

AUTISTIC MELTDOWNS, BURNOUT & FIRST RESPONDERS

A PRACTICAL GUIDE

WRITTEN BY VIV DAWES, AUTISTIC ADVOCATE

About Me

I am a late diagnosed autistic parent of a neurodivergent teenager. I am an autism advocate, writer and lived experience trainer. I have 25 years experience working with vulnerable adults and young people, including as a Snr Practitioner for the NHS in a women's prison, where I managed a team of prison drug workers. Many of the people I have worked with were also neurodivergent.

I am a member of the Police Independent Advisory Board in the Rushmoor and Hart area and am passionate about making sure that autistic people are able to access the support and adjustments they need in all settings, including in the criminal justice system.

Find out more on my website <https://www.autisticadvocate.co.uk/>

About This Book

This book is designed for any first responders, primarily police officers, or anyone in the emergency services, who may come into contact with an autistic person experiencing a meltdown, a shutdown and autistic burnout. The book can also be used by social workers, mental health professionals and other professionals working with autistic people. This book gives you some basic information about what autism is and will give you an understanding of what autistic meltdowns and shutdowns are and how to respond appropriately. The book also explains what autistic burnout is, its causes, symptoms and what will and what will not help the autistic individual.

Why is it so important to understand autistic meltdowns, shutdowns and burnout? It is common for many autistic people to reach crisis point and in this crisis, they need very particular help and support, which differs from people who are in crisis but not autistic. The suicide rate amongst autistic people is also very high, with autistic adults 10 x more likely to take their own lives and autistic women 13 times more likely.

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Glossary

Neurodiversity The diversity of human minds, the infinite variation in neurocognitive functioning within humans.

Neurodivergent Sometimes abbreviated as ND, means having a mind that functions in ways which diverge significantly from the dominant societal standards of “normal.”

Neurotypical Often abbreviated as NT, means having a style of neurocognitive functioning that falls within the dominant societal standards of “normal.”

Neurodiverse A group of people is neurodiverse if one or more members of the group differ substantially from other members, in terms of their neurocognitive functioning.
(Dr. Nick Walker)

Autism A different neurotype/type of brain. It is not something a person lives with or a disorder but a different way of seeing and experiencing the world. An autistic person has different sensory, communication, social and executive functioning needs. Autistic people are not high or low functioning but all have different needs.

ADHD A different neurotype. 50–70% of autistic people are also ADHD. There are 3 types of ADHD – Hyperactive, Inattentive and Combined. An ADHD brain has different levels of certain hormones and neurotransmitters (Noradrenaline, Dopamine and GABA). Some people who are ADHD find medication can be helpful with executive function differences (impulsivity, emotional regulation, decision making, working memory, etc)

Glossary Continued

Monotropism Autistic brains are monotropic, which means they are pulled in more intensely, more strongly towards one or several interests. Constantly changing focus and not being able to hyper-focus on interests can be debilitating. Hyper-focusing can lead to what is called a 'flow state' and can help an autistic person to regulate and be very productive.

Double Empathy "Rather than describing autistic people as having an impaired 'theory of mind', Double Empathy explains autistic communication, interaction and empathy and how this differs to non-autistic people. It also explains why autistic people can feel othered, isolated and misunderstood, which in turn can lead to mental health problems". (Damian Milton)

Stimming This is anything that is stimulating (stimulates the nervous system) and is calming, brings joy, and helps regulate the sensory system or emotions. Every autistic person has different 'stims' - which might be dancing, clapping, clicking fingers, vocalising, stretching, singing, rocking, or tapping; there can even be visual stims too. All kinds of things can be stimming and it is to be encouraged (unless of course, a stim is dangerous or causing harm).

Alexithymia (Alex-ee-thy-mea) This means "having no words for emotions" and 50% or more of autistic people have alexithymia. It does not mean they don't have emotions, but it does mean they can struggle to identify, explain and express their emotions and the emotions of other people.

