

Anxiety and Autism (teens and adults)

Anxiety is an intense fear, worry or dread, typically out of proportion to the situation.

Autistic people may experience increased anxiety for a number of reasons. These include:

Difficulty with managing sudden or unexpected changes

Autistic people often have a hard time coping with sudden or unexpected changes to our plans or routines. This can be things as small as food being put in the wrong bowl, or a favourite shirt not being clean. Autistic people may build their plans and routines on each other and one thing being out of place can have a bit of a domino effect and disrupt numerous aspects of the day or week. This also includes being interrupted during a task or hyper-fixation, or not being able to finish something you were doing.

Tips for managing:

- If you want to be able to cope with unexpected changes, you may want to try introducing small changes here and there. Such as changing up your routine, wearing different clothes, meeting people in different places, or sitting in a different seat, for example. Find small things to change to expose yourself to variations and reduce the chance of you developing rigid expectations about how things need to go.
- If you'd prefer to keep things the same but would like to have tools to cope with anxiety that comes up when things do change, you could try some of the below:
 - Give yourself some time and space to process the change and prepare for it
 - Breathe. It's okay to be upset but take some deep breaths and just pause for a moment
 - Find ways to reduce the change as much as possible or find positives in the change. Make it fun.
 - Think in advance about what unexpected changes might happen. Could there be unexpected noises? Could there be a fire alarm? Could there be spontaneous plans? Consider these things and what you might do in each situation. But don't overthink and catastrophise. Only use it to plan ahead.

Transitions

Transitions require managing changes, which, as explained above, can be challenging for autistic people. Transitions include:

- Starting in a university or education provider
- Moving on from one activity to another (such as screen time to mealtime)
- Leaving one location or room to go to another
- Starting a new job
- Moving out of home

Tips for managing:

- Plan for transitions well in advance.
- Give yourself warnings at different intervals (perhaps set different alarms letting you know how much time you have left).
- Give yourself plenty of information about what will be changing, what that looks like, when it will be happening etc.
- For transitions such as starting at university, see if your provider will allow you to visit in advance so that you can prepare prior to starting.
- Have a visual plan for the day and/or a visual timer that indicates how long you have left for an activity.
- Take your time. You don't have to do things immediately. If you are starting a new job or moving out of home for example, these are things that take time and you will have to face the anxiety at some point but do it when you are ready.
- Have a designated safe space in different locations you might regularly transition to. This could be a quiet room on the campus of university, a corner in a library, or a meeting room at work.
- Bring comfort items or things you enjoy to the place you are transitioning to.

Unfamiliarity

Getting used to new things can take some time as it is a change to one's environment, routine or plan. It's difficult to know what to expect.

Tips for managing:

- If you are going into an unfamiliar situation such as going on vacation or starting in a new university or job, it can help to bring something with you that is familiar and comforting to you. This might be certain clothing items, a stuffed animal, foods you like, or for some it may be a device such as a tablet or phone.

Uncertainty

Uncertainty can impact several aspects of life. Many autistic people need a plan or struggle with not knowing things. For some this can be anxiety around things like not knowing what's on the other side of a door or what's going to happen in a movie.

Below are some more examples:

- Various day to day life scenarios like: You need to get to work by a certain time but there could be traffic, so you have to allow time for that. It's also raining so there could be accidents on the road so you should probably allow additional time just in case. On top of that, you'll need to find parking and then walk to work and since it's raining, people might be more inclined to drive rather than take public transport so there might be less places to park your car, so you probably need more time to find somewhere to park and walk a further distance to work.
- Knowing what you're going to eat; do you need to set aside time to cook it? Have you got what you need to make the food? Is someone else making the food? Is it something you like? Is it something that causes you distress due to sensory issues? Is there going to be another option?
- The time that you're meeting someone; When people give vague times such as 'sometime in the afternoon' this can be quite stressful as it means you don't know when the person will arrive and it makes it hard to start or focus on other things.
- People running late; this can result in worrying you got the time wrong or getting stressed if you had a plan that required the person to arrive on time, for example if you had a booking for an activity or event.
- Not knowing the plan for the day; this also makes it hard to plan for and manage sensory difficulties and meltdowns.
- Not knowing how long something is going to happen, for example how long guests are going to be in the house or how long you're going to be out.

