Autistic Burnout & Extreme Burnout Crisis

Understanding Autistic Burnout and
Extreme Burnout Crisis in
Autistic Young People And Adults

Viv Dawes Autistic Advocate

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Introduction

I have produced this booklet for anyone wanting to understand Autistic Burnout and Extreme Burnout Crisis, but especially any professionals working/caring for Autistic people and their families.

My name is Viv Dawes and I am an Autistic advocate, trainer and author. I have over 25 years experience of working with extremely vulnerable young people and adults including within the NHS as a Senior Practitioner, managing teams of forensic drug workers in women's prisons.
Much of my work over the last few years has been around training parents, individuals and professionals in what Autistic Burnout is. I have written several books and have trained hundreds of people, helping them understand what Autistic Burnout is and what helps the individual with recovery.

Autistic Burnout is a serious and debilitating experience for any Autistic person and must be taken very seriously by anyone caring for, supporting or working with the individual. Getting the wrong support can significantly affect the possibility of recovery.

I am not a medical professional. What I write is from lived experience and experience of working with neurodivergent individuals. Any person reading this experiencing Autistic Burnout or Extreme Burnout Crisis should seek professional support and advice.

If you need support because you are struggling with your mental health, here are some organisations that support people in crisis.

If you need urgent medical help then always call 999

- www.autisticmentalhealth.uk - support around mental health for autistic people
- Samaritans - to talk about anything that is upsetting you, you can contact Samaritans 24 hours a day, 365 days a year by calling 116 123 or jo@samaritans.org
- Papyrus -if you're under 35 and struggling with suicidal feelings, or concerned about a young person who might be struggling, call 0800 068 4141 or email pat@papyrus-uk.org, text 07786 209 697.
- National Suicide Prevention Helpline UK - 0800 689 5652 (6pm–3:30am every day).
- Shout - If you would prefer not to talk but want some mental health support, you could text SHOUT to 85258. Shout offers a confidential 24/7 text service providing support if you are in crisis and need immediate help.

If you have difficulty hearing or speaking, it might help to use the Next Generation Text Service (NGTS) Typetalk/Text Relay app on a mobile device or computer.

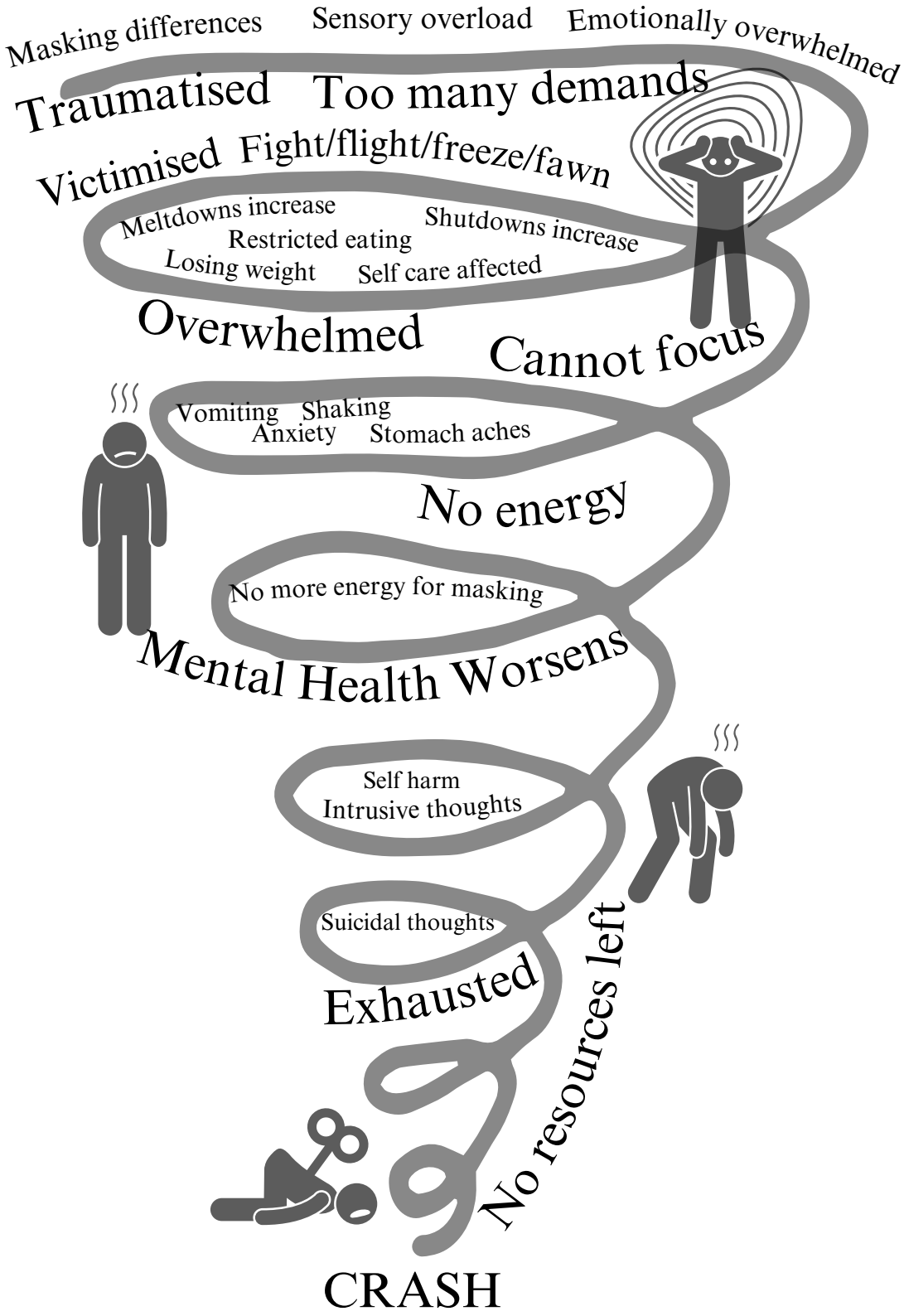
Autistic Burnout

The Royal College of Psychiatry 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.
Its anecdotal basis and the lack of systematic research mean that burnout does not have the status of a formal syndrome or disorder. Nevertheless, the concept captures the need to consider the effect of adjusting somebody's setting, support, and style of life before assuming their malaise to be a recognised psychiatric disorder." (Royal College of Psychiatrists, The psychiatric management of autism in adults.).

