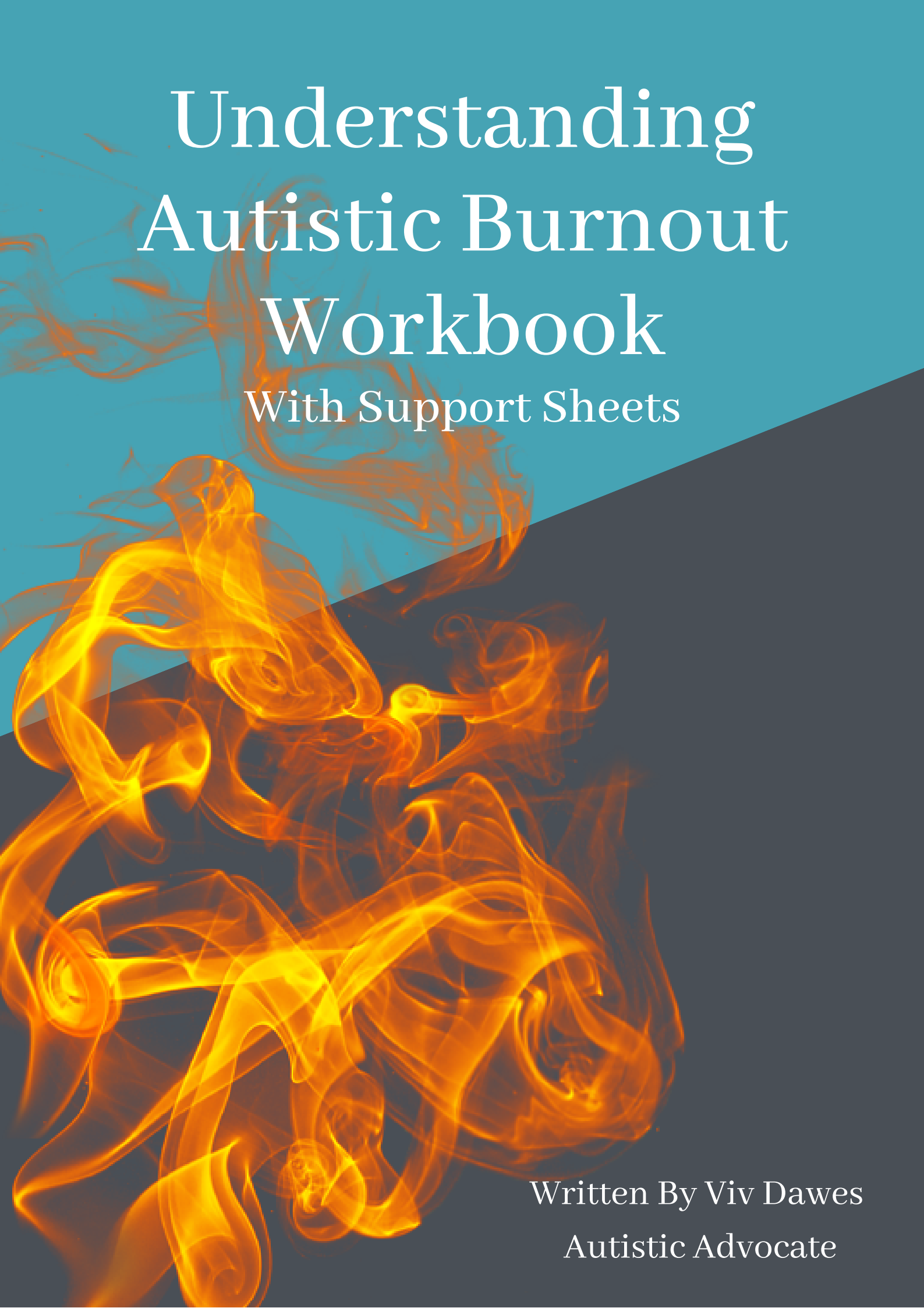




Understanding Autistic Burnout Workbook

With Support Sheets

Written By Viv Dawes
Autistic Advocate

To The Reader

This book is designed to be used by autistic and other neurodivergent adults, (parents of autistic children/young people and professionals may also find it helpful), to help them understand autistic burnout and learn about causes, triggers, prevention and how to heal. It is concise and written with people experiencing autistic burnout in mind. The book will talk about autistic burnout, but I do recognise that all neurodivergent people can experience burnout. The information in this book comes from personal experience, other autistic people's experiences of autistic burnout and research.

The book does briefly mention some difficult topics, but it will also seek to give autistic people, autistic families and professionals, some tools to aid learning, understanding and prevention.

The Author

I am a late diagnosed autistic parent of a neurodivergent teenager. I am an autism advocate, writer and trainer. I have 25 years experience of working with vulnerable adults, including as a Snr Practitioner for the NHS in a women's prison and running an addiction recovery programme for 10 years. Many of the people I have worked with were also neurodivergent.

I have been on a journey of discovery over the last 13 years regarding autism; this is when I first started to really understand what autism was. Initially, however I had no idea that I was autistic myself. and it wasn't until my son was diagnosed, that I decided that I needed to fully embrace my different brain.

I am not a doctor, a mental health professional or an intellectual. I write from lived experience. You should always consult your GP, a health professional and any mental health team that you are under, regarding anything relating to your health, mental wellbeing and any medication you take.

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 (weekdays 10am-10pm, weekends 2pm-10pm and bank holidays 2pm–10pm), email pat@papyrus-uk.org or 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.



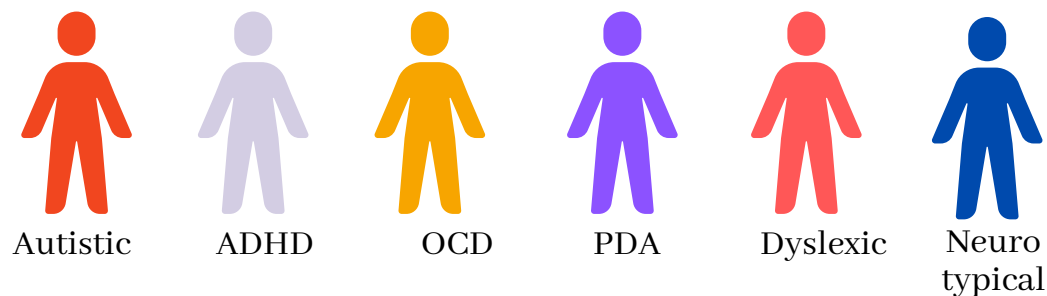
What Is Neurodivergence And What Is Autism?



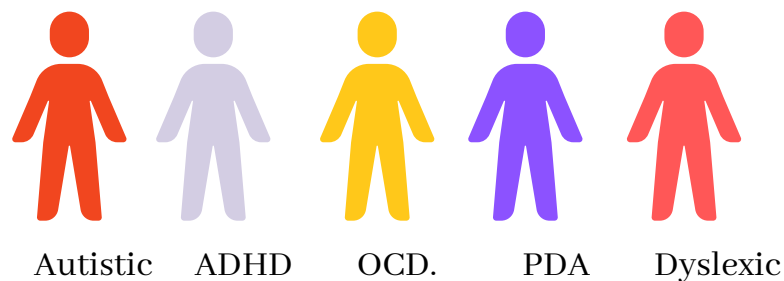
Neurodiversity and Neurodivergence Explained

Neurodiversity is the understanding that we all have different types of brains (neurotypes). However, neurodivergent people are people whose brains differ from neurotypical brains. Many neurodivergent people are multiply neurodivergent for example autistic and ADHD

This group of people are Neurodiverse



This group of people are Neurodivergent



(Not exhaustive lists)

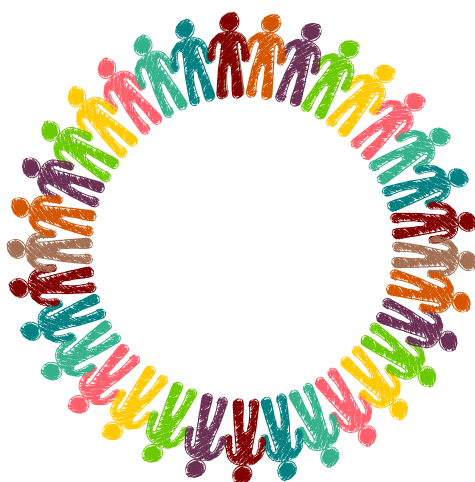
What Is Autism And What Is Neurodivergence?

Many autistic people, autistic researchers and autistic intellectuals, have coined new terminology and theories, that explain what autism is and what it means to be autistic, such as Neurodivergence, Double Empathy and Monotropism.. These theories are more validating than the pathologising, medicalised models of autism.

The DSM V (Diagnostic Manual of Mental Disorders) is one of the official descriptions of what Autism is, that clinicians and many professionals will refer to. Autism is however not a mental disorder, or a condition that is either mild or severe. The labels of ASD and Aspergers Syndrome are both based upon outdated, pathologising models of autism. They are described as something a person 'has' and that the individual has impairments and deficits in their social and communication skills, as well as other 'dysfunctions'.

Many in the autistic and neurodivergent community do not see autism in this way. Being autistic actually means the person has a different kind of brain, not a broken brain.

"Neurodivergent, sometimes abbreviated as ND, means having a mind that functions in ways which diverge significantly from the dominant societal standards of normal..... A person whose neurocognitive functioning diverges from dominant societal norms in multiple ways , for instance, a person who is autistic, dyslexic, and epileptic can be described as multiply neurodivergent" www.neuroqueer.com



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, <https://neuroqueer.com>)

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)

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 regulate and be very productive. Monotropism is a theory of autism developed by autistic people, initially by Dinah Murray and Wenn Lawson.

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)

Stimming This is anything that is stimulating (stimulates the nervous system) and is calming, brings 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 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.

An Autistic Brain Is 'Monotropic'

"Monotropism is a theory of autism developed by autistic people, initially by Dinah Murray and Wenn Lawson. Monotropic minds tend to have their attention pulled more strongly towards a smaller number of interests at any given time, leaving fewer resources for other processes. We argue that this can explain nearly all of the features commonly associated with autism, directly or indirectly.....Monotropism is one of the key ideas required for making sense of autism, along with the double empathy problem and neurodiversity. Monotropism makes sense of many autistic experiences at the individual level. The double empathy problem explains the misunderstandings that occur between people who process the world differently, often mistaken for a lack of empathy on the autistic side. Neurodiversity describes the place of autistic people and other 'neurominorities' in society."

www.monotropism.org

Being monotropic can mean that trying to focus on too much input 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 be not only be challenging but can throw them completely. "Switching tasks is hard and new plans take work."

Its 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.

In burnout, some autistic people can experience mania and hallucinations and may find it challenging to stop focussing upon intrusive, distressing thoughts.

David Gray-Hammond explains this: "Once something places us into a state of burnout, autistic minds seek to return to their natural state of monotropic attention tunnels. We hyperfocus. We then get caught in an attention tunnel regarding something that is traumatic to think about, unable to shift our focus from that attention tunnel. This causes distress. Tanya Adkin refers to this as a monotropic spiral. As we become dysregulated, our sensory experiences also become dysregulated. This is where we may start to have hallucinations, and experience emotional dysregulation such as paranoia or mania".

A Better Understanding Of Autism

Monotropism "is one of the key ideas required for making sense of autism, along with the double empathy problem and neurodiversity" (<https://monotropism.org>)
The following are 6 'starting points' for understanding autism through monotropism theory.

'Theories and Practice in Autism' (Fergus Murray 2018) introduces six starting points for understanding autism in terms of monotropism (<https://monotropism.org/explanations/>):

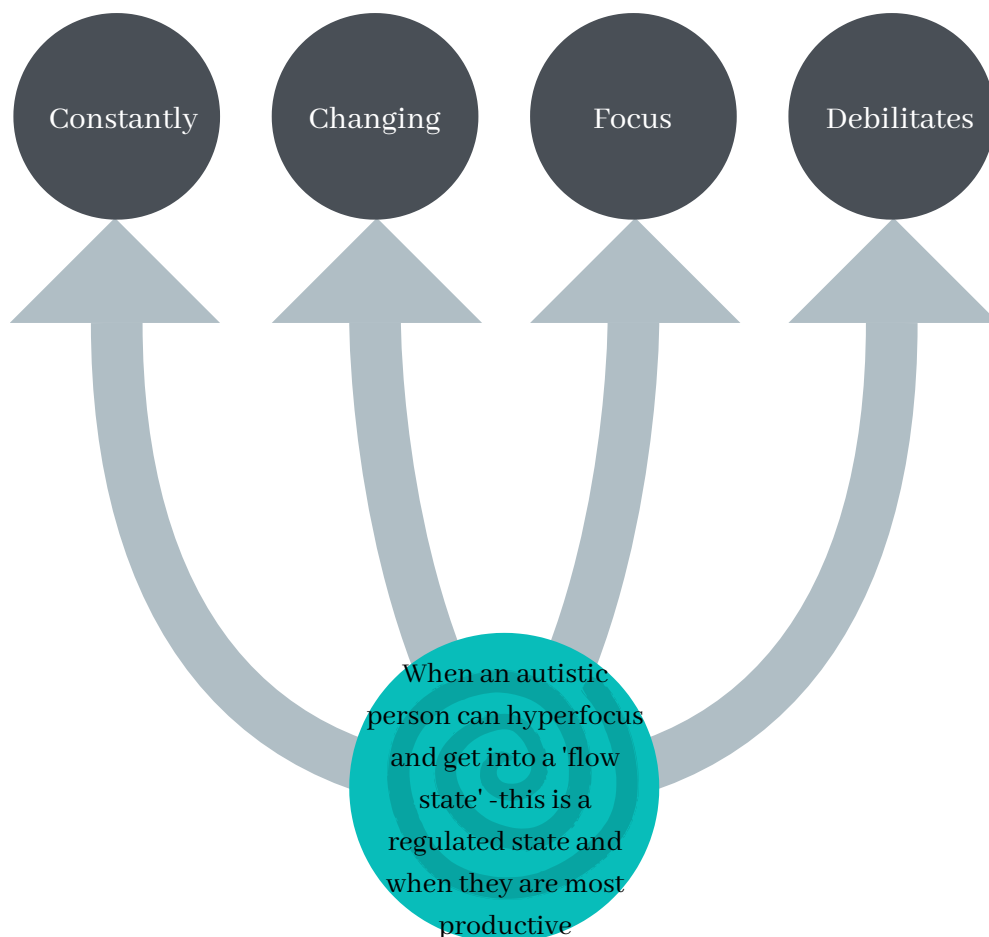
1. Coping with multiple channels is hard. This can be sensory channels or other information streams.
2. Filtering is tricky and error-prone. Sometimes I can't tune things out, other times I filter them out completely.
3. Changing tracks is destabilising. Task-switching is hard, and new plans take work.
4. I often experience things intensely. Usually, things that relate to my concerns and interests.
5. I keep looping back to my interests and concerns
It's hard to let things drop.
6. Other things that drop out of my awareness tend to stay dropped. I may need reminders.



