Autism and Wellbeing

Anxiety and Autism

What is it?

Anxiety is your body's natural response to stress. It is normal in certain situations and can even be helpful to some extent. We refer to three kinds of anxiety:

- **normal/situational anxiety** — This covers times when it is understandable to be anxious. For instance, feeling 'butterflies in your stomach' when sitting an exam or feeling a little stressed about a job interview. This sort of anxiety can feel unpleasant, but it can also spur someone on to prepare/plan for situations and can make them concentrate harder on certain tasks.
- **autistic anxiety** — There is a certain amount of extra anxiety autistic people experience on a day-to-day basis. They generally refer to this as 'autistic anxiety'. Due to communicating with people who have a fundamentally different communication style, executive functioning problems and sensory differences, they tend to have a higher 'base rate' level of anxiety compared to non-autistic people. At 'normal' levels this anxiety can be difficult to deal with but still allows the individual to lead a fulfilling life.
- **anxiety disorder** — While autistic people may have higher general levels of anxiety than our non-autistic peers, if they are constantly anxious or feel it is significantly impacting on their daily life, they may have the third kind of anxiety: a diagnosable anxiety disorder.

The psychological symptoms of an anxiety disorder can include: feeling worried/restless/tense, struggling to concentrate, mind racing or going blank, indecision, having vivid dreams, and an impending sense of doom.

The physical symptoms can include: dizziness, heart palpitations, breathing rapidly, struggling to sleep, sweating, trembling, tingling, numbness, and gastrointestinal problems (stomach issues).

Anxiety can occur on its own, but it is also often accompanied by depression. If you think you might have an anxiety disorder, you might want to check out our section on depression as well.

Why might autistic people have anxiety?

There are a lot of reasons why anxiety is such a huge problem for so many autistic people. There is a high chance they have experienced social interactions gone wrong, for instance, some may be anxious about it happening again before social events.

There are also a lot of sensory elements that can add to anxiety in autistic people. Being in situations where the lights are too bright, or the background noise is too loud can be extremely challenging and cause anxiety. Worrying about whether they might experience sensory overload can even be a source of anxiety.

Masking, struggling to identify and regulate their emotions, difficulty with transitions, and changes to routine are also all reasons autistic people can experience such high anxiety levels.

What can I do if I think I have anxiety?

If you are autistic or know someone who is autistic and you do think you may have an anxiety disorder, the best first step is to see your GP (or another health care professional if you are already under their care – like a midwife or psychiatrist).

Your GP should assess you and talk through your treatment options, which may involve medication, some sort of therapy, or a combination of the two.

If you feel unable to tell your GP or another health care professional, try to tell someone else you trust as a first step.

What can I do myself?

Alongside the advice given by your GP (or if you want to do something to help while waiting to see a GP or while building up the courage to tell somebody) there are some things you can try yourself to help.

If you are unsure about the source of your anxiety it can help to keep a diary of the times you feel anxious. Note down the day/time you feel anxious, what you feel (a general sense of worry/obsessing over an upcoming event/racing heartrate/fast breathing) and what else you had going on that day. Look back over it when you feel calm and see if you can identify a pattern. There are some apps that allow you to track various things like mood and anxiety, which may be useful.

Try to manage your sensory needs as best you can. Finding yourself in constant sensory overload or constantly seeking out sensory input can be very anxiety-inducing. You can:

- Make sure your environment is comfortable for you in terms of the temperature, how bright the lights are, noise levels, comfortable seating etc. You may require addition supports to achieve this like headphones and/or ear defenders or sun glasses.
- Make sure you have seen to any interoceptive needs you might not notice like hunger, thirst, going to the toilet.
- Make sure you are wearing comfortable clothing and have to hand any stim toys you might want to access.

You can try to build routine and structure into your day-to-day life to give yourself some stability and predictability. For some autistic people a very flexible routine may be less likely to cause anxiety. It is also essential to schedule/allow yourself downtime, especially after events that are likely to be stressful or intense.

Avoiding or decreasing your caffeine and/or alcohol consumption can also help with anxiety and anxiety symptoms, although if you tend to consume very high levels this might need to be done slowly and/or with the supervision of a doctor.

Panic Attacks

If someone is feeling particularly anxious and/or have an anxiety disorder, they may experience panic attacks. Having a one-off panic attack is relatively common and about 1 in 10 people get them now and then.

While the specifics of each panic attack can vary from person to person, they generally involve some of the following symptoms:

- Sense of impending doom (perhaps even convinced you are dying)
- Heartrate feels faster/harder
- Dizziness or feeling unsteady
- Shaking/trembling
- Hyperventilating/feeling like you can't catch your breath/feeling like you're being smothered
- Sweating/feeling hot or cold
- Chest pain
- Nausea/sudden urge to go to the toilet
- Feeling disconnected from surroundings
- Numbness/tingling

Panic attacks can look a lot like several medical emergencies such as heart attacks, asthma attacks or anaphylactic shock. If you are in any doubt, it's always best to seek medical attention (including dialling 999 if you think the situation is an emergency). Many people call ambulances thinking they are having a heart attack, only to find it was a panic attack – even medical professionals can confuse the two at first glance – so there is no shame in this.

Once you have had a panic attack, it is often easier to identify it as such the next time.

If you find you are having panic attacks, there are some strategies that might help you deal with them.

- Focus on breathing slowly and make your 'out breaths' (exhalation) longer than your 'in breaths' (inhalation).
- Tell yourself you are having a panic attack and will be okay.
- Try some grounding techniques like: identifying a certain number of things you can see, hear, touch, smell and taste; or submerge your hands in water and focus on the feeling; or do some stretches; or recite a poem or song lyrics.
- When you are feeling calm it might be helpful to write yourself a letter which explains you are safe, and then you can read this when you are having a panic attack. Alternatively, you could ask someone you trust to record a message on your phone or write a note for you to listen to or read when you feel a panic attack starting.

Depression and Autism

What is it?

Clinical depression is a type of mood disorder that can range from mild to severe. Depression can have many symptoms including psychological, physical, and social.

The psychological symptoms can include: a persistent low mood, feelings of guilt, low self-esteem, feeling hopeless, struggling to concentrate, being tearful, feeling easily irritated, thoughts of suicide and/or self-harm.

The physical symptoms can include: headaches, feeling tired, a change in appetite, low/no libido, insomnia, moving or speaking slowly and unexplained achiness.

The social symptoms can include: less interest in usual hobbies, struggling more than usual with partaking in social occasions and keeping in contact with friends and family.

Why might autistic people have depression?

Anyone can experience depression, but autistic people are four times more likely than their non-autistic peers to develop depression. While the definitive reason for this is still being researched, it is not particularly surprising given the single greatest predictor for whether someone will develop depression is loneliness.

There are many reasons autistic people are likely to be lonelier than the wider population. Not only do autistic people often struggle to successfully communicate with non-autistic people, but they also struggle to communicate too (this is known as Dr Damian Milton's Double Empathy Problem). This can mean, even in ideal circumstances autistic people may end up isolated.

And autistic people are often not in ideal circumstances in the first place. They are less likely to be in employment, meaning fewer opportunities to befriend colleagues and less money for social activities even if they do have good relationships, and they need to consider their sensory needs when finding times and places to socialise.