In a 2021 research paper published, the researchers Samual Arnold and Julianne Higgins et al, described Autistic Burnout as " a severely debilitating condition with onset preceded by fatigue from camouflaging or masking autistic traits, interpersonal interactions, an overload of cognitive input, a sensory environment unaccommodating to autistic sensitivities and / or other additional stressors or changes. Onset and episodes of autistic burnout may interact with co-occurring physical and / or mental health conditions". Arnold, Higgins et al, (2021) "Defining autistic burnout through experts by lived experience".

Autistic burnout is not like occupational burnout, in that it's caused by overworking or studying, etc. Autistic Burnout is the result of an individual experiencing prolonged exposure to environments that are not inclusive and not adjusted for an Autistic person's needs. Dr Luke Beardon from Sheffield Halllam University talks about "Autism plus environment = outcome". In other words seeking to change Autistic people is not the answer to preventing things like burnout and Autistic people reaching crisis, it is not about teaching Autistic people neuro'typical' social skills or coping skills but it is about adjusting environments and the systems within them, to make them more suitable for Autistic people.

Autistic Burnout is "A state of physical and mental fatigue, heightened stress and diminished capacity to manage life skills, sensory input and social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with your needs" Judy Endow (www.judyendow.com/advocacy/autistic-burnout/)



The Most Common Characteristics of Autistic Burnout

Cannot focus on interests/passions
Demand avoidance increasing
Dissociation
Difficulty with: memory, emotional regulation, impulsivity, motivation, organising, decisions, focus, brain fog (executive functioning skills)
Fatigue/exhaustion
Find it hard/harder to communicate my thoughts and feelings
Hallucinations
Headaches/migraines
Increased anxiety
Increased sensory seeking/stimming
Intrusive thoughts
Irritability
Less tolerance for other people/withdrawal
Losing weight due to restricted eating
Meltdowns increased
More rigidity in thinking and less able to be flexible
Regularly experiencing mental/emotional overwhelm
Rejection sensitivity dysphoria increasing
Self-harm
Sensory overload
Shutdowns increased
Sleeping less
Sleeping more
Stopped doing things I enjoy
Struggling more with communication – speaking, texting, online communication, phone calls
Struggling to motivate myself to do my usual activities
Struggling to go out
Struggling with self-care – washing clothes, showering, brushing hair/teeth, eating adequately
Suicidal thoughts

Misdiagnosis of Autistic Burnout

Many Autistic people (children or adults) are only identified as Autistic once they reach crisis point; this is why early identification and diagnosis is so crucial if we are to help Autistic people avoid crisis. Many Autistic people are misdiagnosed with things like EUPD before they are identified as Autistic (especially girls, women and people raised female). There are crossovers between Autism and personality disorders such as EUPD but too many Autistic people are misdiagnosed, which can mean they are more likely to hit crisis in many cases, as the approaches for supporting someone who has EUPD will too often not help an Autistic person and especially if they are in burnout.
Autistic Burnout features are often misdiagnosed as EUPD traits by clinicians. There are also crossovers with depression and although there are similarities (and for many burnout can lead to depression), if burnout is treated as depression it can mean the individual's experience gets worse, far worse. Autistic Burnout will not respond to many of the things that can be suggested as treatments for depression such as talking therapy. medication or group therapy. This will mean potentially exhausting them even further.

“In some cases, marginalised Autistic people get stuck with mental health diagnoses that are even more reviled and misunderstood than Autism is. It’s quite common for Autistic women to be incorrectly labelled with Borderline Personality Disorder (EUPD) ... This is a really disastrous diagnosis [and] is many therapists’ least favourite condition to work with.” (Dr Devon Price, 2022 “Unmasking Autism - The Power of Embracing Our Hidden Neurodiversity”).

“Its anecdotal basis and the lack of systematic research mean that burnout does not have the status of a formal syndrome or disorder. Nevertheless, the concept captures the **need to consider the effect of adjusting somebody’s setting, support, and style of life before assuming their malaise to be a recognised psychiatric disorder.**" (Royal College of Psychiatrists, The psychiatric management of autism in adults.).

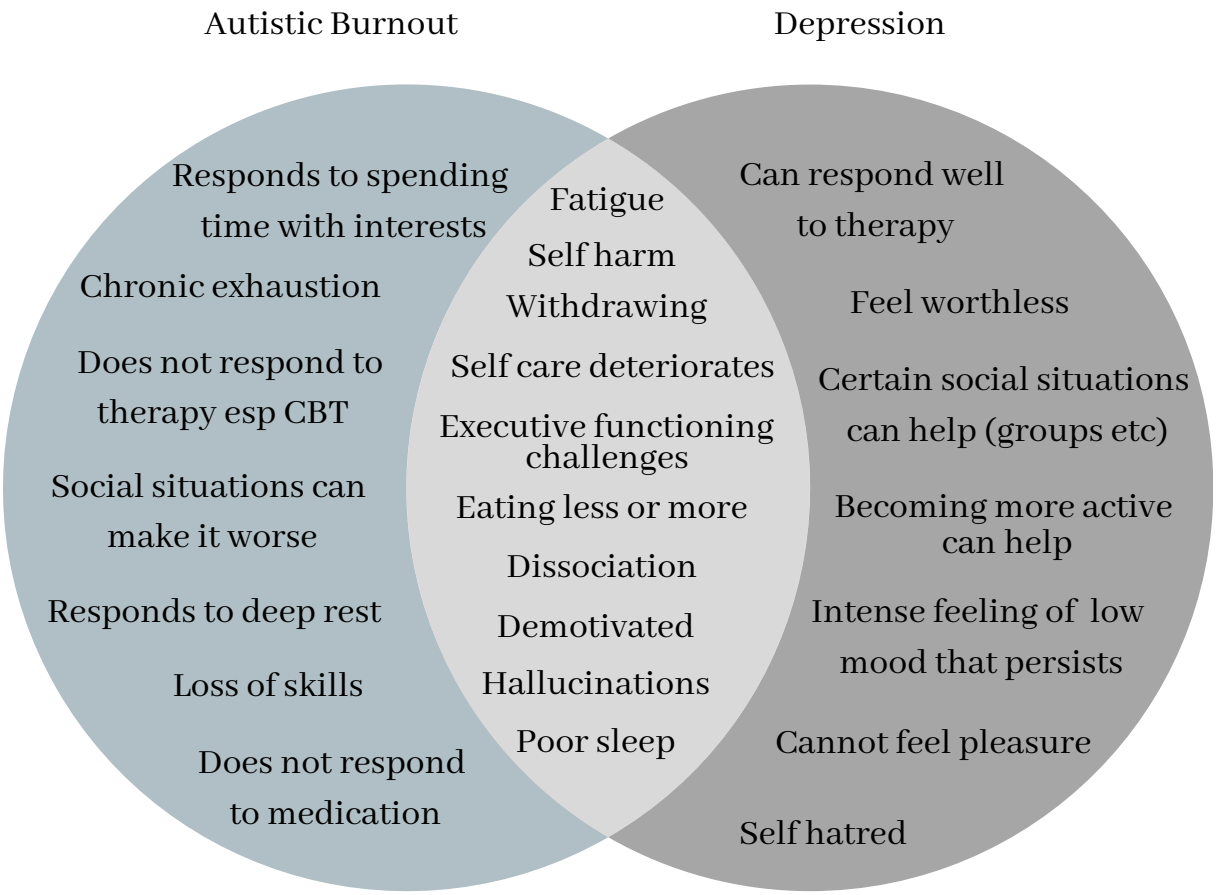
“Autistic burnout is a debilitating syndrome preceded by an overload of life stressors and the daily challenge of existing in a neurotypical world, frequently misdiagnosed as depression, anxiety, bipolar disorder, borderline personality disorder or other conditions” (Arnold, Higgins, Weise, Desai, Pellicano, Trollor, (2023). “Towards the measurement of autistic burnout”).