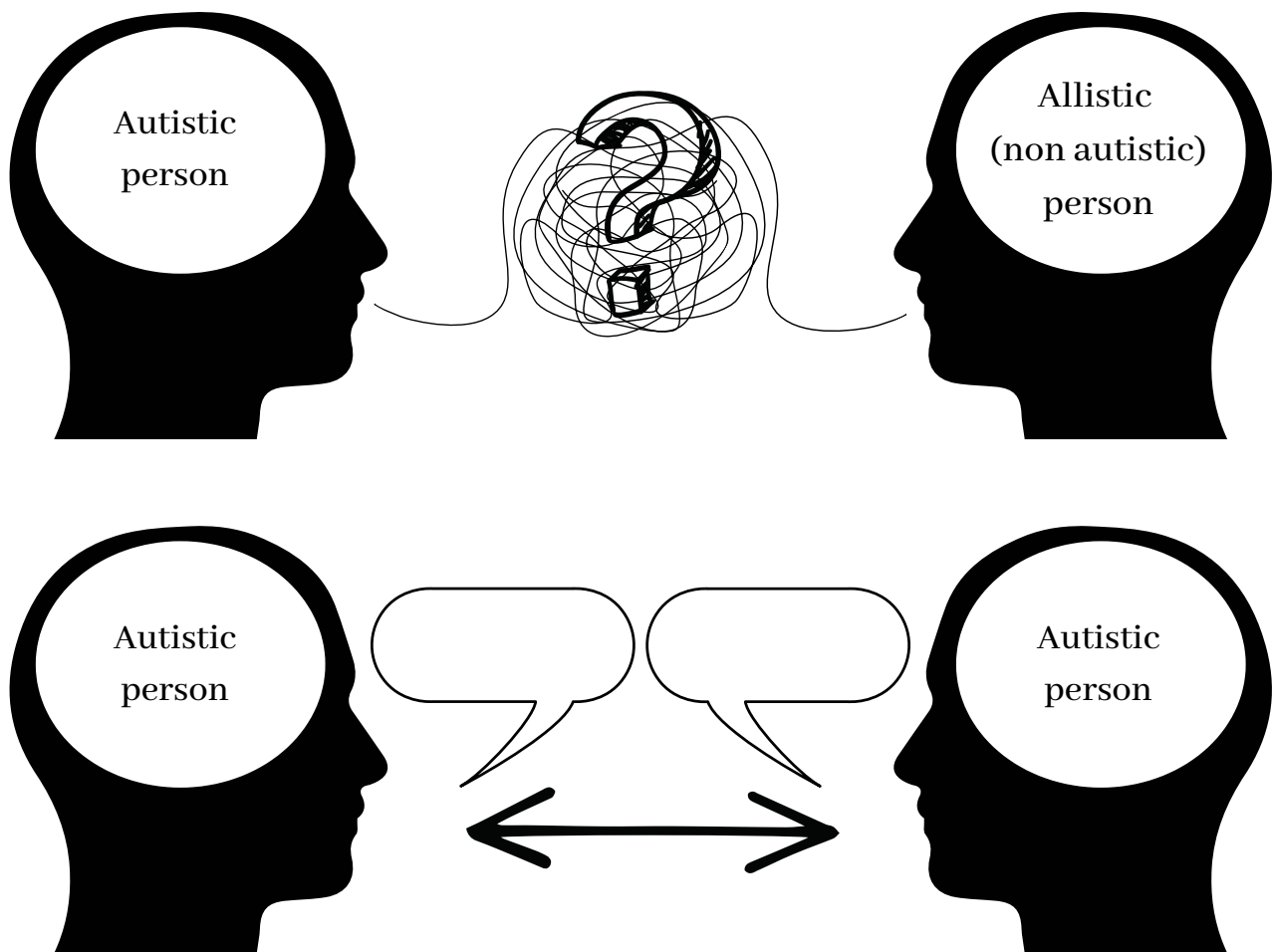
Hyper Focus And Monotropic Split

Constantly changing focus and not being able to hyper-focus on interests can be debilitating for autistic people. Hyper-focusing can lead to what's called a 'flow state' and can help an autistic person regulate, be less stressed and very productive. Monotropic split happens when an autistic person has to keep changing focus, constantly changing channels and is unable to get into a flow state. This is exhausting, debilitating and leads to emotional and sensory overload and could eventually lead to burnout.

When autistic people are in "environments where they must perform like a polytropic person, the amount of attention to detail they apply to multiple attention streams doesn't decrease; all that happens is the monotropic mind experiences trauma by being pushed into trying to give more attention than any individual can cognitively give.....The monotropic mind is having to split its attention and give more mental energy and attention than it has available to be able to withstand the environment it is in and remain safe" Tanya Adkin, www.emergentdivergence.com.



The Problem of Double Empathy



"Autistic people experience the world and express emotions differently to non-autistic people, (also referred to as Allistic people). "We communicate, experience and display emotions, interact with others, form relationships, and sense the world around us, differently to non-autistics. That doesn't mean that we don't have emotions or feel empathy. But it makes it difficult for non-autistic people to understand and to empathise with us. And us with them." (Reframing Autism)

Damian Milton, an autistic lecturer in 'Developmental and Intellectual Disabilities' at The University of Kent, first coined this term in 2012. 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.

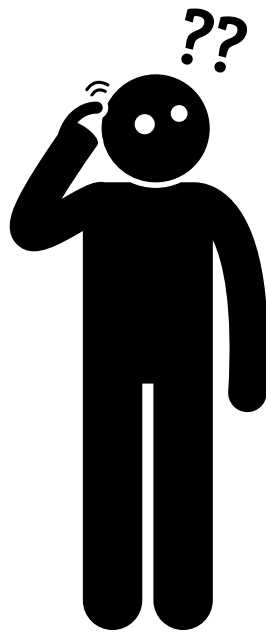
What is Autistic Burnout?



Why It's Important To Understand Autistic Burnout?

Many autistic people and other neurodivergent people, can experience burnout. Autistic burnout can tip the individual from low level, daily burnout into a spiral of crisis and extreme burnout crisis. It can be devastating for the individual and may be life changing.

Sadly, many autistic people can experience suicidal and other intrusive thoughts when they are in crisis, and they are at higher risk of suicide. According to a recent study, autistic children are 28x more likely to have suicidal thoughts, autistic people are 9 x more likely to die by suicide and autistic women are 13 x more likely. Preventing crisis is crucial and it is possible. So understanding autistic burnout is an important factor in supporting the needs of autistic people.



Different Types Of Burnout And Potential Triggers

We've all probably heard someone talk about how they are "burnt out", or how they 'need to avoid burning out'. It's a term we all think we understand to mean that a person has become extremely stressed and exhausted, *because* they have worked or studied too hard, 'burning the candle at both ends.' That is 'Occupational burnout'. Most people do not appreciate that there is a difference between occupational, parent/carer and the burnout autistic and other neurodivergent people can experience. Anyone can experience occupational and parental/carers burnout. Autistic burnout however is a particular physical, psychological and sensory state experienced by autistic people.

Occupational Burnout Triggers.

- Expectations
- Demands
- Workload
- Mental load
- Time pressures
- Not enough support
- Emotional overwhelm
- Poor boundaries
- People pleasing
- Mental health- issues
- Low wage/income
- Doing multiple jobs

Parental/Carer Burnout Triggers.

- Expectations
- Demands
- Lack of support
- Emotional overwhelm
- Financial stress
- Dealing with professionals
- Feeling judged
- Mental health issues
- Gaslighting
- Accusations of Fii
- Children struggling with school attendance

Autistic /ND Burnout Triggers.

- Extended periods of masking
- Sensory overload
- Emotional overwhelm
- Expectations
- Demands
- Poor boundaries
- People pleasing
- Trauma/PTSD
- Gender dysphoria
- Rejection Sensitivity
- Dysphoria
- Mental health issues

These lists of triggers are not exhaustive

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.

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 "threat reaction" (Kristy Forbes, Neurodivergent specialist), 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. Some people also experience hyperactivity and speeding up during burnout and I suspect that this is especially people who are AuDHD.

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.

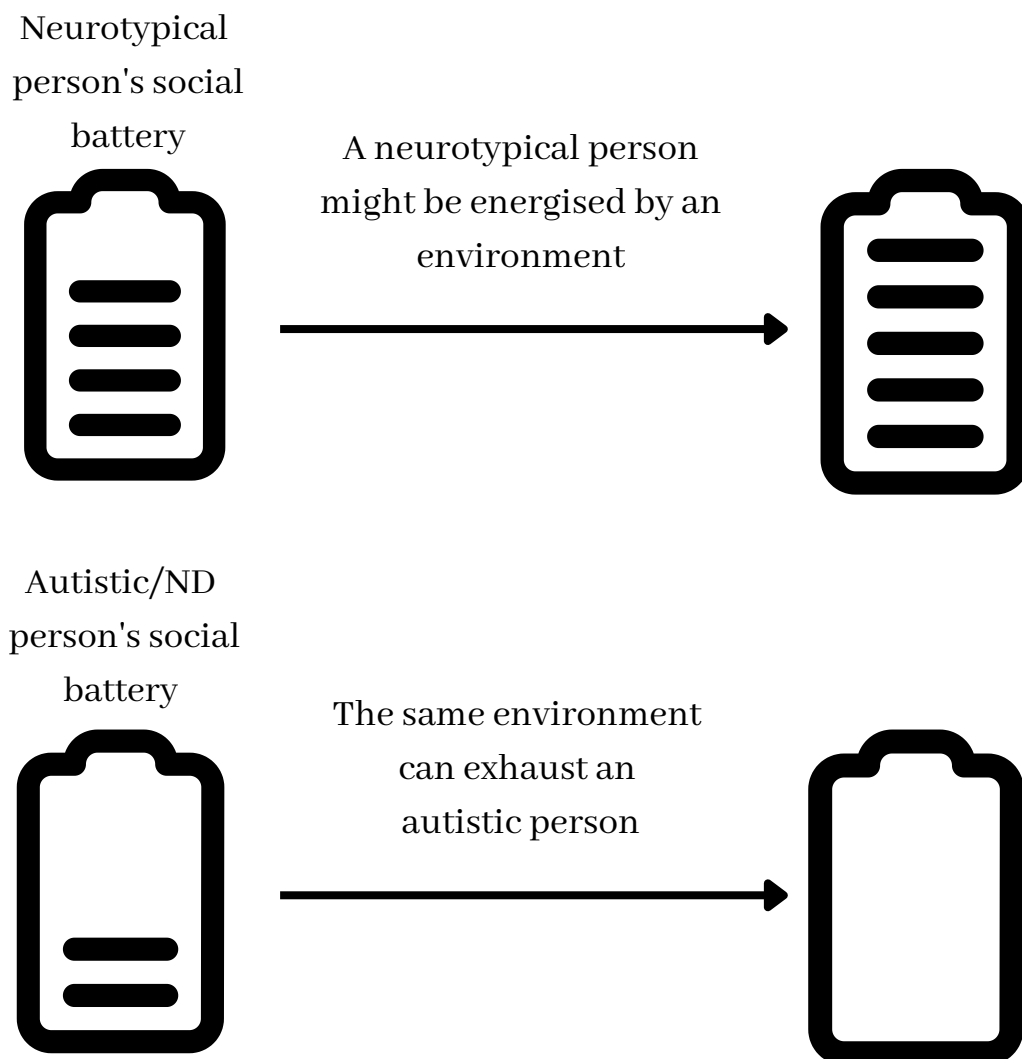
When an autistic person is experiencing burnout, they will feel drained, exhausted, spent and that they have "no resources left to cope with or manage daily life" (Raymaker et al, 2020).

Social Hangovers

(Daily low level autistic burnout)

Due to sensory, executive functioning differences and masking in social situations, autistic people can find environments that are not 'appropriately adjusted', very challenging to be in. This can lead to daily 'social hangovers' also known as social fatigue. From my own experience as an autistic person (with ADHD) and the parent of a neurodivergent teenager, I have both experienced this and observed this in my son.

The image below helps explain social hangovers for autistic people. Autistic people already enter social situations with lower levels of social energy than neurotypical people (who may actually be re-energised by social environments, that can exhaust neurodivergent people).



