- Sleep
- Fresh air
- Dark room and white noise
- Patience, time and understanding from my family and friends
- Help with recognising that I am burning out as I don't realise until I am there
- Removing myself from the situation. If at home, going to my bedroom. If I am not at home, comfort eating helps to get me through but doesn't solve it
- Building up into doing structured tasks bit by bit

How can the adults in your life help?

When you are in the process of meltdown, shutdown or burnout, explaining to someone what helps can feel absolutely impossible. A group of researchers in Canada¹ decided to ask autistic young people what they wanted the adults in their lives to do when they were in meltdown. These young people concluded:

1. **Know the things that make me feel out of control**
2. **Learn the strategies that help me regain control**
3. **Understand the things that make me feel worse**

These might be three things you want to have a think about, and then consider sharing with the people important to you.

We also asked a clinical psychologist what they had learned about managing burnout, meltdown and shutdown from working with autistic teenagers:

"In my view, the best way to cope with shutdowns, meltdowns, and burnouts is prevention. Think about activities, sensory experiences, passions, people and things that are calming, soothing and restore your energies. If at all possible, increase access to these in your everyday life. Schedule them in because they are as necessary to you for a healthy body and mind as eating, sleeping and breathing."

Another way you can look at prevention is by applying the **Spoon Theory**. This was originally created by a writer called Christine Miserandino who experiences chronic illness, but has since been used to explain why everyday life can be so overwhelming and draining for autistic people.



¹Phung, Jasmine and Penner, Melanie and Pirlot, Clémentine and Welch, Christie. (2021). What I Wish You Knew: Insights on Burnout, Inertia, Meltdown, and Shutdown From Autistic Youth. *Frontiers in Psychology*. 12. 741421. 10.3389/fpsyg.2021.741421.

SPOON THEORY

In spoon theory the spoons are a physical manifestation of energy. Everyone wakes up with a certain amount of spoons in the drawer and each activity takes a certain amount of spoons away or gives a certain amount back.

Sadhbh wakes up with 30 spoons	Task	Charlotte wakes up with 30 spoons
Sadhbh couldn't find her jumper for school and her mum wouldn't let her go without it (-2 spoons)	Get dressed for school	Charlotte doesn't like how scratchy the jumper is and her dad changed what kind of detergent he uses and the clothes don't smell nice (-3 spoons)
Sadhbh hates making her bed, it's such a hassle and she'll only mess it up when she goes to bed (-1 spoon)	Make your bed	Charlotte loves how her bed looks when it's made, it makes her feel organised (+1 spoon)
Sadhbh got to have coco pops for breakfast (+2 spoons)	Have breakfast	Charlotte's brother made breakfast and he always messes it up her porridge, but she made her own tea and that was nice (-2 spoons)
Ruins the taste of the coco pops from breakfast (-1 spoon)	Brush your teeth	Charlotte hates how the toothbrush feels and sometimes it makes her feel sick (-2 spoons)
Sadhbh has 28 spoons for school	Go to school	Charlotte has 24 spoons for school

Relaxation

James Hynes Chadwick

Sometimes when I'm not so sure,
I need to take a break.

I have to count to five or ten,
And use my breath to take.

The sequence helps to make me calm,

By breathing in and out.

This helps me stay calm with my mum,

BUT PLEASE DON'T EVER SHOUT!

Yoga helps me to stay fit,

With all the yoga poses,

Like cat, cow and downward dog.

It's sure that I don't feel enclosed.

My eyes start to close

And I'd be sleeping like a log.

Sometimes, naturally, nobody knows,

How I need the world to defog.

My breath I breathe through my nose,

I can become as calm as this frog.



What is the HSE?

The HSE (or Health Service Executive) runs all of the public health services in Ireland.

Obsessive-Compulsive Disorder

Obsessive-Compulsive Disorders (OCD) happen more often in the autistic community compared to non-autistic people. Let's break down the name firstly. Obsessions are intrusive thoughts that you don't want in your head. For example, you might have the repeated idea that you will make someone you love sick if you touch them with your hands. Compulsions are habits/actions that you do in response to obsessions. For example, you might repeatedly hand-wash even though you know logically your hands are clean. **Sometimes, autistic peoples' stims can be misunderstood as compulsions.** However, to meet the diagnostic criteria for OCD, those compulsions need to be causing you distress and interfering with your life to some extent. Stimming can often look like compulsions - both can be viewed as repetitive and are often done when stressed (though we do not only stim when stressed of course). It is so important that your doctor or therapist separate stimming from disordered compulsions to prevent you being encouraged to stop stimming. Stimming can be a wonderful coping mechanism. There is nothing disordered about this, so it should not be the focus of therapy.

Eating Disorders

Your experience of eating as an autistic person can be affected by physical and sensory differences. We explain this further in the Food chapter by the way! As well as this, sometimes the environment can seem so overwhelming that focusing on food can become a way of controlling what feels uncontrollable. This can often look like a strict control of the amount of food eaten, the number of calories consumed, and/or an obsession with reducing weight. So, how do we know when controlling what we eat becomes an eating disorder? An eating disorder is when a desire to lose weight comes with a critical voice telling you that your body is not good enough. There is a fear of gaining weight. **If this is something you want to learn more about, more information on eating disorders can be found on bodywhys.ie.**



Outside of my family and friends, where do I get help with my mental health?

The HSE can at times provide help. To get help from the HSE, you first go to see your GP. You can start going to the GP by yourself when you turn 16.

What should I say when I see my GP?

There is no exact script we can give you, as every person's experience in speaking to the GP is different. We can however give you suggestions on how to prepare for this which we do later on in this section.

What will the GP do if I tell them I am having mental health problems?

First and foremost, your GP should listen and validate your concerns.

At the end of your discussion with the GP, they have different options on what they can do next:

They can send a letter to your local **primary care service** to request you see a psychologist, occupational therapist, or other relevant health care professional. Primary care supports people of all ages with 'mild/moderate' mental health concerns. It is usually the first place you are referred to for help. The psychologist can provide therapy and advice for your mental health, and the occupational therapist can support you in other ways like how you are sleeping, eating and how you are spending time in your days. You can also access primary care without going to the GP (if you Google where your local primary care service is and then call or write them a letter to their address).

You might be having difficulties in many areas of your life including your mental health and you might need the support of a team.

You might then need the support of the **Children's Disability Network Team (CDNT)**. They are designed to have a psychologist, occupational therapist and speech and language therapist on the team (and maybe others too). They often provide support with coping with emotions, communication differences, and living a life you wish to live (among many other things). You can ask the GP to refer you to the CDNT, or there is a form online your parents can use to access this support.

Sometimes primary care or the CDNT might suggest that your mental health difficulties need the support of **Child and Adolescent Mental Health Services (CAMHS)** - pronounced 'cams'). A team of healthcare professionals work in CAMHS to support young people with 'moderate/severe' mental health concerns. If you need medication you might go to CAMHS. If you are over 18 years of age, you would instead go to the **Adult Mental Health Services (AMHS)** - pronounced 'alms'). The type of therapy you might receive in these teams depends on the type of mental health problem.

What is a Primary Care Service?

Primary Care is all of the health services that you can find in your community, like GPs, or the public health nurse. They tend to work with the person in isolation, rather than within a team of professionals

What is the Children's Disability Network Team?

A CDNT is a team of healthcare professionals working around the child; they often have psychologists, OTs and SLTs, providing supports for children and youths with disabilities.

Medication

We are not doctors so we are not the best people to write about medication. However, we do know that any doctor who prescribes your medication should explain how to take it, and inform you how to contact them if you feel the dose (how much you are taking) isn't working for you. Because of how coming off a medication suddenly can affect you negatively physically and mentally, they should also provide you with a follow up appointment to talk about how the medication has made you feel.

IMPORTANT

Ask if the person you chose to work with is qualified to provide therapy and is accredited with a governing body (these are organisations that monitor good practice for their members e.g., the Psychological Society of Ireland). Unfortunately, terms like 'counsellor' and 'therapist' and even 'psychologist' are not protected in Ireland as of yet.

There are a growing number of neurodiversity affirmative doctors and therapists who are hugely skilled at supporting you. However, unfortunately autistic adults and teenagers can often feel that doctor and therapist appointments are somewhere they do not feel safe to unmask, and that the support/therapy is designed entirely for non-autistic people.

IMPORTANT

If certain therapies, such as CBT, are not adapted for autistic people or delivered affirmatively, they can reinforce previous traumas where a person has been told how they think and feel is invalid. That is not to say that every aspect of these therapies is unhelpful. Many autistic people find it helpful to research these therapies before beginning them, and to work with their therapist to apply the parts that are helpful to them, and dismiss the parts that are not.

Currently, there can be a long wait for a first appointment with the services we mentioned above. We have put together a list of alternative services and supports that you may wish to take a look at the end of this resource

Emily (17) experienced this

"I know for me I would always come out quite overwhelmed from my therapy sessions as they followed no structure and I never knew what to expect. I find auditory information hard to process so verbal with written information works better for me, which wasn't provided to me in the majority of my therapy sessions."

As did Parm (28):

"Nothing stressed me more than an appointment with the counsellor my parents got me. The call to confirm I was coming (why do they call? If I wasn't coming, I'd tell them), the waiting room, the "how has everything been this week?" (what does that even mean, what did he want to know?), not knowing when the appointment would end. It actually made me so angry that my parents, who knew I hated talking to strangers, thought that talking to a stranger would improve my mental health. I do get now they were desperate to help me but it didn't make it any less frustrating. My mum sometimes says "what should we have done instead?" and that's a hard question to answer for many reasons. As an adult, I have therapy with someone who is neurodivergent themselves."

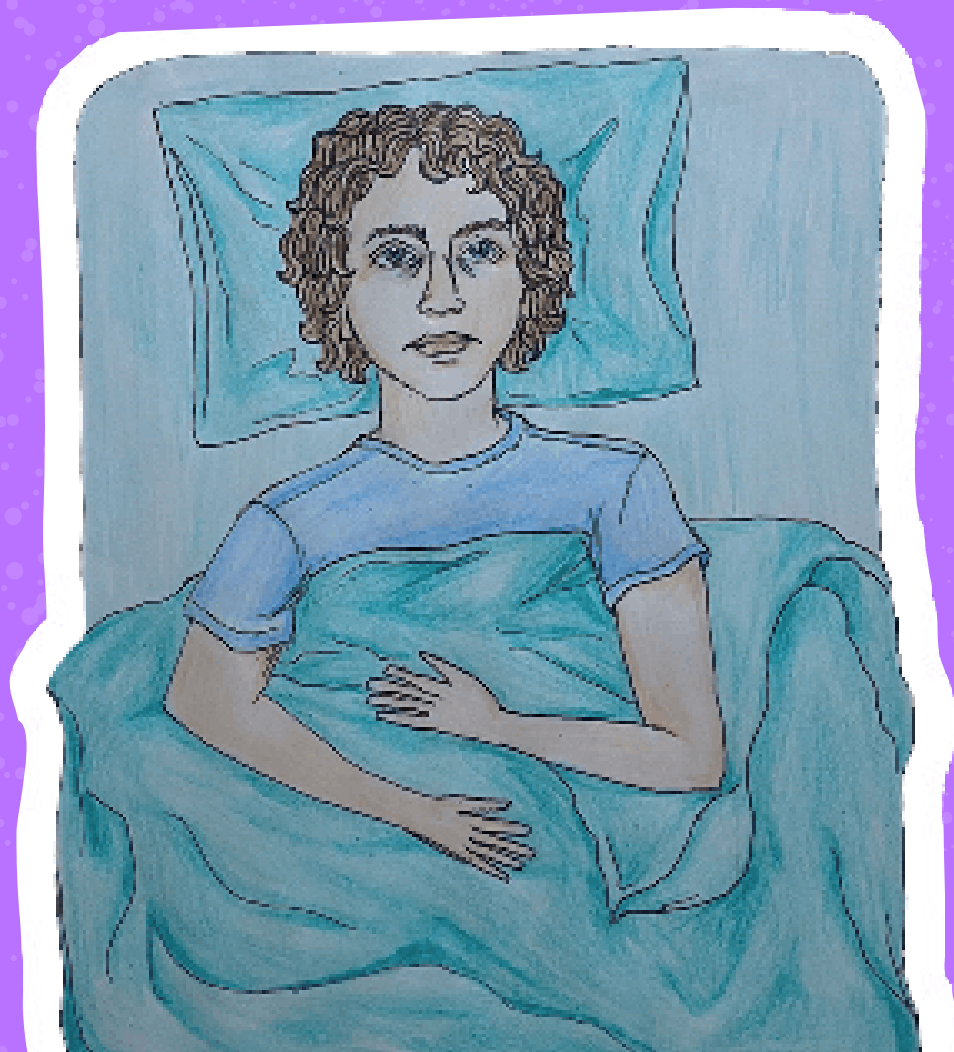




Here are some examples of accommodations you can ask your doctor or therapist for.

