

# Understanding Autistic Masking A Guide for Parents and Carers

#### Introduction

This is a short guide to autistic masking aimed at parents and carers. It has been written in partnership with autistic people. It can be helpful for people supporting and caring for autistic children and young people, to understand what masking is, why it happens and how tiring it can be. This guide gives suggestions of ways to create environments that are accepting of differences, so that children and young people feel safer being themselves.

When children and young people are masking, people around them might not recognise how difficult they are finding things. Knowing more about masking helps us to understand the need to look beyond the words children and young people say or initial impressions. This guide may be useful to family members and others who are advocating for a child or young person, to help others understand them better. This information may be useful to families of children with and without a confirmed diagnosis.

# What is autistic masking?

- Autistic masking involves the autistic person covering up how they are actually feeling. They may hide how they are feeling about the world around them, their preferences, and their reactions to sensory issues, communication or social experiences (also referred to as 'autistic traits').
- Masking is a coping strategy for many autistic people.
- Masking can help autistic people avoid feeling as though they are different or stand out. They may copy behaviour they have seen in non-autistic people.
- Sometimes an autistic person may choose to mask how they are feeling but often, particularly in children and young people, it is unconscious and they are not aware they are doing it.
- Masking may help an autistic person cope in different situations but is also immensely tiring and comes at a cost to their mental health and wellbeing.
- Nearly 75% of autistic people (male and female) surveyed, report masking all or some of the time to avoid being seen as visibly autistic.
- You might also hear people talking about camouflaging which is a similar thing.

## Why does autistic masking happen?

Masking tends to happen as a coping or self-preservation strategy. It may be a way for an autistic person to avoid feeling stigmatised or judged negatively for being themselves or from being bullied or discriminated against.

# What might we notice if someone is masking?

People around a child or young person may not be aware they are masking. If a child or young person is masking most or all of the time, people supporting them may just think that is 'just the way they are'.

Parents and carers might recognise signs of masking, before friends, wider family or people at school but they might not have called it that. Children and young people may seem to have coped well in school but may have a 'melt down' at home. Often the pressure of holding it together or masking in school results in the child or young person becoming upset or emotional when they are in a safe space where they do not need to hide how they are feeling.



Children and young people may use different masking strategies to cope with different parts of the life. These might include:

- Using a small number of learned phrases in social situations, e.g., to greet people, ask questions, engage in conversations, or respond to others
- Forced or copied smiles, eye contact, gestures, expressions
- Hiding, minimising, or diverting others from topics of interest they think they are perceived to get too focussed on
- Engaging in activities and conversations that are not of interest to them but known to be or thought to be preferred by other people
- Stopping themselves from 'stimming'. Stimming can help many autistic people feel calm and well
  regulated. Examples of stimming include using preferred repetitive movements or noises, such
  as hand flapping, rocking, or humming. Individuals may worry that stimming will be perceived as
  weird or unacceptable. Some individuals might use more subtle versions (e.g. humming quietly)
  or just not use this important way of making themselves feel better
- Going with the flow so as not to stand out and resisting their own needs and preferences
- Hiding reactions to sensory experiences which are painful or distressing (e.g. putting up with the noise from hand driers)
- Relying on others to talk and make decisions in a group
- Attempting to control all aspects of a social situation to make their world feel more predictable
- Copying other people's words, actions, accent and non-verbal communication from real life or from TV or popular culture

# Is masking a good thing or a bad thing?

Masking can feel like a necessary strategy in the short term, for example individuals might use it to:

- Avoid negative attention, stigma or bullying
- Feel like they fit in and are included in a friendship group
- Feel accepted
- Succeed in social settings of school and in their community
- Avoid harassment or for personal safety

Some autistic individuals have told us that masking is an essential coping strategy which helps them have positive experiences.

- However, for many people it is not seen as positive and can actually increase stress levels.
- Regular masking can have a negative impact on mental health and wellbeing because it requires 'relentless vigilance'. This means they must always be alert to how they behave in every situation. This can be exhausting for long periods of time.

#### How does it feel?

An autistic young person told us:

"I think I realised very early on that if I put on a kind of bubbly and happy persona when I was at school, it was easier to feel accepted and liked by my peers and by teachers."