Sensory Needs Our 8 senses include: Sight, Hearing, Taste, Touch, Smell, Interoception (internal senses) Vestibular (movement and balance) and Proprioception (external senses). Autistic people can be hypo (under) or hyper (over) sensitive to different senses.

What Is Autism and Neurodivergence?



What is Autism?

There are numerous theories about what Autism is and sadly a lot of these theories are based upon medical and outdated models of Autism. These outdated theories are very pathologising.

A more 'neuro' affirming model, that most autistic people prefer –is to see autism as a brain *difference*, a different 'neurotype'. Being autistic means the person has a different way of experiencing and being in the world. There are theories explaining what autism is, that have been devised by autistic researchers and these are: Neurodivergence, Double Empathy and Monotropism.

It is also not just people raised male that are autistic, but people raised as female can be autistic too, although women and girls are often diagnosed later. It is also not uncommon for an autistic person to be both autistic & ADHD, with about 50-70% being both.

Just to clarify, autism is NOT:

A mental disorder

A mental health problem

Something that needs fixing

A problem a person has

Something that is mild or severe

High or low functioning

A syndrome

An abnormality or impairment

Being defective

Something you recover from

A childhood disorder

Something that causes the person distress or anxiety

All autistic people are considered vulnerable under the law and it is especially important that police officers recognise this, because in recent studies only half of autistic people who had contact with police, were considered to be vulnerable by the attending officers.

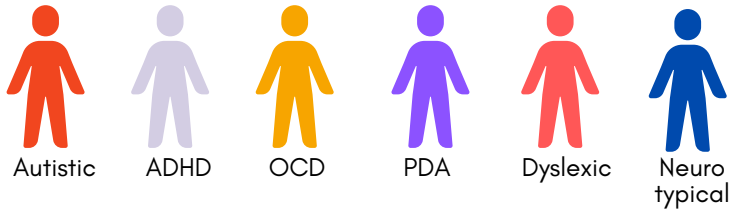
Neurodiversity and Neurodivergence Explained

Neurodiversity is the understanding that
we all have different types of brains (neurotypes).

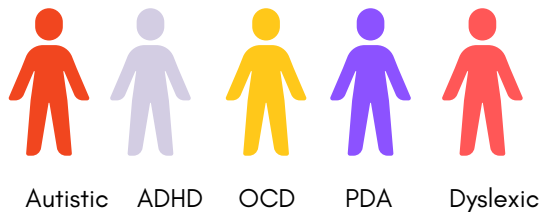
However, neurodivergent people (autistic, ADHD, PDA etc) are those
whose brains differ from neurotypical brains (people who are not
autistic, ADHD, PDA etc).

Many neurodivergent people are what's called multiply neurodivergent
for example autistic and ADHD, or PDA and OCD, etc.

This group of people are Neurodiverse



This group of people are Neurodivergent



(Not exhaustive lists)

Identity First Language

Autistic people prefer **identity first language**. By this I mean that autistic people do not 'have' autism but are autistic. Autism is not a condition or a disorder. An autistic person cannot experience anything or be anything other than an autistic person.