Tips for managing:

- Reducing uncertainty can significantly reduce stress and anxiety. Creating plans for the day, including meal plans, can be helpful. How detailed these plans need to be depends on the autistic person and to what degree uncertainty is an issue for them. However, be aware that sometimes when a plan is made, it can be very stressful to deviate from the plan at all. So, it's usually better not to put anything on the plan that has a high likelihood of changing.

Challenges in neurotypical social situations

Uncertainty also comes into social situations and may cause anxiety around not knowing what other people are thinking or feeling, and worrying you might be interpreting them incorrectly. This is especially the case if you've repeatedly gotten into trouble and not known why, or frequently been misunderstood, misinterpreted social situations, had miscommunications or been told you're getting things wrong. Autistic people may feel anxious about not fitting in or feeling like we don't belong.

Below are some more examples:

- What if I've misunderstood the dress code and end up being the odd one out?
- Are people going to arrive "fashionably late" or are they going to arrive at the time that they said they would? What is considered fashionably late?
- Did they think I wasn't listening because I didn't make eye contact?
- Did I talk too long about that topic? Were they actually interested or were they bored?
- Am I coming across as awkward? Am I staring too much? Have I made enough eye contact? Am I fidgeting too much? Am I smiling at the wrong time? I don't want to be weird.

Tips for managing:

- Have a safe person you can get reassurance from or ask for clarification
- For education providers and workplaces:
 - Create FAQ documents that explain the expectations or norms. It's important that this is done in a way that does not expect the autistic person to be less autistic but rather explains how things work and what to expect. For example, you might explain that when people ask, 'how are you?', they usually aren't really asking for a proper answer. It's more of a greeting or form of polite small talk. But it is then up to the autistic person if they wish to change how they respond to that in the future. You might explain things like where they can park their car, or what sort of regular social gatherings there are.
 - provide professional development for staff on neurodivergence. Having a good understanding of neurodivergence will give the necessary tools to support or accommodate the learning, work and social environments of neurodivergent people, but also increase staff's ability to be more understanding and open-minded for everyone.

Gift giving and reactions

Receiving gifts may be a source of anxiety for some autistic people as it is a social situation where there is typically some kind of reaction that is expected from the giver. You're often expected to pretend to like the gift even if you don't and you need to look excited or happy or show the right emotion. This can be challenging for autistic people who may express emotion differently and may be more inclined to be honest and upfront. Even when the autistic person genuinely loves the gift, the way that presents isn't always interpreted correctly by the gift giver. Because of this, getting the reaction right can be daunting for an autistic person, especially when it's in front of several people.

Tips for managing:

- It's okay to open the gifts when you're alone, you don't have to make it a show.

Communication differences

As with social situations, autistic people often find themselves getting into trouble or miscommunications due to differences in how we communicate and interpret language. This can cause a lot of anxiety as it's something that can be very difficult to avoid when people are not particularly understanding of autism. Below are some examples:

- Did they think I was too blunt or rude?
- Did they think I was insulting them when I told them that they had split ends in their hair?
- Are they actually asking how I am or are they just engaging in polite small talk?
- They asked me to bring them a glass, did they want something in the glass? I'm getting water but what if they have a drink with them that they want to pour in the glass and they don't want water? What if I bring them an empty glass and look stupid because they don't have anything to put in it?
- When an autistic person mimics another person's tone, particularly a person in authority, they can get into trouble as it can be perceived as raising their voice, talking-back, or disrespecting the authority figure. The problem is that, often, the autistic person isn't intentionally mimicking the other person's tone and may not even be aware they are doing it.

Tips for managing:

- Have a safe person you can get reassurance from or ask for clarification
- For Friends, family, lectures, support network etc.:
 - Take what the autistic person is saying at face value. There doesn't always need to be underlying meaning to what people are saying.
 - If you didn't say something out loud, don't expect the autistic person to know it was implied.
 - Kindly explain how you're interpreting things and why you're interpreting them the way you are. It's stressful getting in trouble and not being given an explanation as to what we got wrong because the person believes that we should know what we did wrong but in reality it was a miscommunication.
- For education providers and workplaces:
 - Create FAQ documents that explain the expectations or norms. As explained above, it is important that this is done in such a way that it does not expect the autistic person to be less autistic. The work should not fall solely on the autistic person to adjust their communication to avoid miscommunications. A little bit of understanding can go a very long way with autistic communication.
- Provide professional development for staff on neurodivergence. Having a good understanding of neurodivergence will give the necessary tools to support or accommodate the learning, work and social environments of neurodivergent people, but also increase staff's ability to be more understanding and open-minded for everyone.