Another reason autistic people may be more likely to be affected by depression is because experiencing trauma increases the likelihood someone will become depressed. Since autistic people have often suffered trauma – whether through traumatic 'treatments' for their autism, abusive relationships, which they're more likely to experience or traumatic social experiences – it stands to reason they are more likely to have depression.

Of course, while they might increase the chances, you do not need to be isolated or have suffered trauma to be depressed and if you think you have depression you should take it seriously.

Depression or autistic burnout?

One thing autistic people need to consider when they think they might be depressed is the possibility that they are experiencing autistic burnout rather than depression. The two can look very similar. Autistic burnout occurs when an autistic person has been under intense and/or prolonged stress. Prior to reaching burnout the autistic person may have had to mask too much, might have experienced many autistic crisis points in a relatively short space of time, and might have been through significant change.

Someone going through burnout will tend to feel exhausted, have a reduced tolerance to sensory stimuli and find certain things like masking and executive functioning much more difficult or impossible. The loss of (or difficulty performing) certain skills means autistic burnout is often referred to as a 'regression', especially in children, although the skills are generally regained once support is put into place and the autistic person can recover from the burnout.

If you are autistic and are unsure whether you are experiencing depression or burnout, ask yourself whether you have been under a lot of pressure recently (burnout tends to happen when life stressors become too high for too long), and whether you still get pleasure from your hobbies and special interests (depression often leaves you uninterested in these things whereas focusing on special interests can actually help during burnout).

What can I do if I think I have depression?

It is certainly not inevitable that you will suffer from depression if you are autistic, and there are various treatments and strategies to help if you think you *are* depressed.

If you do think you may be depressed, the best first step is to see your GP (or another health care professional if you are already under their care – like a midwife or psychiatrist).

Your GP should assess you and talk through your treatment options, which may involve medication, some sort of therapy, or both.

If you feel unable to tell your GP or another health care professional, try to tell someone else you trust.

What can I do myself?

Alongside the advice given by your GP, there are some things you can try to help.

Try to get into a good sleep routine. Both autism and depression can affect sleep cycles so this may be difficult (or even impossible for some people) but there are certainly things that might help like:

· Avoiding caffeine after 4pm (though, if you are ADHD as well as autistic this may be less effective).

· Avoiding screens for an hour before bed (unless a screen/TV show/music on in the background allows a smoother sleep transition).

· Keeping your bedroom cool but not cold.

· Only using your bedroom for sleep/avoiding using it for anything stressful if space allows.

Try to spend some time outside every day. This doesn't have to mean a two hour long hike; hanging the washing up outside, wandering round the garden for 10 minutes or going for a short walk to the shop all help to build up the amount of time you spend outdoors.

Try to exercise several times a week. While going to the gym, joining exercise classes and playing team sports are all excellent forms of exercise, not everyone has the time/money/inclination for such things. However, local walks, online yoga classes, swimming, fitness videos and jogging round the garden are all great alternatives.

A really important step to take is to try to find emotional support. While doctors and professionals can often offer specific support to get you through certain periods, finding peer support you can turn to at any time is invaluable. It is worth seeing what there is in your area (try looking on notice boards in community centres, GP surgeries, town halls and libraries and at your council's website) but if there is nothing available or you are unable to attend there are many online support groups.

What can I do if I think I am experiencing autistic burnout?

If you think you are in autistic burnout you could support yourself by looking at the possible current stressors in your life. It is possible some of these stressors can be eliminated entirely or reduced/changed. Acknowledging that you may need support with certain areas as an autistic individual and finding helpful adaptions and supports can help reduce some stressors.

For example: using alarms to remind you to complete certain tasks, asking for help when you need it, taking regular breaks when feeling overwhelmed can all help.

Acknowledging and accepting sensory differences can reduce the chance of sensory overload. Exploring your sensory preferences and discovering sensory input you find soothing, as well as identifying those you find triggering, can help you avoid sensory difficult situations and leave you better equipped to put into place sensory soothing activities.

Spending time immersed in your special interests (SpIns) can also help bring you out of burnout sooner. And accepting your autistic identity – and surrounding yourself with other people who are supportive of you as an autistic person – can also both help during burnout. Finding some autistic peer support, either online or locally, can help. Hearing the lived experiences of other autistic people can be hugely validating.

Please feel free to contact us if you feel you need support with potential burnout.

If you need support with depression, here are some helpful resources:

Scottish Association for Mental Health (SAMH)
www.samh.org.uk
0141 530 1000

MIND
www.mind.org.uk

Breathing Space
www.breathingspace.scot
0800 83 85 87

Samaritans
www.samaritans.org
116 123

Penumbra
www.penumbra.org.uk

Eating Disorders and Autism

What is it?

An eating disorder is a type of mental illness that involves disordered behaviour around eating. These behaviours can include: limiting the amount of food being eaten; finding ways to get rid of calories/food already eaten through induced vomiting, excessive exercise, taking laxatives etc.; or binging on large quantities of food.

Why might autistic people develop eating disorders?

While the research into this area is still relatively new, there is reason to think autistic people are more prone to developing eating disorders than non-autistic people.

There are several possible reasons for this.

Autistic people process sensory information differently to non-autistic people, which often means certain foods are either intolerable due to their texture or incredibly pleasing due to their texture. If this is taken to an extreme it can lead to either a very limited diet or overeating of certain foods for the sensory experience.

Often, eating disorders are not actually about food at all. Sometimes deciding what goes into your body can feel like the only thing you have control over. In times of stress this can spiral into restricting food intake. Skipping meals also has an impact on the chemicals and hormones your body releases and some people recognise this (either consciously or subconsciously) and use it to regulate their emotions (something some autistic people can struggle with).

Sometimes an eating disorder can develop from a special interest taken too far. Special interests in the environment, animal welfare, calories, food preparation, food technology, healthy-eating, home baking, exercise etc. can all potentially slip into an eating disorder if taken to extremes.

Some autistic people have problems fitting in socially and an eating disorder might ensure they are slim (or might seem to offer that option), which is often seen as desirable and perceived as something that can make someone more popular. They might also focus in on one specific thing they dislike about themselves and struggle to view the ‘whole’, which can lead to body dysmorphia.

It is also possible that an eating disorder can be triggered by abuse, which is sadly more likely to affect autistic people. Someone who has been sexually abused might try to avoid anyone being sexually attracted to them again by using food to change their body shape.

Sometimes routines and rules around food and eating can get out of hand and when they go too far, this can also lead to an eating disorder.

What can I do if I think I have an eating disorder?

It is important to tell someone if you think you have an eating disorder. While eating disorders can absolutely be treated, anorexia is the mental health condition with the highest mortality rate out of all mental health conditions so getting help is paramount.

You can tell your GP, who should be able to advise you on the best next steps. The GP might refer you to a therapist or other professional.

Eating disorders tend to be treated with group therapy, though other options are available. Unfortunately, group therapy often does not work so well for autistic people so it can be a good idea to mention this fact to your GP or any professional to whom you are referred.

What can I do myself?

It is recommended to get professional help if you have a severe eating disorder. However, if you feel like you are perhaps slipping into disordered eating habits or you need some ways to cope while you build up the courage to tell someone there are some things to consider.