It is important to point out that not all Autistic people have a diagnosis and may self identify. Getting a diagnosis is a privilege for many due to the cost of private assessments and the long waiting lists. Self identification is valid and should always be respected and taken seriously.

For More Information About Autism And Misdiagnosis:

- Dr Judy Eaton: https://aspireautismconsultancy.co.uk/autism-personality-disorder-misdiagnosis-and-stigma/
- Laura Fusar-Poli, Natascia Brondino, Pierluigi Politi, Eugenio Aguglia. (2020) “Missed diagnoses and misdiagnoses of adults with autism spectrum disorder”https://www.researchgate.net/publication/344138171_Missed_diagnoses_and_misdiagnoses_of_adults_with_autism_spectrum_disorder
- Regarding the difference between burnout and depression: https://studentlife.lincoln.ac.uk/2021/05/18/the-difference-between-autistic-burnout-and-depression/
- Adult Misdiagnosis: https://thinkingautismguide.com/2022/10/adult-misdiagnosis-the-default-path-to-an-autistic-identity.html

The Crossover Between Autistic Burnout & Depression



What Causes Autistic Burnout?

The <u>main</u> causes of autistic burnout are

- Prolonged masking- which is exhausting
- Sensory overload
- Too many demands and expectations that outweigh the individual's capacity to manage them.

Being Autistic means having a different kind of brain (neurotype) and living in a world that is mainly designed for the predominant type of brain (neurotypical) is hard; it leads to the *different* needs of Autistic people often being unmet. There is also a great deal of stigma, ableism and misunderstanding surrounding Autism and this leads to many Autistic people masking their differences. This can take the form of:
Fawning (people pleasing)
Hiding differences, stims and interests
Mimicking and copying
Camouflaging

Autistic masking is mostly subconscious. It is also exhausting and significantly affects mental well being, as it means the Autistic person will often push themselves beyond their comfort zones, will hide distress caused by things like sensory overload, suppress stimming, be compliant and fit in to appear more *acceptable* (according to neurotypical, neuro-normative standards).

When the prolonged demands of an environment outweigh the Autistic person's capacity, it can lead to stress, overwhelm, trauma and to burnout. Those demands can be many things including:

Sensory overload (or even deprivation)
Too many expectations
Having to switch focus too often
Interrupted flow states (unable to hyperfocus on interests)
Neurotypical social and communication expectations that lead to Autistic people masking
Too many people in an environment
Too much information
Not having enough autonomy
No flexibility/time for different processing
Transitions/ too many changes
Lack of understanding by others
Lack of/not enough structure and predictability
Not understanding need for movement and spontaneity for some

Research Papers Published On Autistic Burnout

"Having All of Your Internal Resources Exhausted...

www.liebertpub.com

Towards the measurement of autistic burnout - Sam...

journals.sagepub.com

Confirming the nature of autistic burnout - PubMed

pubmed.ncbi.nlm.nih.gov

(PDF) A conceptual model of risk and protective f...

www.researchgate.net

https://www.autismcrc.com.au/sites/default/files/reports/3-076RI_Autistic-Burnout_Final-report.pdf

www.autismcrc.com.au

Interoception And Alexithymia

'Interoception is the perception of sensations from inside the body and includes the perception of physical sensations related to internal organs function, such as heart beat, respiration, satiety, as well as the autonomic nervous system activity related to emotions.' Price et al (2018)

”Interoceptive awareness is your body's ability to interpret if you're hot, cold, hungry, thirsty or in pain. If you can't work out how you feel you won't be able to regulate your sensory system and consequently your emotions will also be dysregulated. In a dysregulated state autistic people are more likely to experience meltdowns and shutdowns, as their capacity to manage will be outweighed by all the other demands of being in a state of confusion due to difficulties with interoception awareness and alexithymia. It's all linked, it's all connected, not understanding this or not having ways to support managing it can seriously impact mental health and the ability to have a good quality of life. The combination of being multiply neurodivergent and having interoception processing difficulties is complex.“ (Autistic Realms, https://www.autisticrealms.com/)

The word 'Alexithymia' comes from Greek, meaning 'no words for emotions'. A person with this **does** have emotions, but struggles recognising them, explaining/describing them or expressing them. It can also make it harder for some Autistic people to understand emotions in others (tone of voice, facial expressions etc).
It is not just Autistic people who have alexithymia, but it is however very commonly experienced by autistic people (as many as 60% of Autistic people can have it in varying degrees).

An Autistic person with alexithymia is more likely to have interoception differences, which can together increase the chances of mental health difficulties. It can also mean that an Autistic person does not recognise things like anxiety or exhaustion.

An AuDHD person (Autistic and ADHD) with alexithymia may be more likely to struggle with impulsivity, substance use, and anxiety, they will struggle more to regulate their emotions. You cannot regulate if you don’t recognise you are experiencing something like anxiety or depression.