Bullying

Autistic people are vulnerable to bullying and may not feel like they can reach out for support. They may feel like they are overreacting, or if they report the bullying, they might be further isolated or ostracised. They may worry or feel that they'll be blamed or told it's their own fault that they're being treated the way they are and perhaps if they 'fit in' more it would be different. They may also not realise that the way they're being treated isn't okay. This can cause significant anxiety and can be incredibly isolating.

Tips for managing:

- Expecting the autistic person to hide their autistic traits or change who they are to fit in more, is not a solution to bullying. It simply teaches the autistic person that who they are is not okay and it makes someone who's supposed to advocate for them, just another one of their bullies. For example, an autistic person shouldn't be told to make more eye contact, stim less, reduce their use of sensory or comfort tools such as headphones or weighted stuffed animals.

Difficulty identifying or regulating emotions

Having a hard time identifying or describing one's emotions (also known as alexithymia), paired with poor emotional regulation can make it difficult to manage or prevent meltdowns. This can mean that sometimes it feels like meltdowns and shutdowns come out of nowhere. This can cause anxiety as it means you can't really know if or when it's going to happen.

Tips for managing:

- Develop a vocabulary of emotions. You may need to use unconventional signals to identify different emotions. Relying on smiling and crying could direct you the wrong way if you struggle to identify how you are feeling. So, you may notice that when you are happy you might be more inclined to think about your favourite activity for example. And perhaps when you're sad you want to stay curled up in bed. Take notice of your different behaviours as well as what you feel in your body at the time, and what you're thinking about. Then use this to start labelling what your different emotions look like.
- You can also try reading *How do I Feel?* By Rebekah Lipp. This book also comes in a pack of cards and lists different emotions and what they might feel like.

Executive dysfunction

Executive dysfunction can cause anxiety in multiple ways. Executive functioning is your ability to start, plan, prioritise and stay on task. Below are some of the ways that executive dysfunction may cause anxiety:

- With executive dysfunction, tasks, or parts/steps of tasks, all end up having equal priority. This can mean that it feels like there are an overwhelming number of things that need to be done all at the same time and it can be hard to know where to start. For example, if you need to clean your room that might mean needing to pick up rubbish, but the bin is full so you need to take that out too. You need to make your bed but there's homework, stationary, a laptop and laundry on it as well so that needs to be dealt with. You need to vacuum the floor but to do that you need to pick up anything else that's on the floor. There are also some dishes that you need to take to the kitchen and put in the dishwasher, but the dishwasher is full so you're going to have to empty that as well. When your brain struggles to put steps in order, all of these small pieces add up and it becomes very stressful to start any task.
- Maybe you need your space to be tidy but you can't get it tidy due to executive functioning challenges so now the mess is causing anxiety.
- What if people think I'm being lazy?

Tips for managing:

- Have a body double: having a body double simply means having someone else exist in the same space while you get a chore or task done. Sometimes it helps if the body double is doing a similar task, or checking in every so often; sometimes it's enough to just have another person in the room.
- Write out a checklist of what you need to do
- Create step by step visual instructions
- Goblin tools: Goblin tools is a website that will break down tasks in to steps <https://goblin.tools/>
- Set reminders on your phone

Being in waiting mode

Being in waiting mode is when you know you have a task or appointment coming up and you're waiting for that time to approach. For many neurodivergent people, starting any other task while in waiting mode can be very difficult and anxiety provoking. Below are some reasons why:

- What if I have to stop mid-task to attend my other commitment
- What if I get distracted and miss my commitment
- I can't focus until I've finished my commitment, but I'm supposed to be getting other things done and so now I'm going to get into trouble or have a huge amount to get through after my commitment
- If the task is something like remembering to get food out of the oven, the anxiety might be that you could forget and end up causing a fire or burning your food.
- If the commitment is meeting up with someone, the anxiety might be that you could be late, and the person might think badly of you.