Long periods of masking,
sensory overload, emotional
overwhelm, environmental pressures,
monotropic split.
Autistic person's needs not met
Other possible triggers - gender
dysphoria, puberty, menopause, etc

If the cycle is not
broken by the
person getting
significant rest and
out of survival
mode, then
burnout continues

Autistic Burnout Can Be Cyclical

THREAT
REACTION/SURVIVAL MODE
Fatigue, losing exec function
skills, anxiety, meltdowns,
shutdowns, withdrawal

Mental health worsens, possible
self harm, substance abuse,
hallucinations and mania can be
experienced. Autism+ADHD, OCD,
PDA etc, may mean a more
complex presentation and
experience

Everything affected - thoughts,
emotions, physical & sensory
state, eating, communication,
self care etc

School, college or work
can become impossible
places to be due to
debilitating symptoms

Common Characteristics Of Autistic Burnout

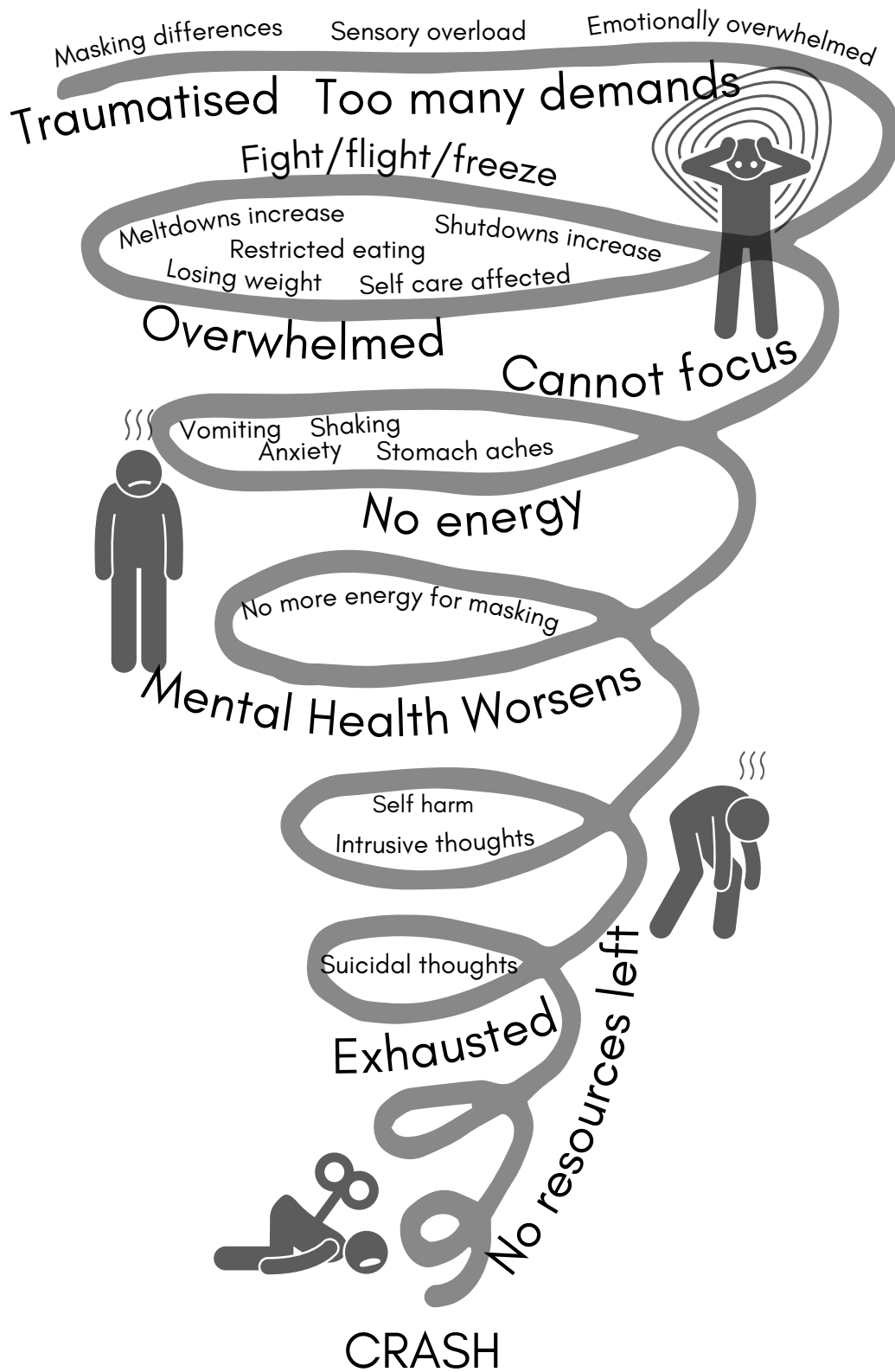
- Fatigue/ exhaustion – may be extreme
- Increased sensory overload
- Loss of skills such as: working memory, flexibility, focus, emotional regulation, self monitoring, impulse control, planning, organisation, task initiation
- Increasing meltdowns and shutdowns
- Worsening mental health (burnout can lead to depression)
- Intrusive and suicidal thoughts in many cases
- Eating changes/eating less or more
- Increased anxiety
- Situational lack of speech -shutdown/survival mode
- Self harm in many cases (starts or increases)
- No energy to mask so more 'autistic traits'

Other Diagnoses Can Overshadow Autistic Burnout

It's not uncommon for autistic people to have other diagnoses or even misdiagnoses, prior to an autism diagnosis, (a person can of course self identify autistic). If for example, an autistic person has a Bi Polar or personality disorder diagnosis (or misdiagnosis) like BPD/ EUPD, and they present with symptoms of these, then it can mean autistic burnout is missed by clinicians and professionals. This can lead to the wrong support being given to the individual, or no support in many cases.

Autistic burnout may 'look' like depression/clinical depression. Depression is very often experienced by autistic people, but it is important to differentiate between depression and the symptoms of autistic burnout. Autistic burnout however can lead to depression and even *possibly* physical conditions such as Fibromyalgia (Kristy Forbes).

Neurotypical therapies suitable for depression, given to an autistic person experiencing burnout, could potentially exacerbate autistic burnout symptoms. The individual needs to rest their mind and body, not engage in more talking and interaction, as this means using up more of their energy.



Hallucinations

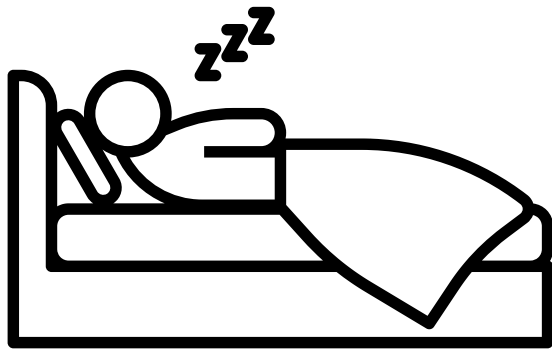
When experiencing autistic burnout crisis, autistic people, including children and young people, can experience hallucinations. Researchers have found that Autistic people are up to 3 times more likely to experience hallucinations. Hallucinations can be auditory, tactile (touch), or visual. Hallucinations have been linked to isolation and bullying and differences in brain chemistry (neurodivergentinsights.com/autism-infographics/hallucinations-and-autism).

Hallucinations can sometimes be frightening for people experiencing them and they may fear they are experiencing psychosis. Hallucinations however do not necessarily indicate psychosis or Schizophrenia, as many mistakenly believe. Autistic people can of course have co-occurring mental health conditions, such as Schizophrenia, but it is important to not assume hallucinations and psychosis are an indication. It is common for autistic people to be prescribed anti-psychotic drugs and for many, these end up being wholly unsuitable. I am not however saying they are never appropriate and you should never suddenly withdraw any medication that you are prescribed. If you do not believe the medication you are prescribed is helping, then make sure you discuss this with the mental health team and or your GP, to put a plan together.

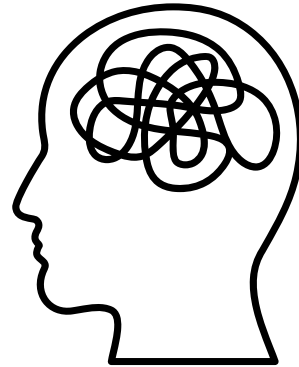
Hallucinations that autistic people experience in burnout, can be linked to extreme sensory overload and differences in certain levels of neurotransmitters such as GABA. Auditory hallucinations could be described as very loud intrusive thoughts. Because an autistic brain is 'monotropic', these intrusive *loud thoughts* can be focussed upon very intensely and the autistic person may find it very hard to think about anything else (Monotropic spiral, Tanya Adkin and David Gray- Hammond, (2022) "Where psychosis and autism meet the bitter pill to swallow" and "Autistic people and the burnout psychosis cycle") This can be extremely distressing as the intrusive thoughts may be very demanding in nature and may be experienced for example as a voice telling them that they should do something that maybe they are struggling to do because it is an expectation.

If you are experiencing hallucinations, then do discuss this with a mental health professional if you are worried, Here is a helpful website to visit for more information: neurodivergentinsights.com/autism-infographics/hallucinations-and-autism

Autistic Burnout Symptoms Might Be



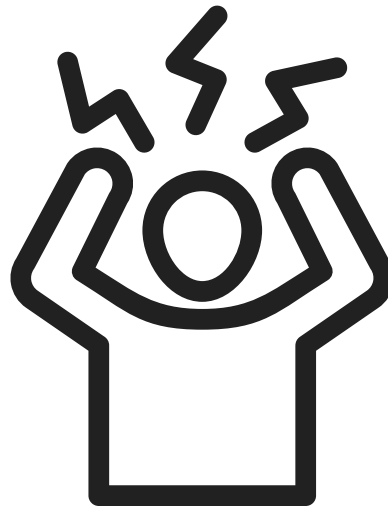
Cannot get out of bed due to exhaustion, may stay in/ in bedroom all the time/alot



Brain fog, confusion, exec functioning difficulties 'scatterbrain'



Intrusive thoughts



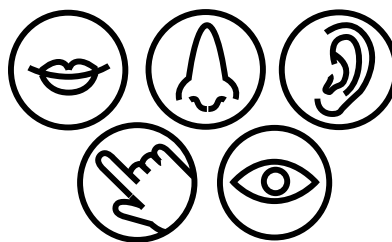
Increased meltdowns



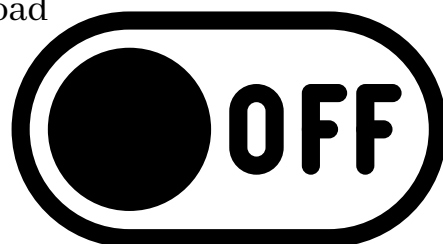
Feeling depressed



Fatigue/no energy/exhausted



Sensory Overload



Increased shutdowns

Exhaustion

I have spoken to many other autistic people about their experiences of exhaustion and burnout, especially those who are autistic/ADHD. Prior to crashing, some did not appreciate that they had been experiencing exhaustion and that they needed to 'stop' and rest. For so many people this may be impossible because of responsibilities and attending school or work, etc. But without resting the mind and body, then it leads to shutdowns, meltdowns and burnout.

Some of the people I spoke to went on to experience extreme burnout crisis, which significantly affected their lives and their families. The exhaustion they describe is profound and all encompassing. Reacting to the symptoms of burnout with things like drinking alcohol and abusing certain illegal drugs, can be devastating.

Autistic/ADHD burnout

As many as 50%-70% of autistic people are both autistic and ADHD (AuDHD), "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.

Many neurodivergent people are multiply neurodivergent, for example: Autistic and ADHD, Autistic and OCD, or ADHD and OCD, etc. ADHD brains naturally have low levels of two important neurotransmitters (chemical messengers) Dopamine and Noradrenaline (also known as Norepinephrine). Noradrenaline plays a role in the body's stress responses and helps to regulate sleep, alertness, arousal, attention, cognitive function and blood pressure. A lack of noradrenaline can cause lethargy, fatigue and a lack of focus. Dopamine plays a key role in movement and affects motivation, perception of reality, and the ability to experience pleasure.

It means that ADHD brains can be "chemically wired" to seek more dopamine and noradrenaline- which can lead to impulsivity and risk taking (for some this might mean using alcohol and drugs, which in turn can lead to criminal behaviour). Neurodivergent people in burnout and using substances to cope, can often find symptoms such as paranoia and anxiety are made worse.

Executive Functioning

There are different types of cognitive processes- including language , memory, attention, etc. Cognition means the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses. Executive functions are cognitive processes and autistic people have executive functioning *differences*, "altered neural processes, which impact how our prefrontal cortex manages these executive functions." (Embrace-autism.com)

Executive function takes place in the frontal lobe of the brain and includes;

- Working memory
- Decision making
- Planning and prioritising things
- Organising skills
- Time management
- Impulse control/self control
- Emotional regulation
- Task initiation
- Focus
- Flexibility
- Reflection upon self and actions
- Stress tolerance

When an autistic person is experiencing autistic burnout, they often describe losing executive functioning skills. This loss of executive functioning skills is caused by the brain being in survival mode; a part of the brain called the Limbic system hijacks the Pre Frontal Cortex (where executive functioning is controlled) which leads to fight/flight/freeze. Some autistic people also talk about not fully regaining their executive functioning skills after burnout, or it taking time to get them back. An ADHD brain has executive functioning differences, in fact, the main traits of ADHD pertain to executive functioning differences. People who are ADHD can also experience burnout.

What Causes Autistic Burnout?



What Causes Autistic Burnout?

The main causes of autistic burnout are masking, sensory overload and too many demands and expectations. Spending too much time in social situations, (especially environments that have not been reasonably adjusted for autistic people), can be very draining. Masking is exhausting, as it takes so much effort for an autistic person to fit in. Masking is not a conscious decision that an autistic person makes; it is very often subconscious. Sensory overload, like masking, also causes trauma and leads to high levels of anxiety, which in turn increases the likelihood of shutdowns and meltdowns.