Sensory Overload Can Lead To:

- Angry outbursts
- Anxiety levels increase
- Banging/hitting head
- Body temperature changes
- Bumping into things
- Cannot communicate
- Cannot focus
- Clumsiness
- Confusion
- Covering ears due to auditory sensory overload
- Difficulty processing thoughts/brain fog
- Distress
- Disorientated
- Distracted
- Dissociated
- Exhaustion
- Finding it hard to make decisions
- Headaches/Migraines
- Heart beating faster
- Increased masking
- Increased stimming
- Irritability, frustration, anger
- Meltdowns and shutdowns
- Not talking or changes in communication
- Rocking
- Stammering
- Wanting to run, escape, leave

Extreme Burnout Crisis and Burnout Spin

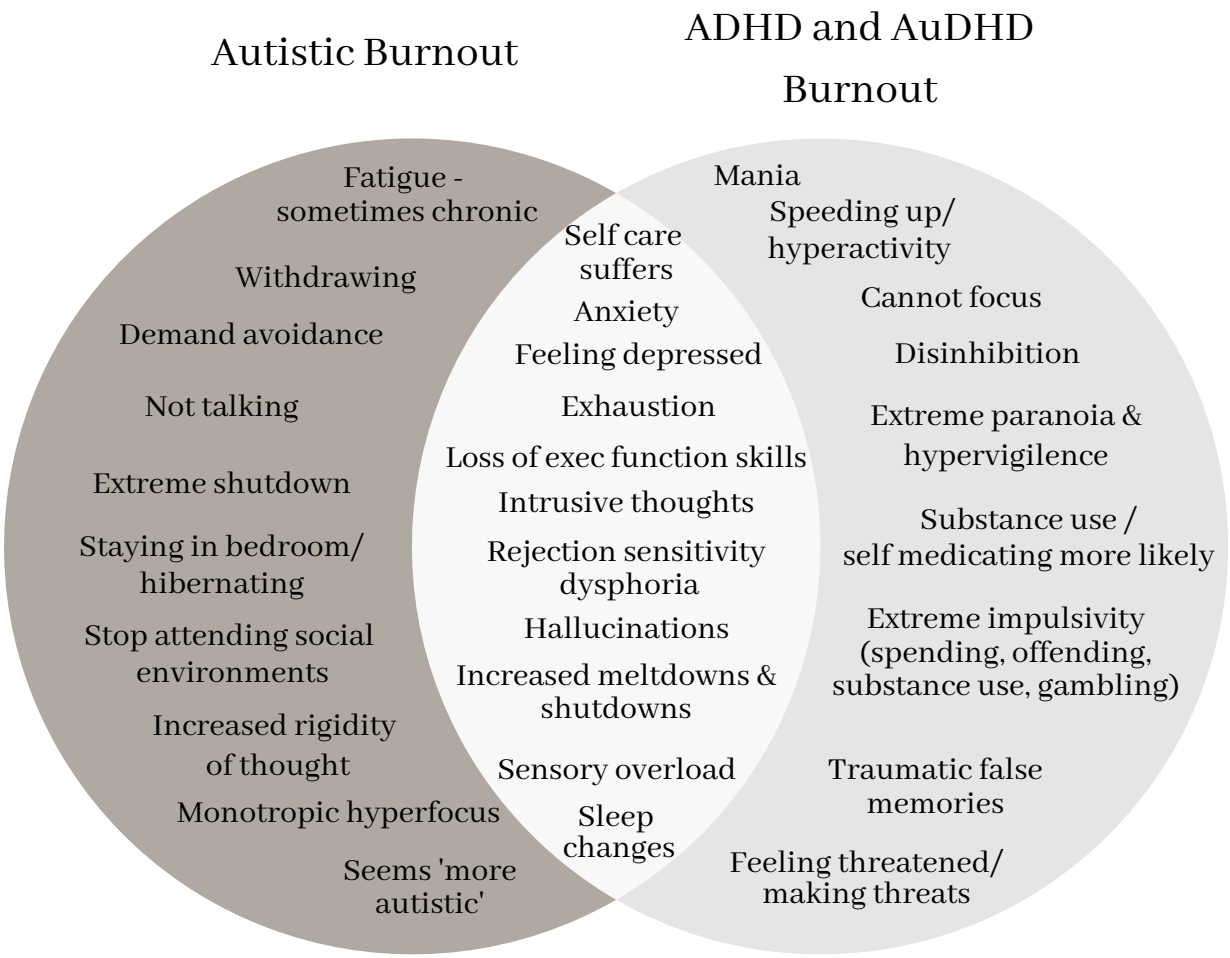
For some Autistic people, who may also be ADHD, known as 'AuDHD', their experience of burnout can present differently and they may experience Extreme Burnout Crisis; this can have very severe consequences. Their presentation may include hallucinations and they may seem manic. 50-70% of Autistic people are also ADHD (and some are prescribed ADHD medication). Executive functioning is one of the main differences in an ADHD brain, particularly due to lower levels of Dopamine and Noradrenaline. Executive functioning includes emotional regulation, decision making, planning, working memory, self control, task initiation etc. Many associate hyperactivity with ADHD but hyperactivity is not just about physical hyperactivity but mental also, "Hyperactivity in ADHD can be very misunderstood. It does not always look like someone constantly on the go or acting as though they're driven by a motor. A person can be physically exhausted, laying on the couch, and still be hyperactive in their thoughts." Jillian Enright, Founder of Neurodiversity MB.

Being AuDHD can mean it is hard to stop and rest, due potentially to constant churning, racing thoughts; add to this the executive functioning differences (due to biochemistry). Those racing thoughts might also be stuck intrusive thoughts, that are really hard to shift and can be very distressing. Because Autistic and AuDHD brains are more likely to be Monotropic, they focus intensely on fewer things. In monotropic attention tunnels it can be very intense (and things outside the attention tunnels become muted) and that might also mean intrusive thoughts are also intense. For those autistic or AuDHD people who have Alexithymia ("no words for emotions"), poor recognition of their emotional state means they might not be in touch with not only their emotions but also things such as how exhausted they are. This is exacerbated by the fact that those with Alexithymia are also likely to have more challenges with interoception.

