DR EMILIA MISHEVA

AUTISM: WHAT DOES THAT MEAN FOR ME?

A guide for newly-diagnosed young people

London Borough of Hounslow

Hounslow Educational Psychology Service

London Borough of Hounslow
Educational Psychology Service
4th Floor – Hounslow House
7 Bath Road, Hounslow
TW3 3EB

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Introduction

If you're reading this booklet, you've probably been diagnosed with autism recently – and finding out you're autistic might have left you with many questions. The important thing to remember is that discovering you're autistic doesn't change who you are – but it might help you understand yourself, your strengths and your differences a bit more. Another very important thing to remember is that autism isn't an illness, even though you may have met with a doctor to find out whether you're autistic. Autism is a normal difference in how people think – we all have different brains, which makes the world a less boring place! It's a bit like eye colour – the majority of people in the world have brown eyes but that doesn't mean that having blue eyes is an illness or any less "normal" – it's just different.

There's no one way of being autistic and this booklet will try to help you find out what being autistic means to *you.* You can use it in whatever way works best for you – you can read it chapter by chapter, or you can dip in and out of it and focus on the topics that interest you most.

You might notice that we say "autistic", rather than "person with autism" here– this is because we know from research that this is how most autistic people prefer to refer to

themselves. You can choose how to define yourself, though – you don't have to go with the majority if it doesn't feel right for you!

In the next pages, we will look at the different traits of autism – that is, the things that autistic people often have in common with each other. As no two people are the same, some of these might sound familiar to you and others – less so. After each topic, you will have an opportunity to share your thoughts and what that specific trait looks like for you. If you want to, you can then share this with your family members, friends or teachers, so that they understand you and your needs better.

1. Masking/camouflaging

Some autistic people develop strategies to fit in with others and this is known as "masking" or "camouflaging".

For example, you might be:

- Making eye contact even when this feels uncomfortable
- Rehearsing conversations in your head
- Trying to hide when you're not comfortable or when it's all too much because you're overwhelmed (by things like loud noises, bright lights, several people talking at the same time), which can leave you feeling exhausted
- Paying close attention to other people's behaviours, reactions, clothes or interests, and trying to copy those to fit in

These are not necessarily things that you're doing on purpose –you may not realise that you're masking but you may have learnt over time that this is what you need to do to fit in.

Masking can be an exhausting and you may feel very tired after masking for longer periods of time - for example, after a birthday party or after a long day at school.

Masking/camouflaging

What are your main "masking" behaviours or strategies?

Are there any particular places or situations where you're more or less likely to mask?

More likely to mask	Less likely to mask

Are there any particular people around whom you mask more? Why do you think that is?

Are there any particular people around whom you don't mask your autism? Why?

How does masking make you feel?

2. Externalising vs internalising emotions

Some people show their emotions and reactions in an easy-to-notice way – in other words, they *externalise* their emotions. For example, when they're upset, they might raise their voice, get up and leave the classroom or throw an object. Others are more likely to keep their feelings in, or *internalise* them – this means that they may look calm when they are, in fact, finding things very difficult.

If you're autistic and you internalise your feelings – particularly when you're finding things difficult, others might think that you seem "fine" and not realise how much you're struggling.

Some autistic people find it easier to show their emotions and how they really feel at home. So, you may find that after a busy day at school, you become more emotional at home, or you need a quiet space and to be away from people.

Externalising vs internalising emotions

Do you externalise or internalise your feelings more?

Where and when do you tend to internalise more? Why?

Can you think of any examples where you internalised your feelings or distress

At school	At home	In social situations

Where and when do you tend to externalise more? Why?

Are there any particular feelings that you tend to internalise more? Why?

Are there any particular feelings that you tend to externalise more? Why?