- ▶ **If you want more structure:** Explain that it is helpful if the session keeps to the same format each time.
- ▶ **If you prefer closed questions rather than open questions (e.g., what's that like for you...):** Ask that open questions are avoided and that you will not find it rude if closed questions are used with you. Lots of non-autistic people find closed questions rude and will avoid them, so pointing out this difference might help.
- ▶ **If you find closed questions do not give you the space to answer fully:** Explain that you find if you do not give the information when it comes into your head, it is very likely you will not be able to remember it later.
- ▶ **If you dislike being asked to explain something you have already explained to other healthcare professionals:** Ask if the information is already in your notes. If you are worried this might sound rude, explain that you appreciate they are probably trying to hear the experience in your own words, but if it is in your notes, you are very happy for them to use this information.
- ▶ **If you find the professional is unpredictable when they are going to switch topics:** Explain that you have a preference for being told explicitly when the topic is changing, and/or when you have answered the question.
- ▶ **If you find 'small talk' a frustrating part of a session:** Explain that you are aware they are probably making conversation to get to know them, but this is not something that makes you feel more comfortable. Offer a concrete alternative, perhaps that you skip this part, or that you agree on a topic you both find interesting and use that each session.
- ▶ **If you leave the session and forget everything discussed:** Explain that you have a lot of sensory information to drown out in the session, as well as a lot of communication to process, so having the key points of the session written down would enable you to access the session fully.

SLEEP, FOOD, SELF-CARE



SLEEP

In this section, we talk about **sleep** and how problems with sleep may affect you. If you find reading about sleep stressful, we suggest you skip this section

Does being autistic mean I sleep differently?

If sleep is difficult for you, it can feel so unfair that not a lot seems to help or improve it. Did you know that research says 50-80% of autistic people have issues related to sleep compared to non-autistic people?³

No, that doesn't mean that it is inevitable that you as an autistic person will never sleep well. However, it may mean despite trying your hardest to sleep all night, you are more likely to wake up early, have difficulty falling/ staying asleep (insomnia), or need a specific routine or place in which to sleep. Frustratingly, it is not yet well understood why this is.

How do we know if we are getting enough sleep?

There are guidelines to tell us what most bodies need in terms of sleep. However, when we're not sleeping for long periods, those guidelines can just feel like being judged for not being able to achieve those hours of sleep. Sometimes, we then instead need to focus on our own bodies. YOU know that YOU are getting enough rest if you are not drowsy during the day and can do the things you need to do.

Did you know?

There is a lot of discussion in the autism community about a commonality of being 'night owls' - people who are very productive and energised late at night, with a preference for slower mornings. However, the 'night owl' lifestyle is easier when you are in college or the workplace, and have more control about choosing environments that suit your body clock. In secondary school, you don't have this flexibility and this can feel like you are working against your natural sleep routine.

How do we know we are doing the 'right' thing to get enough sleep?

You can easily get sleep guidelines on Google. In life, guidelines are generally made by people intending to be helpful, sharing what works for 'most' people. Guidelines are never what works for 'every single person on Planet Earth'. If you asked ten people you know what helps them to get to sleep, they will not give you identical responses.

If you do want to improve your sleep, think about what worked well for YOU on a night or nights you slept well previously. How can you recreate that routine or place?

³ Cuomo, B., Vaz, S., Lee, E., Thompson, C., Rogerson, J. and Falkmer, T., 2017. Effectiveness of Sleep-Based Interventions for Children with Autism Spectrum Disorder: A Meta-Synthesis. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy*, 37(5), pp.555-578.

Julian (15) shared how sleep is for him:

"I know how tricky sleep can be with autistic people as our brains can have irregular melatonin levels, the sleep hormone. I take melatonin in medicine form to help me sleep.

I have always envied those who can sleep whenever, wherever. Like my Grandmother. Or even those who choose to stay up late, as they have the choice that I do not. If you are suffering with Insomnia you should tell your parents or GP and they can recommend help that's right for you.

In Summer curtains are also a huge help for keeping the light out. But if you're like me and you have none, a night mask will work just as fine.

I also recommend 'cat napping', or simply resting your eyes and letting your imagination run wild. I've found that as a writer with a hectic day of school I can never find the time to daydream like I did as a kid. So night time is when I let my stories come to life. You can do the same thing with other people's stories and characters and let your imagination get carried away too. This may not work for you, but with long nights without any sleep it can help pass the time. Just like counting sheep, before I know it, thinking of my stories sends me off to sleep. So I wanted to share my unorthodox technique just in case it helped anyone in any way out there.

I have a friend who also found it relaxing listening to my snippets of audio I sent to them of me reading *Pride and Prejudice*. Listening to calming music or audio books can also help with falling asleep. Make sure to try some of these out to see what works best for you, and doing some research might also lead you to more helpful tips to getting some well needed sleep. **Know there are options, you just need to pick the right ones for you!"**



Claire's (28) approach to sleep has changed as she has got older:

"My sleep only improved ironically after I had children, and spent time working out what exactly worked for them in getting the best sleep possible. Before that, I followed Google's instructions on better sleep to the letter, and I never got anywhere. No more caffeine after 12, leaving the window open, phone in drawer etc. The weird thing is I am very good at advocating for myself as an autistic woman in situations like work, airports etc. **I am not so good at advocating for me, with me, if that makes sense.** I made myself do all the things non-autistic people do to help their sleep, got mad at myself when they didn't work, and didn't give myself any understanding or empathy at all.

When my child was diagnosed as being autistic too, I was so immediately accepting on why sleep was different for her to my other child, and jumped immediately from trying the 'normal' things to working out what worked on the days she slept okay, and trying to recreate those. **Why hadn't I had that same acceptance and empathy for myself?**

So now...

- ▶ I have a cup of tea last thing every night. Maybe caffeine isn't good for my sleep, but I worked out that my body recognises that warm tea is a cue I am winding down.
- ▶ I have my phone on sleep mode from 10pm, so no new messages come through. BUT, and this is a big but, that limits my time on Whatsapp, rather than stopping me altogether. If I am having a laugh on our Whatsapp group I don't punish myself and turn it off, but if I am getting sleepy and not on my phone anyway, it limits me checking it.
- ▶ I use my duvet and heavy pyjamas all year round. Google kept telling me the importance of a 'cool' bedroom. Turns out I need warmth to sleep.
- ▶ I focus on rest rather than sleep. I used to think, "Aghhh I only slept 4-8am". Now I think, "I rested 11pm-4am, and I slept from 4am-8am. Realistically, from 11 - 4 I wasn't dancing around or doing work reports. My body and mind was still getting a break."
- ▶ I used to focus on my 'routine' the hour before I lay down, and now I try to think about my whole evening. On a night where I have been out until late, particularly somewhere I have experienced sensory overload like a restaurant, I accept my sleep probably won't be the best.

This whole list might have the opposite effect on your sleep. However, that, to me, is the secret. Focus on what happens when YOU get a good night sleep, not what other people do to sleep."

The term 'self-care' has many meanings. In this context, we mean it as 'taking care of your body'. As well as all the other changes we have mentioned, the teenage years spark change in your body (read more about this in the Puberty chapter) and therefore change how you then take care of your changed body. However, for girls especially, it can feel like you are immediately expected to understand the new 'rules' about grooming, and you are also expected to know without anyone teaching you about it.

What you are rarely told is that when it comes to self-care as a young adult, you have CHOICES in how you look after your body.

Make-up and fake tan (beauty products)

Many autistic people have a low threshold for touch and smell. This means you might feel light touch and smell odours much more strongly than others. Therefore, beauty products can feel unbearable on your skin. **This is not you being 'precious' or 'fussy'** - it has long been established that many autistic people experience certain sensations more strongly. However, when it feels like the vast majority of people your age look a certain way by using these products, the desire to be able to use them without discomfort can be very strong.

Choices

- ▶ If you want to start using makeup, you may not know where to start. A good starting point can be choosing one feature (e.g., lips) and choosing one product for that (e.g., lipstick). Youtube and Tiktok are full of video tutorials to show you how to use the products.
- ▶ If makeup on every part of your face is uncomfortable, but you do want to have some makeup on your face, you can use a more 'statement' look on one of your features. What this means is using a brighter colour or texture on one feature. That could be a brighter/darker lipstick, a bright liquid eyeliner, some glitter on the corner of your eyes. Again, Youtube and Tiktok can give you ideas for this.
- ▶ If you are already nervous about a social event, adding in something different to your appearance can add to those emotions. You might instead try the new makeup product in your house first, then build up to wearing it in front of other people.
- ▶ It can be a good idea to bring face wipes with you if you wear makeup out to something. If it starts to feel uncomfortable, you can excuse yourself and go to the bathroom to use the wipe and clear it off. That way, you do not need to wait until you go home.
- ▶ If you want to wear fake-tan, you do not need to wear it all over your body. A lot of people might just wear it on the skin that is showing when you have your outfit on.

In this section, we talk about different ways you might take care of your body including body hair removal, showering, hair-washing and beauty products. If you find reading about these topics stressful, we suggest you skip this section.

- ▶ If someone asks you “why don’t you wear make-up and/or fake tan?” it can be hard to know how to answer. **You can answer honestly or you can give what we call a ‘filler’** answer - an answer just to get you through the moment. ‘Filler’ answers for this question could be, “My skin gets very irritated by it” or “It actually doesn’t suit me”. You can then turn the conversation back to them and ask “What brand of makeup/fake tan do you wear?”
- ▶ If you aren’t sure what colour make-up to get, you or an adult can ask at the make-up shop counter for a ‘tester’. This is a small sample of the make-up that you can try for free. The staff member at the make-up shop counter will be very used to being asked for testers. It is a very common thing that people do.

Ciara (15) shared a tip for when she uses fake tan:

“I hate looking pale in photos beside my friends, but I can’t cope with the biscuit smell of fake tan. For Christmas, my sister got me a tan that goes on like make-up right before you go out - instant tan. I still don’t like the sticky feeling on my skin, but it is much less sticky than overnight tan, and there is zero smell. The absolute best bit is that when I come home from being out, I can shower it off right away and it is GONE from my skin just by using shower gel. I feel more confident with fake tan on and I don’t think there’s anything wrong with that.”

Why do some people wear make-up?

Make-up can be a form of creative expression for some people. For others, they may use it because they feel it enhances parts of their face they like (e.g., a coloured eye-shadow that emphasises your eye colour). For others, they may use it to cover something on their face they feel self-conscious about (e.g., they may use a ‘concealer’, a skin coloured product to try to hide a spot). Unfortunately, many of the make-up brands available still only cater to lighter skin colours and are by no means inclusive. Well known make-up brands that do include shades for dark skin tones include Maybelline, Fenty and MAC.

Removing hair from your body

Another grooming task that comes into focus as a teenager is body hair removal. Many teenage boys/men remove the hair on their face and occasionally their chest, and many teenage girls/women remove the hair on their face, underarms, legs and around their vulva. There is no ‘set’ age when people start removing their body hair. It is usually when it begins to bother them.

Did you know?

In recent years, many women have stopped removing some or all of their body hair, arguing that hair removal should not be an expectation placed on women to be considered well groomed or attractive. Further, women have argued that they should not be under pressure to remove body hair to please men or other women.

One reason both men and women do remove body hair is to reduce body odour (BO). Sweat gets trapped in hair and this can then lead to an unpleasant odour. Often, the person can quickly adapt to the smell of their own BO and may not smell it, while others around them can smell it strongly. Often, when a person can smell the BO of another person, they can make an assumption that the person has not washed themselves.

Choices

If you do want to remove some of your body hair, there are numerous ways to do it. A person can shave, wax, epilate, cream, bleach or thread hair to remove it. Again, there are many videos on Tiktok and Youtube that show how this looks.

If you find hair removal unpleasant but would still like to do it, you can limit how often you do it. For example, you may only choose to do it when you will be exposing that area of the body and it won't be covered by clothes. If you decide to do this for your underarms, you may need to be more aware of BO in that area due to the sweat glands we have there.

Starting to shave your face

You might notice that you are starting to grow facial hair. As our faces develop differently, where we start growing hair can depend on the person. You might notice hair growing on your upper lip, sideburns, chin, cheeks and neck - initially very thin at first, before growing thicker as you get older. It can also look like fluff which can grow on your face at first before growing thicker over time.

Choices

There are a lot of ways you might choose to wear facial hair - from being clean shaven (having no facial hair), to stubble (a little facial hair all over) to a moustache (facial hair above your lips) or a goatee (facial hair above your lips and around your chin). You might decide to not shave at all for a while and have a beard.

When starting to shave, it can be hard to know which razor suits how you want your face to look. You can get an electric razor if you would like to have stubble or you can use a manual razor if you prefer to have no hair on your face.

Bear in mind that there are different sensations that come with using each type of razor. For example, a manual razor may make a scraping sound and the sensation of this may be irritating. There may also be a greater risk of cutting your face or you may be sensitive to shaving gel or shaving cream.

Electric razors may make a buzzing noise or may vibrate when you use them, but it may help shave your face more quickly and the sensation of shaving may be smoother on your skin.