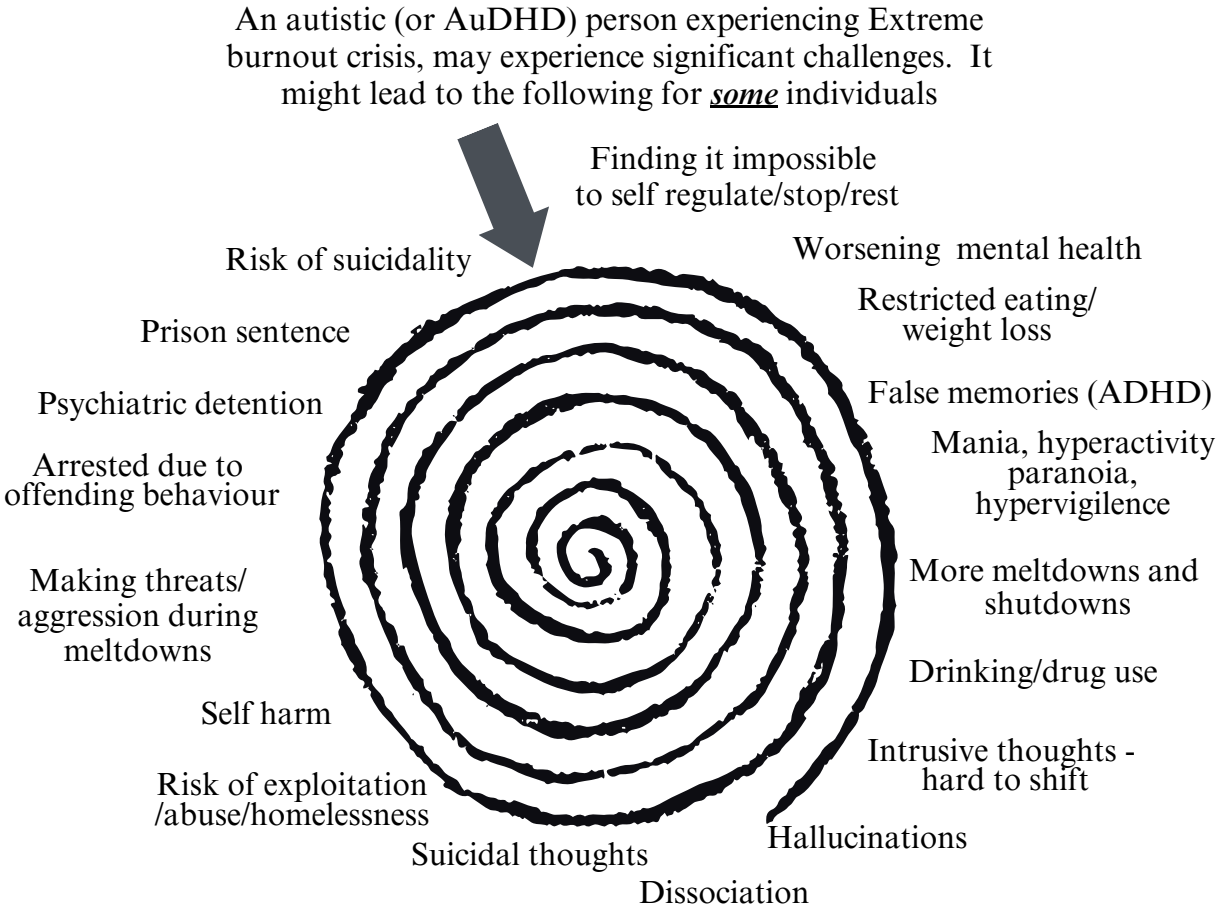
In a state of Extreme Burnout Crisis, some may find themselves and their lives spinning significantly out of control. I call this Extreme Burnout Spin. They are likely to experience more meltdowns and shutdowns and their meltdowns will be very distressing for them, although for others these may seem very aggressive. It is vital to understand that Autistic meltdowns are NOT tantrums or the person trying to get their own way or manipulate. (See further on for info re meltdowns).
This crisis could for some also be exacerbated by any substance use/ alcohol use. If the individual is using substances this can make them more anxious and paranoid and will add to their intrusive thoughts, possible hallucinations and could lead to drug induced psychosis. It is however important to not assume an individual is using substances but there is a increased chance of substance misuse in ADHD and AuDHD individuals. The individual can present as very chaotic, impulsive and manic. They may be experiencing very intrusive and suicidal thoughts and may even experience false memories. False memories can be completely false memories of something traumatic or can be based upon something that has happened to them in the past but not as they are describing.

Differences between Autistic and AuDHD Burnout

An Autistic or AuDHD person's experience of burnout does not mean they will experience *everything* in this Venn diagram, but it shows you the differences there can be when an Autistic individual is also ADHD and in burnout.



Extreme Burnout Spin



The infographic above mentions psychiatric detention and this is something that many Autistic people who have reached crisis have experienced. Sadly psychiatric units often do not help them in burnout as they are not a suitable environment - Autism is not a mental disorder. However there are times when the only way to help an individual stay safe is in a unit. The staff in a unit must try to accommodate the *different* needs of the Autistic person - their sensory, social and communication needs and recognising the individual is anxious, exhausted, overwhelmed and overstimulated.

It also mentions prison because neurodivergent people are disproportionately more likely to end up in prison/involved with the criminal justice system, (especially those who are ADHD or AuDHD). In a state of crisis an Autistic/AuDHD person may sometimes make threats during a meltdown, these can be **misinterpreted** and can lead to police involvement, arrest and in some cases ending up with a prison sentence (because of the seriousness of the threats made and behaviour of the individual).

Suicidal thoughts can be very common, especially in crisis and with suicide being the leading cause of early death in Autistic people- I cannot stress how important it is to support an Autistic person in crisis (who may also be extremely isolated) to feel safe, particularly by understanding what their needs are as a neurodivergent individual.

Hallucinations

When experiencing an extreme autistic burnout crisis, autistic people, including young people, can have hallucinations. Researchers have found that Autistic people are actually up to 3 times more likely to have hallucinations. Hallucinations can be linked to extreme sensory overload and differences in brain chemistry (for example differences in GABA levels). They are also linked to experiences of isolation and bullying: Psychology researchers at Sunderland University (including Kieran Rose and Dr Amy Pearson), in their 2022 study, "found high rates of interpersonal violence and victimisation within personal relationships. The trauma of victimisation led to high levels of masking within relationships which often led to exhaustion and burnout".