Try to manage your sensory needs as best you can. For autistic people, sometimes an eating disorder can be triggered by certain sensory needs. You can:

- Make sure your environment is comfortable for you in terms of the temperature, how bright the lights are, noise levels, comfortable seating etc. You may require addition supports to achieve this (like headphones and/or ear defenders or sunglasses).
- Make sure you have seen to any interoceptive needs you might not notice like thirst, going to the toilet, whether you're too hot or cold.
- Make sure you are wearing comfortable clothing and have any stim toys you might want to access.

Perhaps, make sure you have any snacks you like in an easily accessible place. Sometimes when autistic people are overwhelmed or going through autistic burnout we don't have the executive functioning to prepare meals. At least if you have some options that require little effort, you can easily grab something if you do suddenly realise you are hungry.

Finding peer support you can turn to at any time is invaluable. You do not need to tell them about your eating habits but having general support in place means you are less likely to struggle with a whole range of things, which can have a positive knock-on effect. It is worth seeing what there is in your area (try looking on notice boards in community centres, GP surgeries, town halls and libraries and at your council's website) but if there is nothing available or you are unable to attend there are many online support groups.

For more information on eating disorders, you can check out the Beat website: https://www.beateatingdisorders.org.uk/

Masking

What is it?

Masking is something that has become much more talked about recently as understanding of autism has grown, but what is masking, why do autistic people do it, and what is the impact of masking?

Everyone projects slightly different versions of themselves depending on the situation – the person you present at work is likely to be different from the person you are on a date with, out with friends, or even at home.

Some people talk about masking in terms of putting on a persona – ensuring they don't swear in the middle of a meeting at work for example. They may hide that impulse to do so as it may not be seen as appropriate, even if they want to. So far so good you may argue, but the amount that autistic people mask can create all sorts of problems.

When autistic people talk about masking, they are not talking about holding in swear words. Generally, what they mean is masking being autistic and trying to pass for what is perceived as "socially acceptable". They mean masking a core part of their being and making themselves very uncomfortable in doing so. When someone says to an autistic person that they don't look autistic, it's likely because they are masking.

Masking can start at a very early age, particularly for those with a highly developed sense of self awareness. Many autistic people realise even as relatively young children that they are quite different from others. When others notice those differences, this can often lead to not being included in games, not being invited to parties, not being asked to join in in any form. So, the autistic person, upon realising that their differences can lead to exclusions, very often makes the decision to project an image of themselves to show that they do belong to that group, or they can feel pressured into hiding how different they are so that people stop calling them "weird" and start including them.

Observing and copying how others socialise

"I was 3 or 4 years old when I realised that other children communicated and socialised differently from me. I remember observing them at playgroup to see how they initiated play with each other."

- *Marion, former CEO of Autism Understanding Scotland*

Masking can mean observing others to copy the way they socialise (see also our page on Autistic Communication), watching how other people interact with each other and attempting to copy that. Observing how to initiate conversations, observing how to keep those conversations going, learning key words and phrases that others respond positively to.

This can be done in several ways – observing others in the playground, classroom, office, or bar. It could also be through watching TV and movies to see how characters develop their friendships and sustain them.

This can lead to taking on a persona of a socially successful person, projecting confidence when in fact they feel none. It can be adopting mannerisms, hand gestures. It can mean modulating the tone of their voice more, so they appear more animated. Basically, the autistic person becomes a psychologist or social anthropologist and uses that information to attempt to blend in.

Feigning Interest

Masking can mean feigning interest in something to be included in conversations. Spending time watching TV shows so they can take part in conversations in the office break room, taking up a hobby, they have no interest in, watching a sport they don't care about – these are all things that many autistic people have done in the attempt to fit in with others. Suppressing talking about their actual interests, even suppressing participating in interests, so that they could spend time doing something to generate social interactions and make those interactions easier.

"As a girl growing up in the 80s and 90s I had very little interest in New Kids On The Block, East 17 or Take That, yet I learned the names of the band members and listened to their music so that when the other girls in my class spoke about them I knew who they were talking about and could join in."

- Marion, former CEO of Autism Understanding Scotland

Wearing Uncomfortable Clothes

Masking can mean wearing uncomfortable clothes. Due to sensory issues around touch, some fabrics are really difficult for some autistic people, yet if everyone in your social group is wearing them, many autistic people have put up with the discomfort in a bid to fit in and appear like everyone else.

The same goes for wearing make-up – some autistic people love it, but for others, the feel of it on the skin and the fact their face looks different can be really difficult.

Yet clothing and make-up can be heavily linked to their identity. Making themselves physically uncomfortable in order to project that they belong in a group is highly problematic. Given that many autistic people do not stop processing sensory information too, if they are wearing make-up or clothing that they are uncomfortable in, they can be feeling that discomfort continually until the object is removed, possibly longer.

Giving Eye Contact

Masking can mean giving eye contact when you don't want to. For many autistic people eye contact is difficult and may be painful. For some of them, they cannot concentrate on what others are saying if they are giving eye contact — so they trade off being able to engage properly in the conversation for looking like they belong in the conversation.

Some autistic people can give eye contact quite happily but may not realise the social expectations around when to look away and come off as aggressive when they are feeling relaxed or romantically interested when that is not the case. Both those scenarios can then create further social complications.

Ignoring Sensory Needs

Masking can mean ignoring autistic people's sensory needs. Pretending that they don't constantly hear the humming of the electricity in the walls, or that the material is not scratchy, maybe that they are fine with hugging their friends or shaking hands when actually they aren't. It is ignoring their discomfort so as to appear more agreeable, or not too sensitive.

Hiding Stims

Masking can mean spending a lot of energy on hiding their stims — those stims that help regulate emotions and sensory input, help with concentration, just to appear more "normal". While everyone stims to some extent, many autistic people have had others point out their stimming and question why they do it while informing others they are being "odd". Some autistic people have had others back away and refuse to engage with them due to their stims. In some countries, due to lack of understanding by authority figures, it can be physically dangerous to stim in public as it marks autistic people out as different, particularly for people in the BAME/BIPOC community.

The cost of masking

Masking can mean working so very hard on projecting the "socially acceptable" version of themselves that they melt or shutdown as soon as they get home from school or work from the sheer exhaustion of it all.

"I'm personally aware of the fact that my need to maintain my masking behaviours as a young woman (who was unaware of being autistic) was pivotal in my study and career choices. I actively avoided stretching myself academically because I instinctively knew that I wouldn't be able to keep all of the balls in the air. I also limited myself in career choices for the same reasons"

- Rony Casement, Autistic woman

It can also mean that you mask so hard for such a long time, it is hard to work out who is the real you. What does the real me like? What does the real me want to wear? How do I want to spend my time? Who am I?

To mask or not to mask?

Many people become aware of how much they are masking as they are exploring whether or not they are autistic. They might start thinking about whether the masking is helpful. What are the benefits of masking, what are the benefits of not masking anymore?

The only person who can answer those questions is yourself. Stopping masking will grab the attention of others. If you have never stimmed by flapping your hands in public before but you start doing so, people will take notice! Changing so that you are giving people less eye contact also gets noticed. Whether you want to discuss this conscious effort to mask less or not, you may end up fielding questions about it.

Raising it in conversation before easing off some masking may help. It can also lead to broader conversations about what autism means to them personally. And it can let autistic people experiment a little about what they are, and they are not comfortable or safe doing in public.

