

# Autism Hub

## West Cheshire



Burnout

# What is autistic burnout?

- *“It is being drained, wounded to such an incredible degree-like your battery has run dry.”* (Raymaker et al., 2020, p. 9).
- According to Raymaker et al., (2020) burnout occurs after:
- persistent long-term daily stress
- a mismatch of demands/expectations on the individual (in contrast to their capacity)



# What is autistic burnout continued?

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- Key features:
- All encompassing exhaustion
- Draining of personal resources
- Increased sensitivity to sensory stimuli
- Loss of skills (such as executive functioning, speech or the ability to cope)

**Discuss**

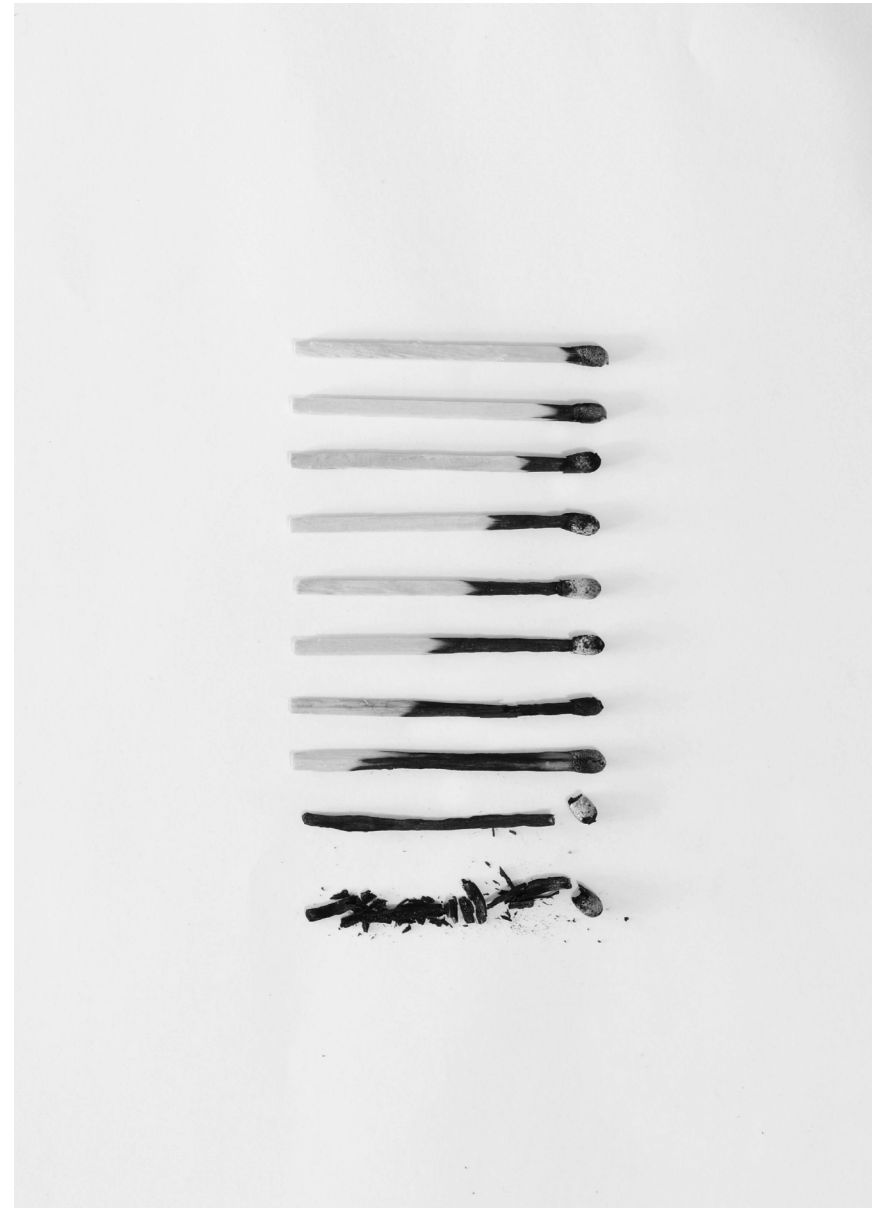




Burnout is frequently experienced by autistic individuals, affecting their quality of life.

Burnout is normally associated with work in the human service sector. Yet, in the case of autistic individuals, it is frequently sadly part of their life experience. Endow (2016) describes the experience as reaching her limit beyond her internal capacity to keep up with the non-autistic world

**Discuss**



# Why?

- Boren (2018), an autistic adult describes burnout as a:
- *“price that is paid , to keep up with the pretence of neurotypicality”*
- This hardly seems a fair cost for trying to keep up with the non-autistic way of being!