Tips for managing:

- Book appointments or meetings at the start of the day to avoid being in waiting mode all day.
- Come up with a list of time-limited tasks that can definitely be done without running into the task or appointment. Some examples might be seeing how many things you can pick up and put away in 15 minutes (with a timer on); or watching a TV episode or video that is definitely 20 minutes long.

Sensory processing differences

Many autistic people have differences in their sensory perception. Often that can mean being hypersensitive to stimuli, for example being able to hear the electricity of lights and power outlets, feeling almost suffocated by strong smells, or being more sensitive to certain fabrics. It can also mean needing more input such as movement or pressure in order to function or regulate oneself.

This can cause anxiety for a number of reasons:

- Am I going to have access to the tools I need to cope (such as headphones or active seating)?
- Are people going to think I'm weird for needing to move around or stim?
- Are people going to think I'm not paying attention because I'm doodling or fidgeting
- I can't pay attention because there's too much noise and light and smells and my clothes are hurting me but I'll get into trouble or be seen as rude if I walk out
- What if I can't communicate when I get overstimulated so I can't explain why I'm suddenly unable to cope?
- How long am I going to have to tolerate it?
- Am I going to have enough down time afterwards?
- School can be a sensory nightmare that sometimes doesn't understand or allow the necessary accommodations and it can be easy for a child to get into trouble when they suddenly become so overstimulated that they have a meltdown or simply cannot cope or focus anymore.

Tips for managing:

- Create a sensory diet as part of your routine. This means allowing time before or after periods that you know might be overstimulating to decompress or allowing time for getting sensory input prior to going into a situation where you know you will need to be quiet or still.
- Use headphones or earplugs to manage noise levels
- Use active seating
- Have a quiet space

Lack of access to special interests or comfort items

Autistic people may rely on particular objects or interests as means of regulating themselves. Being denied access to these things can be a significant source of anxiety.

Pathological Demand Avoidance

Some autistic people have an autism profile known as Pathological Demand Avoidance. In short this is an anxiety driven inability to comply with demands. Individuals with PDA may feel significant stress just at the idea of potential demands. For more information on PDA:
<https://autismnz.org.nz/wp-content/uploads/2024/07/PDA-Pathological-Demand-Avoidance.pdf>

How anxiety might present

Below is a list of some of the ways anxiety may present, but it is important to note that many of these traits overlap with autism and/or ADHD and may show up in people who are not experiencing anxiety. When a combination of these traits appear or cause distress, it might be worth considering looking into anxiety.

- Being rigid in need for routines, familiarity and plans
- Asking a lot of questions or needing a lot of information to prepare for new or different environments or situations
- Indecision
- Seeking reassurance
- Self-doubt
- Shutting down
- Avoidance
- Overthinking/ruminating
- Running away/eloping
- Hyperfixating
- Scripting: autistic people may spend a significant amount of time scripting and rehearsing conversations or scenarios. This may also include practicing facial expressions and body language.
- Meltdowns
- Panic attacks
- Flapping/aggressive stimming
- Increased heartrate
- rapid breathing
- sweating
- tiredness
- shakiness
- racing thoughts
- chest pain or tightness
- hot or cold flushes

How anxiety might present

- Proprioceptive input/pressure; use weighted blankets, weighted stuffed animals, or tight hugs
- Use something cold: get outside, put ice on the back of your neck, take a cold shower, eat some ice cream or a popsicle
- Take some slow breaths
- Go sit somewhere dark and quiet and less overwhelming
- Get some exercise, go for a run, do some jumping jacks, dance
- Medication
- Talking therapy
- Make sure you're getting enough sleep
- Have a bath or shower
- Think about something you're really interested in or engage in an activity you really enjoy.
- Listen to music
- Write your thoughts down. Get them out so they stop going round in circles.
- Remember that anxiety is often irrational. Reassure yourself that everything is okay and be kind to yourself.

More information

- <https://www.autistica.org.uk/what-is-autism/anxiety-and-autism>