Stimming does come with a stigma attached – it shouldn't but it does. The stigma will only go once it has been normalised and the rest of society has been educated about what it is and why autistic people do it. And remember that not every autistic person wants to or is obligated to be an ambassador for their community!

They don't all have to flap their hands in school and work. It is understandable if they don't want to do something that might make them stand out, especially if they have worked hard for a lifetime trying to show that they don't stand out. So perhaps there are other stims that do the same job but are less conspicuous. Or perhaps they don't care and want to flap away in places they are comfortable in, the choice is ours! There are many different fidget objects, some more discreet than others, and the choice is theirs which they choose.

It is always worth remembering that for some, openly being autistic in public can be dangerous, especially if they are BAME/BIPOC and especially in certain countries. In some circumstances, masking autistic traits helps keep many autistic people physically safe from harm. It is absolutely not ok that this is the case, but it is unfortunately true. It is also something to bear in mind when travelling. How is autism viewed in the location you are going to? The ability to be openly autistic is a basic human right, but not every autistic person is privileged enough to be able to exercise that right. And even those who are not in physical danger when they are openly autistic still face significant stigma.

While unmasking in public may not be an option for all, it is still important for autistic people to find places to be their authentic selves in private. This can be very hard for people who live with others who are not understanding or accepting of autism.

Masking and crisis points

At some point if you have been masking for a long time, you may hit a crisis point or autistic burnout and not be able to mask any longer. Consistently masking is very bad for our mental health, and when the mask drops it can be a very distressing time as it can lead to all sorts of questions about who we are. When the mask drops, who is left behind it?

The very good thing that can come out of this is that it affords the opportunity to find out who we really are – and live our life in a way that better supports us. It allows the chance to explore those sensory needs and start using aids to help mitigate any difficult sensory experiences (like wearing headphones and sunglasses when shopping) and help sensory seek things that will soothe (like using a weighted blanket or stim toy). It can allow us to indulge in special interests we may have previously kept quiet about.

Dropping the mask

Dropping the mask, at least in certain circumstances, can also be a large part of self-acceptance. It is accepting that you react to things differently, that you may socialise differently, that you may be interested in different things, or with a different intensity. It is accepting that maybe you will come across as slightly odd at times. Or very odd. It is accepting that you are uniquely yourself, and that is a good thing.

This is where joining the autistic community and having role models who are autistic themselves can be really useful – people who you can talk to about all the different aspects of you that you are exploring. People who validate those experiences and can say, yes, your differences are really similar to my differences too. Read other articles by autistic adults and you will see many of them saying similar things.

"I'm happy to say that the process of becoming aware of being autistic and exploring then embracing that element of my identity has allowed me to leave most of that self-protective masking behaviour behind."

- Rony Casement, Autistic woman

Supporting autistic people

If you have autistic people in your life, you can support them by allowing them to drop our masks when they are with you – allowing them to stim, engage in special interests of their choosing, wear clothing that feels comfortable, using things like ear defenders and sunglasses in public.

When they feel valued and accepted as their authentic self, they do not have the same need to supress or hide who they are. It can be really difficult to stop masking as it can become second nature, but the improved mental health, self-knowledge and self-care can make it worth the effort if it is safe to do so, even if only in private.

PTSD and Autism

What is it?

PTSD stands for Post-Traumatic Stress Disorder and is a specific kind of anxiety disorder caused by a traumatic event.

The psychological symptoms can include: nightmares, flashbacks, irritability, repetitive and distressing images and/or sensations, feelings of guilt, obsessing over the event and why it happened, thoughts of self-harm, and difficultly concentrating.

The physical symptoms can include: insomnia, pain, sweating, trembling and nausea.

The social symptoms can include: avoiding socialising with certain people or going to certain places that might trigger flashbacks and unpleasant feelings. Children may also re-enact the traumatic event in their play.

All these symptoms can take time to develop. Generally, they will become apparent within a month after the traumatic event but sometimes it can take months or even years.

Why might autistic people have PTSD?

The cause of PTSD can be any occurrence that is traumatic for the person who experienced it. This can include the sorts of events many people associate with PTSD like military action, being in a car accident, being sexually and/or physically assaulted or suffering abuse. But it can also include all sorts of other events like a distressing childbirth experience, the death of a family member or even pet, or a distressing health scare.

Many autistic people experience gaslighting throughout their lives, even though it may be unintentional. They may have been told they are too sensitive, that clothing is not scratchy, that noises are not too loud and that they are generally overreacting when they are actually processing input differently. Consistently being told they are ‘wrong’ can have a negative impact on their self-esteem and general mental health. When this happens over and over, the cumulative effect can be traumatic.

Complex PTSD (cPTSD) develops when someone is exposed to repeated traumatic events like abuse, neglect or violence.

There is still little research in the area of PTSD in autistic people and whether they are more likely to suffer from PTSD but there are some good reasons to think they are. You are more susceptible to PTSD if you have ever had depression or anxiety and we already know autistic people are at higher risk of both anxiety and depression. Also, unfortunately, autistic people are more likely to suffer traumatic events for a variety of reasons so they are at higher risk of experiencing something that could cause PTSD.

What can I do if I think I have PTSD?

If you do think you may have PTSD or cPTSD, the best first step is to see your GP (or another health care professional if you are already under their care, like a midwife or psychiatrist).

Your GP should assess you and talk through your treatment options, which may involve medication, some sort of therapy, or both. If the trauma was recent, they may also suggest waiting a short while to see if the symptoms diminish on their own. This is normal and does not mean you have been dismissed or ignored.

If you feel unable to tell your GP or another health care professional, try to tell someone else you trust.

What can I do myself?

Alongside the advice given by your GP (or if you want to do something to help while waiting to see a GP or while building up the courage to tell somebody) there are some things you can try yourself to help.

If you are struggling with flashbacks (a sudden re-experience of an element of the traumatic event – sometimes like a video playing it or part of it again, sometimes noticing smells/sounds/tastes relating to the trauma, sometimes feeling pain or pressure or other physical symptoms, sometimes experiencing the same emotions felt during the trauma) there are some things you can do to try to help.

During a flashback you can:

- Focus on breathing slowly and make your ‘out breaths’ (exhalation) longer than your ‘in breaths’ (inhalation).
- Try some grounding techniques like: identifying a certain number of things you can see, hear, touch, smell and taste; or submerge your hands in water and focus on the feeling; or do some stretches; or recite a poem or song lyrics.
- Comfort yourself and take care of your sensory needs (this may mean using a weighted blanket, listening to comforting music on headphones, re-watching a series or film you like).
- Focus on an object that reminds you of the present and/or of being safe (you may wish to carry such an object with you, just in case).

When you are calm you can try to help with future flashbacks by:

- Keeping a diary of your flashbacks, including details like what you were doing/where you were/who you were with. This can help you to learn your triggers and maybe even help you to spot early warning signs that a flashback may be imminent.
- Making something to help you feel safe when you have flashbacks. This might be a recording of yourself or someone you trust telling you that you are safe, and the trauma is over. Or it could be a letter for you to read along the same lines.

As with other anxiety disorders and depression, peer support can be an invaluable source of support if you are able to find it. Online communities can be extremely useful if you are unable to find any 'real life' groups.