# Key factors

- Masking/camouflaging: adjusting behaviour, to appear as if not autistic.
- Identified by Raymaker et al (2020), as the most stressful life experience for autistic individuals. Masking increases the “*cumulative load*” (Raymaker et al., p. 1), as it decreases the “*emotional energy*” (Tierney et al. (2016), p. 82) of individuals.
- Camouflaging frequently results in exhaustion, draining physical and emotional resources (Hull et al. 2017).



# The autistic voice:

- *“Being something that I neurologically am not is exhausting”*. (Boren, 2018)

**Can you relate to this?**



## Raising expectations:



- Strategies such as masking/camouflaging can lead to support needs being underestimated
- Endow (2015): the bar was set higher at a level that she just couldn't sustain







## Interoception :

*“Interoception allows us to feel our internal organs and skin and gives information regarding the internal state or condition of our body”*

(Craig, 2002 cited in Mahler, 2017).

The impact of camouflaging can be further complicated by interoception difficulties. An individual with reduced interoceptive awareness may not be aware of the stress they are under until they reach their tipping point or burnout (Pearson and Rose, 2020).



# Staying within our capacity

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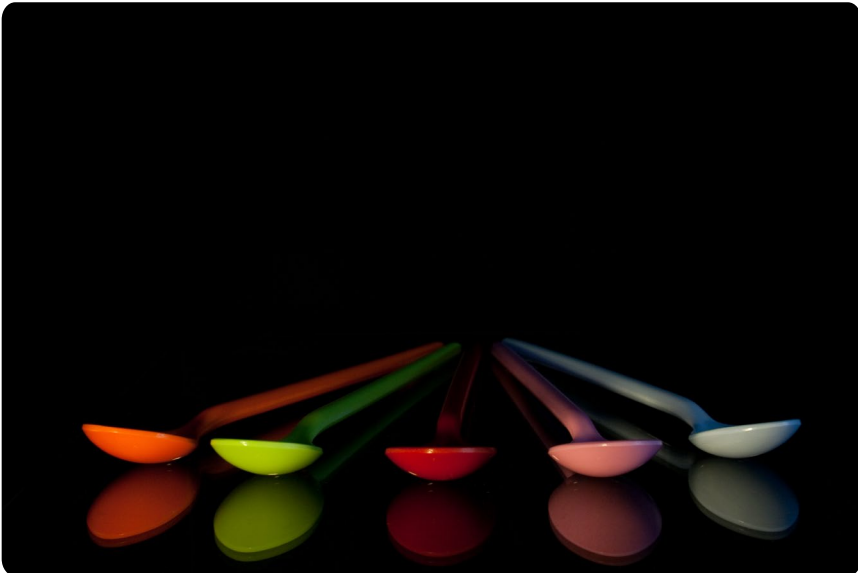
The importance of not exceeding our capacity to cope: our ***“cumulative load”*** (Raymaker et al., 2020).



# What is spoon theory?



- “*Spoon theory*” was conceived when Miserandino (2003) explained what living with Lupus is like to her friend, whilst out for tea. She grabbed spoons that were nearby, using them as a metaphor for her daily energy supply. Miserandino (2003) explained how she has to plan and think about everything due to her limited supply of energy or spoons, with one spoon being used every time she does an activity.



# Spoon theory explained:



*"I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking if I don't try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else? I had to at least try.*

*At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell I grabbed spoons off the other tables." (Miserandino, 2003).*

- See below for a link to the original article written by Miserandino (2003)

<https://bit.ly/3BfVNPS>

# Pacing:

Spoon theory has been adopted by different communities, being used to describe the strategy of pacing

Pacing= limiting the number of daily activities that are stressful or demanding to the individual, scheduling relaxation/rest time (Goudsmit,2004)

A fluid process with individuals adjusting their activities, depending on how they are feeling





## The autistic voice:



*“Viewing the world through the lens of spoon usage completely changed my life” (Knight, 2018, n.p).*

*“ Wearing the mask of neurotypicality drains my batteries and melts my spoons.” (Boren, 2018, n.p)*

# Energy accounting

Similar to the “*spoon theory*”, Toudal (2017) created the strategy of “*energy accounting*” to help her cope at university. The “cost” of different activities are established, as well as the credit that others give, rather like balancing the books. Toudal (2017) recommends:

- discovering what your personal limit is, as well as when it varies
- planning your daily life so that you don't exceed your personal limit
- including activities that replenish your supply of energy.



# Trying to keep up:

- Autistic individuals frequently provide accounts of battling through a world that is *“governed by neuro-typical expectations and norms”* (McGuinness, 2021, p. 60).
- Supportive environments where individuals feel comfortable and accepted to be themselves, where diversity is celebrated and embraced are imperative. Seek out individuals who value you! The West Cheshire Autism offers a community environment that embraces and values diversity, as well as the opportunity to talk through difficulties such as burnout.