3. Autistic Burnout

Feeling under a lot of pressure for long periods of time – for example, when you're preparing for an important exam, or when you've been making yourself do things you find difficult day after day, can leave you feeling very exhausted. For some autistic people, having to mask every day while they're in a busy classroom, for example, can make them feel so exhausted that they struggle to do things they would usually be able to do, like talking to other people, leaving the house or being in busy places.

Autistic people who are burn out may also struggle with motivation and starting activities, as well as planning and organisation (these are also called "executive functions" and you can find out more about them in Chapter 17).

Autistic Burnout

Have you experienced autistic burnout?

What caused it?

Was there anything that would have helped prevent it?

What and/or who helped you recover from it, if you have reached that stage?

4. Special Interests and Monotropism

Many autistic people have things that they're really passionate about. These interests don't have to be particularly unusual– they can be just about anything. You may find that when you're focused on your special interest, hours can go by without you realising and that it brings you a lot of joy.

Monotropism is another way of saying that some autistic people can stay very focused on one area of interest, and can find it difficult to move on to new activities or tasks.

While some autistic people's special interests may be more scientific (physics; astronomy; maths), factual (historical facts; timetables) or to do with technology (computers; computer games), they don't have to be. Examples of interests include:

- Collecting objects that you're curious about or make you very happy
- Researching and collecting factual information on topics you're passionate about - such as TV shows, actors, musicians, film or book characters…or even autism itself
- Books
- Fashion
- Animals

- Art
- Writing
- Theatre
- Sports

Your special interests can bring you a lot of joy and, for some autistic people, they can also become an escape from the outside world, particularly when overwhelmed.

Special Interests

What are your special interests?

Have your special interests changed over time?

How do you feel when you're engaging in your special interests?

What do you take out of your special interests? What do they bring to your life?

Do you enjoy sharing your special interests with other people, or prefer to enjoy them on your own? Why?

5. Autistic joy

Autistic joy is the feeling of great happiness that some autistic people get from experiences or activities, like their special interests. Some examples include:

- Your special interests, hobbies or activities that you can get lost in because you're so invested in them
- Having your sensory needs met – for example, jumping on a trampoline, swimming or simply being in water, wearing a particular item of clothing that fits "just right" and is made of the right fabric
- Being in the company of animals or people around whom you can be your authentic self, without the need to mask

Autistic joy

What are the things in your life that bring you joy?

What does happiness look and feel like for you?

Who are the people (or animals!) in your life that bring you great joy and happiness? How do they make you feel?

6. Sensory Processing Differences

We all make sense of the world around us through our senses:

- Hearing
- Sight
- Taste
- Smell
- Touch
- Balance
- Movement and awareness of our own body in space.

You may find that you're *hyper*sensitive (or very sensitive) to some types of sensory information, and *hypo*sensitive (less sensitive) to others.

Sound and noise – you may find that loud noises and some sounds are much harder to tolerate than others, and make you feel overwhelmed. These could be anything from several people talking at the same time, to the sound of someone chewing or high-pitched noises. For some people, it isn't the sound itself that is the issue, but the fact that they are not in control of the duration and volume – so, if they were the one making the sound, they would be able to tolerate it.

You may also find that you are hyposensitive – less sensitive - to sound in some situations. For example, you may be hypersensitive to noise produced by other people,

but at the same time, greatly enjoy loud music in your earphones.

Touch – you may find touch, such as being hugged or held, overwhelming and uncomfortable if you are hypersensitive to touch, or you might really enjoy being squeezed or hugged tightly if you're undersensitive to touch. You may find the feel of some textures difficult to tolerate (e.g. certain types of fabric and how they feel against your skin – like itchy jumpers)

Taste – you may find the taste of different foods very strong and overwhelming and, because of that, you might prefer foods that have a relatively plain and predictable taste (e.g. biscuits; a specific brand of chicken nuggets).