If you need support with your mental health, here are some helpful resources:

Scottish Association for Mental Health (SAMH)
www.samh.org.uk
0141 530 1000

MIND
www.mind.org.uk

Breathing Space
www.breathingspace.scot
0800 83 85 87

Samaritans
www.samaritans.org
116 123

Penumbra
www.penumbra.org.uk

Applied Behaviour Analysis and Autism

ABA is a very controversial topics in the autistic community and some of the following content may be upsetting.

The history of ABA

ABA stands for Applied Behaviour Analysis and was developed in the 60's and 70's by a Norwegian-American clinical psychologist called Ole Ivar Lovaas. Lovaas' aim was to make autistic children indistinguishable from their non-autistic peers because, at the time, autistic children who were obviously autistic tended to be locked away in institutions and were thought (by society and medical practitioners) to be 'beyond help'.

While Lovaas' desire to give autistic children a chance at life outside an institution (not pleasant places in the 60's and 70's) might have come from a good place, his methods were overtly abusive. As well as giving positive feedback to autistic children when they displayed behaviours Lovaas deemed good or appropriate, Lovaas also 'discouraged' behaviours he deemed negative or inappropriate (like stimming or avoiding eye contact). This discouragement took the form of slapping, shouting and even giving the autistic children electric shocks.

Despite the brutal nature of ABA, it was highly sought after by parents of autistic children because it was the only resource available that gave the hope of their children being able to live in society alongside their peers, albeit false hope.

As time passed, ABA practitioners started to recognise some of the abusive elements inherent in ABA and dropped many of the 'discouragements'. The term 'ABA' is often avoided these day and other therapies that are extensions of ABA are often given another name like 'Positive Behaviour Support' (PBS).

Modern ABA/PBS

Modern-day ABA and PBS practitioners (or any of the many therapies that have been derived from ABA) assert that they use techniques that are 'fun' and 'flexible' and nothing like the techniques of the past. The emphasis is usually on the fact that all intervention is tailored to the specific individual needs of each child.

ABA/PBS practitioners tend to focus on the 'ABC Model' in their sessions. ABC stands for 'Antecedent, Behaviour, Consequence' and involves looking at the "cause" (or 'antecedent') of each behaviour displayed by an autistic person as well as the 'consequence' of the behaviour.

Both the 'antecedent' and 'consequence' in this model can be engineered by the practitioner. For instance, the practitioner asking the child to make eye contact despite it being uncomfortable or painful for the child (the 'antecedent'), child reluctantly maintains eye contact (the behaviour), practitioner rewards child with praise or a sticker, food, or screen time etc. (the consequence).

ABA/PBS practitioners say this is simply taking the natural way children interact with the world already and adapting it to teach the child. An example of the ABC model occurring 'naturally' may be that the child is thirsty (the antecedent), so asks for a drink (the behaviour) and receives one (the consequence). Or it could be that there's a loud noise that overloads the child (the antecedent) so the child has a meltdown and throws a toy (the behaviour) and the toy is broken (the consequence).

ABA and PBS practitioners use this model to try to change autistic children's behaviour in a variety of ways. Some of the less controversial aims can be to help the child with socialising or help them to learn to read and write. Some of the more worrying aims can be to stop the child from stimming or force them to make eye contact. The methods used irrespective of the aims, however, are very controversial.

Why even modern ABA and PBS are controversial

Given the fact the 'punishment' part of the 'consequence' in ABA and PBS has largely been dropped (in the UK, at least), some people might wonder what objections could still be made against ABA/PBS. Unfortunately, there are quite a lot of reasons.

1. Some practitioners do not have good aims

The worrying aims of some practitioners, mentioned above, is one of the problems with ABA/PBS. There are still many misinformed people who wrongly think they should be forcing autistic children to make eye contact, for example. Not only is eye contact often uncomfortable (and even painful) for autistic people but it can stop them from being able to even listen and process information properly so it is completely pointless and tends to stop the very thing many practitioners are trying to achieve (the autistic child listening to what is being said to them). Other practitioners still try to stop autistic children from stimming, something which can be essential for wellbeing.

2. Autistic people should not be made to 'act non-autistic'

Even when stimming is not stopped or discouraged and eye contact isn't forced, one of the biggest complaints about ABA and PBS is simply that its goal is to make autistic people appear neurotypical. Being autistic means their brains are literally physically different to non-autistics. They do not have broken neurotypical brains and there is no way to 'fix' their brains so that they stop being autistic. In fact, many of them don't want to stop being autistic, even if that was an option.

Having a goal of trying to stop autistic people from appearing autistic is hugely offensive and stigmatising. There is nothing wrong with being autistic, which means there is also nothing wrong with behaving like an autistic person. While it can be helpful for some autistic people to learn about non-autistic communication and socialising alongside many other useful things (just as it can be useful for non-autistic people to learn about autistic communication and socialising), the goal of making an autistic person seem non-autistic (as Lovaas wanted when he first created ABA) is extremely troubling.

3. Too much emphasis is placed on an immediate 'antecedent'

Another problem with ABA/PBS is its limited scope when looking at the 'antecedent' part of the ABC model. Many texts talking about ABC only talk about one antecedent or only look at what happened immediately before the 'behaviour', which goes against everything we know about people, behaviour, and autism.

Typically, there is not any one thing that causes a behaviour as the story below illustrates.

I remember once breaking a glass and then having a meltdown. Anyone watching me would probably have concluded that breaking the glass caused the meltdown…and they would be completely wrong. I have broken many glasses in my life and have almost never had a meltdown because of it. However, on that occasion I had also recently moved house so was dealing with a lot of change. I had been out that morning into busy and noisy traffic and had spent time with lots of other people at university, so I was already overloaded from sensory input.

Breaking the glass had very little to do with my meltdown. It was likely I would have had a meltdown that day at some point and the supposed 'cause' could have been anything from burning my toast to being unable to find the scarf I wanted to wear. The real cause of the meltdown was the weeks of stress surrounding a big move, the uncertainty I felt at living away from my parents for the first time, the sensory overload I experienced at living in a busy city for the first time. The meltdown had been building for weeks and the glass really had nothing to do with it whatsoever. So, how helpful would it have been to have someone work with me over my response to glassware breaking? Not at all helpful. And it would have completely overlooked all the actual problems I was having.

- Felicity Goodhall, former Senior Autism Practitioner, Autism Understanding Scotland

It is exactly the same when ABA and PBS practitioners focus solely on the things that happen to children immediately before a 'behaviour' without taking the wider context and child's experiences for the last few days or weeks into account.

4. High rates of PTSD in autistic people who have had ABA/PBS

Perhaps the most compelling argument against the use of ABA/PBS for autistic people is the evidence that suggests autistic people who have had ABA/PBS therapy are at considerably increased risk of PTSD. A paper published in 2018 looked at the rates of PTSD in autistic people who had undergone ABA/PBS compared to those who had not. The paper found that the autistic children and adults who had been exposed to ABA/PBS were 86% more likely to meet the criteria to be diagnosed with PTSD than those who were not.

(source: Kupferstein, Henny. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. Advances in Autism. 4. 00-00. 10.1108/AIA-08-2017-0016.)

It seems parents/carers were unaware and largely reported satisfaction with the therapy, almost certainly not realising it had traumatised the child.