For some people hallucinations can be a sign that they are extremely stressed and starting to experience burnout. Hallucinations can be auditory, tactile or visual and I have described auditory hallucinations as sometimes being **very loud intrusive thoughts**. "Other abnormal perceptions include strange body sensations such as experiencing a burning sensation and strange feelings in the body, hearing one's own thoughts or fearing those near you can hear your thoughts" (Dr Neff, neurodivergentinsights.com). Some Autistic people describe experiencing strange sensations, seeing shadows, feeling burning sensations and experiencing seeing/feeling spiders. Feeling and seeing spiders can be a sign of extreme anxiety (seeing and feeling spiders is common in people who have used stimulant drugs known as 'coke bugs' due to extreme anxiety, paranoia and dopamine imbalance). It's common for people to experience hallucinations just as they're falling asleep (hypnagogic), or as they start to wake up (hypnopompic). (https://www.nidirect.gov.uk/conditions/hallucinations-and-hearing-voices)

Because an autistic brain is 'monotropic', these loud intrusive thoughts can be focussed upon very intensely by the individual and the autistic person may find it very hard to think about anything else, entering into a kind of dark wormhole with these thoughts. This can be extremely distressing. These intrusive thoughts may be very demanding in nature and may be experienced for example as a person or society telling them that they *should, ought to, must* do something (something that maybe they are struggling to do because it is an expectation or a demand and not hearing voices). With an autistic or AuDHD brain especially, it can feel like it never switches off; the constant racing thoughts can be exhausting.

Hallucinations do not necessarily indicate Schizophrenia or psychosis, as many mistakenly believe. Autistic people can of course have co-occurring mental health conditions but misdiagnosis is devastating for autistic people. Many autistic people are misdiagnosed because of these kind of experiences. Rather than a mental health diagnosis being considered by clinicians, they should always consider the chance the autistic or AuDHD individual may well be experiencing autistic burnout and that they are exhausted, overwhelmed and need to rest their mind.

Masking and victimisation

As many as 50-89% of Autistic people experience victimisation by people they know. This is from a study by Keiran Rose, Dr Amy Pearson and Jon Rees. (https://osf.io/5y8jw/)
That victimisation can take many forms and is mostly due to masking- fawning. Masking is very common in Autistic people and is usually very prolonged, often many years and mostly subconscious. It is a trauma response and it leads to exhaustion and burnout: Masking is more likely because of:

1. Stigmatisation of what Autism is and what it means to be Autistic.
2. Not being identified at an early age (or at all).
3. Not understanding what it truly means to be Autistic.
4. Being in environments that are not adjusted or accommodating of Autistic people's sensory, social and communication needs.
5. Not having a sense of who you authentically are.
6. Others around you, including professionals, having a poor understanding of what it truly means to be Autistic.

Masking is often what is known as 'fawning' and means Autistic people can very often put the needs of others before their own needs, they can end up people pleasing and going along with things that may be very harmful to them. Autistic people are more likely to be (for example) victims of:

Domestic violence (9/10 Autistic women and people AFAB have been victims of DV)
Bullying and mate crime
Financial exploitation
Cuckooing (when members of an organised crime group/ gang take over your home in order to deal drugs or hide stolen goods etc)
Sexual abuse/exploitation (92% of Autistic girls, women and people AFAB have experienced sexual abuse when unidentified/undiagnosed)
Being groomed into gangs/crime/drug use and dealing
Modern day slavery

This is one reason why professionals understanding Autism and what it means to be Autistic is crucial. It's critical they understand what Autistic masking really is and it's links with exhaustion and burnout. Early identification and diagnosis are so important and a change of attitude towards what it means to be Autistic. Changing high demand environments so there is flexibility to suit the needs of Autistic people. Helping Autistic people to be who they authentically are so they are less likely to mask and understand their sense of self.

Safeguarding the Autistic individual in crisis

Things to consider in relation to the safeguarding of an Autistic or AuDHD person in crisis:

- They may be self harming. This may have started in crisis or be something they have a history of. It is not attention seeking and is a sign that they are distressed in some way, likely to be extremely anxious and could be experiencing sensory, psychological and emotional distress (as well as other trauma possibly. It's important to always show compassion towards anyone self harming. They must also be made aware that *carrying* around *any* kind of sharp implement that is used for the purposes of self harming could be considered a weapon if they were ever arrested and searched by Police.

- They *may* be using substances. This may again be something that has started or increased in crisis. Substance use can trigger, accelerate and amplify symptoms they are experiencing in crisis, which could make them more at risk of experiencing hallucinations and drug induced psychosis if they are using certain substances. It can also put them more at risk of suicidal and other intrusive thoughts.

- Autistic and other neurodivergent people are considered vulnerable under the law and can be more at risk of exploitation, bullying and things such as domestic violence, cuckooing and even modern-day slavery. With an Autistic person their crisis may be linked to this kind of exploitation, bullying and victimisation, it may also be linked to isolation. If you suspect that the person is a victim of exploitation such as cuckooing you should contact the police (this can be reported to the police online also) and you can report the situation to social services also. To find out more about cuckooing (often linked to county lines gangs) go to: https://crimestoppers-uk.org/keeping-safe/community-family/county-lines Masking their differences (especially fawning (people pleasing) can put Autistic people in harm's way as they may be involved in things in order to please others, keep or make friends because they feel isolated and lonely. Masking is not something they can just stop doing and is usually prolonged over many years often. Masking makes having boundaries with others more challenging for some.

- Suicidal thoughts may lead to attempts and keeping an Autistic person safe may involve psychiatric detention if a respite placement suitable for Autistic people is not available. Inpatient staff should be very clear that the individual is Autistic even if other diagnoses are on their medical record. Things like sensory, social and communication differences must be taken into consideration. Staff should also be aware of how to support an Autistic person experiencing meltdowns and shutdowns.

- Autistic girls, women and people raised female are significantly more at risk of sexual abuse and violence.

What Are Autistic Meltdowns?

Meltdowns occur when the autistic person is **extremely** stressed and in fight/flight mode (shutdowns are freeze mode). Meltdowns are not bad behaviour, or attention-seeking. The Autistic person is not trying to get their own way or manipulate other people. **Autistic meltdowns 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!

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.