# Joy:

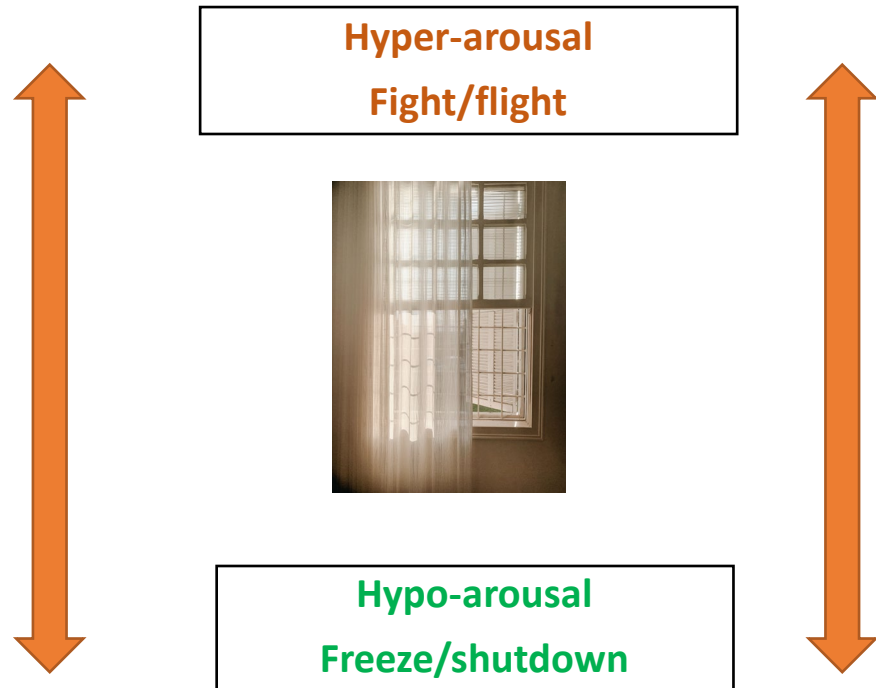
- Engaging in activities that you enjoy is essential in order to replenish your personal resources. Loyd-Williams (2020) provides a moving narrative of autistic joy and how, when an autistic person engages in their passions, their whole body lights up with happiness, energizing them in the process. Engaging in activities that bring you joy are a priority to balance the demands on you and avoid burnout. See the link to the blog below.
- <https://autistrhi.wordpress.com>

Search for autistic joy on her website





# The window of tolerance:



Our bodies have a level at which they work best. This was put forward by the Yerkes-Dodson Law back in 1908! This law proposes that neither physiological arousal that is too low, or too high, is optimal for us to operate at our best.



# Optimize capacity:

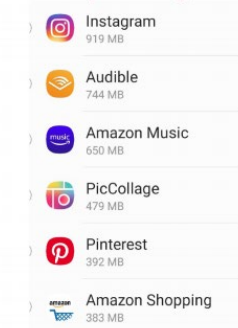
McGuinness (2022) likens this process to phone optimization:

*“Each of us has an ideal at which our bodies work their best. Staying in this ideal zone is like phone optimization. Actions like turning down the brightness on our phones or uninstalling apps that drain the battery help the battery last longer. Practicing self-care and self-regulation helps to keep you in that ideal zone, optimizing your capacity to cope day to day”.*



## Our ideal Zone

Each of us has an ideal at which our bodies work their best. Staying in this ideal zone is like phone optimisation. Actions like turning down the brightness on our phones or uninstalling apps that drain the battery help to make the battery last longer.