5. ABA/PBS conditions already vulnerable people to obey without question

Another terrifying side-effect reported by many adults who have been through ABA/PBS is that it strips autistic people of their ability to set boundaries, leaving them more susceptible to abuse. When a practitioner consistently stops a child from following their natural instincts and instead teaches them to blindly follow instructions that make them uncomfortable, this conditions them to accept other people pushing their boundaries and making them do things they don't want to do. Many autistic adults feel they were abused later in life because ABA/PBS as a child skewed their ability to set and enforce boundaries.

Is any sort of ABA/PBS okay?

With ABA/PBS permeating so much of the recommended therapies for autistic people, many are desperate to know if any ABA/PBS is okay. This is a difficult question to answer, partly because of the fact there are so many different therapies that fall under the ABA/PBS umbrella.

Cognitive Behavioural Therapy and Autism

What is CBT?

CBT stands for Cognitive Behavioural Therapy and is a kind of talking therapy used to treat a range of conditions, including depression and anxiety.

There are different ways CBT can be delivered. One-to-one sessions with a therapist are common but online therapy and groups sessions are also available. Sessions tend to focus on trying to identify and then change unhelpful thought patterns and behaviours. There is normally homework/work to be done outside of the structured sessions with CBT.

Does CBT help autistic people?

Since CBT is so adaptive and can be used to treat a whole range of mental health conditions like depression, anxiety, and PTSD it is often the first suggestion when it comes to poor mental health. While it can be used to help autistic people with various problems, there are a couple of issues when it comes to CBT and autism.

Firstly, CBT should never be used to 'treat' autism itself. There is nothing wrong with being autistic, it is not something that can be 'cured', and no good therapist will try to treat autism on its own. It should only be used for mental health problems, which autism is not.

Secondly, because CBT is generally geared towards helping people to stop worrying about unrealistic scenarios it isn't always very helpful for autistic people, who are often anxious about very real scenarios that really do happen. When the thing you're anxious about is having to engage in small talk at the till in a shop then telling yourself you won't have to make small talk is of little help since it's not true – you probably will have to make small talk!

Should I pursue CBT?

Some therapists are very good at adapting CBT for autistic people and some autistic people seem to respond to it better than others. So, while it is important to be aware of some of the issues and limitations around CBT for autistic people, it may be worth trying if you can find a good practitioner.

Occupational Therapy and Autism

What is OT?

OT stands for occupational therapy and is a type of therapy that can help with physical, sensory, and cognitive difficulties. The aim of occupational therapy is to allow people to do everyday tasks and make sure they can access and take part in meaningful activities.

As well as helping and supporting autistic people with day-to-day difficulties, occupational therapists can also input into the assessment process when someone is pursuing an autism diagnosis. Occupational therapists can also help develop appropriate reasonable adjustments at school or work.

Because the remit of an occupational therapist is quite broad, the specifics of sessions with them can vary quite a lot. You may see an occupational therapist at a hospital or GP surgery, or they may visit at home, school, or work. They will talk to you about your needs so the first session will often be a lot of talking and answering questions. After they have all the information they need, they will decide how to help.

Does OT help autistic people?

OT can be a very helpful therapy for many autistic people who need support for a variety of reasons.

Some of the things OTs can help with are:

- Creating a sensory profile
- Creating a sensory diet
- Suggesting reasonable adjustments for school or work
- Gross motor skills
- Fine motor skills (e.g. handwriting)
- Living independently

Speech and Language Therapy

What is SALT?

SALT stands for Speech and Language Therapy and is a kind of therapy used to help and support anyone who has difficulties with communication (or with eating/drinking/swallowing). It doesn't matter whether the problems communicating are physical, psychological, or emotional – a speech and language therapist can help with any of these. SALTs treat both adults and children.

As well as helping and supporting autistic people with communication, SALTs are often involved in the assessment process when a child is suspected to be autistic (and occasionally adults, too, though adult assessments often do not rely on SALT input).

The sessions are often one-to-one and may involve talking, and/or exercises the therapist thinks will help. For children, this often takes the form of play.

You or your child will probably be given exercises to do at home in between sessions.

Does SALT help autistic people?

SALT can be a very helpful and effective therapy for autistic people with difficulties communicating. The one-to-one nature of the therapy tends to suit autistic people well and a good speech and language therapist can make a big difference for many autistic people.

Some of the things a SALT can help with are:

- Stammers
- Difficulty pronouncing words
- Struggling with turn-taking in conversations
- Providing or recommending language aids
- Communicating with non-autistic people
- Situational mutism
- Understanding non-verbal communication cues
- Social stories

Meltdowns, Shutdowns and Elopement

While everyone experiences anxiety, fatigue, fear, emotional overload, sensory overload, and stress, in autistic people, these experiences can be heightened. Many autistic people feel a constant level of anxiety higher than most nonautistic people and can increase very easily.

When the anxiety, stress, fear, or sensory overload becomes too much, many autistic people will sometimes experience either a meltdown, shutdown or run off (elopement). These are fight, flight, or freeze responses, and are what happens when the autistic person has reached a crisis point. All autistic people have their own ways of reacting during a crisis point.

Meltdowns

Meltdowns might look like tantrums, but they are very different – here is a table highlighting some of the differences between meltdowns and tantrums.

Meltdown	**Tantrum**
Not in control	Controlled
Does not stop when you give in to demands	Stops when you give in to demands
Less likely to stop themselves from getting hurt/less aware of danger	May throw themselves to floor/around the room but still aware of the danger
May not be looking for attention/your reaction	Looking for attention/your reaction
Happens because of being overtired/full of emotions (good and bad) /overwhelmed/too much or too little sensory input	Happens when the person wants something

Meltdowns are extremely distressing. During a meltdown there are lots of different behaviours autistic people might display. They may scream, cry, shout and possibly lash out or self-harm.

During a meltdown, they have basically gone into survival mode and are lashing out as a means of self-defence. They cannot take any more of the emotions, sensory input, whatever else has triggered the meltdown, and they need space to gather ourselves. Meltdowns can lead to shutdowns – this does not mean that they have calmed down, they will still need the space.

Shutdowns

A shutdown means that the autistic person is basically trying to withdraw from the world. During a shutdown, many autistic people will lie down on the floor regardless of where they are, or find a quiet corner to curl up in. This can happen in supermarkets, other people's houses as well as at school, parks, anywhere.

Many autistic people will become non-speaking during shutdowns, cry, may seek out a dark, quiet space. While shutdowns are much quieter, they are just as distressing for the autistic person as a meltdown. A shutdown may lead to a meltdown if they are not given the space to deal with it.

Elopements

Elopement is the flight response. This is when an autistic person cannot take any more of whatever is going on and they literally cannot stay. They may or may not have a safe place to go in mind, but they cannot stay where they are. Autistic people may feel the need to meltdown or shutdown but do not want to do it in front of others, and they may not be able to verbalise what is happening.

Melting or shutting down is sometimes perceived as "failing" by many autistic people, particularly if they have been made to feel bad about them in the past. Eloping may come across as extremely rude, but it may be a survival tool.

Causes of meltdowns, shutdowns, and elopement

Fear, anxiety, fatigue, stress, and sensory overload are some of the major factors that contribute to meltdowns, shutdowns, and elopement. When feeling too much of any or all of those, it's possible that an autistic person will reach a crisis point and either melt or shutdown or run off.