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

Meltdowns might look like:

- Screaming
- Shouting
- Crying out
- Aggression
- 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

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 person is mentally, physically, emotionally exhausted and experiencing sensory overload

A - Anxious
The autistic person 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 person may go into a shutdown state (or from a shutdown into a meltdown)

Support during an Autistic meltdown

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 overwhelmed and once in a meltdown, they cannot stop it from happening but need appropriate support.

This support usually means:

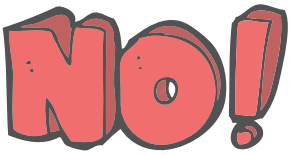
- **No touching them**
- **Reducing talking to them**
- **Reduce voice tone and volume**
- **Do not ask lots of questions**
- **Give them plenty of space and time to stim and self regulate**

- 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
- 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

What will not help an Autistic person in 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

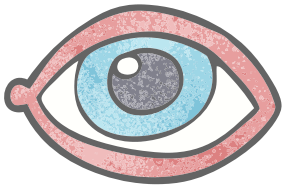
Sit next to them rather than stand over them

Try to limit speaking, esp questions

Do not shout at them.
Be gentle and compassionate

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

Recovery

When an Autistic person is experiencing Autistic Burnout there are a number of things that will not help them, especially any therapeutic approaches suited for neurotypical people, people who have EUPD or people experiencing depression. They are very overwhelmed, exhausted (including emotionally and mentally), and experiencing sensory and emotional overload. They cannot start any journey into recovery in environments that caused or could further cause more sensory overload, exacerbate intrusive or suicidal thoughts. What the person desperately needs is to be and feel safe. Recovery from Autistic Burnout takes a long time- months and some people take years.

Sensory - They need help to reduce their sensory overload and be able to fulfill any sensory seeking. This might mean noise cancelling headphones, fidget toys, going for a walk, stimming, weighted blankets. It all depends upon the individuals sensory needs -which is different for every Autistic person.

Monotropic needs: Most Autistic and AuDHD people are more likely to have Monotropic brains and will focus more intensely on fewer things. Time spent with their interests and passions can help to regulate them but for some they may be really struggling to focus and achieve a flow state. For those who can get into attention tunnels with something that really matters to them, this can be a safe, regulatory and restorative space.

Emotional: It might be very hard for some Autistic/ AuDHD people to recognise and describe what emotions they are feeling due to alexithymia, interoception and executive functioning differences, they may need help and support to understand and explain.

Physical: Due to interoception differences an Autistic/AuDHD person may hyposensitive to their internally signals (pain, hunger, thirst, body temp, emotions, etc). Again they may need help to understand and explain what is happening. Equally some may be hypersensitive to these signals.

Mental: They are very likely to be mentally exhausted, overwhelmed, extremely anxious and may be experiencing depression also. Remember however *burnout* does not respond to treatment for depression.

Social: Some social environments may be extremely triggering, overwhelming and exhausting. Time with other Autistic people where they are less likely to mask can be very helpful if they are able to, rather then too much time spent in unadjusted, unaccommodating environments.

Communication: An Autistic/AuDHD person needs to be able to communicate in their preferred way and not made to communicate in ways that may be overwhelming, especially when experiencing burnout. Many Autistic people experience shutdowns and may stop talking/communicating or experience situations where they cannot talk. Some Autistic people do not communicate verbally by speaking at all. Many Autistic people may also not like eye contact and this along with speaking should not be forced.

R Restorative activities that recharge and help regulate will look different for everyone.

E Energy levels will be very low in burnout and as an Autistic person energy levels always need to be considered.

S Be aware of what sensory needs they have - what they seek and what they avoid. Remember it's about changing the environment and not the person

T Time - do not put a timescale on healing and recovery from burnout and take a day at a time

- Radical acceptance and lifestyle changes may be needed
- Embracing authentic Autistic identity will help
- Not pushing or being pushed is crucial
- Low demands are essential
- Time with interests can help with regulation and feeling safe
- Lower expectations
- Help may be needed to prioritise
- Support with executive functioning may be needed
- If ADHD is medication needed/needing tweaking?

Autistic Burnout Recovery Prescription

01 ACKNOWLEDGE EXHAUSTION, STOP PUSHING YOURSELF AND TAKE REGULAR BREAKS, PACE YOURSELF, PRIORITISE. BE AWARE OF YOUR ENERGY LEVELS AND WHAT USES UP ENERGY/ RESTORES ENERGY.

02 REDUCE OR REMOVE DEMANDS AND EXPECTATIONS CAUSING ANXIETY AND EXHAUSTION (ESP THOSE THAT LEAD TO MASKING)

03 TIME WITH INTERESTS AND PASSIONS- A MONOTROPIC FLOW STATE CAN BE A PLACE OF RESTORATION, SAFETY, REGULATION AND REPAIR

04 TIME ON OWN/LESS TIME IN SOCIAL SITUATIONS. REMEMBER SOCIAL SITUATIONS CAN BE VERY DRAINING CAUSING SOCIAL HANGOVERS

05 UNDERSTAND AND EMBRACE YOUR AUTISTIC IDENTITY. EMBRACE YOUR AUTHENTIC AUTISTIC SELF.

06 REST- HOWEVER THAT LOOKS FOR YOU PHYSICAL/PSYCHOLOGICAL/SPIRITUAL/EMOTIONAL

07 SENSORY NEEDS- WHAT IS CAUSING OVERLOAD? WHAT SENSORY INPUT DO YOU NEED? WHAT COULD HELP YOU WITH INTEROCEPTION?

08 TIME WITH NEUROKIN/ LEARNING TO UNMASK IN SAFE PLACES. UNMASKING IS NOT EASY BUT OFTEN SAFER WITH OTHER AUTISTIC PEOPLE.

09 SPEND TIME STIMMING (HELPS WITH REGULATION). DON'T LET ANYONE TELL YOU STIMMING IS WRONG OR WEIRD - EVERYONE STIMS BUT AUTUSTIC PEOPLE DO SO MORE.

10 TIME AND SPACE- IT IS GOING TO TAKE TIME TO HEAL. IT TOOK YOU A PROLONGED PERIOD OF TIME TO GET INTO BURNOUT SO IT WILL TAKE TIME TO HEAL OR YOU MAY GO BACK INTO BURNOUT AGAIN

Crisis Support Plan

Not every Autistic person experiencing burnout leads to being in an extreme crisis, but its a good idea to plan for the possibility of reaching a place of crisis, when you/they will need more help and support.