If you are beginning to shave your face you can follow these steps.

Wash your face - Try to wait to shave until after your shower or wash your face with water first before starting to shave. If your skin is prone to acne, this will make it much easier to shave.

Apply shaving gel or foam all over the parts of the face you want to shave - Working up a lather which will help the razor to cut the facial hair. If you feel sensitive to any of the gels used, you do not need to use them if you are using an electric razor.

Start shaving - Use your razor to take gentle strokes to the parts of your face that you want to shave. Try to avoid taking too heavy strokes as this helps avoid cuts to your face or skin irritation. Shave in the direction of where your hair is growing (or shaving with the grain) as this might be more comfortable.

Have a post shave routine - Wash your face after you finish shaving to make sure that the shave gel or foal is removed, and splash your face with cold water. Afterwards, you can apply aftershave balm or moisturiser on your face which will help to soothe your skin after shaving - whilst this may not be ideal on a sensory level, it is helpful as it reduces irritation or inflammation on your skin.



Washing your body

One grooming task that many would consider they have no choice in is washing your body. However, if you find something extremely difficult, and all you hear is "It's not optional.. You need to do it"... that often doesn't make it any easier. **What may make it easier is knowing you have choices in how you keep your body clean.**

Compromises can be:

"You want me to wash every night. That is not going to happen, what can we agree on instead?" (agreements could be the sink wash or use of wipes)

*"I don't want to shower for *insert event* but I will change into clean clothes".*

Choices for your body

- ▶ Some people love bathing or showering. If you are someone with a high threshold for touch, meaning you might seek or crave extra pressure on your body, a warm and high pressure shower might be very appealing to you.
- ▶ If you find a shower overstimulating and overwhelming, you can try showering with the light off to help reduce some of the sensory overload. Of course, you still need to be able see where your feet are to remain safe.
- ▶ If you don't like washing in the shower or bath, there are other ways to wash your body. The most convenient way is to have a 'sink bath'. Stand by the sink. Fill the sink with warm water, and add a shower gel you can tolerate. Use a flannel to gently wipe your body.
- ▶ If you do consider a sink bath, but feel that having water all over your body will still be uncomfortable, you could prioritise areas that are most likely to smell if not washed. For most people, this will be underarms, feet and vulva or penis - The Key Three. You can again use a flannel to gently wipe these three main areas.
- ▶ If you dislike the feeling of drying your body with a towel, use a towelled dressing gown instead. When you finish washing your body, put the dressing gown on. This will dry your body for you!
- ▶ Lots of people dislike seeing themselves naked, and also might dislike the sensation of air on bare skin. This can make you want to avoid washing. If you have a sink bath, you do not need to be naked. You can wear a very oversized vest. This means you can still access different parts of your body, without being naked.
- ▶ If the smell of body washing products is overwhelming for you, you might consider ones for sensitive skin which generally have no smell. Other people buy their washing products in medical supply shops where they will generally have no scent at all.
- ▶ If a mix of smells is overwhelming for you, you could try buying all of your washing products (shampoo, shower gel etc) and adding one safe scent to them. You can also use soaps or shampoos that have a neutral fragrance. You can use essential oils to do this (a teeny amount is needed).
- ▶ If the sensation of water on your skin is just unbearable, try body wipes. Again, you can prioritise The Key Three. Medical supply stores will often have pre-soaped large body wipes. If you are using face wipes, that's okay. However, one wipe will not be enough to clean your full body. You may need up to ten!

- ▶ You have more options aside from flannels and wipes: you can try cotton wool, makeup remover pads, sponges, loofahs etc. All of us have different preferences for textures on our skin... that's why there are so many options out there!
- ▶ If you struggle with putting on deodorant after you wash, you can apply the deodorant to the armpit of your top/shirt rather than your skin itself. Be warned however - if the top is pale the deodorant might stain it!
- ▶ If you spray on perfume or aftershave to hide body odour, it often doesn't work. It creates two smells rather than hiding one bad smell.
- ▶ If you find it difficult to keep your belongings organised, it can be overwhelming how many products are needed for self-care. You can use labelled washbags or baskets for the specific task, and then you don't need to sort through lots of bottles and tubs (e.g., 'everyday wash', 'hairwash' etc).
- ▶ Often a really frustrating part around washing can be that it causes you to take a break from your special interests, or doing something you enjoy. It is then very hard to break your focus from what you are enjoying to go and do something you don't enjoy or see a need for. It might sound strange, but having a set day and time that you wash your body can make it more doable.
- ▶ Parents, and other adults in your life, can become upset and frustrated if you are not washing regularly. Your parents might be worried that without washing you will smell of BO, and then people in school may be nasty to you about this. Your parents are likely to want to protect you from this. If you wash very rarely, this can also mean your bedroom or the bathroom at home smells of BO, and they may not like that smell. Even knowing all this, it can still be hugely frustrating when you feel other people want to make decisions about how you look after your own body.

For your hair

- ▶ Firstly, let us agree with you that hair washing can be a complete sensory shock. It is actually quite rare that anyone, autistic or not, enjoys washing their hair, especially if it is long and thick. Similar to body washing, you have **choices** when it comes to washing your hair.
- ▶ Hair does not need to be washed as often as your body - it depends on your preferences, the type of hair you have (e.g. African), how long your hair is and your tolerance for the buildup of things like grease and dandruff.
- ▶ Much like body washing, consider the scent free options you can use for shampoo.
- ▶ Dry shampoo can help stretch out the time between washing your hair. However, people often make the mistake of putting on dry shampoo right before they leave the house. Instead, spray it all over your head before bed, and then brush through in the morning. This means the spray has had time to soak up the grease.
- ▶ Hair accessories can be used to hide greasy hair. A hat, wide headband or bow can be particularly helpful.

What does it mean if someone says I have greasy hair?

Between hair washes, oil and sweat builds up in your hair and can make it appear wet. If someone says your hair looks greasy, they are usually implying it has not been washed recently, and is dirty. If you want to check if your hair looks greasy, look at the roots (the hair closest to your scalp). If your hair looks wet, or is stuck to your scalp, then your hair is greasy. Some people's hair gets greasy two days after washing it, some people's hair will take longer.

- ▶ The more you touch your hair, the more grease you add to it. If you can wear your hair up, this can mean you need to touch it less, and therefore wash it less.
- ▶ You can wash your hair less often if you like to wear short hair styles like the short back and sides (known sometimes as 'skin fade') or a buzz cut. However, if you would like to keep wearing these styles, this also means having to get your haircut more often i.e. every 2-3 weeks.
- ▶ Washing your body at the same time as your hair can be overwhelming for lots of people. If you have a bath, you can kneel over it to wash your hair. If your hair is short, you can likely use the sink.
- ▶ Did you know that older adults with breathing difficulties often wear a visor in the shower to stop them getting shampoo in their eyes? It might sound strange, but it is actually very clever. Yes, you might be worried you look a bit daft wearing a visor in the shower, but nobody sees the visor but you.
- ▶ If you find running water and suds on your hands uncomfortable, you can wear gloves, or use a sponge.
- ▶ If you know what is happening in the week, you can schedule your hair wash around then. Know you are staying home for the weekend? Sunday night may then be a good time to wash your hair in preparation for school on Monday. This means you can again stretch out time between hair washes.

Talent (21) shared how she has learned to adapt her hair care routine:

"Because of the texture of African hair, I feel like I spent my childhood having my hair pulled at by my Mam, aunties and different salons. We eventually settled on that just my Mam and one auntie would touch my hair. I also found the smell of all the products we used to use excruciating. My Mam was really good at helping me find one brand was tolerable, and we stuck to that.

I used to have braided hair but all the tilting of my head made me dizzy, and the pulling made me nauseous. A warm towel did help a bit with this. Now I am in college I keep the simplest style possible, so it is the least maintenance possible for me. It also makes my cheekbones look good... if I do say so myself."

In this section, we talk about different eating habits and routines. If you find reading about eating stressful or uncomfortable, we suggest you skip this section.

FOOD

For autistic people, one of the biggest misunderstandings and unfair judgements is that the way you eat is a 'behaviour'. By this we mean that is something that can be changed by being given rewards for 'good eating' or having something you like being taken away when you do not eat 'good foods'. Often you can be told you are a 'fussy' or 'picky' eater and that becomes something you believe about yourself.

No, no, no! First of all, **not liking a food is not the same as having a strong sensory aversion to a food that makes eating it impossible.** Secondly, eating is a VERY complex skill. It requires movement, perceptual, sensory and thinking skills, to name a few.

It is seldom anyone actually explains *why* you have had to be careful about what you eat. **Here are some reasons you might find eating certain foods problematic:**

- ▶ Your mouth has many receptors that 'pick up' touch and smell. If you are sensitive to texture and smell, your mouth might find certain foods painful.
- ▶ On the opposite side, if you find you don't register touch like other people you know, then your mouth might have difficulty recognising what's in it. That can be frightening.
- ▶ If you find things like writing or cycling difficult, motor or movement skills might be something you find challenging. Eating requires movement and coordination of your tongue, lips and jaw. If someone finds handwriting hard, they might get a laptop instead. People generally accept this. However, people seem to find it harder to understand eating as a motor skill.
- ▶ Lots of foods are so unpredictable. Let's take a banana as an example. One day it might be yellow and taste quite bland. The next, it's brown, with a mushy texture and tastes quite sweet. Again, people often accept unpredictability can be challenging for autistic people. However, they seem to find it hard to apply this to food, and how it can make mealtimes very stressful.

Many autistic people have discovered the foods that make them feel safe and happy and stick to them. At its core, this decision is logical. What only eating a small range of foods DOESN'T mean:

- ▶ It doesn't mean you or your parents don't understand nutrition. Most of us have been seeing the same food pyramid since junior infants. Of course, we know the benefits of vegetables! But again, eating is not a behaviour. Knowing a courgette will nourish your body doesn't mean your mouth becomes less sensitive to the texture.
- ▶ It doesn't mean you eat like a child. There is no rule that foods like chicken nuggets are banned once you turn thirteen. Foods that make you feel safe and happy are not only for a child.
- ▶ It doesn't mean you are weird. If you started eating a curry breakfast on the Dublin bus, you would probably get lots of stares. However, in Sri Lanka for example, this would be considered totally normal. Much like everything else, whether something is considered 'weird' is subjective.



Some people might want to try introducing new foods on their terms. For example, if they find themselves feeling sluggish or if they are having tummy or skin issues. If you are considering this, here are some general suggestions:

- ▶ Think about where you are trying the new food. If it is in a place you already find stressful (e.g., family Christmas party) or where you are experiencing sensory overload (e.g., school canteen), adding in the sensory shock of new food is probably being very hard on yourself.
- ▶ 'Where' can also be where you are sitting, especially if coordination is difficult. For example, if you are sitting on a bar stool, you might want to pick easy-to-eat food like chips. This is because your balance is already suffering from being on the high chair, so it isn't wise to add the extra level of coordinating knife, fork and plate.
- ▶ If you have safe foods, can they accompany the new food on a side plate? If you don't eat the new food, you still enjoy your meal.
- ▶ If you are sensitive to smell, touch or what you see, try introducing a similar food in those areas to food you already like. For example, a biscuit is similar visually, orally and in texture to cream crackers.
- ▶ Adrenaline suppresses our appetite. There's a reason we push our dinner away after an argument. If you are feeling stressed or upset, it is probably not the time to try a new food.

Sam (25) described how sensory safety has always been important to him when eating:

"Having different tastes in food was always something which got me unwanted attention growing up. I remember how worried I would get on an infrequent occasion I had been invited to a friend's for dinner. **I'd watch their parents make dinner and see they wouldn't make it like my mum, which made me want to put it in my mouth and eat it even less.** If it wasn't made in a 'normal' way which I had seen before then it definitely wasn't going to taste like anything 'normal' which I had eaten before.

I not only was very specific with food taste and texture, I also worried about where it came from and how it got to being on my plate. For me, pre-packaged food like crisps, biscuits, crackers were always my safest options. This made the secondary school canteen a real challenge for me. Walking into the canteen the smell of the room instantly made my tummy feel sick. I would look at the food options available and feel worse not knowing how they were made or where they had been. Eventually I found a pasta option which was made in front of you so I could finally fit in and sit and eat with my friends. Although they only did the flavour I liked on 2 days a week so I didn't eat on the others.

These struggles continued for me as I grew up and started eating out at restaurants with friends. I find it a little easier now but still difficult. I know what I like and I stick to those foods. I now eat enough foods that I can find something to eat in most restaurants. **I have some fantastic friends who don't question or judge me when I ask the waiter or waitress to remove everything from my burger except for the cheese.** I've learnt that it's okay for me to do that. Over the past few years, I have managed to start trying new foods as I always want to be able to eat more of a variety, but I no longer am so hard on myself if I don't like them."

