

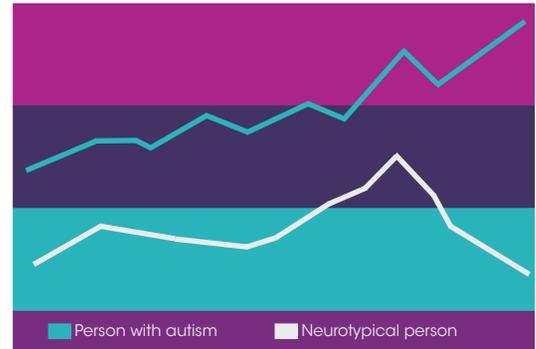
Managing stress and anxiety

Supporting people with autism

This information sheet is designed to give an introduction to stress and anxiety in people with autism, and how best to support them.

We all suffer stress, to different degrees and levels of severity and we all get anxious sometimes. However, neurotypical people (people who do not have autism), realise when they are becoming stressed or anxious and can take positive steps to relieve this.

When we wake up in the morning we generally start at a very low level of stress (see diagram) and this may rise through the day as stressful events occur. However, a person with autism may start their day with a much higher level of stress and anxiety. This means that they may reach crisis point more quickly than others.



Anxiety is very common in people with autism. Around 9.2% of the general population suffers with an anxiety disorder of some kind, whereas, in people with autism the number rises to something more like 30%. These numbers only account for those people diagnosed with an anxiety disorder but many more people, particularly those with autism, suffer with heightened stress and anxiety levels and this has a significant impact on their quality of life. Anxiety can be caused by a huge range of triggers and these will depend entirely on the individual, their likes and dislikes and their past experiences.

Sensory issues

Many people with autism have sensory issues. This means that they are over-sensitive or under-sensitive to some kinds of sensory input. Sensory input is anything that is interpreted by our physical senses – sight, hearing, smell, touch, taste, where our body ends and the rest of the world begins (sometimes referred to as proprioception), and balance (sometimes referred to as the vestibular sense).

Problems with interpreting information from each of the senses can increase stress, as it is harder to make sense of the world. Sensory issues may also be very intrusive for a person, particularly if they are over-sensitive to the environment around them such as smells and sounds. For some people, their sensitivities are so extreme that bright lights, loud noises or strong smells may be physically painful to experience. These difficulties can make everyday life considerably more difficult and therefore stressful and fear of these triggers could go on to cause people severe anxiety about encountering these environments.

Struggling with these sensory issues can also make it considerably more difficult for people with autism to relax once they are already stressed. Loud noises and bright lights, for example, may make it difficult for somebody to think clearly enough to work out what they need to do to reduce their stress. Even if the solution is as simple as leaving the situation, the person may be too distracted and distressed to process this.

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Sense	Hypersensitivity (over-sensitive)	Hypo-sensitivity (under-sensitive)
Sight	Covering eyes, dislikes sunlight/ bright lights	Stares at objects and people, uses hands to explore items as well as vision
Smell	Wears the same clothes over and over, dislikes perfumes	Smells objects and people, seeks out strong smells
Taste	Fussy eating, gags easily	Eats everything, mouths objects
Touch	Does not like to be touched, dislikes messy play or activities	Seeks out deep pressure hugs and holds, fails to notice injury
Hearing	Covers ears, hears sounds not noticed by others (e.g. fluorescent lights buzzing)	Bangs objects and doors, likes loud places like crowds or busy roads
Vestibular	Moves slowly and cautiously, dislikes bending	Crashes into things, likes to spin or swing
Proprioception	Struggles to manipulate small objects, turns whole body to look at something	Appears floppy and leans on things, applies too much force in everyday tasks

You should establish what sensory issues the person with autism has and then find ways to make things easier for them.

For example, it may help for them to wear sunglasses or noise-cancelling headphones or to use a swing or a sensory room. Once you have started to help the person to cope with their sensory needs then they may start to experience a lower level of everyday stress and be better equipped to cope, thereby reducing their long-term anxieties.