Smell - you may find some smells strong and overwhelming, including ones that you come across regularly in your day-to-day life (e.g. perfume, cooking, petrol). You could also be hyposensitive to smells, meaning that you seek out certain smells that you enjoy, as they may have a soothing effect on you

Sight - if you are hypersensitive, you may find bright, fluorescent or LED lights uncomfortable on a sensory level. If you are hyposensitive, you may also find certain types of light soothing and enjoyable to look at for extended periods of time (e.g. lava lamp-type light), lights that make patterns and colours

Vestibular (balance) – if you are hypersensitive, you may find any disruption to your balance uncomfortable and this could also lead to motion sickness and nausea. If, on the other hand, you are hyposensitive, you may actively seek out movement, and particularly enjoy activities like swings, trampolining and certain fairground rides. As always, these are not mutually exclusive – it is possible that you greatly enjoy the motion or the physical sensation of movement when in a car, bus or train, but you may nevertheless experience motion sickness in some of those

Proprioception (awareness of your own body in space) – some autistic people struggle to identify their body's position and distance from other people and objects, and some bump into things, knock things over or find it difficult to judge how far they are from objects or other people. You might also seek out sensations that make you very aware of your body's position in space, such as leaning against a hard surface, deep pressure on your muscles, tight hugs and sleeping under a weighted blanket.

Hyperarousal – if you are overstimulated because you're in a very busy environment you're not in control of (e.g. on public transport or in crowded spaces) or because there has been an unexpected change to your usual routine – or for any other reason that could overwhelm you, you could become *hyperaroused.* That means that you could feel "on edge" and become particularly sensitive to sensory overload and react more intensively to things that you may

usually be able to tolerate. You may become more anxious and you may need a quiet space, low in stimulation and demands of any kind, in order to feel calm, regulated and "yourself" again.

Hypoarousal – similarly to hyperarousal, hypoarousal is also caused by being overwhelmed by your environment. However, the key difference is that when you're hypoaroused, you may feel "flat" and as if you need to "switch off" from your surroundings. You may also find it harder to maintain your attention and focus on what is going on in your immediate environment.

Sensory Processing Differences

What are you…

Hypersensitive (oversensitive) to	Hyposensitive (undersensitive) to

Do your sensory processing differences affect your diet and food choices?

What helps you manage your sensory processing differences?

Are there any particular places or environments that you find

Soothing	Overwhelming

Are there any particular situations or places where you feel “on edge”?

Are there any particular situations or places where you become overwhelmed and want to “shut down”?

7. Sleep differences

Many autistic people have difficulties with sleep, or different sleep patterns. For examples, you may:

- Find it difficult to settle into a routine before bed, or "switch off" from the day properly – you might be going over events or conversations that happened during the day, or thinking about the following day
- Struggle to fall asleep or stay asleep during the night
- Have very specific routines around bedtime, such as the order in which you get ready, what your room and bed need to look like, as well as preferences in terms of the temperature and the light in the room
- Struggle to wake up in the morning and feel tired, sleepy and not fully awake during the day. This, in turn, could make it harder to concentrate during the day, make you more sensitive to sensory overwhelm and make masking more difficult

For some autistic people, the night is the main time when they feel alert – this might be because it is usually quieter and everyone else is in bed, which could mean that you feel calmer and better able to focus.

Sleep differences

Do you work better during the day or at night? Why?

What helps you fall asleep at night?

Do you have any difficulties around falling asleep or staying asleep? If so, what do they look like for you?

8. Interoception

Interoception is our ability to tell when we feel:

- Hunger
- Thirst
- When you need to use the toilet
- Being too hot or too cold
- Pain

Some autistic people only become aware of hunger, thirst or needing to use the toilet when they're extremely hungry, thirsty or desperate to use the toilet. This could mean that you may feel uncomfortable during the day but you may not always be able to tell why.

You may also be very sensitive to sensations like your stomach being full, changes in temperature or changes in your body during your periods.

Interoception

Are there any particular internal bodily signals that you find hard to identify?