SCHOOL

SCHOOL

You might absolutely love school. If you do, that is brilliant. Likewise, you might be indifferent or you might also really, really dislike it. Regardless of liking school or not, one thing we regularly hear from autistic teenagers is how much of an **enormous effort** school is. What the extra effort goes into varies from person to person. For some it is the organisation of their school bag, lockers, homework and all the other bits. For some it is trying to follow what the teacher is saying whilst blocking out all the background noise. For others it is the navigating of the other students; who to sit with, what to do during break, the birthday party invites etc.

What all of these extra efforts have in common is leaving a person completely overwhelmed. This overwhelm and stress often shows itself in wanting to avoid school, or becoming angry and frustrated when not listened to about school. Another way this overwhelm shows itself is by not showing itself at all until you are at home in a safe place. We often call this process **The Bucket** and use it as a way to explain to parents and teachers what is going on.

Before we describe The Bucket, we want to let you know it is quite similar to the Spoons theory we told you about in the Mental Health chapter. Some people prefer describing overload using the Bucket, and others prefer using Spoons.

The Bucket

The Bucket is similar to the Spoons, except in reverse. You leave for school in the morning with an empty bucket.

On the journey in, you notice that your shirt has been washed with different detergent and the smell begins to bother you. The bucket starts to fill. At breaktime, a boy in your class makes a joke you don't follow and another girl points out to everyone that you don't get it. You feel like responding that nobody here seems to get the jokes you make, so what's the difference? You choose not to respond and instead clench your jaw and try to laugh. **The bucket fills higher.**

French class is your last class of the day. When you grab your books at the lockers, the noise is insanely high. You realise when you sit down that you have brought your German vocab book by accident. **The bucket fills doubly high.** You ask the teacher to be excused, and she reminds you not to mumble. You hear sniggers. She tells you you have 2 minutes. It is not possible to get there and back in 2 minutes so you say it's fine and that you don't need it as clearly as you can. **The bucket feels very heavy now.**

In the car journey home, your Dad asks how the day was. You wish he could tell by looking at you that you absolutely don't want to talk. When you don't answer, he talks on and on about the holiday you have coming up. The noise is excruciating. **The bucket is dangerously full.**

When you arrive home, your Mum greets you by shouting from a different room, "WAS EVERYTHING OKAY?". **The bucket overflows.** You shout 'SHUT UP' and bang into your room. You hear your Mum say to your Dad, "but I only asked one question". **It was not the one question.** You feel terribly guilty.

If you do manage to explain the Bucket to your parents or teachers, the well-meaning solution offered to you is often 'but you should say something when you're struggling'. But how? If your biggest priority in school is not drawing attention to yourself, **how do you communicate that you are struggling so that someone hears but not everyone finds out?**

What works for you?

Do you find it easier to describe overload using Spoons or Bucket? Perhaps you use both.

One possible suggestion: If you have a teacher or SNA you trust at school, can you communicate that the Bucket has filled up further by using an action rather than a conversation? For example, if a conversation at break stresses you out and you are then finding it hard to focus, is there a certain copybook you can hand to your teacher that she knows symbolises that you need a break - a chance to empty the Bucket a bit. If you aren't sure how to ask a teacher for this kind of support, here is something you could try saying:

"I am getting overwhelmed at school for lots of different reasons, but I don't want everyone to know this. Can we work out a way I can show you I need a break without me having to say it?"



Neurodivergent

Jaymie Lycaon Aleister Doyle

Bright fluorescent lights, give me
unending pains

Unfavoured textures of food or
clothing give me

inner itches

And how loud noises irritate me

so much

Unprepared social situations frighten
me

If you have got this far you may now
know that

I am on the spectrum

Being Autistic is part of me and with
the everyday

Struggles it's difficult

Yet I'm proud to be neurodivergent

than non-autistic

I am more creative than

any non-autistic person I've met

Your Rights as a Student

As we have discussed so far, school can be a rollercoaster of highs and lows.

Often, it can feel like school is something that is 'done' to you, rather than something you have an active voice in. Of course, your voice has to compete with other voices: the principal, teachers, other students, your parents, the Department of Education. However, you may not be aware that you do in fact have certain legal rights in education. **Often, these rights and entitlements are not something teenagers are taught about, and can be a conversation you are left out of.** While it is absolutely right that your parent/guardian advocates for you, it is you who actually experiences the highs and lows of secondary school, and therefore when your rights are upheld or breached.

Did you know you have certain legal rights as a student?

According to The Education of Persons with Special Educational Needs 2004 (EPSEN), you have the right to an education in an inclusive environment and to participate in the school community. *So, what does that actually mean for you in reality?*

1. Access to Reasonable Accommodations

If you will be sitting state examinations, (Junior and Leaving Certificate), one thing your parents have likely discussed with your teacher is the specific arrangements or supports to enable you to work to the best of your ability. These arrangements, known as reasonable accommodations, can include extra time given to complete an exam, or access to a laptop or a scribe to complete your exam.

Some people find writing in an exam very difficult. A **scribe** is someone who does the writing in an exam for you. You verbally provide them with the answer, they do not come up with the answer for you. Although a scribe can be helpful to some students, if you find it challenging to organise and order your thoughts when speaking, this can make using a scribe very stressful.

2. How do I apply for reasonable accommodations?

In the context of state examinations your teachers apply for you through the Scheme of Reasonable Accommodations at Certificate Examinations (RACE). Unfortunately it is not as simple as you and your teacher thinking you would benefit from an accommodation. Your teacher needs to provide proof that you require the accommodation, and unfortunately that can mean you have to complete more standardised assessments.

If you are entitled to reasonable accommodations for exams, sometimes this is something you aren't told about until very close to the exam. If you are someone who craves routine, this change can be overwhelming. Added to this, the idea of a reasonable accommodation is to put you on a level playing field to other students.

The Painful School Corridors

Isabelle Blum

buzzabuzzbuzz

There goes the bell,
and the sound of

People picking up
their bags, asking
what class

Is next, and then
incomes the painful

Ringing in the ears.

Make it stop.

However, if you haven't had time to practice using the new method (e.g., typing) for the exam, you are again at a disadvantage to other students who use the same method daily (e.g., writing with a pen).

You, or your parent(s), can speak to your teachers about the new method becoming your everyday way of working.

Outside of exams, am I entitled to support?

Reasonable accommodations are not only for exam situations. The UN Convention on the Rights of Persons with Disabilities (CRPD) also outlines your right to receive support in all aspects of school so you can learn and take part as best as possible. This could be in PE class, form time, the canteen, the school grounds etc.

The type of support you should have depends on what it is you are needing support with.

While individual supports are highly useful, many autistic people agree that changes could be made to the **whole school** that would reduce the need for individual support. Here are some examples of changes you might have seen made in your school, or want made in your school:

1. That unnecessary jarring sounds such as the school bell are removed.
2. That the fabric used in the uniform or style of the uniform is changed.
3. That everyone in the school is educated to understand and accept autism, so the onus is not on you to adapt yourself.

Some examples of supports autistic students use, would you find them useful?

For feeling safe in the classroom:

- Having Loop earphones to reduce the noise during free classes.
- A reminder to change your tampon if you use them.
- Going between classes a bit earlier to beat the rush.
- Wearing adapted versions of the uniform so it doesn't cause you sensory discomfort.
- Your teachers knowing not to call on you if you haven't raised your hand.
- If a teacher wants to see your work, they ask you to pass it to them rather than leaning over you.
- Your teacher writing in your journal to give you advance notice of any changes.

For making a task or activity more doable:

- Help with planning out an essay using a mind map.
- Regular support from members of staff such as a Special Needs Assistant or support teachers.
- Your teacher giving the whole class an instruction and then discreetly stopping by your desk to see if you have understood.
- For group tasks, putting you in a group where you feel comfortable and telling you discreetly what your role will be (e.g., being the scribe).

Did you know?

Movement Breaks are one of the most common supports a school puts in place. Movement breaks are basically what the word says; they are breaks with movement in them, like taking a walk around the school. They were originally designed to support students who fidget and find it hard to sit still. If you are offered a movement break, here are some things to think about before you say yes:

- ▶ Is fidgeting helping you to concentrate? If so, you probably don't need to break your focus and leave the room.
- ▶ Do you need a movement break or do you just need a break? Sometimes students will say yes to a movement break just to get away from a noisy or overwhelming situation in class. In many cases, a student will be craving quiet and a break from interaction. If the movement break is quiet with minimal social interaction, then no harm done. However, if your movement break puts you into another overwhelming situation, then that doesn't make much sense.

Emily (17) shared with us an accommodation that has changed her experience of lunchtimes in secondary school:

"Recently, a quiet space for Autistic students who the canteen setting doesn't suit is provided for every day... which is amazing!!! It is also less daunting as there's not too many people, never more than 7 students. For me, this space provides a calmness away from all the chaos and overwhelming components of secondary school life. It also provides me with a structured lunch that I know where and who I am having my lunch with."

A lot of autistic students might also have a co-occurring condition, like ADHD or dyspraxia. Often it can feel that one of your diagnoses or disabilities is supported, but not both or all. Luke (22) shared his views on this:

"I feel like my dyspraxia was definitely ignored and forgotten about due to also being autistic. I never really felt that they took my dyspraxia into account. Until a school therapist identified it, it took me longer than other students to process information, some of the teachers thought it was laziness and lack of care for the lessons. I was a student who behaved really well and was disappointed in teachers for giving me a hard time over this. **It turns out that I was probably trying harder than anybody else there.**

Teachers often said that I was looking out of the window and not paying attention. It is hard to concentrate and follow when people are talking, so my brain might drift off or become overwhelmed. It also made it hard for me to find my way around school when I was younger. When we had to move from class to class, I had to learn everywhere that we had to go. By the time I got to college I was actually quite good at this and helped other students sometimes. **I would find markers to help me navigate**, although one time I did end up on a locked balcony where I was not supposed to be - in my defence, there should have been a sign!

I am a young adult now and am just starting to learn how to walk to my local town, how to use buses, things like that. **My brain was too overloaded in education to learn this stuff, but now I have time to start learning life skills** - For example: I still do not really know how to boil a kettle. Do not let it make you feel bad. You could be highly intelligent and not know how to take the bus, tie your shoelaces, or remember what the teacher told you is happening at 3PM as some examples.



There are usually one or two teachers who are so good at understanding these things. There are lots of adjustments that can be made to help you learn in a school or college. **You can in time be the advocate to help them understand what they need to do."**



Access to Individualised Education Plan (IEP) or Support Plans

While there is currently no legal requirement to have an **Individualised Education Plan (IEP) or support plan** in place, it is often strongly recommended by education professionals. This plan should be written by your teacher, your parents and you.

An IEP/Support Plan should:

- ▶ Be a plan about you; what you need support with in school and what you thrive at in school.
- ▶ Describe how the school environment and the adults supporting you can adapt to provide that support.
- ▶ Describe what your goals are (what you want to achieve in school).

Often IEPs aren't as supportive as they could be. This is because the content may focus mostly on what you find hard. The suggestions to support may focus mostly on you changing yourself, rather than the environment and adults around you adapting. An indicator that this might be the case is if all of the actions on your IEP have your name beside them as the person who is required to change something. **The adults supporting you should also have actions.**

Often, tasks you find hard will be connected in your IEP to things you love, as a means to motivate you. For example, if you find algebra difficult, your SNA might link it to your favourite film. For some people, this works very well. For others, it may feel something you love is being 'contaminated' by something you really do not love.

If you feel unsure about your IEP, you are entitled to:

- ▶ Ask your teacher can you read your IEP.
- ▶ Ask your teacher can you be involved in writing your IEP.
- ▶ Ask your teacher can your IEP be updated.

Some other thoughts we have about IEPs:

When your IEP is reviewed, there may be a suggestion that you no longer require a certain support. This is seen as progress where your independence is increasing. Of course, independence is a worthy goal for many but if doing a task without support will cause you severe anxiety, it is hard then to see that as progress. **You should always be asked by your teachers to share your views on the level of support you receive.**

- ▶ If reading your IEP or sitting in a room with adults discussing your IEP, feels like something you dread - that isn't too surprising. There are very few adults who will voluntarily sit in a room and discuss their vulnerabilities with a group of others. Yet, adults often are well-intentioned by assuming they are doing something positive and kind by encouraging a teenager to do so. Remember when we talked about the 'spoon' theory? Advocating for yourself can be incredibly draining. **You are not a 'bad advocate' if at times you do not have enough spoons left to speak out for yourself.**
- ▶ It is fantastic if you can access support to help your learning in school. It can feel totally miserable to be marked out as the 'one' who is 'different', and needs something 'special' or 'additional'. **Both those statements can be true at the same time.** It is extremely hard to appreciate these supports or your individual way of learning when it leads you to feeling embarrassed, an exception or excluded from the others.
- ▶ The bad news is that school is very often a place where fitting in and doing the same as others is seen as what the goal is or a marker of your success. The good news is that the other phases in your life, college, apprenticeship, workplaces etc generally place much higher value on an individual doing their thing their way rather than everyone doing the one thing the one way.