Change and transition

We all experience change and transition throughout our lives, and some people cope with this better than others. Major changes, like moving house, changing schools or starting a new job, can cause significant stress, which may be even more pronounced in people with autism.

People with autism often need a routine and predictability. This can be due to anxiety, but it may also cause anxiety. Even when a person is able to follow their usual routine, they may feel anxious about something disrupting this or preventing them from following the routine in the future. This can then cause anxiety for the future as well as reinforcing the person's need to follow a routine.

Any kind of change, even seemingly small ones, could cause stress and anxiety to a person with autism. This may be a new support worker, a different shampoo or even a new mug. When change happens to a person with autism, it takes away their predictability and familiarity. This can make them feel vulnerable and scared and can be a source of great stress.

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Transition tends to refer to specific, life-changing events such as starting at a new school, puberty or losing a loved one. These can be extremely difficult times for a person with autism and should be dealt with carefully and sensitively. The key is to understand the person and learn what helps them most and what their specific concerns are. This will help them to make sense of the changes and feel safe and supported throughout.

When a person with autism is stressed, they may seek predictable responses to reduce their anxiety. For example, they may have learnt that behaving in a certain way results in them being sent out of a room. A neurotypical person may see this as a punishment, but a person with autism may enjoy the time alone and therefore repeat the behaviour to escape stressful situations.

The best way to ease a person's anxiety about change and transition is to provide some kind of predictability and consistency and support them to understand what is happening and what will happen next. Some questions that it is helpful to have an answer to are:

- What is the person going to be doing and what is expected of them?
- How long will they be doing this for?
- What will they be doing next?
- When can they do something that they want to do?

Some people with autism may repeat questions or phrases. In this case they may be seeking a predictable response from you. You can also support the person by offering them plenty of time to prepare for a transition between different activities. It is better to tell the person 15, 10 and 5 minutes before you need them to start a new task, rather than expecting them to make the transition straight away.

Communication

Some people with autism struggle to communicate. This may be because they are non-verbal, have some limited ability to communicate, or they may find it difficult to communicate when they are stressed. Some individuals also have processing delays and so you may need to allow plenty of time for the person to respond.

Some people with autism take things literally. This can make them feel excluded from some conversations if they are worried that they are missing the meaning of what others are saying.

Social anxiety

People with autism can have trouble with communication and social understanding and this can make social situations very challenging and stressful. Many people with autism struggle to read body language and facial expressions which can make it difficult to understand the motives of others. This can also sometimes lead to making social mistakes which can mean that people with autism may struggle to make and keep friends.

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Social rules tend to be flexible and may be applied differently throughout a person’s life. For example, there are different rules for children and adults and so new rules need to be learned when a child becomes an adult. This can leave people open to bullying and abuse.

The stress of navigating the neurotypical social world can be more extreme for some, leading to social anxiety, avoidance of social situations and sometimes agoraphobia and other mental health problems.

We can support people with autism by being clear and direct with our social rules. We can also help to guide the person by explaining situations they do not understand and especially situations where they may have made an error and caused offense. We should also try to provide an escape route, which means a way for the person to get out of a situation if it becomes unbearably stressful. Some people find interacting with others extremely distressing and even painful. In this case we should not force company on them, but support them in the least intrusive way possible.

Mental health

Mental health problems seem to be more common in people with autism, and this may be in part due to the high levels of stress and anxiety that they experience. Mental health problems can also cause stress and anxiety. It is important that people with autism are supported to deal with their stress and anxiety appropriately. If you are concerned you should encourage the person to see their GP.