These accumulations of feelings can happen very quickly, or over an extended period of time. Sometimes the thing that has triggered the crisis point doesn't need to be huge – one noise too much, or one demand too many.

Meltdowns, shutdowns, and elopements *always* happen for a reason. It may not be what happened immediately before the crisis point, or it is possible it was the last straw that broke the camel's back, but autistic people do not meltdown, shutdown or elope without there being a cause, and often multiple factors. They never just choose to meltdown, shutdown, or elope.

Common contributing factors can be:

- *Fear of the Unknown* — Not knowing what is happening next. Many autistic people need to know what is going to happen next and may need to know what the whole day/week looks like.
- *Feeling Pressure* — Many autistic people feel that they cannot make a mistake. Some autistic people will only do something when they see the point of it, and if they do something, they often feel a need to be able to do it well. Autistic people can be perfectionists. As a consequence of this, any perceived criticism can be extremely difficult to handle, and can lead to a crisis point.
- *Unexpected Changes* — Unexpected changes to plans or routines can be difficult for many autistic people. It can lead to a feeling of loss of control. Sometimes plans do have to change last minute, this is something autistic people have to get used to, but this can lead to a crisis point. Contrary to popular belief, many of them are fine with change when they have some choice and control over the change.
- *Sensory Overload* — Different autistic people react to sensory input in different ways. Knowing what their sensory sensitivities are, and sharing their sensory profile with school or work can be very important.

- *Emotional Overload* — Emotional overload doesn't just happen when autistic people feel negative, too many positive things can be tricky too (e.g., Christmas or birthdays. Very lovely, very much to cope with). Too many emotions can lead to a crisis point.
- *Physical Exhaustion* — The toll of socialising, being around other people, trying to filter sensory information while socialising, all these things can be physically exhausting for autistic people. Physical exhaustion, especially when coupled with any of the other factors above, can lead to a crisis point.
- *Masking Too Much* — The stress of hiding their authentic autistic selves can be exhausting and lead to a meltdown. Many children appear to be ok at school then meltdown at home. The same can happen at university or work as they grow older. If they are having a meltdown as soon as they get home, they are not ok at school or work and would benefit from support.

While they look different, these 'fight, flight, or freeze' reactions are very similar, and just as distressing for the person experiencing them. They are extreme reactions, and generally out with the control of the person melting/shutting down or eloping. It is not a reflection of their ability to be a friend, neither does it have anything to do with their ability to empathise. It is a neurological event and all to do with being overwhelmed by emotions and/or other stimuli.

Remember, each individual autistic person will have different triggers, different amounts of sensory input/stress they can cope with. No two autistic people are the same, even when it comes to crisis points.

When a Meltdown/Shutdown/Elopement Happens (for autistic person having the meltdown)

- Remember that this will pass. You will not feel this way forever.
- You are not lesser for having a crisis point. They happen to just about every autistic person.
- Try to remove any triggers if possible.
- Get yourself somewhere you feel safe, especially if you cannot remove triggers
- Try to remember what kind of sensory input you find calming.
- Take your time working through the crisis point. If you rush yourself into getting back to normal, you will likely hit another crisis point really quickly.

When a Meltdown/Shutdown/Elopement Happens (for the bystander)

- Stay calm yourself. Even if the autistic person is lashing out, stay calm. Many autistic people will feed off your emotions too, so you getting upset will make them more upset. Try to keep your tone of voice as normal as possible as changing that might make a crisis point worse.
- Try to remove anything that may have triggered the crisis point that you can see - if possible, try to change the environment to make it easier to cope based on their sensory profile (lighting, noises etc) if possible, and encourage others to move away.

- Give them space but ensure they are safe. Forcing them back into a classroom/work/an environment they have ran out of will be traumatising. If in school and if possible, send a PSA to keep an eye on them so you know where they are. In work, implement any agreed upon strategies for dealing with meltdowns.

Different autistic people will need different responses. If you have autistic family or friends, or work with an autistic person, it can be sensible to discuss strategies that will work for them in advance. Some strategies that may help are:

- Empathise. "I can see you're really upset. Can you tell me what is making you feel so upset?" This will help to validate their feelings and recognise the emotion they are experiencing (may be helpful for those with alexithymia). They may not be able to respond, but it may let them know you are there for them. You may have to wait until the crisis point has passed before they are able to communicate again.
- If they are lashing out, gently say "I don't think you want to hurt me, that won't help you." All communication must be done with consideration and should serve a purpose, and it may be better to remain quiet.
- Give them some space to calm down, but do not tell them to calm down, they are not choosing to feel this way.
- Tight squeezes help some autistic people to feel better if they can be tolerated, but for some autistic people, a squeezy hug might cause a meltdown. Do not touch the person having a crisis point unless this is an agreed upon course of action decided before the crisis point is reached.
- Don't hurry. Extra pressure may exacerbate things. It does not matter if they are going to be late or miss out on something, they need to get through the crisis point first.

When any of these things happen, autistic people are likely to be physically and emotionally drained. It can take them a long time to recover from crisis points, sometimes days or even weeks, especially if they have reached a crisis point several times in a short space of time. No matter how distressing it is for others to see, it is much more distressing to feel that way. Remember that they are not doing it to give anyone a hard time, they are having a very hard time themselves.

Avoiding Crisis Points

Traditional methods for dealing with undesirable behaviour will not stop meltdowns, shutdowns, or elopements. Positive reinforcements for when autistic people do not hit a crisis point do not address the reasons why they are happening in the first place. Nor do they support them to use strategies for mitigating the crisis point. They just encourage autistic people to mask that they are autistic. Time outs are something many autistic kids enjoy. Raised voices will exacerbate the situation. Taking away items of special interest will be upsetting and not actually change anything.

In order to best avoid a crisis point being reached, it is important to ensure the environment is suitable and the autistic people using it feels secure and understood.

At home, all autistic family members may have different, often conflicting sensory and/or social needs. Explore and discuss what each individual person needs to feel safe and respected. It is ok to set boundaries to protect everyone.

In schools, staff can talk with the pupil and their family and use an Autism Appropriate Checklist to ensure the class is set up to meet sensory needs. Having reasonable adjustments put into place to support autistic pupils and respecting their autistic lived experiences can make a huge difference to the number of crisis points a pupil hits before, during, and after school.

In work, autistic people can talk with their line manager and colleagues about what reasonable adjustments might be put into place to assist them in their role. Talking to their line manager when they realise they are reaching their limits and on the verge of a crisis point can help.

Other strategies which will help are:

- Learning to recognise the triggers of a crisis point, and the feelings they have before one happens. This will help give them tools to avoid them, and how to deal with them when they do happen.
- In school or work, find ways to leave the class/work area when needed. This might mean putting, e.g., a red card on their desk as a way of communicating "I am overwhelmed, I need some time out"
- Up our knowledge of emotions, how those emotions feel, and what they look like when they feel that way will help. Often recognising emotions can be difficult, especially when they might be feeling many different conflicting emotions at once. Autistic facial expressions often do not match what non-autistic people may express (see autistic communication). Everyone knowing how those emotions are expressed for each autistic person can be very useful. Increased emotional literacy means they are better able to describe how they are.
- Write a list of things that helps autistic people chill out – favourite toys, objects, materials, games, activities, movies, music. That can be incorporated into a social story, song, video, whatever else might appeal, to remind them of the tools both they and the others around them can use to help when they are stressed before they reach a crisis point. This can shared with education settings or work as well as use in the home.
- Make a plan of their day/week/however long is needed. Knowing what is going to happen helps many autistic people feel secure. Many people, including some autistic people, love surprises, but not all. If you are considering organising a surprise for an autistic person, it is worth checking how comfortable they are with having their routine changed without notice, even for something they would enjoy.
- Having others tell them they are valued, and they are working hard to understand them. If they know this, they will feel more secure and their stress levels will likely be lower. Other people don't have to completely understand autism, but it really helps when they accept and support them.