Not just one type of school

Although the majority of autistic students attend mainstream school in Ireland, there are increasing numbers attending special school, autism classes, alternative education and home school. We have included more information on these in our A-Z glossary. The reason all autistic students in Ireland do not attend mainstream school is that these schools do not all currently have enough support in place for every autistic student to be part of the school community.

You or your parents may suggest moving from one type of school to another. This could be for a variety of reasons, but the most common one is so you can be in a smaller class. Autism classes and special schools typically have no more than 6 in the class.. However, moving from one school setting to another in Ireland (e.g., mainstream school to autism class) is unfortunately complicated. This is primarily due to a shortage of school places. Therefore, your parents' efforts to move you to a better suited setting can be incredibly lengthy.



Finn (16) made the move from mainstream school to alternative education.

"I moved into a large secondary school from a very small country primary school. I was very unprepared for the overwhelm and I felt super anxious, I guess more than others would feel. The school itself definitely didn't help. I felt trapped. The timetables, moving around and trying to concentrate in class, then moving to another class. Even at breaks I couldn't relax and was constantly stressing about getting to the next class on time. If they had moved classrooms again, I might be in the wrong room. After a few days I didn't feel I could be in the school.

I tried a few lessons per week after the first month, but my anxiety was too much and I really felt I could not 'learn' or take in any knowledge or retain information in an environment like that. I went into a deep defence mode and didn't want to engage with anyone. **I felt really bad that I couldn't do something as simple as going to school - what everyone else could do 'everyday.**

My confidence was very, very low and I didn't want to do anything or go anywhere. My Mum made contact with the local Education Welfare Officer (EWO) who visited us at our home. She was just brilliant and ensured me that she was here to support myself and my family to ensure that I would get my education, letting us know that other avenues were available to gain an education.

Together we applied for a placement with IScoil, a remote learning programme: <https://iscoil.ie/#what-we-do>. They do have centres to go to also, but I preferred the on-line programme delivery. I didn't get a placement on the first try as places were very limited, however we received a call a few weeks later that more funding had been made available. I was offered a place to start in Sept 2020 studying Level 3 QQI which is Junior Cert equivalent to the national framework.

The iScoil remote programme is designed and tailored to my interests. It is delivered through multimedia content on-line via a software programme called Moodle, which I really enjoy. I log into my subjects everyday, I have on-line tutors for each subject who set the tasks. In addition I have an assigned Mentor, who I talk with once a week via Video, they oversee and bring together everything each day. **Subjects are very hands-on and practical approaches - learning life skills.** My parents then receive an update from my mentor each week of my weekly progress.

The instructional online content combined with individual mentoring and tutoring support offers me guidance 'every day'. I complete each module which is graded and goes towards the final certificate for each subject which leads to QQI accreditation. I love the fact that IScoil is very flexible and adaptable. I set my own timetable and work at my own pace, from home which is my safe place.

So, what's next? I am one of the lucky students to be selected to study a pilot course with IScoil 'Level 4 QQI' which I am returning to complete this year.

On completion I would like to study Level 5 at the local Youth Reach and gain entry to a PLC Course then onto Degree level. For anyone who is autistic, who is experiencing anxiety and overwhelm at school in addition to that feeling of being lost in a system - **I hope sharing my own journey will help you and assure you that there might be an alternative pathway and options available to you."**

Julian (15) made the move from mainstream school to being homeschooled. This is his experience:

"In my case, being autistic in school feels like asking a fish to climb a tree. For ten years I somehow found a way to climb it. But why does the fish need to climb a tree? Can't the fish offer something else of value that the other animals that can climb the tree can't? Why not embrace each and every skill each animal has to offer, instead of just one that some can not give no matter how hard they try? Truthfully, I can't answer that question, since I still don't know.

But what I can give is my own experience. I stayed in mainstream school for as long as I did only for social reasons. What snapped me out of it was the loss of my school 'friends', and that's when I agreed to homeschooling. But as an old saying goes, when something is taken from you, you're given something in return. **What that might be varies from person to person, but what I got made up for what I lost a hundred times.**

That's the beauty of change, something I'm still learning to appreciate. But now that I'm homeschooled, and everything in my life seems different from what it once was when I was in mainstream school, I couldn't be happier. So don't make the same mistake that I did, and don't let the uncertainty of change and fear of what's to come keep you from doing what's right for you. I am also doing A Levels instead of the Leaving Cert, yet another way I've adapted school to suit me. I recommend you find what learning outlet is best suited for you, everything else comes afterwards.

As a neurodivergent person in mainstream school in Ireland, I can only applaud you. Your efforts in surviving school are outstanding. **You have so much to be proud of, even if it isn't a prize or a good report card filled with praise from your teachers.**

It only leaves the question, how many fish does it take to climb a tree? I can't wait to see what we come up with, because I believe without a doubt that one day we'll make school suit all of us."



Moving on from secondary school to beyond...

From 16 years onwards, it is no longer compulsory to be in full time education. You may choose to continue education, others might join the workforce, others might pursue their passions in other ways, and yet others might take some time to figure out what to do next.

Brendan's (26) story:

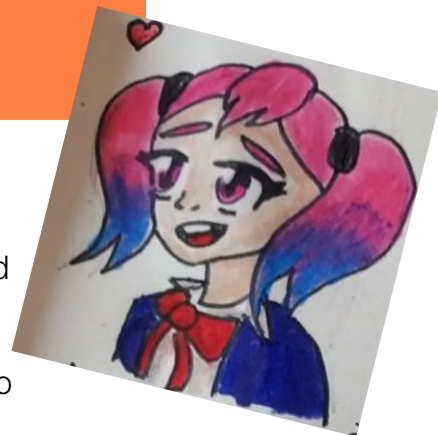
"I left school and went straight into full time work. I knew I wanted to work with autistic children. I felt like I understood them a little better, being autistic myself. I love kids and always have. They look up to you and I can understand what they expect, which is to be kept safe. I get that and I can do that!

I worked as an SNA. Schools are a great place to work for me as they are very routined. I always knew what was coming next and what my day was going to look like. You need to be very organised, and suddenly making lists wasn't seen as weird or geeky like it was when I was a teenager, instead I got lots of praise for it. I especially loved planning trips. Thinking of every small detail and coming up with a plan for every eventuality and every chance of something going wrong. **Something I have done every day my whole life but somehow now is being celebrated?!**

I also loved the challenge of finding out what motivated the kids and what they needed in order to succeed. To me, it was so logical why they did the things they did, and I can't tell you how rewarding it was to be able to advocate for these kids in a way I myself never was in school. And to have people listen to what I thought! The teachers would be desperate to understand how they could help the child, and sometimes I would find myself with a queue of people waiting to speak to me. Now that never happened before.

I then got asked to deliver parent and staff training. I still find them very scary at first but once I start I settle down. I know the information I'm teaching inside out and people are so invested and interested to share your knowledge. It makes me so proud of myself to know that people want to know the things I do and people are interested in understanding children the way I do.

The best thing for me is I have thrived by being myself – whereas when I was younger it seemed like I only did 'well' when not being myself, or being 'protected' by my family. **This is all me."**



Luke (22) Story:

"When I was in school, I really liked certain games like Minecraft, Red Faction and Prototype 2. When I discovered that people were doing videos of them on YouTube, I found it really fun to watch other people play them. Eventually, it inspired me to become just like them by recording my own videos of the games and becoming a bit of a content creator myself. I really liked the idea of Endermen, which are one of the characters in the game, being sweet and friendly. I started with a few gameplay/discussion videos around this subject.

Eventually, I discovered animations and wanted to become an animator, so I ended up making these animations on my Minecraft channel. Eventually, I really got into Five Nights at Freddy's (FNAF) for a similar reason, just this time instead of Endermen from Minecraft, it was a character in the games called Foxy. FNAF happened to be a growing trend at the time, and that was when my YouTube hobby started becoming a business. I made animations mostly of my favourite character in the games called Foxy and they were sweet animations from a horror game! So I expanded on my original passion, uploaded videos and followed what did well in the little community that I was in. **People seemed to really like what I did, the channel grew and became a business.**

Being on YouTube for 10 years now, I have learned so many skills! The practical skills are making 3D animations, a bit of 3D modelling, graphics design, editing programs, sound effects/audio, live streaming software and hardware, commentating, putting scripts together, developing stories, lighting, studio setup, camera setup, the importance of music and how that can express stories, etc.

I also learned a lot of business skills such as understanding your target audience, niches, what other businesses in your area are doing, branding, marketing, ways of earning money, making bids for sponsorships, understanding analytics/statistics and using those to develop your business, the YouTube algorithm and loads of other things! YouTube has sent me on a lot of training events for practical and business skills and some other things as well like how TV studios are run and a Thai cookery lesson. I have also done guest public speaking at VidCon 2020. And I was also on a top disabilities creator video by Jessica Kellgren-Folzard about representation of autism on TV.

I have also been on some really special events such as VidCon and Summer in the City where I meet a lot of other YouTube creators. **It is easier for me to have good conversations with other YouTube content creators because we know a lot about the same stuff.** It has been a lot of fun and I am incredibly lucky. It is stuff that I never would have done in any other way."

The change from school to college

Learning at University or College will likely appear to be quite different to what you might be accustomed to at secondary school. One thing your lecturers (teachers) will often say is, "you need to engage in 'self-directed' or 'independent' learning.". What this means is you are rarely given homework or told exactly what you need to study. It is expected that you will direct your own learning and study. However, you do always have access to what the desired learning outcomes of the subject is, and this can help you to focus on what you should study. Autistic college students can find this loss of structure daunting, and may avail of the college Disability Service to help with what is a brave and significant transition. We are so aware of how this is a point in life that lots of support can be welcome, so AsIAm developed a website full of guidance and advice for you - www.autismfriendlyhei.ie

Clara's (28) reflections on the transition from secondary school to college:

"For most of my time in secondary school, I existed in a state of contradiction. The routine and predictability of school life were a balm to my mind, which felt chaotic as I remained undiagnosed. On the other hand, I craved the freedom to explore my special interests. For me, this was anything related to literature. By the time I was in my sixth year, I was spending all of my spare time looking at the low-quality images of my future student accommodation and trying to predict where I would hang my clothes and plug in my wall lamp.

In late August, my parents dropped me off at the student accommodation. All the anticipation of my academic life led to the moment when my parents drove away. I wanted to be alone, I had said. Yet the second they left, the silence around me became a chasm filled with a howling wind. My new bedroom overlooked another block of apartments. At home, I could see windmills and snowy mountaintops.

That first night was a challenge.

After that first night I found joy in my new life. In the moments when I made friends with people whom I felt truly understood me and took classes that were meaningful to my special interests, it was hard to imagine a happier person. However, it seemed like there were a thousand new changes and adjustments to be made every day. It took me four hours to make a fifteen-minute walk to the LIDL closest to my student accommodation. I could not understand the blue dot on Google Maps or how it moved. The route to my new classrooms felt like the ever-changing stairs of Hogwarts, causing me migraines daily. I felt tearful when I returned to my room successfully, assuming that my exhaustion was a trade I must make to study what I loved more than anything. **Being undiagnosed at the time, I thought this was a trade everyone made.** I also believed that others too felt called to compromise their beliefs and sanity by drinking on nights out and suffering the loud music, erratic strobe lighting, and the smoky air of nightclubs.



As I had not yet received my autism diagnosis, my entire college experience was more challenging than it had to be. However, the difficulties described above did not last, nor did the exhaustion they caused. I still did not understand why I found the world more invasive than my peers. And no, I never learned to enjoy drinking copious amounts of alcohol. **But I did gain the most valuable attribute of my lifetime; the kind of happiness borne from living life as I truly am.** My time in college led me to friends I cherish, a dash of academics that I love and strengthened my faith in myself. I know now what I can withstand, overcome, and how purely I can thrive when surrounded by the joy and love of great friends.

With this community, I found the strength to stand before the doors of the university's medical unit and express the struggles I was having. The GP noted that I experienced sensory challenges, which gave me the remaining three years of my degree in peace. I took my exams in a quiet computer room with five others and noise-cancelling headphones on, and my grades improved. I took a Dictaphone to class, which recorded my lectures and gave me time to sit and absorb the information rather than frantically taking notes. **Being open about my concerns and struggles, I received immense kindness** – kindness I had not experienced in the controlled and inflexible secondary school system.

No, this transition was not smooth. It would be a lie to pretend it was. You are likely questioning everything that makes you who you are, wondering how much you will have to barter away in social niceties to survive another excursion in the education system.

Here is the only balm I can offer, one autistic adult to the next generation. **Be vocal about who you are, without shame or doubt. My words are not an empty platitude but rather genuine advice.** Express your needs to your lecturers, friends, and peers. Your university experience will be made or broken by how honest you choose to be. Your voice does not need to be polished, perfect, and rehearsed. Instead, be honest and unwavering in the support you know yourself to deserve."