How does that affect you on a day—to-day basis?

Are there any internal bodily functions you find particularly hard to ignore?

How does that affect your daily life?

9. Prosopagnosia

Prosopagnosia or "face blindness" means that some autistic people find it harder to remember and recognise faces of people. Some autistic people may try to remember what someone's eyes, lips, hair colour or length look like as a way of remembering what a person you don't know very well looks like.

Struggling with remembering people's faces could mean that you find it harder to make sense of other people's emotions. Some autistic people find that they sometimes find it difficult to connect people's face to the conversations they've had – or remember who they have already met or spoken to.

Prosopagnosia

Do you have any difficulties recognising or remembering faces? If so, does this apply to familiar, unfamiliar faces, or both?

What helps you recognise people's faces? Are there any particular strategies that you use?

How do you think this difference affects you and your day-to-day life?

10. Routines, structure and predictability

Having a clear sense of structure, predictability and order is an important part of many autistic people's lives. Routines can be one way of managing the anxiety you may feel in situations where you have limited control, or where there is a lot of uncertainty and changes (such as at school).

A routine can be anything from wanting to know exactly what you need to do, step by step, when you have been given a task, to having a preferred route to the shops/school/your nearest bus stop. You may also have specific routines in terms of how you manage your time and friendships. For example, you might like to meet certain people for specific activities, in groups or at particular times of the week. You may also have routines in terms of the order in which you do certain activities, as well as how you organise your room and how your belongings are positioned in space.

Routines, structure and predictability

Are there any particular routines or "rituals" you follow regularly? What do they do for you?

Routine	Positives	Drawbacks

Are there any particular places or situations where you need more structure? Why?

How do you respond to unexpected changes or disruptions to plans? What makes it easier to cope with those?

11. Anxiety

Anxiety is something that many autistic people experience but what being anxious feels like is different for each person.

Anxiety can take many different forms – you may feel worried or "on edge"; some people have tummy aches or feel like something is about to go wrong.

Some autistic people find that they get anxious when:

- They're overwhelmed because of too much noise, too many people around them or when they don't know what is going to happen next
- They're in social situations and trying hard to figure out other people's intentions and to fit in
- Plans change or when they're not able to stick to their usual routines
- They've been given unclear instructions or instructions with multiple steps

Because of this, may find that you:

- Avoid anxiety-provoking situations
- Have routines that you like to follow every day that make you feel safe and in control
- Stick to similar activities or familiar environments, places or people

We also need to bear in mind that anxiety doesn't have to "look" a certain way – while some people would go quiet

and try to “blend into the background”, you may find that you talk a lot when you’re anxious, or that you react more strongly or get angry more easily than you normally would (or a mixture of all of these, depending on the situation).

Anxiety

What does anxiety look and feel like for you?

What do you tend to feel, think and do when you're anxious?

Feel	Think	Do

Are there any particular situations, places or people around whom you tend to feel more anxious? Why?

Situations	Places	People

What are the things that help soothe and settle you when you're anxious? Is there anything that you have tried that wasn't as helpful?

Helpful	Not so helpful

What are some of the things others can do to support you when you're anxious? Are there things that are definitely not helpful?

Helpful	Not so helpful

12.Hyperempathy

Empathy is our ability to imagine how another person might be feeling, and to feel their joy or pain. *Some* autistic people can express their empathy or concern in different ways – for example, if you see that someone is upset, you might try to help them practically, thinking about the problem they have or by offering help and comfort in more physical way (e.g. making them a drink).

Some autistic people are very empathetic, to a point where they find it very difficult to stop thinking and worrying about other people's pain – and this is called *hyperempathy.* If you are hyperempathetic, you may find that you feel for other people, animals or even fictional characters in books and films so much, that you almost feel their emotions as your own. You may find that you think about the person/animal/character/news story regularly, which can be very exhausting and overwhelming.