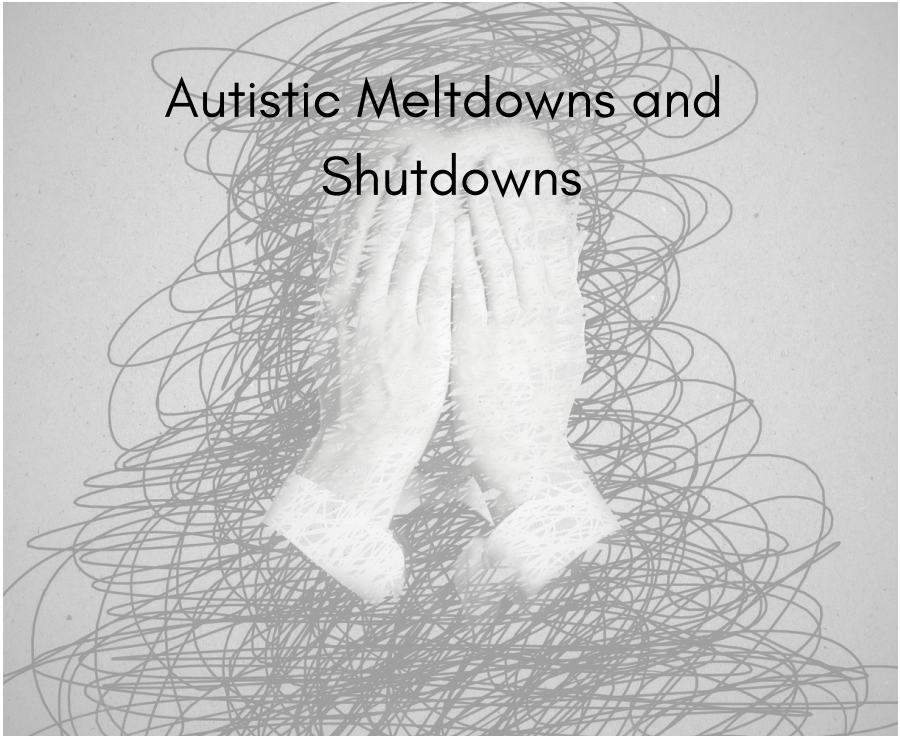
In the 2022 Autism Survey, by Chris Bonello ('Autistic not Weird'), he found that a very high percentage of autistic people prefer identity first language, compared to person first language, however, professionals and parents of autistic children, tend to use person-first language - saying a person 'has' autism.

An Autistic Brain is 'Monotropic'

Autistic minds are monotropic and this means that their minds have their attention pulled more strongly and intently towards a smaller number of interests at any given time, leaving fewer resources for other processes.

Being monotropic can mean that trying to focus on too much is challenging - including sensory input. Everything may be experienced more intensely. Filtering things out is more difficult. Sometimes an autistic person might be able to "tune things out and other times filter them out completely". Changing can not only be challenging but can throw them completely. "Switching tasks is hard and new plans take work. It is very common for autistic people to hyperfocus on concerns, passions and interests. It can be hard to get out of an attention tunnel ('monotropic flow') when you are in one and it can sometimes be distressing to leave it. It can be very hard to just drop things that are being intently focussed upon."

Autistic Meltdowns and Shutdowns



Main features of autistic meltdowns and shutdowns

F.E.A.R

F – Fight/Flight/Freeze

Its crucial to understand that the autistic person (diagnosed or undiagnosed) is very frightened, stressed and highly anxious and their nervous system is in fight/flight/freeze mode

E – Exhausted

Meltdowns and shutdowns are often a result of autistic burnout.

The individual is mentally, physically, emotionally exhausted and experiencing sensory overload

A – Anxious

The individual is very scared, anxious and overwhelmed – they are experiencing sensory and emotional overload

R – Recovery

Recovery time after a meltdown is needed, or the meltdown can escalate and the individual may go into a shutdown state (or from a shutdown into a meltdown)

What Are Meltdowns?

Meltdowns occur when the autistic person is **extremely** stressed and in fight/flight mode; meltdowns are not bad behaviour, attention seeking or tantrums. They are an **involuntary** reaction to a number of triggers, such as: fear, sensory or emotional overload, stress, anxiety, change, confusion, etc. The individual is very overwhelmed!

Long periods of autistic masking (hiding their differences as an autistic person) can also lead to meltdowns, and masking also leads to exhaustion. Other triggers can be: change, sensory overload and feeling overwhelmed by emotions.

Meltdowns can look very distressing, but they are far more distressing for the autistic person experiencing them. They are not panic attacks (although may be triggered by them). The autistic child or adult is very stressed and stressed; once in a meltdown, they cannot stop it from happening but need support.