Here is the roadmap I personally followed:

Contact Your Disability Support Team

"Right now, it might be difficult to imagine what precisely a disability support unit can offer you. When a GP recommended I speak to them, I felt defeat rather than comfort. After all, the college had lectures, social events and career prospects no one could work through but myself. However, my support team provided me with special access to a quiet zone in the library and a Dictaphone to record lectures and weekly sessions to help me plan and cope with my approaching deadlines. Whenever I was worried, anxious or stressed, they were there to talk through my concerns. Although they could not always offer me solutions, sometimes having a quiet, still space on campus was comforting. "

Be Honest With Your Lecturers

"In college, my experience was that Lecturers allowed us to feel more individual and unique than in school. As a result, I was honest and open with my lecturers, explaining my struggles and the limits of my energy levels. I received compassion that continued throughout the entirety of my degree. "

Do Not Compromise Your Social Battery

"It takes time to learn what is right and wrong for you. For example, I attended countless parties and nightclubs that I did not enjoy because I felt that my friendships were based upon me being as fun-loving as possible. It has been nine years, but my best friends from those parties and nightclubs remain with me. Recently, I asked them why they chose to be my friend when I would never enjoy the experiences they do. My friends told me that they loved me for my loyalty, for the intensity of my love that I share freely in return. Treasure your social battery, and the people best suited to you will be drawn to you."

Good luck, and **remember that who you are is never a problem to be solved but an identity to be embraced."**



**PUBERTY,
SEXUALITY AND
GENDER**

Puberty

You might often hear 'puberty's here!' or 'wait until you hit puberty!' but without anybody explaining **what puberty actually is**. Puberty is the period in your life where your body is changing physically from a child's to an adult's. When people say 'during puberty', they generally mean when you are between 13-17 years old.

We have discussed some of these body changes already (e.g., body hair) but we will cover more below. The physical changes differ depending if you are assigned female at birth (AFAB) or assigned male at birth (AMAB). You may wonder why we don't just say 'boy' or 'girl'. It's likely that some of you reading this identify as trans. For trans teenagers, physical changes that are associated with the sex they are born (e.g., periods for men and boys who were assigned female at birth) can be particularly unwelcome and challenging. By us assigning a 'girls' and 'boys' section to our discussions on puberty, we would show a lack of understanding of the diversity of teenagers reading this book.

When reading or hearing about puberty, you may hear adults use the terms 'private parts'. When they say this, they are usually talking about the penis, testicles, vagina, vulva and bum.

In this section, we talk about puberty and the changes your body will likely go through between the ages of 13-17. If you find reading about body changes stressful or uncomfortable, we suggest you skip this section.

You will notice that we do not use the term 'private parts'. Here's why:

- ▶ Puberty and body changes are confusing enough, without using words that don't mean what they say.
- ▶ The words penis, testicles, vagina, vulva and bum are not rude words. They are the names of your body parts.
- ▶ If we know the correct word for our body parts, it is much easier to tell an adult you trust if you have any problem or worry about a body part.
- ▶ When we only hear the term 'private parts' for the areas of your body that underwear covers, we can fail to understand that our entire body is private. A person should have your consent to touch any part of your body, not just your penis, testicles, vulva or bottom.

Why do the names of body parts make me cringe?

Because we have grown up seeing people look embarrassed when they say them, we experience 'second hand embarrassment'.

You might prefer to use slang terms rather than the actual words for this reason.

Even if you don't want to use the words, knowing them can be helpful when you need to say them.

What is the 'right' thing to call my period?

People use different terms for when they are on their period. Common ones include:

- "I'm on my period"
- "I have my period"
- "I am on at the moment"
- "It's my time of the month"
- "Auntie Flo is here"

Most people will know what you mean when you use any of the above terms.

If someone says to you "that's not what you call it", you can say, "oh, that's what my family has always called it"

Is puberty different for autistic teenagers?

Your body does not look different because you are autistic. How your body physically develops is also not different. How you react to these body changes might be different.

Why is this?

- ▶ If wanting things to stay the same is important to you, how your body looks and feels changing might reasonably cause you stress, worry or anger.
- ▶ If you have a low threshold for touch and smell (this is the one where you might feel or smell more strongly!), then BO, periods and wet dreams might be inconvenient or more uncomfortable for you.
- ▶ If you have a high threshold for touch and smell (this is one where you might not notice touch or smell as much), then keeping aware that you have started your period, or that you need deodorant can be stressful.
- ▶ If you have built a routine that works for you in your life, having to now plan for periods, body hair or unplanned erections can disrupt those routines for you.
- ▶ If people in your life aren't in the know about why body changes might cause you stress or discomfort, it can be frustrating trying to explain this.

Body changes

Periods

You know you are having a period when you see a blood spotting or stain in your knickers/underwear or inner thigh.. Usually we associate blood with being cut. There is no cut on your body in this instance, the blood has come from your womb (inside of you). Periods are a part of the menstrual cycle where a person bleeds for usually three to eight days per month. The rest of the month you typically don't bleed.

Period Products

Generally when you are taught about the products you can use to catch the blood before it stains your skin or clothes, you are mainly taught about tampons and pads. For some autistic people tampons and pads will be perfectly suitable, but for others they're part of the problem making periods more sensorially uncomfortable.

Three relatively new options are:

- ▶ **Reusable pads:** These are cloth pads you place in your underwear. They are made of absorbent fabric that can be washed and re-used, they also come in fun patterns that make everything feel less medical.
- ▶ **Period underwear:** These are underwear that look like the underwear people usually wear, but are made of a material that soaks up the blood and doesn't stain your clothes. For those who don't identify as female, the underwear also come in boxer-brief form which could be more affirming than having to deal with one of the more traditional options. You might find it a sensory adjustment to wear period underwear as they are thicker and heavier than usual knickers/pants. A solution to this is to wear thicker material knickers/pants when you are not on your period so that you do not need to adjust at different times of month.
- ▶ **Menstrual cup:** The cup is a small funnel shaped cup made from rubber or silicone that you insert into your vagina, using your fingers to help you. This can be helpful for those who find the frequent changing of pads and tampons overwhelming. Cups can be kept in for eight hours which means less frequent changes to disrupt your schedule and less to remember since you don't have to continue buying new ones. This can also be helpful for those who don't identify as female, as it is a less obvious reminder that you are on your period.



If you would prefer to use pads and tampons, here are some additional tips:

You might find the sensation of any dried blood on your skin uncomfortable. When you pack clean tampons/pads, you can wrap them in an individual wipe. That means you have something to clean yourself with that will be more effective than tissue.

If you don't have a long time to spend in the toilet, all of the steps involved in changing a pad or tampon can make you feel under pressure. Have a routine in place:

- Remove used pad/tampon
- Put used pad/tampon in bin
- Open wipe
- Wipe your vulva in same direction twice
- Put wipe in bin
- Pat dry with tissue paper
- Place new tampon/pad in/on

Avoid buying pads with 'wings'. They are harder to stick on to your knickers/pants.

If you need to go to the toilet to change your pad/tampon, but you do not want to show everyone that you are holding a pad/tampon, we have a trick for you that lots of us use. Have a hair bobbin on your wrist. Tuck the pad/tampon into the bobbin. Cover with your sleeve.

Sorcha (27) and Millie (16) shared their experiences of adapting and caring for themselves when having their period:

"It took me a while to realise that the way that most people handle periods can be so unhelpful, because they can find it 'gross', they are therefore very vague about it. Because people are very vague about periods, there tends to be a lot of scare mongering. **There is a lot of vague and general statements made about periods that are very unhelpful if you are a more literal thinker.**

Periods can also come with some pain, maybe in your back or tummy. Another thing many autistic people who get periods can face is a lack of belief in our pain, because of how we show it differently to non-autistic people. Where a non-autistic person might talk about their pain we might shut down until the pain is too much to bear and then lose our language or get angry. People around us might think we reacted suddenly, when we were trying to manage on our own.

I also personally struggled with the way I felt most non-autistic people tend to treat periods as something that happened and stopped and happened again. This makes it feel like you are constantly transitioning in and out of having a period. **In reality a period is part of a cycle that's always happening inside an AFAB body."**

Millie (16)

"Even when I was a kid I was bigger than all my friends. I have always been bigger than what is considered "healthy". I've always felt comfortable in bigger clothes than what actually fit and this carried on forever. However, the thought of growing up and having body hair, bigger boobs and periods was still daunting. I guess I am technically still in puberty.

My dad and my auntie know it is really important that they tell me exactly what happens to my body as it changes. This might be something you ask your parents to do. It's no good if they are vague! If I am honest, having body hair is very irritating. As well as having to get my eyebrows done because I have really thick and dark hair and I worry about what people might say if I don't get them done. Having bigger boobs (breasts) was also hard to get used to and having to wear a bra was strange. After a while, I got used to it and was able to manage. Now part of the reason I wear bigger clothes is so my t-shirts don't cling to my chest.

Then I started my period. I always thought the idea of periods were gross and it made me feel really uncomfortable when anyone started to talk about it. But then as I got older I realised that there is nothing I can do about it. Now I have become more comfortable to be able to tell some people when I have my period but I don't tell everyone, as I still find it a bit awkward even though every girl goes through it."

Alec (22) shared their experience of their period as a neurodivergent non-binary person:

"I started my period when I was about 11 years old. At the time I thought that I had a normal girl's reaction to starting my period, and some of it was: not wanting people to know I was bleeding, nervous about mood swings and the bad cramps during school. But looking back and talking to more cis women, I found out I didn't have all the same experiences. I hated pads for many reasons, first because I have sensory issues, which made me hate the feeling of wetness, and secondly I hated seeing the proof that I was bleeding. At first, I thought it was the blood, but I helped one of my past partners when they split open their arms.

After four years, I came out as non-binary, changed my name, and started using they/them pronouns. At this stage, I didn't understand why **my periods made me so uncomfortable, not only because of the pain or hormones but I just hated the idea of it.** I would complain to my friends about periods being useless as I didn't want children, and they were just a constant reminder of what my body wanted from me that I couldn't connect with.

During the first couple of days of my period, my cramps and anxiety were so bad I would vomit. After one of these episodes my mom got me an appointment with a Gynaecologist."



Contraception

As you might know, once a person begins to have periods, they are then potentially able to become pregnant each time they have sex. Therefore, if a person who can get pregnant does not want to become pregnant, they should use contraception.

Contraception - also called birth control - is a method or device for preventing pregnancy. The two main methods are **hormonal** (which can mainly be used by people who can get pregnant like the birth control pill) and **barrier** (some which can be used by people with a penis like condoms and some that can be used for people with a vagina like diaphragms). Much like with managing periods, autistic people can find the change to schedule of remembering a pill everyday very difficult. With medication like the birth control pill where forgetting a dose can lessen your protection against becoming pregnant, this can be dangerous. It may be helpful to consider long-term options like the Coil which lasts for 3-10 years from placement, the implant which lasts 3 years from placement or the injection which lasts 1-3 months.

However, none of these hormonal birth control methods can protect against sexually transmitted infections (or STIs) which are diseases that are passed from one person to another through sexual contact. The most common and effective way of preventing STIs is by using condoms, which is a thin latex sheath worn on a penis during sex. **Condoms can also cause sensory problems as latex is a texture that not all people like.** However, condoms are now produced in different thicknesses and textures as well as some non-latex options like polyurethane and polyisoprene (though these do tend to be more expensive).

Jimmy (21) remembered some of his own confusion about wet dreams when he was a teenager:

"I will be honest, I thought I had wet myself. I am sure lots of boys do. I was mortified and got the sheets in the washing machine straight away. I didn't have an older brother, or friends in school to tell me these things. I only realised when I heard about it on a show I watched."

Erections, ejaculations and wet dreams

For those who have a penis, it tends to get larger during puberty, as the rest of your body is growing. You also begin to experience more erections. This is when blood inside your body flows to your penis which makes it hard and sit up. Erections often last for a few minutes.

If a sticky liquid, which we call semen, comes out of your penis this means you have ejaculated. Semen is a new fluid your body starts making during puberty. A slang term for 'to ejaculate' you might hear is 'to come'.

If you ejaculate at night in your sleep, that is called a 'wet dream'. When this happens, you might wake up with a wet spot on your underwear, pyjamas or sheets. This can give you a shock the first time it happens, or embarrass you.

What do I do if I wake up in the morning and realise I had a wet dream?

- ▶ Take off your underwear and pyjamas.
- ▶ Wash or wipe your penis. This is because by not washing it there may be an unpleasant smell.
- ▶ Take your sheet off your bed and put it in your laundry basket/pile.
- ▶ That's it!

It's possible that you don't do your own laundry yet. You can say to your parents or the adult who looks after you that your sheet needs to be washed. **They will know what a wet dream is, and if you are over the age of 13, they are probably expecting this to happen to you.** You may find it awkward to say to them that the sheet needs to be washed, but you mightn't know how to wash it.

You have two possible options here:

- ▶ Ask the adult can they show you how to wash your sheets.
- ▶ Say to the adult that you want a way to let them know your sheet needs washing without talking about it. This could be by leaving a note by your bed or sending a text.