Hyperempathy

Do you experience hyperempathy and, if so, in what situations?

What does hyperempathy feel and look like for you?

Are there any challenges you experience when you're hyperempathetic towards something or someone?

13. Social communication differences

While we know that many autistic people have what we call "social communication differences" – that is, differences in how they think about and make sense of social situations, and how they interact with other people. You may find that you have differences or difficulties with:

- Starting conversations and "small talk"
- Understanding implied meaning – something that hasn't been said directly but is implied in the tone of voice, intonation or facial expression of the other person
- Taking turns in conversations – you may find that you find it easier to either stay relatively quiet or to talk about a topic of interest to you
- You may need to recover for a certain period of time after intense social interaction and masking - for example, you might need a day at home after going to a birthday party or a family event
- Understanding non-verbal communication, such as facial expressions, intonation and tone of voice
- Imagining how another person might act in a given situation based on past experience and behaviour – however, it is also possible that if you're very good at

spotting patterns, you can also identify patterns in other people's behaviour very well

- Making or maintaining eye contact – again, this varies considerably from one person to another. While some autistic people are comfortable with eye contact, others are more comfortable only making fleeting eye contact or avoiding eye contact where possible

Social communication differences

What are the key areas of social communication you find challenging?

Are there any specific contexts or situations that are particularly stressful or difficult for you to navigate socially?

Do you need to recover after periods of intense social interaction (parties, weddings)? If so, what do you tend to find helpful?

14. Alexithymia

Alexithymia (pronounced ah-lexi-thai-meeah)- is a difficulty with recognising and naming your emotions that some autistic people have. While you may be perfectly capable of describing various emotions and what they mean verbally (using words), you may still struggle to identify them within yourself or to distinguish between them.

For example, while some autistic people are able to define the word “anxious”, they may not be able to recognise their own anxiety or easily tell it apart from being overwhelmed, frustrated or irritated. This could make it particularly difficult to tell what makes you anxious or overhwlmed similarly, it could also mean that some therapeutic approaches that rely on being able to recognise your own emotions and identify triggers have to be adapted.

Alexithymia

Do you experience alexithymia and, if so, are there any particular emotions you find more challenging to identify?

When did you first become aware that you experience alexithymia?

How does alexithymia affect you in your day-to-day life?

15.Strong sense of justice and fairness

Fairness, honesty and equality can be particularly important for autistic people and, if this applies to you, you may find that your strong sense of right and wrong is a key guiding force in all aspects of your life – from how you choose your friends and partners, to your future career choices and special interests.

You may also find that you find it extremely difficult to tolerate injustices of any kind, as well as inconsistent rules that only apply to some people. This can be particularly challenging at school, where you're often expected to conform to social norms and not challenge the rules. Autistic people can find this particularly difficult and this can sometimes be (wrongly) interpreted as being defiant or oppositional.

Strong sense of justice and fairness

Are there any causes, social issues, rules or injustices that you care particularly strongly about? What about when you were at school?

What are the most important values or principles you stand for?

Have you ever been in a situation where you witnessed something unjust or unfair? How did that make you feel and how did you react?

16. Autistic inertia

Autistic inertia is the difficulty some autistic people have with starting new tasks and activities, and stopping them. This could also mean that you:

- Find it difficult to start new tasks and you it may seem as though you "procrastinate" regularly
- Find transitions from one task or activity to another difficult because you have to stop what you are doing and start again
- Become stuck if you come across a difficulty or something that you are not able to address or resolve immediately, and struggle to move past it
- Struggle to return to a task or an activity after interruptions

Autistic inertia can also be linked to differences with executive functioning, which we will explore in the next chapter.

Autistic inertia

If you experience autistic inertia, are there any particular tasks or activities that you find harder to start and stop?

Are there any strategies that you have found helpful in managing inertia?