Meltdowns might look like:

- Screaming,
- Shouting,
- Aggression,
- Pacing,
- Injuring self, hitting walls etc,
- Breaking, throwing things,
- Pacing around,
- Rocking,
- Banging head,
- Making threats
- Being rude or disrespectful
- Fleeing due to fear and distress
- Covering ears/eyes
- May be unable to talk/explain/hear

How To Approach An Autistic Person In A Meltdown Or Shutdown

- Approach quietly and calmly – low arousal (don't provoke)
- Do not react but stay neutral
- Keep movement to a minimum wherever possible
- Only one person supporting them at a time is best
- Do not shout at or scold the person. They are extremely overwhelmed, highly stressed and anxious.
- Do not get angry with them or threaten them with hospitalisation
- Do not touch them, as it can be very painful
- Do not ask lots of questions or give lots of commands and do not keep changing the subject
- Speaking/speaking too much may be triggering and overwhelming
- Do not try to make them talk
- Do not try to make them look at you as this may be extremely distressing
- They may not be able to process things you say to them
- Be patient
- You may need to gently repeat yourself as the individual may have a hard time hearing you
- They may not be able to speak
- Communication can be written down on paper as this might sometimes be easier for the autistic person
- Stay with them/nearby, but ask others to leave the room or area.
- Do not stand over them but sit beside or nearby at their level.
- Turn off any loud, overwhelming lights, noises, media and dim lights if needs be.
- Do not restrain them wherever possible – you could severely harm them and cause extreme pain.
- Explain things simply, clearly and concisely
- If arresting, if possible avoid cuffing and avoid the back of a police van, as these may cause pain and more fear and distress.

Important Things To Understand About Autistic Meltdowns

It is important to understand that, unlike tantrums, meltdowns are not a way of getting a need met, they are **not** goal-orientated. Once in a meltdown the autistic person **cannot stop or pull themselves together, or "snap out of it"**. Trying to stop the meltdown will cause more distress. Remember ALL autistic people are legally entitled to reasonable adjustments under the law

Sensory Needs:

Touch

Do not touch the person wherever possible, as any kind of touch can be very painful for autistic people, especially in a heightened state. Consider not using handcuffs if possible as again these may be very painful and distressing

Touch along with other triggers may get a very strong reaction. Do not misinterpret this reaction – the person is scared and in a heightened state.

Noise - avoid the blues and twos where possible

Flashing lights and sirens may be extremely triggering and distressing for an autistic person due to sensory sensitivity.

Keep noise to a minimum as much as possible, as noise may be heard more intensely by the individual. This can even be background noise which can make it hard for the autistic person to hear what is being said to them.

Allow them as much space as possible

Autistic people may feel very threatened by people being too close to them and may react strongly.

Stimming If the autistic person appears to be stimming and is rocking, or other repetitive movement/behaviour, then do not stop them doing this, as this movement is self-regulatory and a coping mechanism that can help calm them. So give them time and space to do this.

Eye contact This may be very uncomfortable for many autistic people, especially when they are experiencing a meltdown. For neurotypical people eye contact is body language that might communicate things like: "I am listening", "I am present" or "I can be trusted" etc. But many autistic people do not like eye contact and may in fact find it threatening and triggering. Do not misinterpret the lack of eye contact in an autistic person and also their facial expressions, which may seem odd, incongruent or flat.

Too many demands An autistic person may react very strongly to too many demands and expectations and too many questions; this may come across as being 'ignorant', rudeness, defiance, guilt, refusal, non-compliance etc. They are highly stressed and anxious and will not respond in the same manner as neurotypical people in the same situation. When an autistic person is extremely stressed, sensory channels will start to shut down – such as their hearing, so do not assume they are able to focus or hear what is being said to them.

Communication

Autistic people have differences in the way they communicate and process communication and so in your interaction with an autistic person you need to take the following into consideration:

Time Give plenty of time for the autistic person to stim and process information. You cannot stop a meltdown. Your job is to keep them safe, not to stop the meltdown (think of it like you would a seizure)

Questions Don't ask too many questions, talk too much or give too much information. They are overwhelmed.

Alternative Communication Consider other ways of communicating other than talking. Some autistic people may need visual aids. -some use something called AAC (Augmentative and Alternative Communication)

Speaking Some autistic people are non-speaking and some autistic people do not speak in certain situations/environments. When experiencing autistic shutdowns, autistic people often stop talking

Eye Contact Eye contact may be uncomfortable for the autistic person

Being literal Autistic people can sometimes interpret things said to them literally. So do take this into account as ambiguity can be confusing. In a meltdown an autistic person may not know how to interpret certain instructions that may be contradictory and confusing.