Many autistic students in school, especially secondary school, can struggle with attendance because the school environment can be very taxing for them: too loud, too bright, too busy, too many demands, and too many expectations, 'Autism+environment=outcome', (Dr Luke Beardon, The Autism Centre at Sheffield Hallam University).

Sensory overload	Masking	Too many demands
Hormones, esp Puberty/Menopause	Changes in routines/structure	Bullying/gaslighting
Too many expectations	Trauma/PTSD	Transitions
Monotropic Split	Emotional overwhelm (due to executive functioning differences)	Not enough /no accommodations at school, college university, work,
Rejection sensitivity dysphoria	Gender dysphoria	Trying to keep everything under control and perfectionism

Masking

Masking is a complex, often subconscious behaviour, also known as camouflaging, mimicking or fawning. It is a trauma reaction, a coping mechanism, due to the stigma of being and feeling 'different' and starts from a very early age. Autistic people mask because of the pressure to fit in and 'appear less autistic', when in social situations and environments, (especially environments that are not adjusted). An undiagnosed autistic person may also not know they are autistic and not understand how masking is affecting them and why they struggle so much in social circles. Masking means that autistic people suppress and hide their differences and the effect this over time can be profound, as prolonged masking is exhausting. Feeling different as an autistic person and fear of bullying and rejection, can lead to masking. It can make unmasking feel unsafe. Unmasking can only initially happen in safe, validating environments, often with other autistic people.

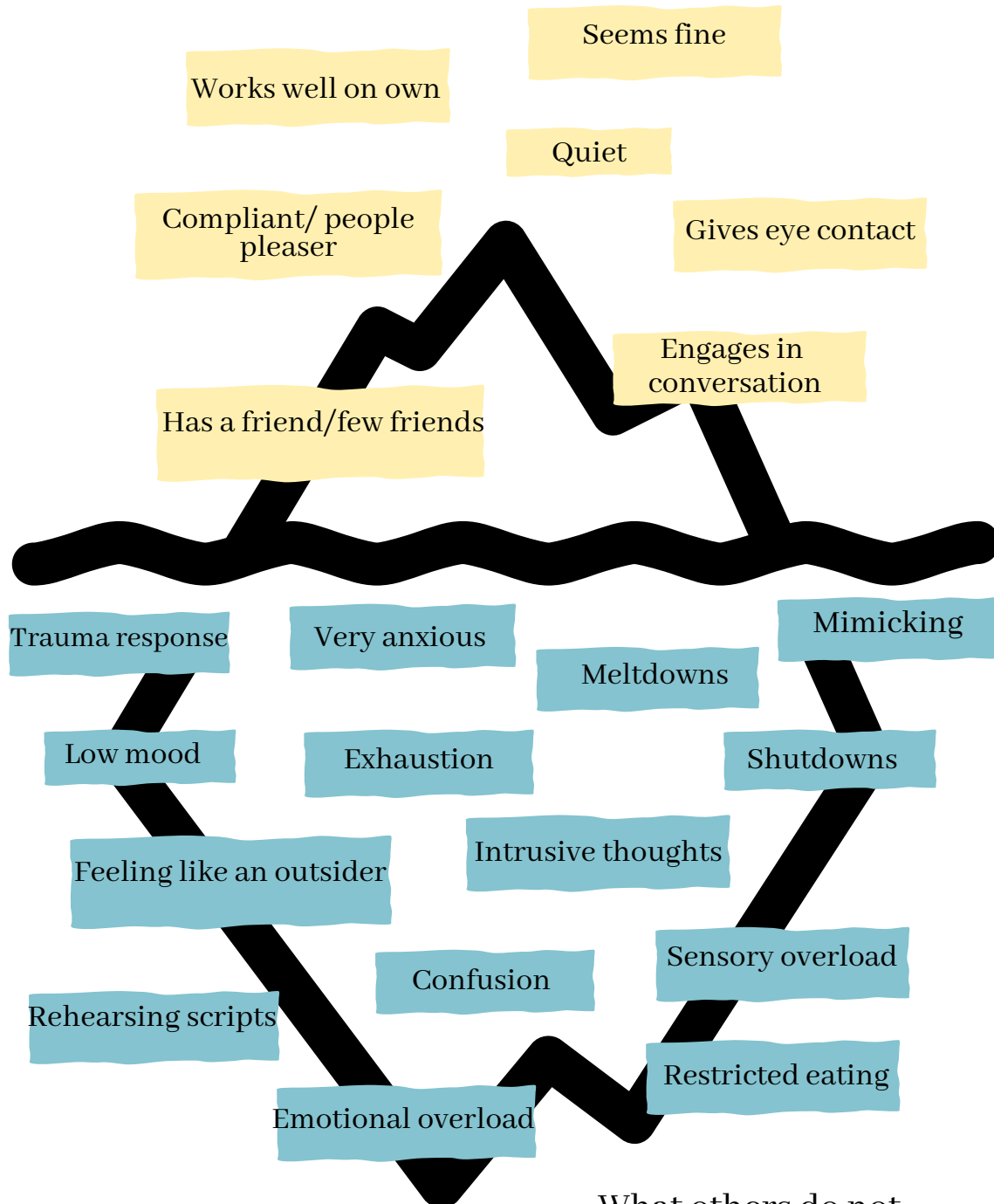
Masking Can Look Like:

- People pleasing/fawning
- Using scripts in conversations (repeating rehearsed, set phrases and words from pre planned conversations/from films/TV)
- Using NT body language such as eye contact, smiling etc
- Hiding differences to fit in with others, esp with NT people
- Pretending to have the same interests as NT people
- Mimicking facial expressions, eye contact, social cues, etc
- Doing what is 'expected' by others/compliance
- Not stimming in public when you want /need to
- Hiding sensory discomfort/pain
- Hiding autistic traits in order to appear neurotypical
- Not 'info dumping' about things you are hyperfocussed on

Unmasking can sometimes be much harder for people because of issues relating to intersectionality. Race, cultural differences, poverty, gender, disability, gender or sexuality, etc. Because of (*for example*) racial and other stereotypes around things like skin colour and 'behaviour'. Autistic black people experiencing meltdowns, shutdowns and other symptoms of burnout (which can be hallucinations and mania in some people) might have their fear and distress misinterpreted as aggression and that this person is a threat, rather than being an autistic person needing support.

The Masking Iceberg

What people might see
on the surface



What others do not,
or might not see

Unmasking

Some ideas to help an autistic person take off masks. These don't have to be done all at once! They can gradually start to recognise the masks. There will be situations where it will be harder to unmask and some situations will not feel safe. The aim however is to mask less.

Find other
neurodivergent
people to unmask with

Embrace and
accept your diagnosis
or self identification

Discover and
indulge
in your
passions

Find others to
stim with
or on your own

Be aware of
'you should'
demanding
thoughts
in your head

Find out from
other ND
people
how
they unmask

You are allowed to
have your own
opinions
and values

Learn to ask for help
when
you need it

Time alone
to 'be
yourself'
unmasked

Too Many Demands And Expectations

Everyone can find it hard when there are too many demands upon them, but for autistic and other neurodivergent people, too many demands and expectations can be extremely challenging to manage and can cause them to feel overwhelmed. This overwhelm can lead to meltdowns, shutdowns and burnout.

For adults and children with Pathological Demand Avoidance (PDA), their demand avoidance can be extreme and all-encompassing. "Many everyday demands are avoided simply because they're demands. Some people explain that it's the expectation (from someone else or yourself) which leads to a feeling of a lack of control, then anxiety increases and panic can set in. • In addition, there can be an 'irrational quality' to the avoidance – for instance, a seemingly dramatic reaction to a tiny request, or the feeling of hunger inexplicably stopping someone from being able to eat." PDA Society.

"Demands can include the sensory, cognitive, or emotional for an Autistic person. The impact of the typically known senses can incur demand on my being (smell, sound, visual etc) but it can also be the additional impact of interoception (knowing how your body feels) or proprioception (where your body is in space)." The Power of the Demand - Autistic Social Worker.

What kinds of things can be demanding for an autistic person:

Star charts

Expectations to achieve certain standards

Rules, house rules, etc

Too much pressure

Information processing

Compliance

Having to leave what they are doing to eat, drink etc

Too much information to process

Too many questions

Showering, washing hair, etc

Exams

Expectation to attend an event, social occasion

Too much praise

Uncertainty

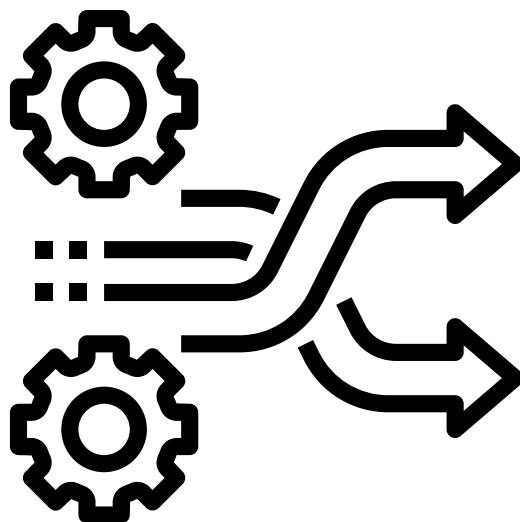
Shoulds/oughts/musts, from others or self imposed

Transitions

Change can be difficult, big transitions and even mini transitions in a day, can all be stressful. But there are some changes in life that are particularly challenging. Autistic people might well find major transitions very difficult to deal with, for example Puberty or Menopause. For many autistic children going from primary school to secondary school, can be extremely demanding, even devastating. For many leaving home, going to college and university are equally as tough.

Big changes in our bodies and our environment, may cause a lot of stress and anxiety. A combination of transitions such as puberty and starting secondary school is for many autistic girls and people assigned female at birth, the perfect storm. If a young undiagnosed autistic person struggles with this transition and goes into autistic burnout, they may no longer have energy to mask their differences any longer. This can be why so many autistic girls are often identified and diagnosed at this stage of life (girls are currently diagnosed 2-3 years later than boys on average). Girls and people assigned female at birth, often have a more internal presentation of autism due to masking.

Mini transitions and having to change focus many times, is also challenging for autistic adults and children, In most secondary schools, autistic pupils are constantly changing throughout a day - from one classroom to another classroom, numerous different teachers, going from classrooms into busy corridors and then outside. They arrive home exhausted, because of all the changes throughout the day, masking and sensory overload.

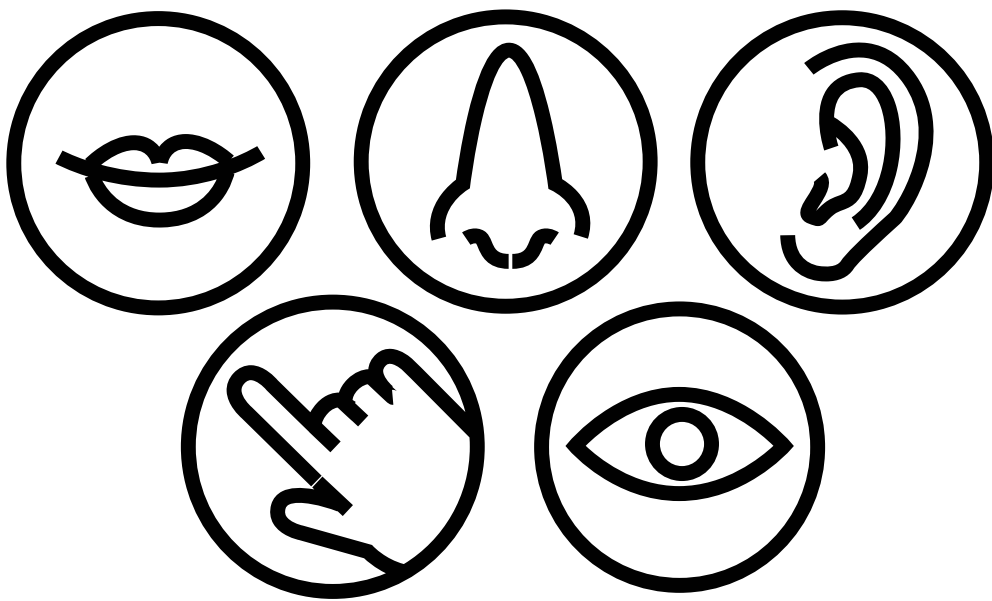


Autistic Burnout Symptoms Tracker.

Tick those symptoms that have increased/heightened/changed

- Fatigue / Exhaustion ☐
- Sensory overload ☐
- Auditory processing difficulties ☐
- Decreased sensory seeking ☐
- Increased sensory seeking ☐
- Headaches/migraines ☐
- Struggle to motivate myself to do my usual activities ☐
- Meltdowns ☐
- Shutdowns ☐
- Difficulty with: memory, emotional control, impulsivity, motivation-
organising, decisions ☐
- Brain fog ☐
- Dissociation ☐
- Anxiety ☐
- Irritability ☐
- Demand avoidance ☐
- Find it hard to communicate my thoughts and feelings ☐
- Regularly experiencing overwhelm ☐
- Rejection sensitivity dysphoria ☐
- Rigidity in my thinking and less able to be flexible ☐
- Less tolerance for other people ☐
- Struggle with communication – speaking, texting, online
communication, phone calls ☐
- Struggle with self care- washing clothes, showering, brushing
teeth, eating properly ☐
- Losing weight ☐
- Loss of skills ☐
- Suicidal thoughts ☐
- Intrusive thoughts ☐
- Sleep disrupted ☐
- Overwhelming emotions ☐
- Feeling numb ☐

The Sensory System



Sensory Overload And Sensory Deprivation

Autistic and other neurodivergent people, have different neurology and a more sensitive sensory system. The problem of sensory overload is common in autistic people and this is not because an autistic brain is broken, the problem is environments (people, places, etc) that can cause sensory overload. Some of these things can be changed, many can be avoided, some cannot be. Each autistic person has different sensory needs; they may be more sensitive to and need to avoid certain noises, smells, lights and textures for example. Some may struggle more with interoception than others (interoception is the sense of what is happening internally). They may also seek after certain sensory input (sensory seeking). Sensory seeking might for example be: biting nails or skin, chewing, scrolling on a mobile, feeling certain textures, and many other things. Each autistic person can learn to understand their sensory diet – what sensory input they want to/need to avoid or what sensory input they want to/need to seek out.