17. Executive functioning

Executive functioning refers to the skills we need to complete complex tasks and activities, and includes:

- Planning and organisation
- Focus and attention
- Task initiation (starting a new activity without being prompted)
- Working memory (remembering information for short periods of time while completing another task with that information; such as mental maths, copying notes from a board)
- Self-regulation (the ability to control your impulses and emotional reactions)
- Time management
- Metacognition (the ability to think about thinking and learning)
- Thinking flexibly

This could mean that you may struggle with getting yourself organised, planning day-to-day tasks (even seemingly everyday tasks such as showering or getting dressed require quite a lot of planning), keeping track of deadlines and staying focused.

Executive functioning

Which aspects of executive functioning do you find challenging, if any?

Have those challenges got better, worse or stayed the same over time? Consider each area of executive functioning you struggle with

Which of the strategies you have tried are helpful and which ones, not so helpful?

Helpful	Not so helpful

How do your executive functioning difficulties affect your life?

18. Diagnostic overshadowing

Diagnostic overshadowing happens when all the differences or difficulties a person experiences are attributed to one cause, without considering other explanations or diagnoses. For example, as described in Chapter 2, an autistic person who masks their differences and has high anxiety levels as a result may initially be diagnosed with anxiety. While this may not be an inaccurate diagnosis, it doesn't give us a complete picture of their needs, however all of their subsequent difficulties may be attributed to the anxiety – without considering that they might, in fact, be autistic.

This could also mean that some autistic people don't have access to the support they need in education, at work or in society, because their needs are not fully recognised.

Diagnostic overshadowing

Have you experienced diagnostic overshadowing? If so, how and why do you think it happened?

How has that affected your experiences of school/education, accessing support and your life more generally?

19. Autistic meltdowns

When you are overwhelmed because of sensory or emotional overload, a sudden change of plans or masking for an extended period of time, you may experience what is sometimes called an *autistic meltdown*.

Meltdowns can feel like very intense reactions that are outside of your control, where you may say or do things that are out of character (e.g. you might throw objects in frustration, or express your distress by shouting). You might feel embarrassed or as if you have lost control after a meltdown – but remember, meltdowns are not tantrums or being deliberately "difficult" or aggressive. They are a stress response and a sign that something in your environment has overwhelmed you, and needs to change.

Autistic meltdowns

Have you had an autistic meltdown? If so, when did it happen – or, if they happen regularly, when do they tend to happen?

Where	When	Triggers

What does a meltdown feel and look like for you?

What helps you regulate after a meltdown?

20. Autistic shutdowns

Shutdowns are often caused by the same triggers as meltdowns (see Chapter 19); however, rather than *externalising* your reaction – or expressing it physically and openly, you might find that you "freeze" and instead "switch off" from your surroundings that are overwhelming you. This can take many different forms:

- You may find having conversations with people very difficult during a shutdown and may go silent or very quiet
- You may find that you crave stillness and predictability, but some people also make repetitive sounds or movements when overwhelmed
- You may seek the familiarity and solitude of familiar surroundings, such as your room, and "isolate" there until you feel regulated again

Often, a shutdown is your body's way of telling you that it is overwhelmed – as with meltdowns, this is usually a sign that something in your environment isn't meeting your needs and has to change.

Autistic shutdowns

Have you had an autistic shutdown? If so, when did it happen – or, if they happen regularly, when do they tend to happen?

Where	When	Triggers

What does a shutdown feel and look like for you?

What helps you regulate after a shutdown?

This guide is a very brief introduction to autism – if you'd like to find out more about it, here is a list of books written by autistic people for autistic people:

- Being Autistic (And What That Actually Means) by Niamh Garvey
- So, I'm Autistic: An Introduction to Autism for Young Adults and Late Teens by Sarah O'Brien
- Young, Autistic and ADHD by Sarah Boon
- The Spectrum Girl's Survival Guide: How to Grow Up Awesome and Autistic by Siena Castellon

What do you think about the guide? Share your views here!