

Autism

AMASE

Autistic Mutual Aid Society Edinburgh

**Helping autistic people
to help each other.**

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What is Autism?

Autism is a profound cognitive difference, meaning that autistic people can think and experience the world in very different ways. Autism is not a mental illness; it is possible to be very happy and well-adjusted, and autistic. It is a difference a person is born with, and not something that can be 'cured'.

The autistic population is extremely diverse. The autistic spectrum is not a line running from 'high functioning' to 'low functioning': Sensory differences, levels of anxiety, social preferences and executive functions all vary depending on the person and their environment.

Although some autistic people also have intellectual disabilities, and other neurological differences like epilepsy and dyspraxia, these are far from universal. The degree and types of support an autistic person might need therefore varies greatly depending on the individual. For example, a person in distress might find it hard to communicate, but that wouldn't tell you anything about their abilities elsewhere.

Autism and Mental Wellbeing

Autistic people are far more likely to suffer from a wide range of mental health difficulties, the most common being anxiety and depression. Recent studies suggest that autistic adults without learning difficulties could be up to nine times more likely to commit suicide than the general population. There are a number of likely reasons for this.

Isolation, understanding and empathy

Being autistic can make a person stand out from their non-autistic peers, because of differences in communication, interests and types of preferred social time, and in how an autistic person might experience the world.

Autistic people don't lack empathy, but differences in how an individual might react to things, and lack of contact with those with relatable life experiences, can make it harder for an autistic person to relate to those around them, or for others to relate to them. This means that many autistic people can feel very isolated, not understood, and not accepted for who they are. They may even have trauma from negative experiences of being bullied, ostracised, misunderstood or left out. Unspoken social rules and non-verbal communication, like body language, can also be very confusing for many autistic people, adding to difficulties in social situations, and a greater chance of being misread.

How to help

Many autistic people find connecting with other like-minded individuals, the broader autistic community and others with shared interests, very valuable in reducing their sense of isolation. It can also improve their self-knowledge, and help them feel more connected with those around them. This can be difficult in person, especially if traveling is a challenge, or if there aren't suitable groups nearby, but online communities and even reading books and blogs by autistic writers can be very validating and a good starting point.

It can also help for the non-autistic people in an autistic person's life to try to connect with them based on their interests, and on their terms. Socialising can be very exhausting for many autistic people, but it is often still desired, so it's important that the person can feel safe in being allowed to be themselves, define their own boundaries, and say when they need alone time. Many autistic people spend a lot of their lives 'masking' to fit in better socially, or putting extra energy into navigating a neurotypically-focused world; it can be very helpful for non-autistic people to try to learn ways to meet autistic people in the middle. It is good to be direct about social expectations and boundaries, as well as being honestly and openly reassuring about common concerns like being left out or made fun of.

Focus and rumination

Many autistic people have the ability to focus very deeply on intense interests, and it can be difficult to stop and switch over to something else. While these interests can be very fulfilling, and at times extremely productive, the flip side of this intense focus can be rumination and perseveration over worries or uncertainties. Many describe a feeling of not being able to 'turn their thoughts off', which can contribute to sleeplessness or difficulty relaxing. When these are negative or worrying thoughts, they can feed into depression and anxiety, and be extremely distressing.

How to help

It can be helpful for a person stuck on a worry to redirect their focus to something they find immersive and enjoyable. It is worth figuring out what is adequately absorbing for times when it's needed. However, task switching and pulling out of loops of focus can be difficult and even painful for an autistic person, especially when if it is experienced as an intrusion, so pressure is often counter-productive.

If it is a worry or uncertainty the person is stuck on, it could help them to try to identify what they are most worried or uncertain about, and if there's any new or more detailed information that might help add certainty. It might also be useful to help the individual think about what aspects of the situation they can control, what they can't, and if there's anything they can do to feel more in control. This might be anything from deciding on an end time for an event, to learning to better identify what their stressors might be, and have a plan for how to counter them.

This intensity of focus also means that autistic people tend to care very much about the things that they are passionate about. It is vital for a person's mental health to be able to pursue their passions, however unusual.

Instability and control

The world can be very unpredictable and confusing at the best of times. Lack of information, certainty, and routine can be even more destabilising for people who struggle with predicting how others may react, with sensory sensitivities and with anxiety.

How to help

Asides from identifying where a person might be able to have some control over an uncertain situation, it can also help to identify what details the person might need to feel more secure.

Reassuring the individual that there are no stupid questions, and that it is ok to ask for clarification or more details, can be very helpful. Having a plan or fixed routine can also be useful for many autistic people, but if the routine is imposed by others, it can add to the sense of not being in control. Helping or encouraging a person to clarify what needs to happen, when, and how, and write up their own plan, can be much more empowering and stabilising.

It is also important to think about the many extremely destabilising things that can worry a person, especially if they are financially insecure. Anxiety and uncertainty over having a stable place to live, a reliable income, adequate supports and accommodations, etc, can be very stressful. It can be helpful for an autistic person to have access to an experienced advocate or mentor, who

can help with navigating and potentially resolving these uncertainties.

Meltdowns, shutdowns and burnout

Some autistic people experience meltdowns, shutdowns, or burnout. While they are not mental health problems in themselves, they can contribute to them, or worsen if a person is experiencing mental health difficulties. They can be caused by sensory overload, anxiety, overwork, social conflicts, sudden unexpected changes to a plan, or a number of other causes.

Meltdowns are usually described as a burst of overwhelming emotion, which can take the form of anger, crying, shouting, sometimes self harm. Meltdowns are intensely distressing, and the individual may have very little control.

Shutdowns are characterised sometimes as 'silent meltdowns', and often involve a person becoming very withdrawn, stuck, tired or zoned-out, and less sensitive to what is going on around them. They may also find it difficult to communicate.