Processing It is important to give plenty of time for the autistic person to process information. Be very patient. In a meltdown they may not be able to process things said to them, or even hear them at all! Sensory channels shut down and this may last for a while until the individual is calmer. Even when calmer, remember their way of experiencing senses will be different to a neurotypical person. It will take time for the person to return to a calmer state again, maybe up to 90 mins or more. They may feel tired afterwards and may also feel very ashamed and guilty. Be supportive and let them know it is not their fault

Trigger Words Particularly in a meltdown an autistic person may find certain words very triggering and (some more than others) may find you saying "No!" difficult. Try to avoid "Should", "Must", "Have to" "Need to" as in the midst of a meltdown these words may be hard for the autistic person to cope with.

What To Do When An Autistic Person Is Experiencing A Meltdown?

These are some of the most important things to remember when engaging with an autistic person experiencing a meltdown. I appreciate there may be times when restraint may be necessary, because of significant harm to self and or others. It's crucial to understand that touch can be very painful for many autistic people and especially challenging during meltdowns.



Do not touch the person unless essential as it could be painful



Do not restrain wherever possible



Sit next to them -if possible but do not stand over them



Try to limit speaking, esp questions



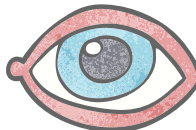
Do not shout at them. Be gentle and calm



Stay calm and remember they are scared



Where possible one person to engage with the person



Avoid direct eye contact where possible



Give them plenty of time

What Are Autistic Shutdowns?

Shutdowns happen when the autistic person is in 'freeze' mode. The same triggers for meltdowns can lead to shutdowns (and meltdowns can lead to shutdowns). A person experiencing autistic burnout will shutdown more than they usually do. The person is very stressed, but has no energy and may seem very low in mood and withdrawn. It is common for an autistic person in shutdown to not be able to talk. Shutdowns can go unnoticed, as they do not look like explosive meltdowns. However, they are feeling the same level of stress and anxiety, as they do in meltdowns, but present as withdrawn and frozen. They are overwhelmed, and exhausted and need a low demand, low arousal approach to help them get back to a place of calm. Don't try to make them talk or communicate with you as this will only cause more distress.

Shutdowns might look like:

The autistic person stops talking/cannot talk

The autistic person may not be able to communicate

Cannot engage

Very withdrawn

Foetal position

Rocking

Hitting themselves

Dissociation – disconnected

Feeling numb

Zoning out

The person cannot focus (may not be able to focus on what you say)

Low mood

The person is exhausted

What Triggers Meltdowns And Shutdowns?

This is not an exhaustive list, but some major examples

Stress There are many physical, environmental, emotional and psychological triggers for stress but for autistic people there are many other things that can cause stress, including too much socialising, masking their differences, too much sensory input, discrimination and ableism.

Social Hangovers Autistic people can find too much socialising exhausting, especially in neurotypical environments.

Sensory Overload Autistic people often experience sensory overload and even sensory deprivation. They may be hyper or hypo sensitive to certain noises, bright lights, certain textures, smells, etc. Sensory overload can eventually trigger meltdowns.

Anxiety Sensory overload, too much socialising and long periods of masking can lead to anxiety building up. It can be very hard for autistic people to sometimes regulate their emotions and high levels of anxiety can trigger meltdowns.

Autistic Burnout In autistic burnout the person can experience increased meltdowns and shutdowns too.

Emotional Overwhelm Because it can be harder to regulate emotions, they can become overwhelming.

Transitions/Change Autistic people can find change difficult and can find constantly changing focus debilitating. Major life transitions can be particularly difficult (puberty, menopause, death of someone, leaving school, college or university, moving house or country, relationships ending, etc)

Gender Dysphoria An autistic trans or non-binary person may experience gender dysphoria when they are misgendered for example. This can be very distressing.