Sensory overload is a significant trigger for autistic burnout and so it is important to understand. Sensory overload, like masking, over long periods causes trauma.

Examples of Signs of Sensory Overload:

- Covering ears due to auditory sensory overload
- Difficulty processing thoughts
- Irritability, frustration, anger
- Stress, fear, or panic.
- Headaches/migraines
- Meltdowns and shutdowns
- Distress
- Wanting to run, escape, leave (flight)
- Not talking
- Cannot focus
- Bumping into things
- Stammering
- Confusion
- Anxiety, or feelings of overexcitement.,
- Restlessness and not able to relax.

Sensory Regulation

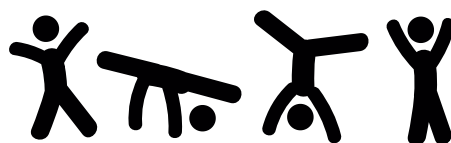
What is stimming?

"The word stimming comes from the phrase self-stimulating behaviours. "Stims are so much more than behaviours. Stims are communication, celebration, self-regulation. Stimming amongst other things stimulates the Vagus Nerve, which calms the nervous system. Stimming also helps with focus, emotional regulation, increases energy and can help improve mood.

Stimming is any of a wide range of actions that we repeat again and again, often rhythmically. Sometimes we use things outside of ourselves to stim with, but just as often we stim with nothing but our own bodies. Stimming is a way of using our senses to calm ourselves, entertain ourselves, and enjoy being alive and in the world". (Neuroclastic).

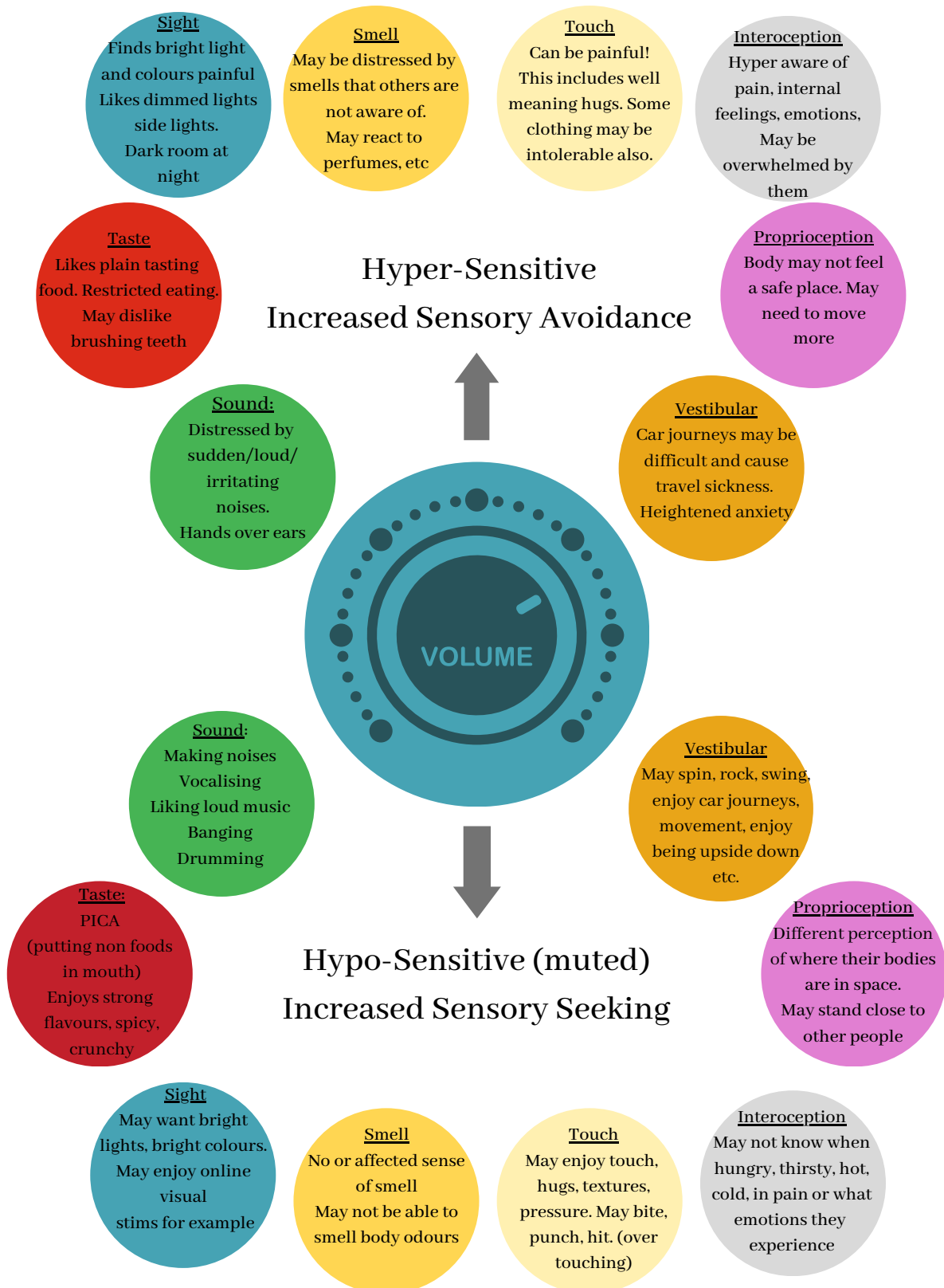
You can stim on your own, or even with others -co regulating. Here are a few ideas for stimming:

- Sight (visual)– <https://www.thearticulateautistic.com/visual-stim-videos/>
- Hearing (auditory) – humming, vocalisations, repeating certain words, singing, listening to a favourite song on repeat, drumming, instruments
- Touch (tactile) – fidget toys, rubbing hands together, chewing (sensory chew jewellery), flicking fingers, clapping
- Smell (olfactory) – wearing a favourite perfume, smelling a favourite cuddle toy
- Vestibular (balance, head movement) – spinning, hang upside down, shifting from one foot to another, stretching up to stand on tiptoe and bobbing, dancing
- Proprioception (external) – bouncing on a trampoline, rocking back and forth, weighted blanket/pressure



The Sensory System

An autistic person can be hyper or hypo sensitive to different sensory stimulus. They can be both hyper and hypo sensitive to different stimulus and this can fluctuate also (that's what the volume control represents) They might also for example be hyper sensitive to one kind of lets say 'auditory' stimulus, but hypo sensitive to another type of 'auditory' stimulus and so on.



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)

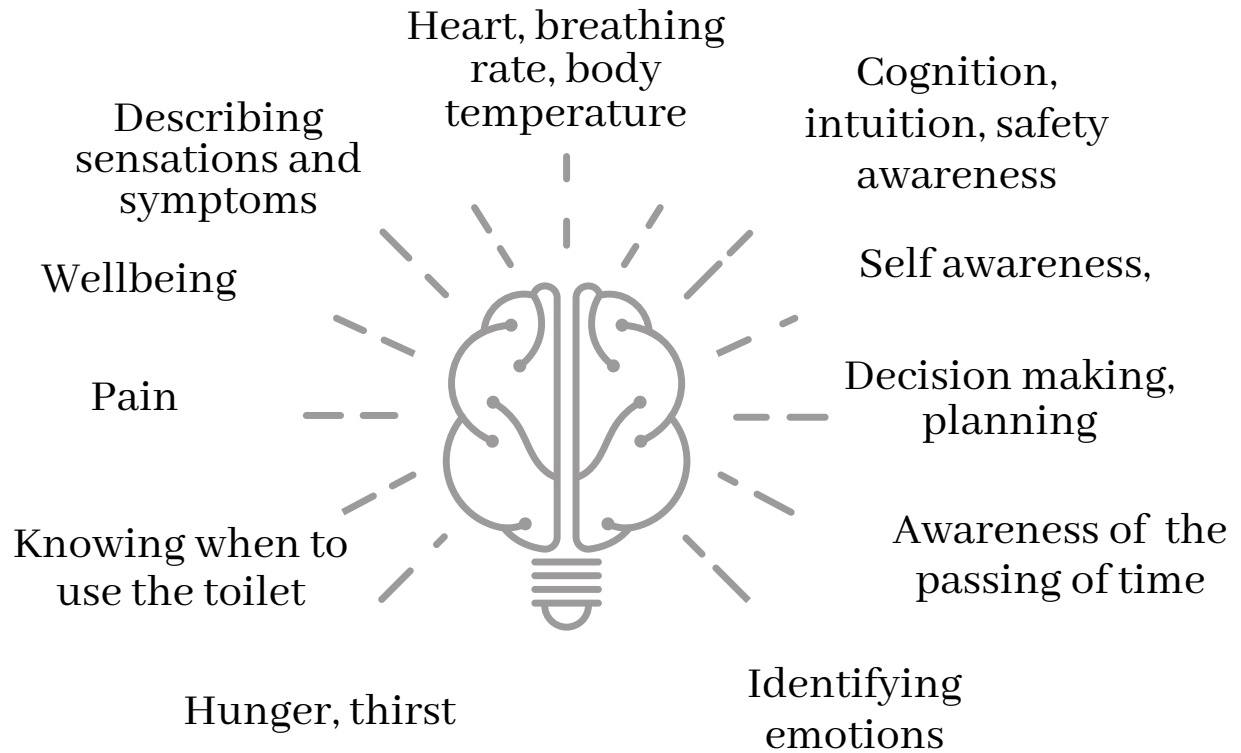
"Interoceptive awareness is your body's ability to interpret if you're hot, cold, hungry, thirsty or in pain. If you can't work out how you feel you won't be able to regulate your sensory system and consequently your emotions will also be dysregulated. In a dysregulated state autistic people are more 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 identifying 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.

Interoception Awareness Includes



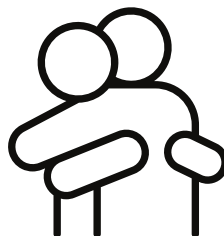
For more information about Interoception
go to www.kelly-mahler.com

Ideas To Help with Sensory And Emotional Regulation

Remember every autistic person's sensory profile is different



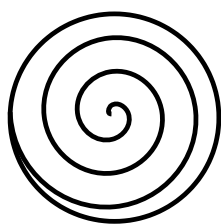
Movement - dance, running, jumping



Cuddling / hugging



Meditation/prayer



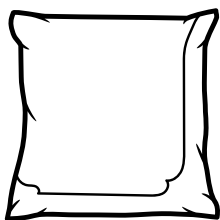
Spinning around



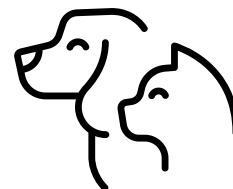
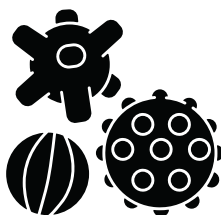
Fidget toys



Listen to music or using noise reduction headphones for silence



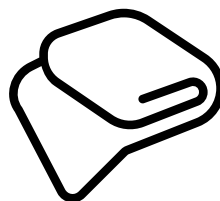
Wobble cushions can help with need for movement



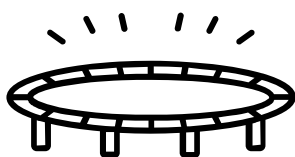
Stroking your pets



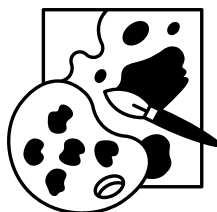
Get out into nature



Weighted blankets can help with anxiety



Trampoline

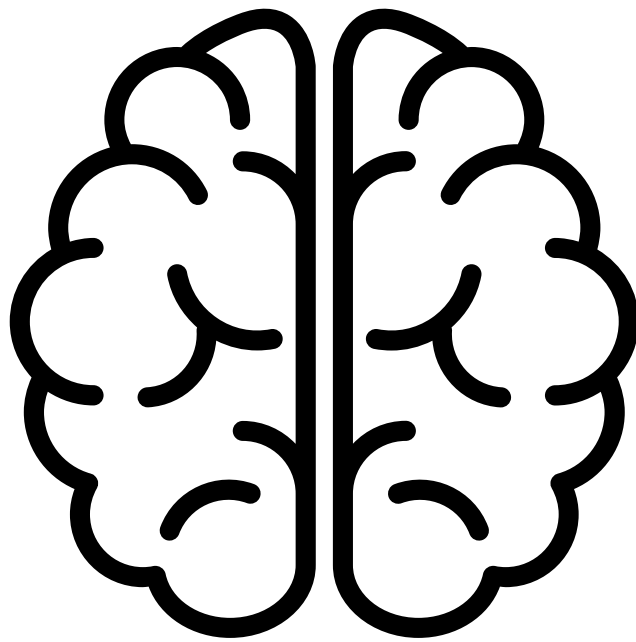


Drawing/painting/writing



Visual stims

Emotions,
Hyperarousal
And Hypoarousal



What Emotions Am I Experiencing?

When you need to check in with yourself, such as what emotions you might be experiencing, it can be helpful to look at names of different emotions, so you can try to work out what you might be feeling.

