

**HARRIET MARKS** (PhD student and DTA:  
Doctoral Teaching Assistant)



# Introduction

- More males are diagnosed as autistic than females
- Gender diagnosis gap may not accurately represent the ratio of autistic men to women
- Current diagnostic criteria focuses on traits or experiences seen in autistic men

(Kok et al, 2016: 1)



- ▶ Autism tends to present 'differently in women than men' (Bedrossian, 2019: 6)
- ▶ 'It is likely that women who do not present with male-specific ASD symptoms are being overlooked entirely' (Kok et al, 2016: 9)

# What I'll cover...



Spoons



Masking



Sensory  
(Dis)Comfort



Detangling  
Sensory  
Reflections



HSPs



Poem:  
Sensitive



Labels &  
DSM



Self-  
Diagnosis



Formal  
Diagnosis?



Poem: I  
Feel Bad



Fluctuating  
Feelings



Poem:  
Thank You,  
Covid



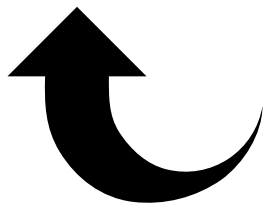
Free  
Speaking



Collage:  
Sensitive

# Spoon Theory

- ▶ Brady (2023: audiobook) discusses the ‘**spoon theory**’
- ▶ Way for sufferers of **chronic illnesses** to explain limited energy levels to others
- ▶ But has since become popular as a way of explaining ‘autistic energy levels’ too
- ▶ Things that drain Brady’s spoons (energy) = make her more likely to have a meltdown



- noisy bars
- fluorescent lighting
- most conversations with fake people
- work meetings
- build up of external noise and light
- excessive masking
- smoking weed & drinking alcohol
- hormonal changes in the week before her period



- ❖ Fern Brady: Why am I angry? Having outbursts when I get home, tearing the place down?
- ❖ Laura James: Why am I so riddled with anxiety, panic, fear?
- ❖ Chloe Hayden: Why am I different, quirky and getting bullied/taken advantage of?

# Masking

An autistic woman participating in Millier et al's (2021: 333) study stated that **'life is masking, masking is life'**, suggesting that 'masking can pervade a person's entire identity, life, and sense of selfhood'

Watching TV show I didn't find funny and practicing laughing along with the laugh track when I was 18.

I found this draining and tiring but didn't want to upset people in future



People telling me that I look miserable, moody or judgmental unless I actively, effortfully smile, laugh and emote.

Confusing ends to friendships, feeling pressure to pretend to laugh and to mask discomfort

Chapman et al (2022: 5) assert that **'masking [is] not limited to suppressing one's autistic self; it involve[s] the suppression of a whole range of sensory and emotional reactions'** and this 'masking of [...] sensory distress' can reinforce anxiety (ibid: 14).

# Masking

- ▶ Garvey (2023: audiobook):
- ▶ I've been told that I don't know how to hide my emotion and I've had people say that they're afraid to tell me things because I'm so bluntly honest.
- ▶ Other people have thanked me for my blunt honesty when I had no idea I was being bluntly honest.
- ▶ I've had people tell me that I'm the most judgmental person they know when inside my head I'm not judging them at all
- ▶ Video for the Q & A section or for you to watch in your own time depending on timings:  
<https://www.bbc.co.uk/ideas/videos/im-autistic-heres-why-i-decided-to-stop-masking/p0gffmp8?playlist=my-autistic-self>

# Sensory (Dis)Comfort

- ▶ DSM-5: '**Hyper- or hyporeactivity** to sensory input or **unusual interest** in sensory aspects of the environment' (American Psychiatric Association, 2013: 50-51).
- ▶ 'Atypical sensory processing' occurs in **69%–95% autistic people** (according to studies referenced by Neufeld et al (2021: 1423))
- ▶ '**Sensory overwhelm**' is 'one of the most common and subtly debilitating' experiences that autistic people can have (Price, 2022: 114).