Autistic Burnout



What Is Autistic Burnout?

The Royal College of Psychiatrists describes autistic burnout as "a state of exhaustion, associated with functional and cognitive deterioration and an increase in autism symptomatology, as a consequence of coping with social interaction (including masking) and the sensory environment. It may be a short-lived state (as at the end of a working day), relieved by a relatively brief withdrawal from the stress. However, longer and more severe stress can produce a more sustained state (which entails some form of innate change) which has to wait on its natural remission. It overlaps symptomatically with anxiety and depression, and there may be a heightened risk of suicide." (Royal College of Psychiatrists, The psychiatric management of autism in adults.).

Autistic burnout is a 'state' of pervasive exhaustion and sensory overload, that can lead to an extreme crisis. As many as 80% of autistic people, children and adults, can experience burnout (Autism Survey 2022, Chris Bonello, 'Autistic Not Weird'), sometimes on a daily low-level basis. It can also be cyclical. There is no 'official' way to describe levels of autistic burnout, however, there is definitely a level described by Keiran Rose (The Autistic Advocate) as "extreme burnout". I would describe this as extreme burnout 'crisis'.

Essentially, when the needs of an autistic person are not met, they can experience burnout and this affects every aspect of the individual's psychological, behavioural, physical, sensory and emotional being. The autistic person's brain is in a chronic state of survival mode (feeling unsafe) and this can be devastating for the individual if it persists. When an autistic person is experiencing burnout, they will feel drained, exhausted, spent and that they have "no resources left to cope with or manage daily life" (Raymaker et al, 2020).

Signs Of Autistic Burnout

Exhaustion

The autistic person is experiencing fatigue that affects every aspect of themselves (physical, psychological, emotional, sensory). They have no resources.

Mood

You may see more mood swings and changes to their moods compared to how they usually present. They may also be more withdrawn and seem very low.

Anxiety

Anxiety levels may increase significantly. –they are in survival mode. Some signs of anxiety can be irritability, struggle to focus, headaches, stomach aches, and vomiting.

Self care and sleep

You may see a change in their eating patterns – more restricted or increased/eating at night etc. You may find their self care changes also.

Sleep may have changed and they might struggle to sleep at their normal time.

Loss of executive function skills

Executive function skills such as decision making, impulse control, emotional regulation, working memory, and other skills can be lost during burnout

Sensory overload & deprivation

Sensory overload is not just a trigger for autistic burnout, but it can become heightened during burnout. The autistic person will experience increased sensory overload, but may also increase sensory seeking.

More meltdowns & shutdowns

In burnout an autistic person can experience significantly more meltdowns and shutdowns

Common Characteristics Of Autistic Burnout

- Fatigue/ exhaustion (mental, physical, emotional) May be very extreme
- Increased sensory overload
- Loss of skills such as working memory, flexibility, focus, emotional regulation, self monitoring, impulse control, planning, organisation, task initiation
- Increasing meltdowns and shutdowns
- Worsening mental health
- Intrusive and suicidal thoughts in many cases
- Increased anxiety
- Situational lack of speech -shutdown/survival mode
- Self harm in many cases (starts or increases)
- No energy left to mask their differences, so more 'autistic traits' may be more obvious

Other Signs

Auditory processing difficulties

Decreased or increased sensory seeking

Headaches/migraines

Difficulty with: memory, emotional control, impulsivity, motivation-organising, decisions