Here are some examples;

JOY	LOVE	SURPRISE	ANGER	FEAR	SADNESS	DISGUST
HAPPY	CARING	SHOCKED	IRRITABLE	SCARED	HURT	DISAPPROVAL
CONTENT	DESIRE	CONFUSED	RAGE	NERVOUS	UNHAPPY	AWFUL
CALM	AFFECTION	AMAZED	FURIOUS	ANXIOUS	DEPRESSED	DREADFUL
OPTIMISTIC	PASSION	STUNNED	ANNOYED	PANIC	MISERABLE	AVOIDANCE
CHEERFUL	ATTRACTED	DISMAYED	JEALOUS	WORRIED	HURT	REVOLTED
HOPEFUL	TENDER	DISILLUSION	FRUSTRATED	INADEQUATE	DISMAYED	LOATHING
EXCITED	ROMANTIC	STUNNED	RESENTFUL	HORRIFIED	LONELY	REPELLED
SATISFIED	SENTIMENTAL	OVERCOME	AGGRAVATED	TERRIFIED	HOPELESS	JUDGEMENTAL

Emotional Regulation

Emotions can often be hard for many autistic people to identify, understand, respond to and describe. The next few pages look at the nervous system, and explain why people can feel very strong emotions, that might lead to feeling overwhelmed or for autistic people could trigger meltdowns or shutdowns.

There are various things that we can do that help with emotional regulation, including using some sensory regulation tools (stimming can for example often help regulate emotions as can hyper focus).

What Can I Do When I Am Feeling Angry, Sad Or Anxious?

If feeling angry you could:

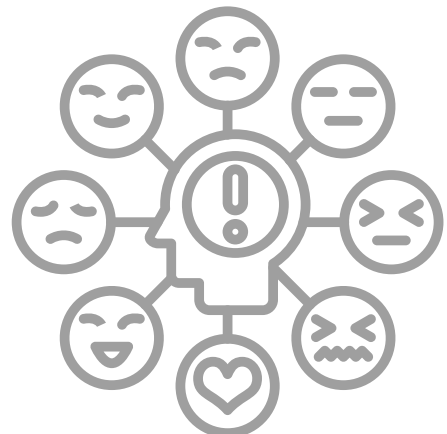
Punch a pillow
Scream into a pillow
Listen to loud angry music or calm music
Tear up old newspapers or magazines
Scribble with a pen on paper
Give yourself space from others if you're with people
Do some deep breathing
Hug a soft toy

If feeling sad and or
lonely you could:

Talk to a friend who you know will listen
Let yourself cry
Listen to calming music
Look at photos of happy memories
Watch a film you know makes you feel good
Treat yourself to something
Call a helpline

If feeling fearful /anxious
you could:

Read or listen something that comforts you
Talk to a friend who can reassure you
Watch something that is calming or funny
Cuddle a blanket/person/toy
Try a weighted blanket
Deep breathing
Do mindfulness exercises



The Nervous System, The Amygdala And The Vagus Nerve

The entire human nervous system is very complex, controlling everything the body does and is made up of many systems. Autistic people's nervous system is more sensitive than a neurotypical nervous system, which means we can be more vulnerable to things like anxiety, stress and sensory overload, etc. Autistic people can also have differences with interoception and may also have alexithymia. These can make identifying internal feelings, sensations, emotions sometimes very difficult. The emotions and body sensations are there (pain, hunger, anger, anxiety) but the individual is not 'tuned in to these'; they may not have words for the internal feelings, emotions or sensations and therefore won't know to respond or how to.

The nervous system is actually made up of many systems, and one of these is called the Autonomic system (involved in involuntary actions such as heart rate, blood pressure, body temperature, sweating, digestion, and bodily functions. etc) The Autonomic system is comprised of the Sympathetic and the Parasympathetic nervous systems.

- The Sympathetic nervous system: This system activates the body and directs the body's response to danger/threat/perceived danger or threat/stress, by causing a flood of hormones like adrenaline, noradrenaline and cortisol to be released. This is due to part of the brain's Limbic System, called The Amygdala (also known as our emotional brain) which triggers the hypothalamus to release hormones.
- This action by the Sympathetic nervous system to any danger/perceived danger, is known as the fight/flight/freeze response.
- The Parasympathetic nervous system works in tandem with the Sympathetic system, by helping to bring balance, slow us down, bringing down the heart rate, breathing rate, etc, reducing adrenaline and initiating de-escalation after stress.
- The Vagus Nerve is part of the Parasympathetic nervous system. It regulates heart rate, temperature, sweating, breathing rate, arousal, digestion and many other involuntary actions. The word vagus means 'wanderer'/vagrant' and this nerve winds its way throughout our organs, including the gut.
- The Vagus Nerve has two sides (PolyVagal Theory): The Ventral Vagal and Dorsal Vagal systems. The Dorsal Vagal system responds to danger/perceived danger, by shutting things in our body down. The Ventral Vagal system however regulates and brings balance.

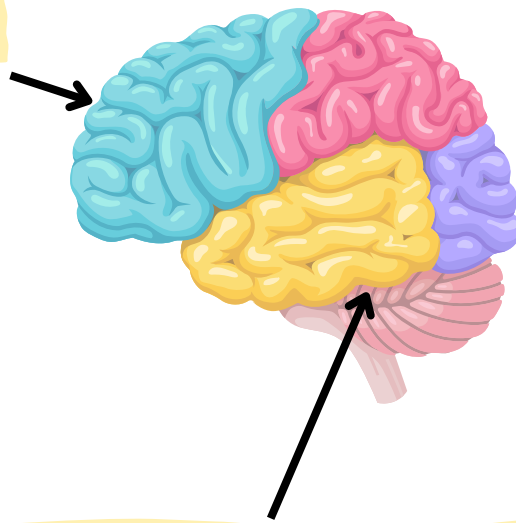
Survival Brain

When the Limbic system hijacks the pre-frontal cortex

The autonomic nervous system is totally committed to protecting you from actual or perceived threat/trauma (and it cannot tell the difference between actual or perceived danger). When the Limbic system detects a threat, the Amygdala triggers the release of cortisol and adrenaline. In survival mode the Limbic system has *hijacked* the Pre Frontal Cortex, leading to the 'loss of skills' experienced by the autistic person.

In survival mode, an autistic person doesn't feel safe (regulated, calm, connected etc); it is impossible to feel regulated in this mode, so getting out of survival mode is the road towards healing and recovery.

Pre frontal cortex- Executive functioning skills



Limbic System (Amygdala, Hippocampus, etc) controls motivation and reward, learning, memory, the fight/flight/freeze/fawn reaction, hunger, thirst, and production of hormones that help regulate the autonomic nervous system.

Hyper and Hypo Arousal

FIGHT/FLIGHT/FREEZE/FAWN

This is based on The Window of Tolerance theory. I do not however believe that autistic people should be taught how to increase their window of tolerance in order to build their resilience to things that can cause trauma. Rather, it is about recognising what their capacity is - in order for them to stay in the safe zone.

Triggers - prolonged masking, sensory overload, emotional overload.
Alexithymia & interception differences make it harder to identify, understand and respond to emotions and internal sensations like pain, anger, anxiety, hunger, thirst etc



Hyper arousal reaction to stress Survival mode (FIGHT/FLIGHT)



Angry, anxious, panicking, chaotic, confusion, racing thoughts
meltdowns, hypervigilant, lack of focus,
(Sympathetic nervous system activated)

Monotropic hyper focus, rest, recharging, passions, interests, music, favourite films, gaming, nature, stimming, art, creativity, and many other things



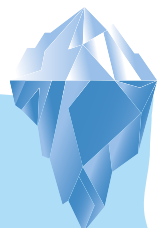
SAFE/Regulated Zone

Regulated, grounded, not stressed, have energy, being themselves, more focussed, calm, connected,
monotropic flow state
(Parasympathetic nervous system activated - Ventral Vagal nerve)

Triggers - prolonged masking, sensory overload, emotional overload.
Alexithymia & interception differences make it harder to identify, understand and respond to emotions and internal sensations like pain, anger, anxiety, hunger and thirst, etc



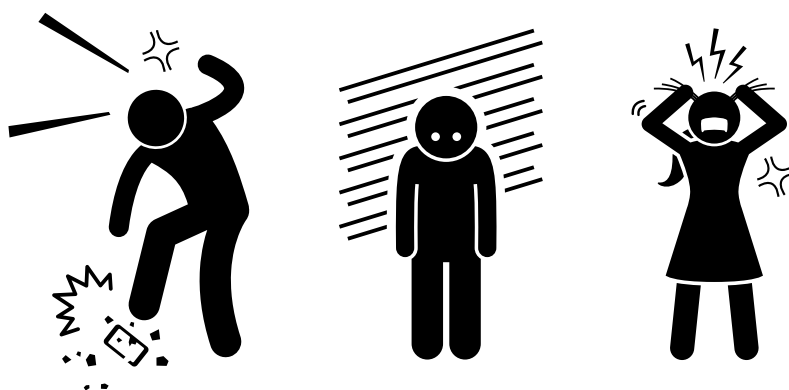
Hypo arousal response to stress Survival mode (FREEZE/FAWN)



Camouflaging, shutdowns, numbness, cannot focus, low mood, dissociation, low energy, not talking, withdrawn, disconnected,
(Parasympathetic nervous system activated - Dorsal Vagal nerve)

Interoception differences and often Alexithymia (many autistic people have this), makes it harder for some autistic people to identify, process and explain internal sensations, feelings and emotions. This can make emotional and sensory regulating more of a challenge, but not impossible.

Meltdowns And Shutdowns



Main features of autistic meltdowns and shutdowns

F.E.A.R

F - Fight/Flight/Freeze

It's 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)

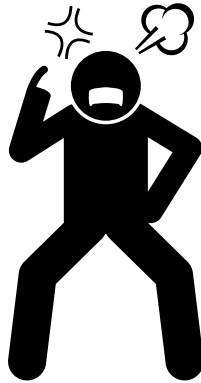
Meltdowns - fight/flight



Screaming,
shouting, swearing



Coke bottle effect -
stress/anxiety builds up at school
and then exploding at home



Explosive

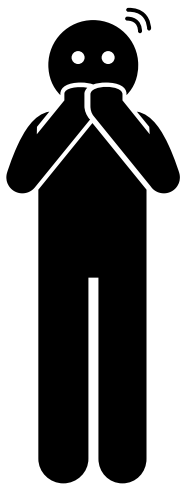


Breaking, smashing things

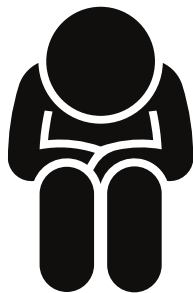


Leave the room/
environment

Shutdowns - freeze



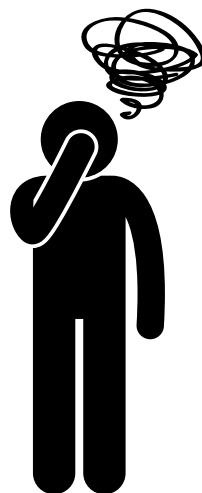
Stop talking



Foetal position,
withdrawn



Feeling numb



Zoning out



Exhausted



Low mood/depressed

What Are Autistic Meltdowns?

Meltdowns occur when the autistic person is extremely stressed and in fight/flight mode; meltdowns are not bad behaviour, or attention seeking. 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! 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. 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

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

How To Support An Autistic Person In A Meltdown Or Shutdown

- Stay calm and quiet- 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
- Lower your position, voice and tone
- 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 - they may not be able to speak
- 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
- 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 (unless they want you to leave and they are safe)
- 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 as you could severely harm them and cause extreme pain

Understanding Meltdowns

What can/tends to trigger meltdowns? If not sure - what triggered the last few meltdowns?

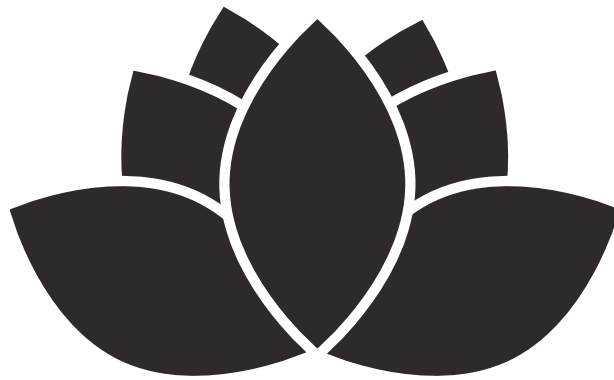
What are the warning signs?

What helps in a meltdown?

What doesn't help in a meltdown?

What can help you/them to stay safe in a meltdown?

What Helps with Recovery And Healing?



R

Restorative and gentle activities that recharge, look different for everyone. To recover the autistic person needs deep rest

E

Energy levels will be very low in burnout and as an autistic person, energy levels always need to always 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 autistic person

T

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



A Day At a Time

'Checking In'

How is my/their mood?

What emotions
might I/they
be feeling?

Use the emotions
chart to help

What sensory needs
do I/they
have right now?

Are there any
demands that need
to be dropped?

Have I/they eaten,
drunk water?

How are
energy levels?

Are you/they
reaching
out to other
ND people?

Its ok to ask for help

Am I/ are they
getting enough
rest?

Interests
and passions can help
with regulating
(Monotropic
hyper focus)

What Could Help With The Healing Process?

Rest as much as possible and
do some gentle soothing
activities

Spend time in safe
validating
environments

Learn about what it
means to unmask

Some non-demanding
routines can still be important

Give yourself
plenty of time to heal

Allow yourself to
stim when you want to

Noise reducing earplugs or
headphones can be helpful

Things like gaming/screens can
help with regulation

It's ok to stay in bed and
rest if you need to and can

Gentle movement is
important, esp if ADHD

Engaging with interests &
passions that can restore energy

Reduce demands and
expectations

Its ok to ask for help

Have boundaries with others

What Will Not Help A Person In Autistic Burnout

It's important to understand that what helps a neurotypical person will often not help a neurodivergent person. Autistic people have different support needs and need different kinds of support. The answer to helping an autistic person experiencing burnout is not talking therapy, as they need to rest their mind, as well as their body.