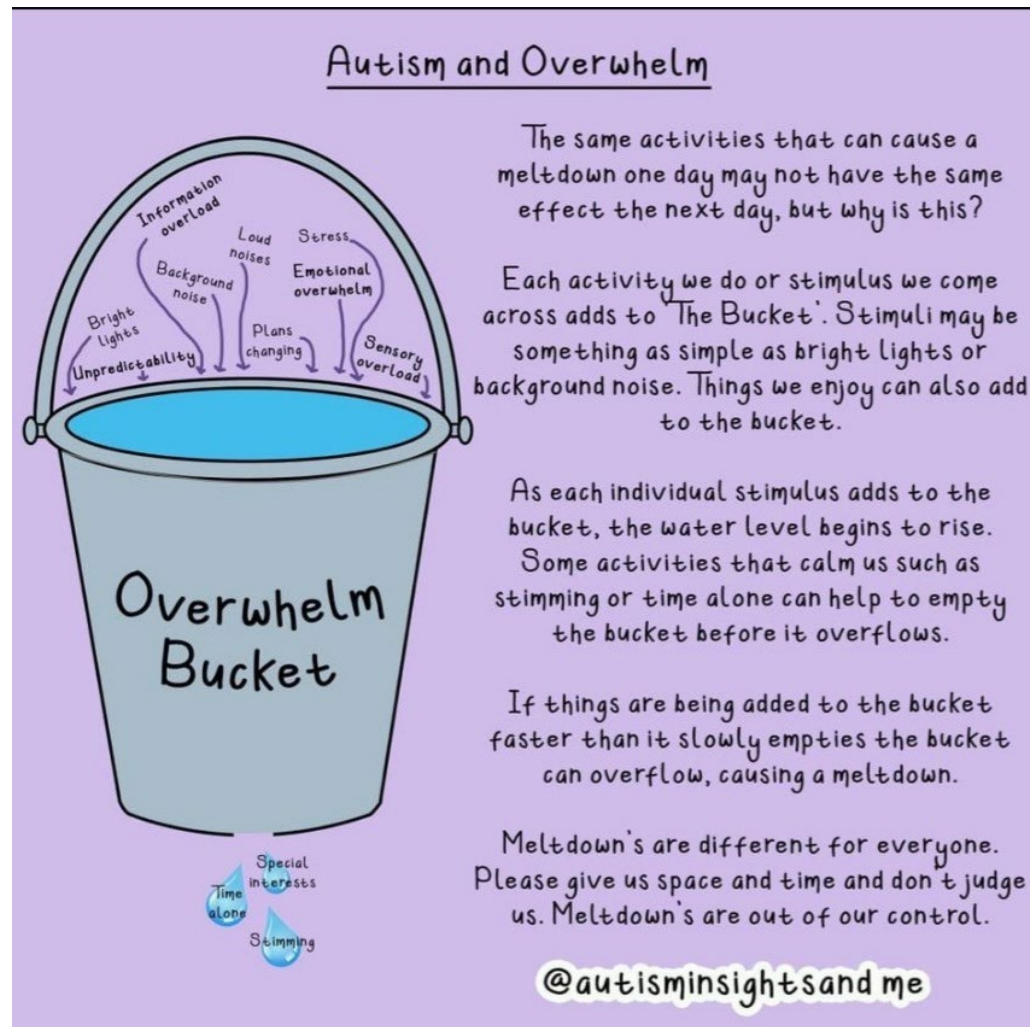
Practicing self-care and self-regulation helps to keep you in that ideal zone, optimising your capacity to cope day to day.

Every activity or stimuli,  
including emotions adds to the  
bucket including things we enjoy.

The water rises!

We can help the water to go  
down by doing activities that  
calm us, time alone, stimming  
etc.

If the bucket fills up quicker than  
we can drain it, that's when  
overwhelm happens leading to  
meltdown, shutdown or  
burnout.

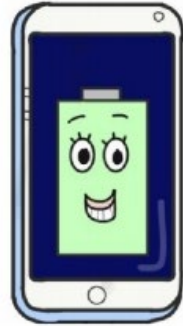




YOU WOULDN'T LET THIS  
HAPPEN TO YOUR PHONE.  
DON'T LET IT HAPPEN TO  
YOU EITHER.

SELF CARE IS A PRIORITY,  
NOT A LUXURY.

## Explaining battery charge



*What if we charged ourselves like we do our phones?*

We don't let our phone run out of battery charge, regularly plugging it in to a socket to charge up. This stops our phone crashing and closing down. Pacing and self-care is a way in which we can stop running out of energy, just like when our phone goes flat. Pacing can be described as not using all of your energy up in one go, taking regular opportunities to rest and do things that help you recover.



Taken from McGuinness, K., (2021). An evaluation of a too, based on spoon theory, to promote self-regulation and avoidance of burnout in autistic children and young people. Good Autism Practice (GAP), 22 (1).

Images courtesy of Ella McGuinness

## Explaining battery charge: Your personal capacity to cope



100%:  
Feeling great



75% Okay,  
have used  
some energy



50% not too  
bad but not  
great



25% Not good,  
used a lot of  
my battery



0% flat battery,  
I'm empty

Taken from McGuinness, K., (2021). An evaluation of a tool, based on spoon theory, to promote self-regulation and avoidance of burnout in autistic children and young people. Good Autism Practice (GAP), 22 (1).


Images courtesy of Ella McGuinness





### **Things I could do less:**

Things I could avoid because they make me tired, stressed or overloaded, draining my battery. Write them down here:



### **Things I could do more:**

Things I know make me feel good but I could do more often to charge my battery. Write them down here:

## It's all about balance

Write your daily activities to either the charging or draining side. At the end of the day if you have more in the battery draining side, you will finish the day with a flat battery.

Battery draining -	Battery charging+

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