Dissociation

Feeling numb

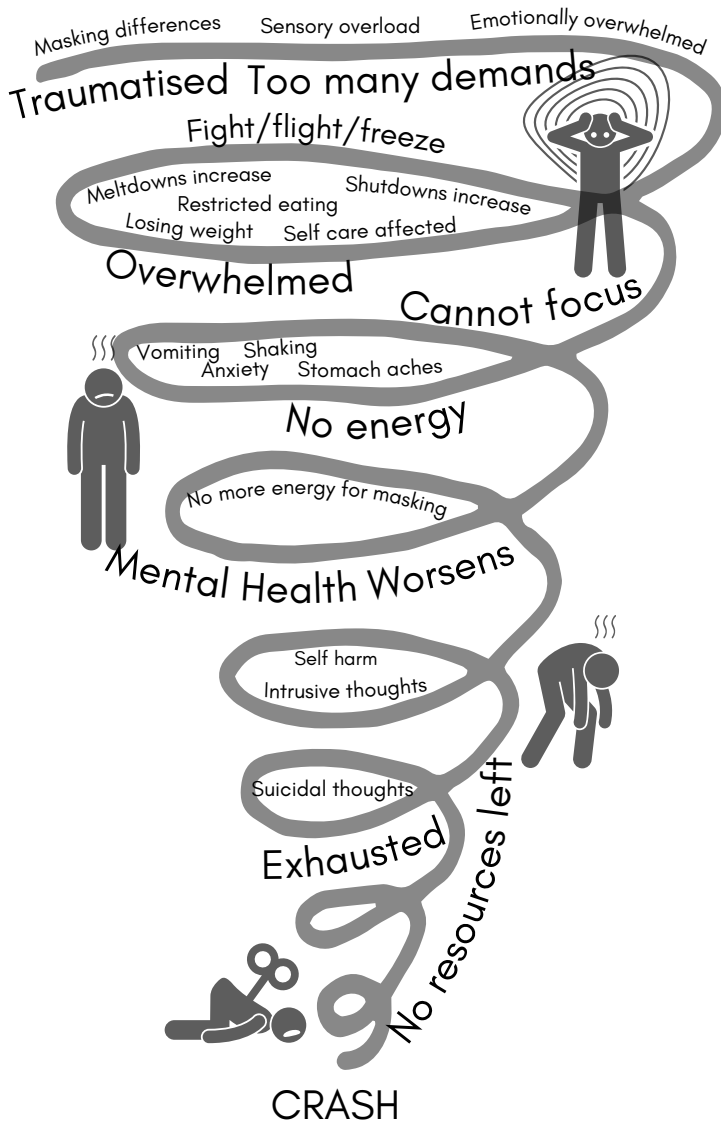
Demand avoidance

Struggles with communication- speaking, texting, online communication, phone calls etc

Self care affected

Not eating/eating less

Losing weight



Extreme Burnout Crisis

In burnout, an autistic person (and particularly an AuDHD* person) may enter into a cycle that can include very distressing meltdowns and shutdowns, drink and drug use, hallucinations and even hyper- mania.

The hallucinations can also be linked to sensory overload.

In this burnout state the autistic person may feel very paranoid and threatened and may make threats, including threats to kill others.

Remember their brain is in survival mode and they are exhausted, extremely scared, anxious and stressed. The following image is based upon what is known as Monotropic Spiral, which was a term coined by Tanya Adkin and David Gray-Hammond, who have written extensively about this issue (see references)



*AuDHD - a person who is autistic and ADHD

Hallucinations

When experiencing an extreme autistic burnout crisis, autistic people, including young people, can have hallucinations. Researchers have found that Autistic people are up to 3 times more likely to have hallucinations.

These do not necessarily indicate Schizophrenia, as many mistakenly believe. Autistic people can have co-occurring mental health conditions, such as Schizophrenia, but it is important to **not** assume hallucinations and psychosis are an indication of Schizophrenia.

Hallucinations can be linked to extreme sensory overload and I have described them as **very loud intrusive thoughts**. Because an autistic brain is 'monotropic', these intrusive loud thoughts can be focussed upon very intensely and the autistic person may find it very hard to think about anything else. This can be extremely distressing. These intrusive thoughts may be very demanding in nature and may be experienced for example as a person telling them that they *should* do something that maybe they are struggling to do because it is an expectation.

Many autistic people are misdiagnosed because of these experiences.

The fact of the matter is that they may be experiencing burnout and they are exhausted, overwhelmed and need to rest their mind. This can be hard because autistic minds, especially autistic people who also are ADHD. They may find that their minds never stop! This is why hyperfocussing on passions and interests can be regulating and grounding, as it helps focus the thoughts. Many people who are ADHD also take medication, which helps with executive functioning in the brain.