If an autistic person is in a state of burnout and not attending school, college, university or work - remember they are not being difficult, it's not 'won't'....It's 'can't'. They are not refusing, or resisting; they are incapacitated and need "deep rest" (Kristy Forbes, Autistic Autism Specialist). The person is traumatised and moving out of burnout towards a place of recovery/healing, means taking tiny steps. If they run before they can walk, things will not improve.

I appreciate that not everyone is in the privileged position, where they can fully rest and take time out. Improving support for autistic people in our communities must allow for this. The autistic person needs to be able to step back from demands and expectations. Pushing and forcing someone in autistic burnout to get active, engage, go out, socialise, do more - will exacerbate symptoms.

Remember in autistic burnout, the brain is in survival mode and does not feel safe.

I have talked to many parents of autistic teenagers (who are in burnout), express concern about how their teenager is: *staying in their room all day, sleeping a lot of the day. Their curtains are shut, they don't go out, they don't socialise and perhaps they game a lot of the day and night.*

None of this will actually harm them and remember that with gaming, they are often connecting 'on their terms' with peers, often other autistic people and gaming can be very regulating. Ultimately, they need to rest. Socialising does not help burnout, especially in environments where they're more likely to mask. Being a night owl can also feel safer for them and less demanding - as it is quieter and no one is around.

When the autistic person feels they are ready, has energy again, then it is about slowly re-engaging. An autistic person can go back into burnout if there are too many pressures and expectations from others or themselves also.

Recovery Is A Journey

From Hibernation to Safety

Recovery from autistic burnout does not mean that the autistic person can just simply return to how things were before burnout was first triggered. A lot will have changed and a lot will need to change- so that they don't burn out again. An autistic person will not fully recover in an environment that caused/causes the trauma (unless significant changes are made).

A place of safety means their needs as an autistic person are met and they are no longer in survival mode (fight/flight/freeze/fawn)

Emergence

Recovery can take months, for some it may take many months.

At first, the person may not want to leave the home at all.

Some may only want to go out of the home for very short periods - that is fine.

In their own time, they will know when they are ready to re-emerge, (when they have more energy and feel safe).

They need to know they are not going to be pressured into anything that makes them unsafe.

Recharging

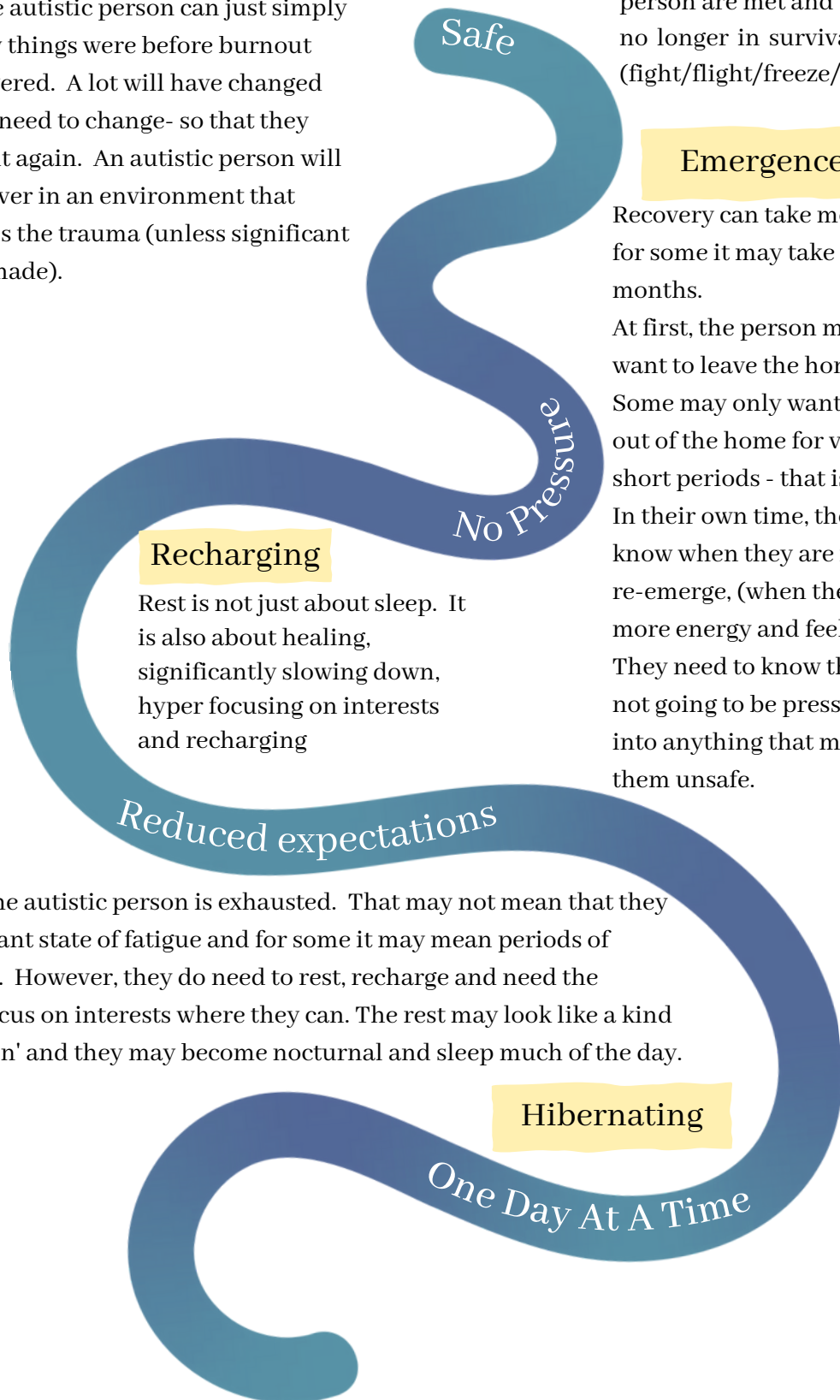
Rest is not just about sleep. It is also about healing, significantly slowing down, hyper focusing on interests and recharging

Reduced expectations

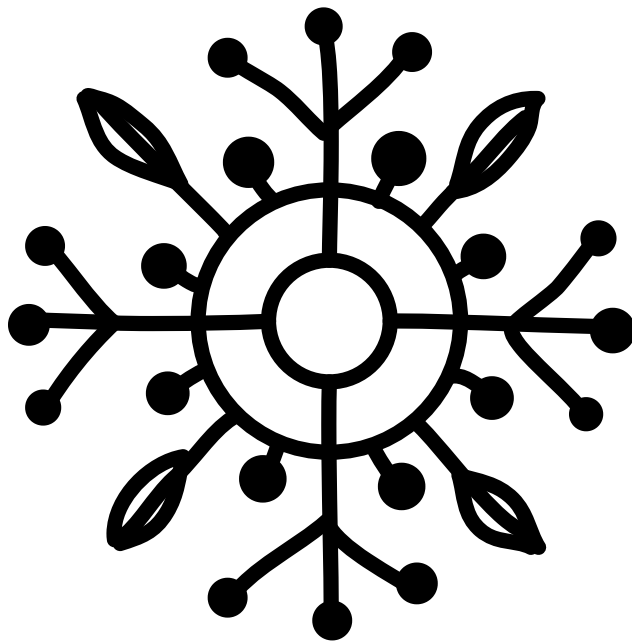
In burnout, the autistic person is exhausted. That may not mean that they are in a constant state of fatigue and for some it may mean periods of hyperactivity. However, they do need to rest, recharge and need the freedom to focus on interests where they can. The rest may look like a kind of 'hibernation' and they may become nocturnal and sleep much of the day.

Hibernating

One Day At A Time



Preventing Autistic Burnout



What Could Help Prevent Autistic Burnout From Happening

"A key strategy for preventing burnout is self-knowledge. Autistic people can learn over time which situations are most likely to trigger burnout for them. They can also watch for signs that they are getting close to burnout. Some autistic people describe feeling disconnected from their bodies or experiencing tunnel vision in this state.

Armed with this awareness, they can develop strategies to avoid burnout."

<https://www.spectrumnews.org/>

Low demand/
low arousal
environments,
inc' at home

Spend time with other
neurodivergent
people

Indulge in and enjoy
interests/ passions as
these can give energy

Be aware of
sensory needs

Accommodations in
school, college, work,
home

Keep an eye
on daily
energy levels

Boundaries with other
people

Sleep/rest is
important

Time alone
when possible

Learning about
unmasking
and stimming

Avoid too much
socialising, esp in
neurotypical
environments

Learn to recognise
internal body
sensations,
feelings, emotions

Prevention

Neuro affirming

Have a positive, neuro affirming outlook about neurodivergence, embracing differences and neurotype. A diagnosis does help many to embrace their neurodivergence and for some, it takes time (often a parent being diagnosed helps an autistic child embrace their diagnosis also).

Lower demands

Remember too many demands and expectations can create a lot of pressure, they can be exhausting and triggering.

Neurokin

Spending time with other neurodivergent people tends to mean less masking and using up fewer spoons. Too much socialising in neurotypical environments can be exhausting due to masking

Monotropic hyperfocus

Being able to hyper focus on concerns, passions and interests is really important. Being able to lose yourself in gaming, gardening, drawing, playing an instrument, reading, writing, crafting, photography or whatever your hyper focus is, can bring immense joy.

Boundaries

Learning about boundaries and how to keep them, will help with future situations and relationships that might use up energy. It can be very common for autistic people to people please

Know your body

Get help/find out how to recognise or understand/interpret internal body sensations, feelings and emotions. Kelly Mahler has some really helpful resources on her website, regarding interoception. An OT may be able to help with sensory integration.

Prevention Continued

Time alone

Time alone is really important (bolt holes), where the autistic person can truly rest and recharge. Autistic people often need time alone

Stimming

Learn about stimming and encourage this; even stim together with others if possible. Co-regulation can help younger children especially. Stimming is a great way to achieve sensory and emotional regulation

Understand masking

Masking is exhausting and learning about this and what unmasking looks like is important. Autistic people will mask more in neurotypical environments, especially environments that have not been adjusted and where there are not any or sufficient accommodations.

Spoons

Learn about keeping an eye on spoons (energy levels) on a daily basis. There are certain environments, people, situations, experiences and activities that use up more spoons

Triggers/causes

Understanding burnout triggers is absolutely essential. This can mean that the autistic person does not experience burnouts in the future or at least experience them less and knows how to recognise them and cope.

Common triggers:

- Prolonged masking
- Prolonged sensory overload
- Very demanding situations and environments
- Too many expectations
- Changes
- Monotropic split

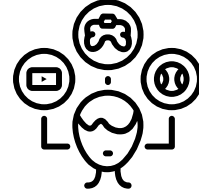
Preventing Burnout



Make regular time to relax



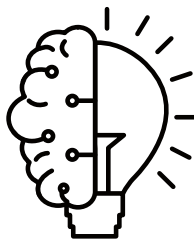
Calming, soothing activities



Engage/hyperfocus on interests and passions



Boundaries with others
Say 'no' to engagements that you don't want to attend



Find your stims



Find your 'neurokin' - other autistic people to connect with



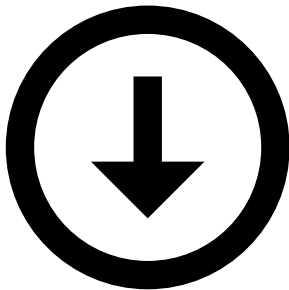
Learn about unmasking - and remember it takes time