- Learn the limits. Three exciting things in one day might be brilliant for some autistic people, but they might be too much for others. How good to have another exciting thing kept for another time. It is ok to take a break and ensure you are considering school/work demands when considering personal events and vice versa.
- Don't make autistic people feel bad about reaching a crisis point. They didn't intentionally ruin anything with a meltdown, shutdown or running off. They didn't do it for attention, they usually feel pretty bad after they hit a crisis point already. Telling them they spoiled something will make them more anxious. Remind them of all the positives and make plans to put more supports in as required.

Autistic people don't reach a magical age where they stop having meltdowns and shutdowns. These are things autistic people don't grow out of, but they can become easier to manage once they know the triggers and have a range of strategies to help them cope. Those supporting autistic people can play a key role in developing that understanding too. One of the most important things autistic people need is understanding – understanding that it isn't their fault. that they are allowed to make mistakes. That they are built differently. That they are appreciated for who they are.

The Coke Bottle Effect

It is important for schools to recognise that they may have some pupils who work beautifully at school, socialise, appear to manage to process all the sensory input and demands that are placed on them. Their parents may come in and say they have huge meltdowns when they get home. This does not automatically mean that they aren't coping with their home life, or that school is totally fine for them.

This is something commonly known as the "Coke Bottle Effect". All that sensory and social input they are processing, as well as the school work, that coke bottle is being shaken up all day long, but they are keeping the lid on. When they get home, they literally cannot keep their lid on anymore, and the emotions (the coke) come erupting out everywhere.

Like autistic children, autistic adults can experience this too after working, shopping, socialising, or anything where they might be experiencing social and sensory demands. Many autistic people, especially autistic girls due to the way girls are typically socialised, are very good at masking their differences and difficulties so they can appear to fit in. This is tremendous hard work. There are a number of reasons autistic people do this. Firstly, many don't want to be singled out as odd as odd children are often bullied. Second, they may not even realise that what they are processing is tougher for them than other children. (see our page on masking, add link)

As a society, we don't always talk about what it is like to process sensory information, so many autistic people may not even know they are working harder than their non autistic peers.

"It wasn't until I attended a training session with Occupational Therapy in my mid 30s that I first realised that I had sensory processing differences compared with others."

Marion, former CEO of Autism Understanding Scotland

Also, as a society, we don't discuss how much hard work it is to socialise, or the efforts individuals put in to do so (see our pages on autistic communication). It is best practice for schools to recognise that if a family tells you that their child is having meltdowns straight away after school that they work with them to help manage the sensory input in school and find ways of helping manage their anxiety.

Autistic Burnout

This is a real problem in the autistic community. Autistic burnout happens when autistic people have had too many crisis points in a short space of time, have been acting too hard to conceal their innate autisticness, or just have too much stress and pressure. It looks a whole lot like depression and can lead to suicidal thoughts even though they do not want to commit suicide.

When autistic burnout happens, autistic people are more likely to engage in self-stimulatory behaviours, some of which may be self-harming, and may show heightened defensiveness. Elopement, meltdowns and shutdowns, mutism and extremely high anxiety are all more common. The autistic person is having a hyper crisis.

Many autistic people mask being autistic for a variety of reasons – to fit in, avoid bullying and often because the mask gives them a sense of identity and protection from the rest of the world. It is likely that the "mask" they wear to fit in and not be seen as different will fall off. They cannot pretend they are just like everyone else anymore. They cannot pretend their sensory issues are non-existent. They cannot laugh at jokes they do not understand, or wear clothes just to look the same as their peers. Being unable to mask being autistic for someone who has masked for a long time can be very confusing, and depending on how their peers react, can be incredibly socially isolating.

Autistic people who had managed eye contact before may no longer be able to do so, socialising will be even tougher, and some people regress in the skills they have gained. As mentioned before, this is a serious problem for the autistic community. Unlike meltdowns and shutdowns, burnout can last for days, weeks, months, and, if not addressed, years. The problems the person is having may not be directly related to school or work, but ensuring they are in the right kind of environment, have understanding teaching staff and colleagues will help. Getting support from outside agencies such as Occupational Therapy can often help too.

Bear in mind that autistic people have a higher risk of suicide, and this is strongly associated with burnout. Autistic women are nine times more likely to complete suicide than non-autistic women and are the only group of women who have a higher suicide rate than men. Supporting and understanding autistic people is of great value to their mental health, and providing the right kind of environment, helping us to feel valued, will increase their sense of self-worth. Education settings and workplaces alone cannot tackle these problems, but they can be part of a solution.

Looking for a Therapist

What to Look for in a Good Therapist

Much of our information on different therapies stipulates a good therapist who understands you is key. However, you might not know what sorts of things to look for when searching for a therapist for yourself or your child.

It is important to remember you are not at fault if you start therapy but find it unhelpful. Sometimes it can take time to settle with a new therapist but if you really feel like the sessions are unhelpful it is okay to say so. It is okay to look for a different therapist if the first is not a good fit and a good therapist will always be happy to make recommendations.

Regardless of the kind of therapy being sought, a therapist should *never* have the aim of 'curing' or 'treating' autism. Autistic people literally have different brain structures. They are not broken non-autistic people and it is impossible for them to become non-autistic. If you are autistic, you are autistic for your entire life.

If you suspect a therapist is trying to make you or your child act in a non-autistic way, this should ring alarm bells. Ideally, autistic people would always have access to therapy from a practitioner with in-depth knowledge and experience of autism but since such therapists are quite rare, this is often not possible.

A good therapist will NOT:

- Force or encourage increased eye contact.
- Stop or repress stimming (occasionally stims may need to be redirected if they are actively harmful).
- Refer to meltdowns as 'tantrums' or imply meltdowns are manipulative/intentional.
- Refer to autism as a deficit/tragedy or assume autistic people do not have empathy.
- Insist verbal speech is the only way to communicate.
- Push boundaries/ignore or dismiss a request to stop something.
- Ignore or dismiss concerns.
- Assume a new autistic client will be just like a previous autistic client.
- Make any sexual advances.

A good therapist WILL:

- Respect boundaries and bodily autonomy.
- Understand and accommodate sensory needs.
- Focus on emotional wellbeing.
- Encourage self-advocacy.
- Recognise signs of distress and reduce demands accordingly.
- Provide support to achieve goals important to the client.
- Listen to their client.
- Ask questions about how the client's autism informs their lived experiences.
- Ask for consent before touching a client.
- Understand the importance of special interests.
- Want their client to feel safe in therapy.
  For more information on harmful treatments in relation to autism, you can go to the NHS Inform website: https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/autism-spectrum-disorder-asd#facts-and-myths-about-autism