What Will And Won't Help An Autistic Person In Burnout Crisis

In a state of extreme burnout crisis it is important to understand that the autistic person is extremely overwhelmed and may need help and support. They have no resources left, they are exhausted and may be a risk to themselves, especially if they are having intrusive and suicidal thoughts. The person is traumatised and they may also be hyperactive and even in a manic state. Sometimes they do need a safe place to be, with people who understand autism and their particular needs.

It is very common for autistic people to reach out for drink and drugs (or more drink and drugs if they are already a drug user or have issues with drinking) when they are not coping and particularly people who are ADHD.

The same is true of people who may have a past diagnosis such as EUPD (Emotionally Unstable Personality Disorder) or Bi-Polar, etc and actually, they are autistic and misdiagnosed. It is of course possible to be autistic and have things like Bi-Polar or EUPD.

Many people however have found that a misdiagnosis rather than an autism diagnosis, meant they did not get the help they actually needed and could not explain why they kept reaching crisis point. Getting an autism diagnosis has for these people meant they had more understanding about themselves and what leads to burnout and into crisis. Knowledge is power.

Autistic Burnout Is NOT depression

Although autistic burnout can share many similarities with the symptoms of depression and can lead to depression, it is not however in itself 'depression'. (Autistic people in burnout can often be misdiagnosed as being clinically depressed). It is very common for autistic burnout to be missed as it is being overshadowed by other things they have been misdiagnosed with, such as Bi Polar or EUPD etc.

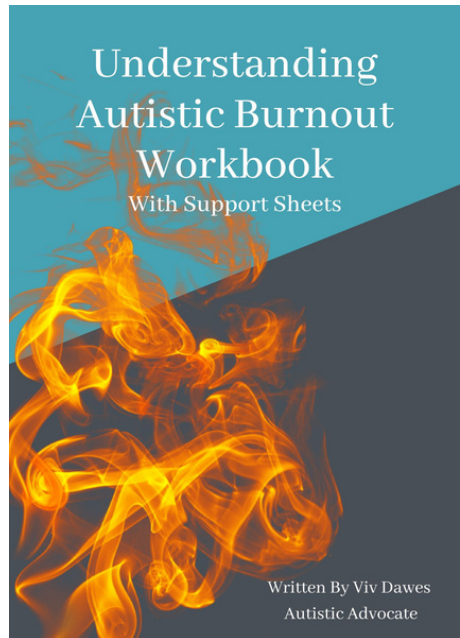
Autistic burnout does not respond to treatment for depression such as typical talking therapies and medication. Medication might help the person with anxiety and depression, but it will not directly help the symptoms of burnout. Many unadjusted talking therapies may also actually exacerbate burnout as the individual will be required to talk and this can be exhausting. (Unadjusted talking therapy means it is not adjusted for an autistic person and will not be neuro affirming, or take into account the autistic person's sensory, executive functioning, emotional, communication and social needs.)

The individual needs to rest their mind and body, not engage in more talking/interaction, especially if that therapy is not adjusted for autistic people. The wrong help could use up more of their energy and continue to make them exhausted. Resting when extremely agitated and hyper-manic is going to be very challenging and they will need support around this.

Once an autistic person has reached a place of severe burnout crisis then an urgent care package of some kind may well be needed and safeguarding taken into consideration. They may also not be eating properly if at all and may not be safe to be on their own. If there is undiagnosed ADHD, they may need medication for this, so a referral for an assessment should be considered if ADHD is a possibility. (The Right To Choose Pathway may be quicker)

Available From My Website To Download And Purchase
<https://www.autisticadvocate.co.uk/>

A pdf guide to purchase and download: A workbook that looks at autistic burnout in detail, such as what burnout is, what the causes are, what signs and what helps or hinders the autistic person. This is also available in a book format from Amazon



Autism support cards that explain briefly that the individual is autistic, what this means and what support they might need. Also available are autistic burnout support cards which explain autistic burnout and how to support the individual.

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