What might be happening in your/their thoughts, behaviour, body and emotions?

What intrusive thoughts I/they might be struggling with ?

How I/they might be behaving?

What might be happening in my/their body?

What emotions *might* I/they be experiencing?

Who could help in a crisis? Name and phone numbers of SAFE people

How can those people help? What is the best way for them to help?

Autistic Burnout Support Sheet

Dear Family Member/Friend or
Doctor/Nurse/Psychiatrist/Social Worker/
Mental Health Worker/ Paramedic/ Police officer, etc.
I am autistic. I am currently experiencing something called Autistic Burnout.

I am giving this to you because sometimes I do not have the words or ways to express and describe my thoughts, feelings or what I am experiencing.
I want to help you understand, so you are in a better position to support me.
Autistic burnout is not depression or EUPD. My mental health is however deteriorating because of burnout.

Some of the main characteristics of Autistic Burnout are:
Extreme fatigue/exhaustion (mental and physical), sensory overload, increased meltdowns and shutdowns, increased anxiety, emotion regulation difficulties and loss of executive functioning skills. Some may also experience intrusive thoughts and hallucinations

Autistic person to tick the boxes that apply currently:

☐ I am experiencing a level of crisis due to Autistic Burnout or

☐ I am experiencing a state of Extreme Burnout Crisis

☐ I am experiencing suicidal and other intrusive thoughts

☐ I am experiencing hallucinations

☐ I am experiencing more meltdowns.

I need you to understand that I may appear aggressive in a meltdown and say things I do not mean, but I am extremely stressed, frightened and overwhelmed. I need a quiet, safe place to regulate.

Glossary

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/neurotransmitters (Noradrenaline, Dopamine and GABA -gamma aminobutyric acid). Some people who are ADHD find stimulant medication can be helpful with executive function differences (impulsivity, emotional regulation, decision making, working memory, etc).

Alexithymia (Alex-ee-thy-mea) This means "having no words for emotions" and 60% or more of autistic people have alexithymia. It does not mean they don't have emotions, but it does mean they can struggle to recognise, explain, and express their emotions and understand the emotions of other people.

AuDHD A person who is Autistic and ADHD is known as AuDHD.

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 strengths and different needs.

Autistic Inertia It is common for autistic people to find it hard to start things (task initiation) and finish things. This is probably partly due to executive functioning differences and can be affected by perfectionist thinking.

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, Senior Lecturer in Intellectual and Developmental Disabilities, University of Kent)

Echolalia Vocalisations which can be noises, words, sounds, accents, impersonations, singing, etc that might be repeated. It's also thought of as vocal stimming. The word echolalia comes from the Greek words 'echo' and 'lalia' and this means "to repeat speech".

Identity first language Most autistic people prefer saying they are autistic, as Autistic people cannot be separated from their identity. This is the most validating language to use.

Interoception is part of the sensory system that helps us to perceive everything that happens to us internally, whether that is respiration, our heartbeat, pain, or things like hunger, thirst, and knowing we need the toilet. Because of the connection with the autonomic nervous system, it is also how we perceive emotions. Interoception can be muted or heightened, under or over-responsive.

Medical (deficit) Model The outdated but the most dominant model of what Autism is, based upon concepts and theories dating back many years.

Meltdowns (fight/flight) It's important to stress that meltdowns are not tantrums, but the autistic person is very distressed and overwhelmed. Meltdowns are involuntary and triggered by stress and many other things. The person is in a state of hyper-arousal.

Monotropism Autistic brains are more likely to be 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 regulate and be very productive. Monotropism is a theory of autism developed by autistic people, initially by Dinah Murray and Wenn Lawson.

Neurodivergent Sometimes abbreviated as ND, means having a mind that functions in ways which diverge significantly from the dominant societal standards of "normal." (Dr. Nick Walker, https://neuroqueer.com)

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, https://neuroqueer.com)

Neurodiversity The diversity of human minds, the infinite variation in neurocognitive functioning within humans. (Dr. Nick Walker, https://neuroqueer.com)

Neurotypical Often abbreviated as NT, means having a style of neurocognitive functioning that falls within the dominant societal standards of "normal." (Dr. Nick Walker, https://neuroqueer.com)

PDA Pathological Demand Avoidance, also known as a persistent drive for autonomy. An Autistic person might have a PDA profile. A person who is PDA can find everyday demands very challenging and may go to considerable lengths to avoid them. They need a lot of autonomy and can experience very high levels of anxiety due to the amount of demands and expectations there can be and a need for control. The following is from 'The PDA Society':

- Resists and avoids the ordinary demands of life
- Uses social strategies as part of the avoidance
- Appears sociable on the surface, but lacking depth in understanding
- Experiences excessive mood swings and impulsivity
- 'Obsessive' behaviour, often focused on other people
- Appears comfortable in role play and pretend, sometimes to an extreme extent
- (this feature is not always present)

Person first language This comes from the belief that the individual is separate from autism. This is the language preferred by professionals but most autistic people feel that this language is invalidating and unhelpful.

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

Shutdowns (freeze) These can be triggered by very similar things to meltdowns and may happen after meltdowns also. They are also involuntary and the person is not attention-seeking or being difficult. The person is in a state of hypo-arousal.

Social Model This is a movement that celebrates, respects and sees Autistic people and their individual needs; it seeks to remove the barriers that there are in society that lead to stigmatisation and ableism.

Stimming This is anything, often movement, that is self-stimulating (stimulates the Vagus Nerve) and is often calming, can bring joy and helps regulate the sensory system and 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 significant harm then it may be more appropriate to redirect the stim).

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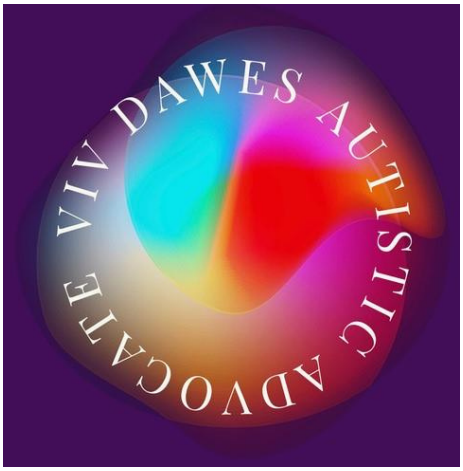

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