What makes me get an erection?

An erection can happen if you touch your penis/or it is touched, if you are thinking about someone you are attracted to, or sometimes for what seems no reason at all. Your underwear may brush off your penis and cause an erection.

A lot of autistic people have skin that is more sensitive to touch, and that can include the skin on your penis. Some people find wearing thicker, tighter underwear can help reduce this sensitivity.

Erections can happen several times a day. Because you can not always predict when you will have an erection, this can be stressful as an erection can be visible to others due to a bulge in your trousers.

There are lots of ways you can hide you are having an erection:

- ▶ Stay sitting down until your penis stops feeling hard.
- ▶ Put your hands in your pockets.
- ▶ Untuck your shirt.
- ▶ Hold something to the front of you.
- ▶ Tie a jacket or jumper around your waist.
- ▶ Wear looser clothes.

If every teenager with a penis gets an erection, do I have to try to hide my erection when it happens to me when I am around another person or people?

Most people do not want to draw attention to having an erection as it is private to them. Drawing attention to your own erection is likely to make other people feel uncomfortable.

Will I always have erections or will they go away?

From around 50 years onwards, it becomes more difficult to have an erection. Wet dreams however do usually stop happening by the time you are an adult.

What's a boner?

A boner is another word for an erection, chosen because the penis becomes hard like a bone. Your penis actually has no bones, it is blood vessels filling up that makes it hard. People also sometimes use the term 'getting hard'.

It is likely you have more questions on these body changes, and questions that might be specific to you. If you find it embarrassing or difficult to speak to your parent, or the adult that looks after you about body changes on the next page you will find some suggestions.

Here are some suggestions:

- ▶ Send a text or leave them a voice note asking your questions. Be very sure you are sending it to the correct person!
- ▶ Talk to them about it when you are doing something that doesn't need you to be looking at each other. This could be in the car, watching tv or playing a board game.
- ▶ Agree on an activity you do when you want to ask questions. This could be a certain board game. When you ask to play that game, then they know you have questions you want to ask.

These conversations should be private, without other people present. The information is personal to you.

As all of these physical changes occur, it can feel like not only our body has changed, but also other areas of our lives.

Aaron (26) shared his memories of how those changes felt:

"For me the entire process of moving from being a kid to being a teenager was overwhelming. A lot of change, in a lot of areas of your life, seems to happen all at once. I liked rules and I felt safe being at home with my Mum. At the same time, I began to feel very different to my peers for the first time. They seemed to want to grow up, break rules and spend less time with their families. **On the one hand, because I felt so different, I really wanted to do the same. On the other hand, I don't like change and I didn't like all that was happening.** It was a very confusing time which probably wasn't helped by the fact that my response to feeling different was to try and pretend I was the same and not take help even when it was offered. As a result, in terms of puberty, I always felt a little bit behind everyone else.

Really, what made me feel different during puberty was definitely timing. In terms of independence and understanding myself and the world, it always felt like it was easy for everyone else and that I was maybe like 2 or 3 years behind. I felt like I was catching up. Whether it was going places by myself, moving on from playing with toys or even thinking about boyfriends or girlfriends, it would seem that my peers would do these things a few years before me.

Whilst I think being a teenager is exciting for most people, for me there was a film of anxiety throughout the whole process. It was only as I got a little bit older, and became more comfortable being me, that I really began to embrace that and explore who I was, for example recognising myself as someone who is Autistic but also a member of the LGBTQ+ community. **I used to think I had to be the same and fight with myself about that** - once I realised that things were easier just being me, I began to really enjoy my teenage years. I guess, for me puberty was about identity. Identity, and an internal struggle to not only understand myself as I relate to others but to learn to accept and be proud of that also."

Eoin (28) shared his thoughts on how puberty is not only what happens in your body, but also what happens emotionally:

"Lots of puberty talks focus on the changes that happen in our bodies. Certainly all the hair and spots were no picnic but I think **the emotional effects were the hardest to cope with**. It can be hard to communicate going from upset to angry at the best of times. I wish I'd learned earlier that it's okay to take a breath and say 'I feel like this because x.' This was also the time in life I realised I was LGBTQ+, which can be scary and confusing. The best advice I can offer when it comes to that is try to replace shame with curiosity. There are lots of safe and confidential resources to help anyone looking for answers like **BelongTo, LGBTQ+ Ireland, TENI or ShoutOut.**"

SEXUALITY AND GENDER

Firstly, let's talk about the difference between sexuality and gender. These two words often seem to be mixed up!

Gender is a deeply personal expression of how a person identifies within their own body - whether that be as a man or a woman or something outside the binary like agender, while **sexuality** relates to who you are attracted to or who you want to be in a relationship with.

Sexuality

This might be something you are thinking about more as a teenager, or something you haven't started thinking about.. This will be an individual process for everyone, whether you are autistic or not autistic.

You might be interested to know that a recent study found that autistic young people and adults are more likely to identify as part of the LGBTQ+ community. Autistic people are also more likely to list their sexuality as 'Other'. However, you can see from the below that autistic and non-autistic people belong to all sexualities.

	Autistic	Non-Autistic
Asexual	10.05%	1.51%
Bisexual (f)	16.13%	13.29%
Bisexual (m)	9.4%	3.48%
Heterosexual	63.03%	83.08%
Homosexual (f)	7.59%	2.44%
Homosexual (m)	7.57%	8.56%
Other	5.71%	0.84%

There may be some terms above you didn't recognise. We can explain below:

Bisexual: A bisexual person is someone who doesn't take gender into consideration when it comes to choosing a sexual partner.

Asexual: An asexual person is someone who is not interested in having sex. It can be stereotyped that autistic people are asexual, because people can associate both autism and asexuality with a lack of emotion, which is a misconception.

In this section, we talk about sexuality and gender identity. If you find reading about sexuality and gender identity stressful or uncomfortable, we suggest you skip this section.



Fun Fact:

The term lesbian refers to the island of Lesbos where an ancient Greek poet named Sappho wrote about her love for other women, this is also why the term Sapphic is used to describe women-loving women.

Some autistic people link their asexuality to sensory issues. Most sexual acts can be very overstimulating, involving different textures and parts of the body that even non-autistic people consider to be very sensitive.

Being asexual doesn't mean that you can't be in a relationship or feel romantic love. A lot of asexual people may not be interested in sex, but they are romantically attracted to men or women or non-binary people or all of the above.

That being said there are people who aren't interested in sex or relationships, and doesn't mean they aren't capable of love and can't have meaningful relationships.

Demisexuality: One of the common sexualities for autistic people that would fall under the "other" category would be demisexuality. Sometimes viewed as a form of asexuality, a demisexual person is only interested in a sexual relationship with someone that they have a close emotional relationship with. They don't experience lust at first sight or sexual attraction to celebrities – though they might find these people aesthetically attractive, in the way a person might appreciate a sunset or a pair of shoes.

Heterosexuality and Homosexuality: Heterosexuality and Homosexuality - or being straight and gay - are usually the first two sexualities we learn about and the most represented in media. Heterosexuality refers to a person that is attracted only to people that are a different gender to themselves - a man who is attracted to a woman and vice versa. While Homosexuality refers to someone who is only attracted to the same gender as themselves. Gay can generally refer to anyone who doesn't identify as straight, but more specifically it refers to homosexual men, while lesbian refers to homosexual women.

Queer: Queer is a broad term used to refer to anyone who isn't straight, it can also refer to anyone who isn't cisgender. Sometimes the LGBTQ+ Community will also be called the Queer Community. Though it is important to remember that not very long ago the word queer was used as a slur and though it has been reclaimed by the community, older people in the community may still find it hurtful and difficult to hear.

Do I have to decide on my sexuality from one of the terms you listed above?

No. Ultimately, the only person who can know the absolute truth about your sexuality is you. Therefore, whether you are sure or unsure or even disinterested in your sexuality is only your business.

Do people change their mind about their sexuality?

Yes. Just like you have a right to identify as any sexuality, it is equally important that you have a right to feel differently about your sexuality at any time.

Do I have to tell people my sexuality?

No. You may feel it is something that is personal and private to you, or you may feel it is something that you are fine with everyone knowing. If you are asked what your sexuality is and you do not want to share, here are a couple of ways to reply:

- ▶ **If you want to be direct, you can say "That's not something I want to discuss" and change the subject. It can be a good idea to have a 'safe' change of subject you use when you don't want to take part in the conversation.**
- ▶ **If you don't feel like being direct, you can say "Oh that's a personal question to ask people, can we talk about something else?"**

Gender Identity

Okay... so that's a bit about sexuality, now back to gender. But wait, what's the difference between a person's sex and gender? Well, sex is biological, it is assigned at birth based on genitalia and is either male, female, or intersex. However, gender is social, it has to do with how we act, how we are treated by those around us and how we perceive ourselves. If our sex and our gender line up, then we are **cisgender** and if our sex and gender don't line up then we are **transgender**.

Transgender: Transgender is an umbrella term that covers lots of different kinds of people, trans men, trans women and non-binary people to name a few. A trans person is someone who identifies with the opposite sex than what they were assigned at birth. So, a trans man is someone who was assigned female at birth and identifies as a man, while a trans woman is someone who was assigned male at birth and identifies as a woman. A non-binary person – or enby – is someone who doesn't identify with either male or female, but as something outside the binary.

Trans people may transition and gender transition looks different for every trans person. Some people use medical interventions (such as Hormonal Replacement Therapy or surgeries) to help them affirm their gender, others prefer to change their gender expression, or perhaps the name and pronouns they go by. In this way, gender transitioning can have psychological, social and medical aspects to it.

Does being autistic mean I experience gender differently?

Autistic people may be more likely to experience gender differently than non-autistic people, and many in the community identify themselves as transgender or gender diverse in some way. There seems to be a number of reasons for this, which isn't exhaustive, but includes:

- ▶ **Many in the community do not see themselves as fitting into or identifying with traditional ideas or expectations around gender.**
- ▶ **Many in the community feel that the autistic and LGBTQ+ communities face a lot of common barriers in society, and since both communities tend to largely see these issues as socially constructed in nature, this builds a greater sense of solidarity, as well as overlap between the two communities.**

The thoughts and stories from our community below reflect there is no script you can follow when exploring, or not exploring, your sexuality or gender:

Erin's Story

"As a teenager, I assumed I knew everything about the world. One of the things I was most certain about was that I was a very straight girl. My first proper crush was Johnny Depp. I eyed up boys in the year above me in school. However, something didn't feel quite right, and I wouldn't have the words to describe it until I was 19 years old.

My relationship fantasies did not extend beyond dating. When I was 17, I had my first romantic thought about a girl. I immediately assumed I was bisexual. However, this discovery made me realise I was actually asexual as my sexless fantasies now extended towards women. However, I am still very much attracted romantically to more than one gender!

My advice is to ignore stereotypes that autistic people cannot experience love and that being asexual is a by-product of autism."

Julian's Story

"Even though I identify as Male, I still dress similar to the way I used to, just with more freedom. I have always loved colour. While I don't necessarily shop for 'Women's' or 'Mens' clothes, you'll find my wardrobe is mostly 'Women's' since I'm drawn to colour like a moth to a flame. I never really understood gendering clothes until someone mentioned that clothes were tailored for the body types of men and women. To better describe this, we call it gender expression.

A boy can wear a dress and that doesn't make them a girl since they identify as a boy, it just makes them a boy who is wearing something tailored for girls. Hence he would have a more 'feminine' gender expression. Gender identity and gender expression are two different things.

A tip from me if the border between the Men and Women's sections in the store are too daunting to cross, try buying second hand. The borders there at most will have a little laminated sign that is easy to ignore. Just in case it's still too daunting, online shopping can give you all the privacy you require. I've found people have actually applauded me more when I wear what I want. Including elderly conservatives who live in the countryside. A wise person also once told me, **"Everyone is too selfish to care about what you're doing."** So start exploring who you are, and feel comfortable in the wild of uncertainty, for there's nothing wrong with questioning it.

I have friends who are 'Questioning' their gender identity, and only realised recently that it's a label you can use just like 'Transgender'. Identifying as 'Questioning' takes the pressure off yourself to figure things out, and stick with an identity you're not comfortable with until you do. Using they/them pronouns are gender neutral for example, and you can use them exclusively or with other forms of pronouns. Someone's pronouns could be he/they, meaning they use both he/him and they/them pronouns.

A top tip for telling someone your pronouns if you're too shy, is to ask them what their pronouns are. **"Before I forget to ask, I was wondering what your pronouns are?"** This way you can find out their pronouns which usually leads to them asking you your pronouns in return. Pronouns correlate with your gender identity, and as we're coming into more inclusive times you can see people showing their Pronouns in their Internet bio more and more. Everyone putting their own Pronouns helps normalise and include the Transgender community online and in real life. This also prevents misgendering from happening in the future.

When it comes to misgendering, I'm the King since I don't work considerably hard to 'pass'. 'Passing' means being perceived as a gender that you weren't assigned at birth. For example, Mulan 'passed' as a boy when joining the army.