"I was so overwhelmed from a sensory and a social perspective, I was never able to focus on academics. I was so overcome by putting on this, lively, very bubbly kind of coping personality to my peers and teachers that the masking was taking it all out of me and I had nothing else to give."



# How can masking affect mental health and wellbeing?

It is widely understood that masking can increase stress and impact negatively on mental health and wellbeing.

- Increased stress and anxiety
- Exhaustion because masking takes so much effort
- Autistic meltdowns or burnout when this all gets too much
- Feeling like a fake or that you're not true to yourself
- Feeling isolated
- Low mood or depression
- High rate of self-harm
- Increased risk of suicide

# What supports might be helpful?

The most helpful support is based on good understanding of your child, how autism affects them and the right adaptations to help them in everyday life. Support provided should be:

- Put in place support before problems arise rather than after (anticipatory)
- Designed to meet the child or young person's individual needs
- Relevant to the setting the child or young person is in (e.g. support will look different in the home to how it would in a cafe)
- Agreed in partnership with the young person and other people who support them

The following may be helpful but not all will be relevant for all children and young people at all times.

#### Safe supportive environment

- Seek out people who are supportive, understanding and accepting of difference, so that your child doesn't rely so much on masking as a coping strategy.
- Reflect on which actions or ways of communicating seem to be helpful or unhelpful to your child.
- As well as listening to the words your child says, also notice and observe the unspoken signals (e.g. going to their bedroom when visitors come to your home).
- Normalise conversations about social differences and social expectations.
- Help other people in the family to understand simple things that might help.

## Anticipate moments of challenge

- Understand that asking your child directly what helps might feel challenging.
- Be prepared to adapt when your child is tired, frustrated or overwhelmed.
- Be accepting that sometimes your child is 'just not up to it'.
- Listen to and take note of what is difficult.

## **Building awareness of what works**

- Observe what aspects of different places your child seems to prefer.
- Show your child that their experiences are respected and they can expect to be heard, e.g. if you don't like labels on your clothes we can take them off.
- Understand that some children might have strong ideas about what will help, and some children will not know what might help. You can help them build this awareness using words that make sense to them.



- Teach and accept the value of stimming. Provide spaces which encourage your child to stim freely, without judgment.
- In the past, your child may have had negative messages about stimming or other regulating activities and been told not to do them.
- You could offer opportunities to use familiar strategies when you see it might be useful, e.g. "Why don't you try rocking?".

An autistic person told us, "When the environment around us allows us to stim freely, it invites us to try out new stims, maybe we'll find a new stim that helps us regulate – that can only be a great thing!"

## **Understanding neurodiversity**

In a neurodiverse world, there is a range of neurotypes. This means that there are different ways that people take in information and respond to the world around us. Most people are 'neurotypical' but lots of people are 'neurodivergent', including autistic people. When we understand different neurotypes, we don't make judgements about which ones are better.

#### Parents and carers can:

- Know that some autistic people have difficulties initiating (e.g. asking for help). Your child might not tell you there is a problem. You could check in and offer safe opportunities for them to tell you what they like and don't like.
- Think about your child's communication preferences, sensory preferences and thinking style.
- Appreciate the benefits of predictability (e.g. doing things when you say you'll do them, setting clear expectations, not assuming that your child has the same assumptions and expectations as other people and providing advanced warning of changes to expectations if possible).
- Where possible, make unwritten rules explicit, e.g. when granny visits she sits in the comfy chair.
- If they are aware that they are masking, reassure them that is okay and that other autistic people use masking too.
- Consider that it may not be helpful to tell your child that you think they are masking.
   Conversations about masking should be handled carefully and respectfully, following your child's lead.

#### Take time to do things your child is interested in

- Where possible, support your child to take part in interests and activities they are motivated by, e.g. by making time and transportation available (if needed).
- Help your child by encouraging them to focus on and enjoy their interests, even if these are unexpected.
- Ask your child about their interests, enjoy those interests with them, or show them that you are proud of their interests in other ways.
- Support your child to spend time with peers with shared interests.