Possible causes of mental health problems in people with autism	
Obsessive Compulsive Disorder	Need for routine and consistency, fear of germs or contamination
Social Anxiety Disorder	Lack of understanding in social situations, repeated lack of success in past social situations
Generalised Anxiety Disorder	Excessive worrying and inability to cope appropriately with stress
Panic Disorder	Stress levels are high enough to cause regular panic attacks or episodes
Agoraphobia	Fear of sensory issues occurring or social anxiety leads to a person fearing situations where escape might be difficult
Eating Disorders	Need for routine and control over surroundings
Oppositional Defiant Disorder	Resistance to change, rigid thinking, lack of understanding of consequences or social compliance
Depression	Consistently high levels of stress and anxiety leading to a loss of hope or motivation

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Behaviours of concern

People with autism generally operate at a much higher level of stress than people in the general population. Imagine the feeling of waking up on a day when you know you have a job interview. This is one way of understanding the stress that people with autism may be under, except that they experience it every day.

This can lead to behaviours of concern. Behaviour like this should be seen as communication and you should ask yourself, what is the person getting from this? If you find a pattern in the behaviour that suggests there is a particular trigger for this person's stress then you can attempt to eradicate that to reduce the person's stress and therefore the behaviour.

Some people with autism say that their first reaction to a highly stressed situation is to feel angry. This is often anger directed towards themselves but is also frequently directed towards the person they are with or that supports them. They may feel that the person has let them down by not protecting them from the stress that they are feeling. But many of those same people also say that they react against the people they love because they know that they are safe with those people and they will not reject them for behaving in a way that helps them to cope. If somebody is particularly angry or stressed it is important to give them plenty of time to calm down and not take anything they say personally.

How to manage stress and anxiety

When supporting somebody who is stressed, keep calm and quiet. Be a consistent, safe presence to help the person with autism feel they can begin to relax. Try to avoid showing that you are worried as this may make them feel less secure and more anxious.

Give predictability and routine by writing things down. You could help them plan their time by providing a dry wipe board.

Ensure that the person you are supporting has an appropriate communication system that they are able to use it properly. This will help them to express themselves and their frustrations and anxieties.

If a person has a particular "stim" or repetitive movement that helps them to feel calm then you should support them in this. "Stimming" can be a coping mechanism and may be a sign that the person is attempting to self-soothe. If the person engages in a dangerous or inappropriate "stim", you may need to work with them to find a suitable alternative way to self-soothe.

Sometimes distraction can be a helpful technique. You may be able to remove a person from a stressful situation for long enough for them to recharge and return. It may also help for the person to listen to their favourite music or use a comfort object that they carry with them to remind them that they are safe. This may be particularly useful to help people to reduce the impact of sensory issues.

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Top tips

- Preparation will allow the person to organise their thoughts, ready themselves and feel more relaxed going in to an activity and this will help them to feel more comfortable once it begins. They may be able to engage with a special interest or hobby beforehand, or arrange to do so after the activity, to reduce their stress levels.
- There are lots of apps that might help, including apps that play soothing sounds and music to reduce stress.
- Seek to reduce sensory input if it is becoming overwhelming, or provide sensory input if the person needs this.
- Remember, a person with severe anxiety or extreme stress levels is scared, not difficult. Support the person to feel safe and secure and this will help them to feel less scared.
- Stay calm.
- Keep a submissive stance and do not attempt to restrain the person, this will help them to see you are not a threat.
- Do not leave somebody unattended if they are in full meltdown, they are extremely distressed and may put themselves in danger.
- Do not try to force the person to speak or make eye contact and do not ask open-ended questions as this may cause more anxiety.
- Do not try to reason with someone who is experiencing a meltdown or tell them to calm down - this is not a possible or reasonable request.
- Do not attempt to interrupt routines or prevent "stimming" or repetitive behaviours, these show the person is attempting to self-soothe.
- Do not take anything the person says or does personally when they are extremely stressed.
- Touch should be offered but never forced.
- Once the meltdown is over, formulate a plan to prevent it from happening again. If you already had a plan, discuss what went wrong and what you might need to add.