Burnout is a broader experience, which might follow a stressful or very exhausting period. It can lead to a person struggling with things they could previously manage, such as self-care, work, or socialising. It can take quite some time to fully recover.

Meltdowns, shutdowns and burnout are all more likely to cause additional problems when a person is under pressure, or experiencing mental health difficulties. Not understanding what they are, and what to do about them, can lead an individual to fear more for their mental health, and think negatively about themselves. Sometimes others can also misinterpret them as being part of much more serious mental health problems. Long term burnout can also feed into depression, and contribute to physical health problems.

How to help

If you are with an autistic person experiencing a meltdown, do not crowd them or barrage them with questions and concerns. Be calm and reassuring, let them take their time and listen to what they might need. Some may not be able to communicate verbally when in distress, even if they are usually very articulate. If necessary and possible, help them get to a safe and quiet place away from things like bright lights, loud noises, and other people.

A meltdown can be very alarming to witness, but remember that it is more distressing for the person experiencing it. Many also struggle with feelings of shame or guilt following meltdowns, which can be made much worse by others reacting in alarm, making fun of them, or diminishing their distress.

It can help for the individual to identify what their triggers might be, and also to identify what might help calm them. This could be the type of environment, such as a darkened room, the use of noise cancelling headphones, certain types of music or videos that they find comforting, or stimming. Short for self-stimulatory behaviour, this can include a huge range of things from rocking and stroking certain textures to watching colourful lights or fidgeting with objects, and can be very useful for autistic people as a way to self-regulate. It could be helpful for the person to figure out what soothes them most, perhaps keeping a few soothing objects on hand.

Sometimes an autistic person might hurt themselves during a meltdown. It is important to recognise that this can be a (usually uncontrolled) attempt to counter or soothe the distressing sensations of the meltdown itself. It can help to try to redirect the person's actions to something safer, or make their surroundings safer - a person might find some relief punching cushions instead of a wall or themselves, for example.

Many autistic people report finding deep pressure really calming, whether it is from a weighted blanket or a tight hug. It is very important, however, that you do not touch a person, especially when they are in distress, without clear consent. Many can find touch very uncomfortable, so it is safer not to touch at all if you don't know someone well, unless they request it.

Shutdowns usually look less dramatic than meltdowns, but can be just as distressing for the individual, and similar strategies can help. With meltdowns, shutdowns and burnout, the person needs adequate calm and quiet recovery time. It could be worth looking into triggers for the problem and what could be done to address them, be it overwork, family stresses, sensory overload or something else.

Seeking professional help for mental health difficulties

Despite being more likely to experience mental health difficulties, large numbers of autistic people report problems with accessing mental health services, and not being understood or taken seriously by mental health professionals. This is often due to a mixture of communication differences with the professionals involved, a lack of understanding of autism, a lack of appropriate services, and services just being inaccessible - such as requiring phone calls, not providing adequate information, or having stressful waiting areas.

Many mental health problems can look different when experienced by an autistic person. The person might not look 'typically' distressed, sometimes to the point of not being believed when they are stating that they are suicidal,

and asking for help. On the other hand, an autistic person might be deemed to be experiencing an acute mental illness when they are in fact having a meltdown.

While it is a very under-researched area, it also seems increasingly likely that many autistic people are affected by trauma, often as a result of bullying, ostracisation and abuse. Things that distress or even traumatise an autistic person can be very different to what are known to be distressing or traumatic for most non-autistic people.

How to help

Because autistic people can present very differently, and might be difficult to read, it is particularly important to listen carefully to what the person is saying about how they are feeling. Reports of distress and thoughts of self harm and suicide need to be taken seriously.

It might be useful to offer to support an autistic person who is seeking professional help, by helping to make the required phone calls, offering to go with them, or discussing their concerns ahead of time. The aim is to help ensure that the GP, mental health team, counsellor, or other professional is taking everything on board, listening to what the person is trying to tell them, and what they want and don't want to happen. There are also experienced advocacy and support organisations and services that may be able to do this or offer additional advice, and could be worth contacting if the person is comfortable with that. Some details for relevant local services are listed at the end of this document.

Autistic people are likely to benefit far more from mental health treatments that are adapted to suit their needs. A person might need more time to process in talk therapy, for instance, find it difficult to stop processing between sessions, or have trouble identifying and naming their feelings directly. They might have different end-goals to what others might assume. It might take a long time to build up trust with some professionals, or be hard to connect at all. There is also growing evidence to suggest that autistic people are far more likely to react unpredictably to a range of medications.

All of this makes it important to communicate effectively about how a treatment is going, what concerns the person might have, and what could be adapted to help. Having trusted individuals providing open-minded support and continuity of care, whether GPs, therapists, support workers, or advocates, can make a huge difference to an autistic person seeking support for their mental health.

Resources and Local Organisations

[AMASE \(Autistic Mutual Aid Society Edinburgh\)](#)

Organisation run by and for autistic people focused on autistic community, education and advocacy

[Number 6 One Stop Shop](#)

Service for autistic adults which offers social opportunities, support and advice on a range of issues

[PASDA](#)

Organisation that offers support for family and loved ones of autistic adults

[SWAN \(Scottish Women's Autism Network\)](#)

Organisation focused on peer support for autistic women, run by autistic women

[Scottish Autism](#)

Charity focused on supporting and providing services for autistic people and their families in Scotland

[Advocard](#)

An independent advocacy organisation with services for people who experience mental ill-health in Edinburgh

[Scottish Independent Advocacy Alliance](#)

A membership organisation aimed at ensuring independent advocacy is available to any independent person in Scotland. Their site lists member advocacy organisations by region.



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