I take being misgendered with a grain of salt. I correct people who I'm close to, and I don't feel the need to correct strangers or associates. If I ever need to correct a new friend I might tell them when the time is right. It can be daunting correcting someone in a group or crowd, so I try to do so alone or over text. **Never feel bad for correcting people for your gender or pronouns, if they're a real friend they should understand.**

I still remember the first time someone asked me for my Pronouns, I was still 'in the closet' and was so shocked I couldn't say anything. It was the first time in my life it felt like someone truly cared who I wanted to be and not just what everyone expected. They continued by telling me it's okay if I 'didn't have any', implying it was okay if I was 'Questioning'.

And at the time I suppose I was. Now whenever I make friends, it's my mission to be that person for someone else, because everyone deserves to have that someone who cares about who you really are. Getting to write this, I hope I can help people without even physically being there!"

Clara's Story

"In my final years at primary school, I watched my friends develop interest in members of boybands, or actors. I did too, but swiftly, I realised the intensity of my interest was significantly less than that of my peers. **I felt an idle acknowledgement of a boy's beauty, but nothing more.** By the time I was fourteen, this had not grown to be much greater than a flicker of interest. It did occur to me once or twice that I might be asexual, but even in thinking that, I know I wasn't. I did have feelings for boys my own age, they did not seem quite as irrational as my peers. It was as though I could set aside the intensity of my feelings in favour of logic, as I can do in all other situations.

It was not until I went to university that I felt as though I had a genuine interest in the dating lives of my peers and the possibility of dating someone myself. Even in this, however, I felt atypical because I could not imagine the idea of using a dating app or getting with a random boy in a club. Everyone joked at this and told me that people rarely met their partners in-person. Like most things, I was irresolute. When I did eventually meet my first boyfriend, I was quick to acknowledge my attraction for him but slow to develop love. In hindsight, **I think I did not recognize the feelings within myself as readily as my non-autistic peers.**

I have never questioned my sexuality. I have read many accounts from queer members of the community, so to describe the opposite, the distinct lack of doubt feels both peculiar and disingenuous. I **wonder though if that lack of doubt is a trait of my autistic irresoluteness.** For me, love is fixed, but early attraction was variable – the only sure part of my attraction was my undeniable heterosexuality."

What is gender dysphoria?

Gender dysphoria is where you experience anxiety or distress because there is a mismatch between the sex that you are assigned at birth and the gender that you feel you identify with. Gender dysphoria can be experienced by any person regardless of neurotype.





Amy's Story

"As soon as I was able to pick my own clothes, I'd swap the pink dress for cargo pants. I'd been voicing my concerns around gender roles much earlier than you'd expect, and it was definitely not due to "ideological" upbringing, since I grew up in a pretty conservative working-class single-parent family. **I just didn't get the point of being destined to only do things that are deemed appropriate based on the genitals you were born with.**

When puberty hit me, I had a bit of a gender identity crisis and thought I needed to conform more in order to fit in and get a date. I started wearing make-up, worrying about my hair and weight and every other part of my body after having been bullied extensively. Alternative social circles then allowed me to have an excuse to wear black band shirts and torn jeans, that wasn't associated with gender.

I did question whether I was transgender for a while, but I think there is no clear-cut definitions.

I personally never bothered to identify as any gender in particular. When someone asks, I say female just to avoid any confusion or discussion, but **I really feel apathetic towards the entire concept of gender** and wish we'd stop talking about it altogether. I just don't see it as an important part of my identity because I don't put importance on gender in general. You do you, whatever makes you feel comfortable and confident!"

Skylar's Story

"With both my gender and sexuality, I had a very sharp moment of realisation that I was different and once those moments happened, I couldn't deny it to myself at all. I've heard professionals ponder why autistic people are more likely to be queer, and I think it's just because we are more honest with ourselves.

I came out as queer when I was about 15 and I was one of the first queers my peers met. I didn't realise this at the time but me coming out and being so vocal about being queer meant that I ended up being the first person a lot of other queer people came out to and still do.

I was 21 when I came out as non-binary. I had always struggled with conforming to my sex assigned at birth and I was quite androgynous throughout my teenage years. I didn't have the language to express how I felt until I was in college and met other non-binary and trans people who I could relate to."

Sorcha's Story

"At first my bisexuality was treated as a social norm that I didn't understand, it was cute and silly that I would tell my female friends on the playground that we'd get married and have bunkbeds. It's something that I thought I would grow out of.

My first few relationships were with boys – though they weren't more than holding hands and sitting next to each other – but when I was fourteen a girl asked me out. She was pretty, I liked her aesthetically, I didn't see why this relationship would be any different than the others. It ended up being my longest relationship until I met my husband.

The way I found to explain it to myself is that I've never been particularly interested in my partner's gender, I don't consider it to be a very important part of who I am. If my partner were to wake up one morning with their body entirely changed nothing would change for me.

I did consider whether my general disinterest in gender meant some sort of identification there, but **I like being a woman**. I'm attached to an idea of matriarchal power, a sort of maternal, eldest daughter powerfully caring femininity that I can't remove from how I consider myself. It might not be how other women view themselves but it's how I view myself."

Jessie's Story

"I had never really questioned my gender until fifth year. I am in second year college now, but in fifth and sixth year I was part of a WhatsApp group where most of the others were questioning their gender and that was the main topic of conversation. It was weird, because although I don't think it was the group's intention, I felt I should probably do the same. I actually physically sat and made myself think about it, but my mind kept going blank, I had no profound thoughts - I just really felt like a girl. I think it really had less to do with what other people were saying to me about their gender, and more to do with **I literally didn't know how to connect to others' experience without feeling I had to have the exact same experience** and say "me too". Like I didn't know how to say "I don't feel the same way but want to hear more about how that is for you." I am sure any autistic person reading this is thinking what I'm thinking, that the need to mask played a big part here."

Millie's Story

"Trying to identify with a sexuality or gender was quite confusing. **I was given so many options and then that made me question everything I thought I knew.** At a young age, I never really had an interest in boys and I saw boys as more friends than anything else. When I got to secondary school it made me question my sexuality. I always knew I was a girl but I was confused on whether I was into boys or girls.

After wondering for a while I settled on the fact that I liked girls and boys were friends and nothing more. I was fortunate enough to have a very supportive family and when I came out it was fairly easy and nothing changed. I tend to keep my sexuality a secret but if someone asks me about it I will tell them.

I don't really wear clothes that fit the "gender norm" for a girl and I wear more clothes "fitted" for boys. In the past I have been mistaken for a boy but I never really let it affect me. The last couple of years I have found clothes that work for me from both "sections" in shops. I wear more "girls" clothes than what I did but on a day to day basis I wear more "boys" clothes."

Claire's Story

"For me, being a girl is not about the way you dress or act. For me, it's just a label to describe what body type you are. I don't think you are not supposed to feel "girl this" or "girl that" all the time or at all... In my view, you can feel super masculine and still be a girl. You can still be a girl and play with dinosaur toys."

Jaymie's Story

"I am from the autistic community and I am proud of all my identities. Only come out when you feel ready and safe to do so never feel pressured to come out."

TO FINISH UP...

**WHAT MAKES YOU,
YOU**

As an autistic teenager, you might have had to attend many medical appointments and assessments, or read your assessment reports or IEPs. This might mean you have had a lot of exposure to hearing or reading about what is difficult for you. Whereas in contrast, someone who has not attended similar medical appointments or gone through assessments may be totally unaware of what other people think their difficulties to be. Completely common things that they do as a teenager (e.g., get cross when the WiFi cuts out) have not been examined and analysed, like it may feel they have been for you.

Potentially, those difficulties you have read and heard about have become cemented in your mind as a large part of what makes you 'you'. Yes, an awareness of what challenges you is important when it comes to advocating for yourself and your needs. And yes, if those difficulties are dismissed by someone saying, "but aren't you so good at xyz", this can make you feel completely unseen.



However, your identity is not 'finds things more difficult than other people'.

So, as we finish out this book, have a think. If someone asked you to describe what you are like as a person, what would you say? Would you talk just about what you think you don't do well at, or would you also talk about what you do very well at? ... Your strengths. You see, strengths are often things that come 'naturally' to us, so we don't always notice them or think about them. We asked the AslAm community to help us conclude by sharing with us their strengths, and this is what they said:

"I don't bow to peer/social pressure."

"I am open-minded and less susceptible to prejudice and stereotyping."

"I see patterns in things."

"I am stoical, non-pushy, reflective, authentic, and true to self."

"I'm able to spot when something is off with someone."

"I have the ability to see past the fake exterior"

"I feel great empathy and I have friendships"

"I am fearless."

"I delve deeply into topics and become very knowledgeable."

"Sensory joy is a lovely thing that brings me pleasure."

"I am always on time."

"I have a strong moral and ethical code."

"I get so much happiness out of all my interests and hobbies."

"I spot details and irregularities."

"I'm passionate about what I love and this spills into my career. If an autistic person is doing something they love, they are unstoppable!"

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Many thanks to the artists who brought this resource to life:

Caitlin Brisbane
aka

Kutischic

A stylized, handwritten signature in black ink, consisting of the letters 'i' and 'g' intertwined.

iigracie.com

A handwritten signature in black ink, appearing to be the letters 'Orh' in a cursive style.

RESOURCES:

Minding your mental health

Crisis Intervention & Support	Overview	Contact
Suicide or Survive (SOS)	Free online wellness workshops and programmes	Call: 01 272 2158
Samaritans	Provides emotional support 24/7.	Call 116 123.
BodyWhys	Support service for those experiencing eating disorders	www.bodywhys.ie Helpline: 01-2107906
Pieta House	Provides support for those in crisis and at risk of suicide. They have both text and phone crisis support and provide 1:1 therapy too.	Call: 1800 247 247
Childline	Provides 24 hour support to children and teens up to 18 years of age. You can talk with Childline in confidence, about anything that might be on your mind.	Freephone: 1800 666 666
Text 50808	Text 50808 is a free 24/7 text service, where you connect with a trained Crisis Volunteer. The Crisis Volunteer will introduce themselves, reflect on what you've said, and invite you to share at your own pace. You'll text back and forth, only sharing what you feel comfortable with.	Text HELLO to 50808.

Counselling & Therapy	Overview	Contact
Jigsaw	Mental health services for mild to moderate concerns are provided online or face-to-face for young people. You can access this through self-referral (jigsaw.ie.)	<p>Find your local office here:</p> <p>Visit Jigsaw.ie The National Centre for Youth Mental Health</p> <p>If you are under 18 you will need a parent/guardian consent</p>
Helplink Mental Health	Free, low-cost online counselling services and educational resources.	www.helplink.ie
Grow Mental Health Recovery	Weekly online peer support groups. Podcasts, practical resources and information.	<p>Email:info@grow.ie</p> <p>Information line 1890 474 474</p>

Wellbeing Programs	Overview	Contact
Minding Your Wellbeing	Free series of online video resources to learn and practice essential elements of mental wellbeing such as mindfulness, gratitude, self-care and resilience from HSE Health and Wellbeing.	Minding Your Wellbeing Programme - HSE.ie

Mental Health Apps	Overview	Contact
Mindshift (by Anxiety Canada):	MindShift CBT teaches about anxiety, helping users to engage in healthy thinking and to take action. Users' check-in each day to track their anxiety and work with tools in the app.	Search android or iphone app stores
Headspace	A mobile app that teaches meditation and easy-to-use mindfulness skills. Map your journey, track your progress, 'buddy up' with friends, and motivate each other.	Search android or iphone app stores

Puberty, Sexuality and Gender

Resources	Overview	Contact
LGBT Ireland	Offers helplines and in person support groups.	www.lgbt.ie LGBT Helpline - 1800 929 539 Transgender Family Helpline - 01 907 3707
BeLonG To	Youth Services Support, information and groups for LGBTI+ young people in Ireland, their parents and carers, and other professionals.	www.belongto.org
Text LGBTI+ to 086 1800 280	Text LGBTI+ to 086 1800 280 to chat confidentially with a trained crisis volunteer anytime	086 1800 280
Transgender Equality Network Ireland (TENI)	TENI have various support services and resources accessible through their website	www.teni.ie
Outhouse / ShoutOut	Outhouse have community supports, a library and cafe space in Dublin and an advocacy and training branch called ShoutOut	www.outhouse.ie
#mycontraception	#mycontraception is a website that allows you to compare possible birth control methods and weigh up the pros and cons of each option in your situation.	www.mycontraception.ie
Split Banana	Split Banana is a sex education website that offers guides for disabled teens and young people.	www.splitbanana.co.uk
Hannah Witton	Hannah Witton is a disabled sex educator, she has a youtube channel, a podcast called Doing It and hosts round tables for other disabled creators to talk about sex and relationships.	www.hannahwitton.com
Clue	Clue is a free app that allows you track your period and symptoms, unlike some other period tracking apps they also have a very firm position on data security.	Search android or iphone app stores