#### Schedule downtime

- Encourage downtime.
- Ask your child what they need you to do to help them to feel calm. Some children and young
  people may not yet be able to tell you. You can observe what they seek, e.g. do they like
  enclosed spaces, lots of movement or soft, fluffy blankets?



• You might encourage your child to focus on and enjoy their interests during downtime. Doing nothing is okay too.

# What might encourage masking?

We are starting to understand that some therapies or expectations placed on children and young people could encourage masking, such as:

- teaching children to use social 'norms' for eye contact instead of using their own gaze
  preferences (e.g. we can avoid a child having to mask if we accept quick glances, or looking away
  while listening)
- or building up a tolerance to sensory experiences they find hard, when in actual fact, they are hiding their natural reaction (e.g. we can avoid a child masking, if we accept that for some children different foods need to sit apart on the plate)

As our understanding of masking and what may help a child or young person evolves, we can all ask...

- Will our expectation of this child or young person encourage masking?
- Is this the right expectation of the child or young person?
- If it is is there a better way to help them meet the expectation?
- If the expectation is not right is there a different approach we could take?

This might mean that, for example, instead of an expectation to join big family gatherings, it might be helpful to remove the expectation for some children to go at all and for others it might be helpful to take an iPad or to identify a quiet area they can go to when they need a break.

## **Personal stories:**

We asked some autistic partners about their experience of masking.

#### Personal story 1

"My relationship with masking is a complicated one. Being diagnosed with autism in adulthood, for me, meant that I had been masking for a very long time and didn't know it. It's something we are encouraged to do, even though we are not overtly told to do it. Certain behaviours are encouraged and others discouraged. Now, I find myself masking, particularly at work, sometimes I am aware of it and intentionally masking, other times I am not. I know that it's exhausting, completely exhausting. When I get home, I am often too tired to do anything, cook, answer the phone, reply to a friend's text message. Even watching a new TV show or a new episode of a familiar TV show is too much, I'll re-watch an episode I've seen before, possibly hundreds of times before! I'll go to bed early. As a one-off, this might be something we all do, it's manageable, but for me, and many other autistic people this is a regular occurrence. That's where the problem lies, because we're no longer living, there's no energy left for that. What we're doing is surviving, I got through the day because of masking but at a huge cost. It might seem like a helpful solution, but it's just a patch. The real problem is that we live in a world which is not always accepting of diversity and difference, and that's what needs to change. I mask for you, not for me. I mask so my family know I love them, so my friends know I care about them, so I can be taken seriously at work. I mask to avoid prejudice and discrimination.

Ultimately, if I were asked to stop and take down my 'mask', I couldn't do it, I use it so frequently I don't know where my mask ends and I begin."



#### Personal story 2

Another autistic person told us that masking is sub-conscious, occasionally useful, very tiring, and often deeply ingrained in the psyche of a person.

"The realisation I was masking came a few years after my autism diagnosis in early adulthood. I had been using various techniques all throughout my life with the general intention to blend into the background and just be like everyone else. Sometimes this masking would allow me to thrive in social environments such as school or the workplace, but it would always come at a cost hidden to all others. I was exhausted and often depressed, I'd come home from school with only the energy to be alone and often I'd have to have a nap — no one outside of my home knew the toll it would take.

I'm now over 10 years past my diagnosis, and I am more comfortable with who I am and what works well for me, yet I cannot stop masking. I have stimming behaviours which I've suppressed, I utilise carefully practiced conversations, and often remain unable to keep up with all the demands of life due to exhaustion."

# **Useful links and references**

In partnership with Enquire (the Scottish advice service for additional support for learning) we have created a short guide to speaking to your child's school about your child's masking. Available at <a href="https://enquire.org.uk/enquire-resources/">https://enquire.org.uk/enquire-resources/</a>

#### Other resources:

- https://autismawarenesscentre.com/what-is-autistic-masking/
- https://neuroclastic.com/masking-and-mental-health-implications/
- Listen to a personal experience about masking by Immie
- Sedgewick, F., Hull, L., & Ellis, H. (2021). Autism and masking: How and why people do it, and the impact it can have. Jessica Kingsley Publishers.