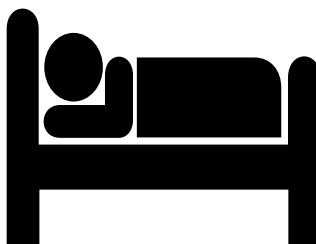
Pay attention to sensory needs



Keep an eye on your daily energy levels



Low demand environments



Sleep is important



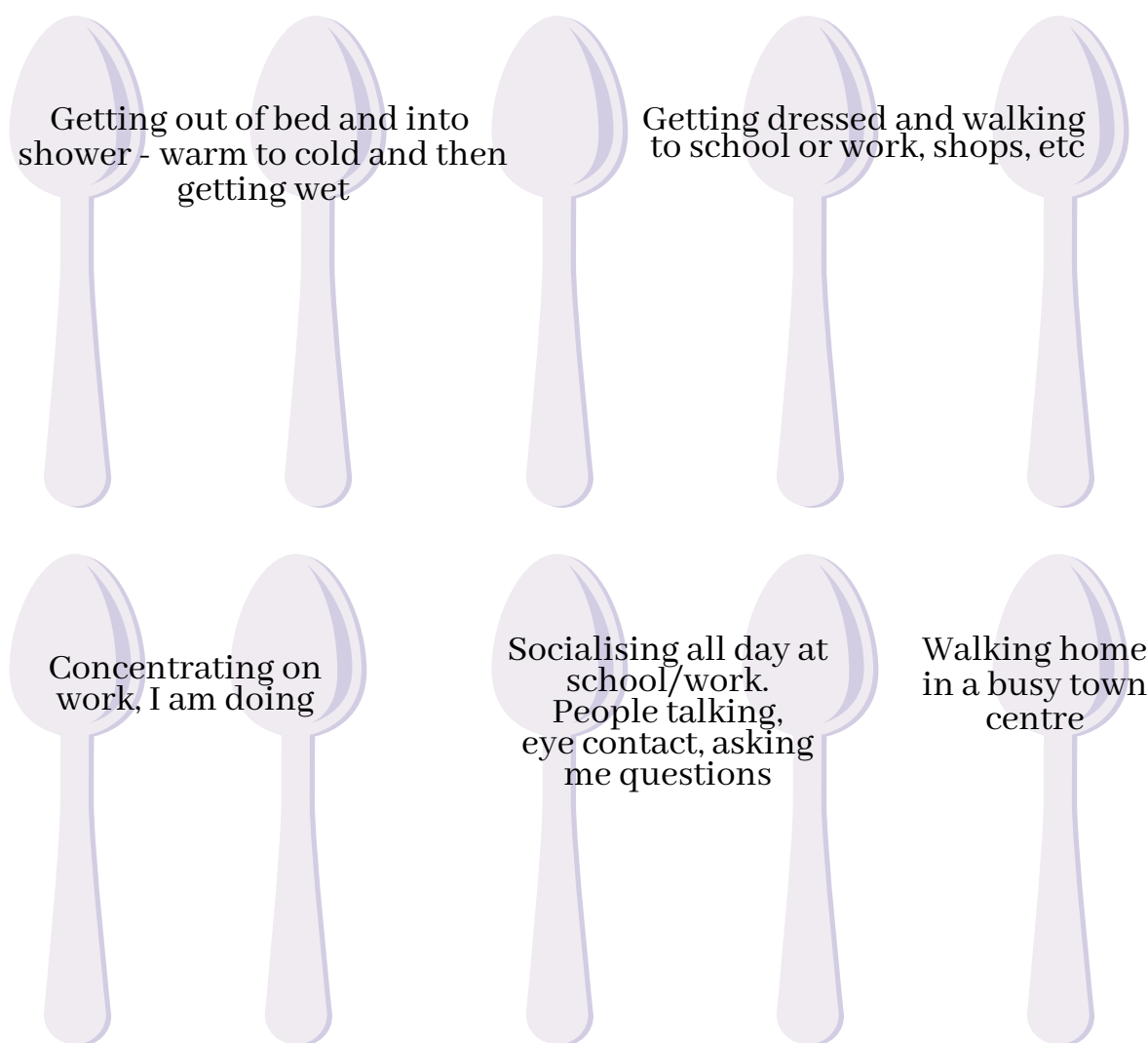
Lifestyle changes may be needed

Spoons



Everyone has a certain amount of mental, social and sensory energy for each day. That energy is symbolised by spoons. Neurodivergent people have less spoons compared to neurotypical people. Once we have used up all our spoons, we risk becoming exhausted

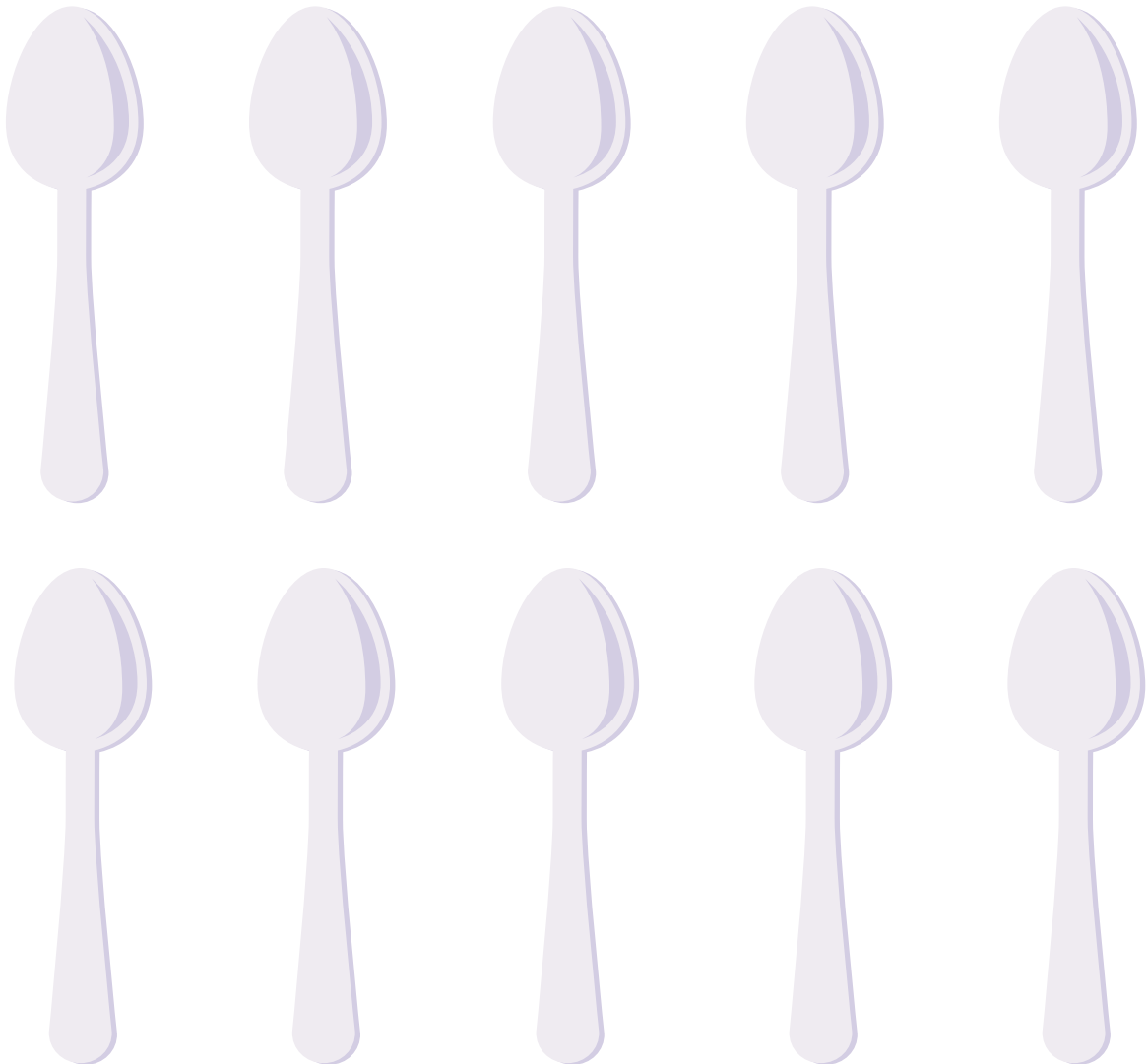
Lets say an autistic person starts the day with 10 spoons, what does each spoon represent? Here is my example and there is a sheet for you/them



Spoons



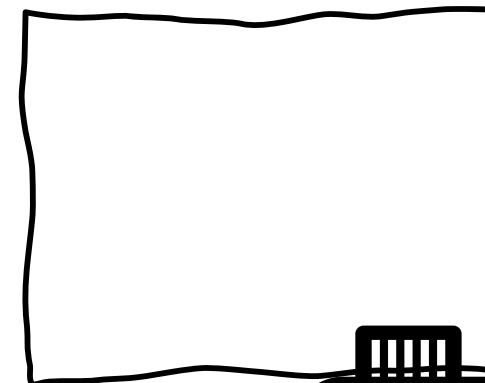
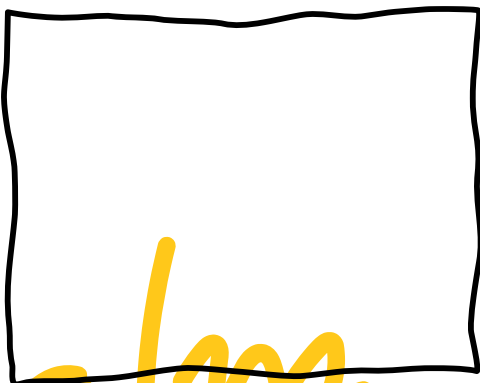
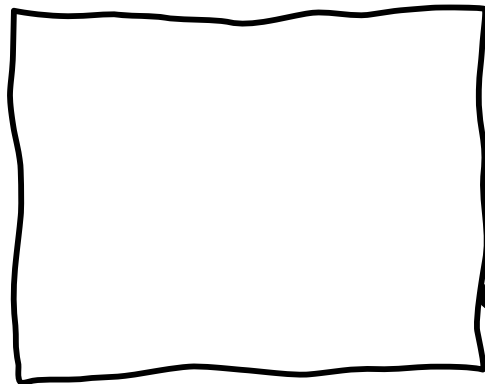
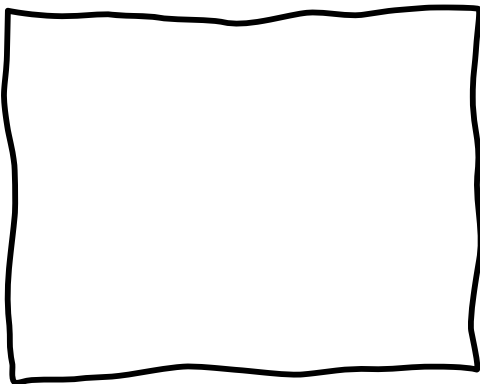
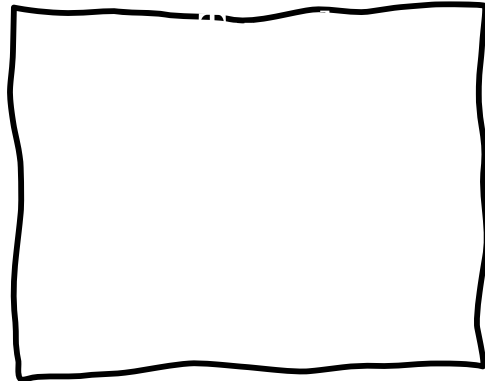
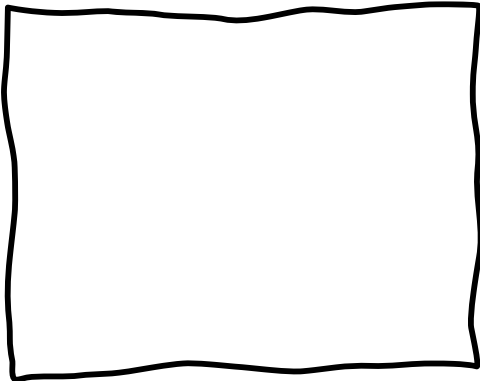
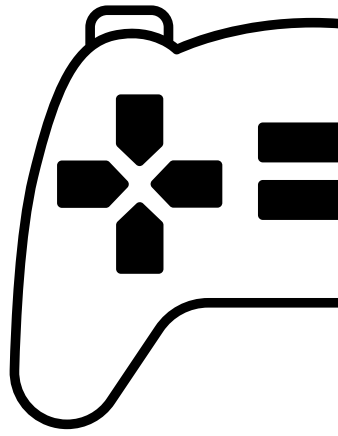
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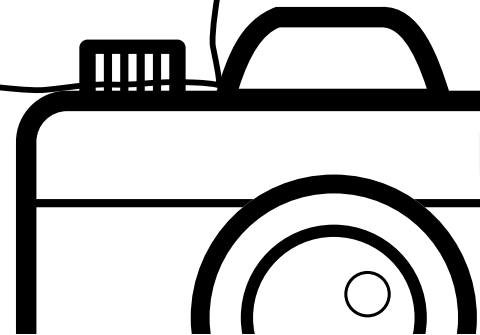
Passions And Interests

As part of healing and also preventing burnout, what activities, interests and passions could I/they focus on and include in my/their life?

Do this when ready. No pressure.



Calm



Warning Signs Of Autistic Burnout



What Are Burnout Warning Signs?

What are the signs that you/the autistic person is heading for burnout?

Think about which environments trigger you/them.

Are there any relationships or social environments that are triggering?

How do you know if you/they are getting exhausted?

Are there other physical signs - such as vision narrowing, headaches etc?

What tells you/them that senses are overwhelmed?

What indications are there for being emotionally overwhelmed?

Remember increasing meltdowns and shut downs are a sign.

Are there any hormonal/emotional triggers?

My Crisis Support Plan

Not every autistic person experiencing burnout leads to being in an extreme crisis, but it's 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?

Support Sheets For Autistic Burnout And Meltdowns



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 clinical depression -although it may look like depression. My mental health is however deteriorating because of burnout.

Some of the main characteristics of autistic burnout are:
Extreme fatigue/ exhaustion, sensory overload, increased meltdowns and shutdowns, increased anxiety, emotion regulation difficulties and loss of executive functioning skills such as: working memory, mental flexibility, decision making and self-control, etc

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 crisis due to autistic burnout
- ☐ 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 calm down.

Autistic Meltdown Support Sheet

Dear Family Member, Friend OR
Doctor/Nurse/Psychiatrist/Social Worker/
Mental Health Worker/ Paramedic/ Police officer, etc,

I am autistic and can experience autistic meltdowns. Autistic meltdowns are not tantrums or attention seeking, but are an involuntary response to stress and sensory overload, etc. I cannot help having meltdowns - they happen to me and I cannot always control them.

In a meltdown I might (e.g shout, hit head) :

When I am in a meltdown, please do not touch me, shout at me, stand over me, stare at me, ask too many open questions. It is best if one person supports me.

What does NOT help me in a meltdown:

What DOES help me in a meltdown:

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Viv Dawes is a late diagnosed autistic/adhd advocate, writer and lived experience trainer. She is also the parent of a neurodivergent teenager.

"Having experienced autistic burnout myself and known many autistic people who also have gone through this, I know how very serious it can be. Autistic burnout symptoms include extreme exhaustion, sensory overload and loss of skills. It significantly impacts autistic lives, affecting everything including self care, mental health, employment, education and can lead to an extreme crisis."

The aim of this book is to help autistic and other neurodivergent people, understand autistic burnout -what it is, what the triggers are and the symptoms. It also seeks to help autistic people discover how to heal and find ways to prevent further burnouts.

This book is also suitable for professionals working with or caring for autistic people, and for parents of autistic children and teenagers.