Garvey (2023: audiobook):

- ▶ (Challenges and) **strengths of sensory differences**
- ▶ E.g. visual strength of spotting patterns helped me in my intensive care nursing career
- ▶ More easily spotting subtle changes indicating deterioration. E.g. Could hear tiny differences in patient breathing. Praised often
- ▶ Many of my sensory differences bring the most joy to my life

I knew I experienced **heightened sensory sensitivity**

But felt confused when trying to contextualise, describe and label some of my childhood, teenage and adult sensory sensitivities



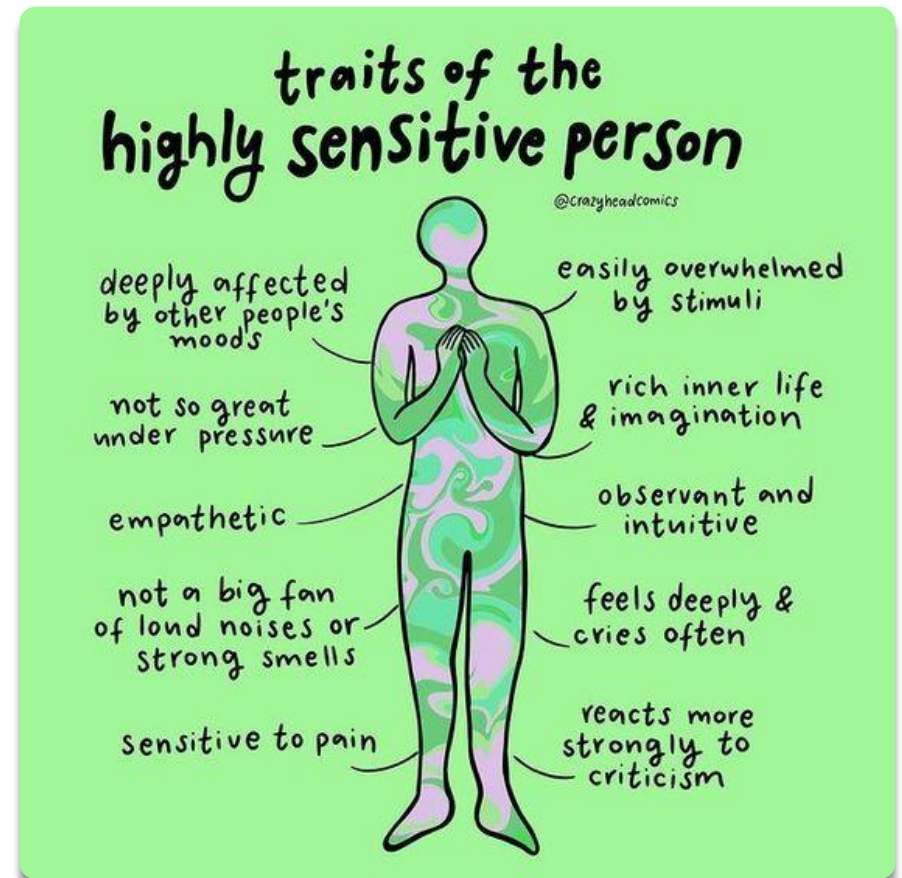
# Detangling Sensory Reflections

| Childhood   | Teens   | Adulthood   | Post-Covid   |
|---|---|---|--|
| <b>Hypersensitivity</b> to loud noises, bright lights, certain textures and strong smells   | Same issues. Better at <b>hiding</b> it.<br><br>Worse if hormonal   | Better again at <b>hiding</b> it. Especially with <b>alcohol</b><br><br>Worse if hormonal   | <b>Hyper (!!!) sensitivity and no alcohol to help.</b><br><br>Hormonal for longer  |
| Hatred of being in bright, loud shops. Crying, begging to leave. Shaky.<br><br>Shutting the windows in the library in primary school to escape playground noise | Going to the changing room to sit and shut my eyes for a bit.<br><br>Dizziness/feel faint/fainting due to sensory input. School too loud. | Dizziness/feel faint/fainting.<br><br>Alcohol helped me massively to be tactile, hug people, cope with worse textures and other sensory input | Shops → Migraines, exacerbated dizziness/feel faint/fainting, tinnitus, exhaustion, need to sleep more.<br><br>Often can't hide (e.g. swaying, earbuds, glasses) |



# HSPs

- ▶ Highly Sensitive Person (HSP) = sensitive emotional and in terms of their senses
- ▶ Two counsellors have verbally diagnosed me as a Highly Sensitive Person (HSP)
- ▶ Aron's term refers to people who are 'intuitive, emotionally astute, and easily overwhelmed' (Price, 2022: 75) and statements such as 'Other people's moods affect me', 'I am easily overwhelmed by things like bright lights, strong smells, coarse fabrics, or sirens close by' (Hovet, 2019) may resonate with HSPs.
- ▶ Although many people now believe a HSP is an autistic person (ibid; Price, 2022) and some of the highly sensitive people she described have now found out they are autistic (Price, 2022: 75), Aron believes they are separate diagnoses.



## 'Sensitive'

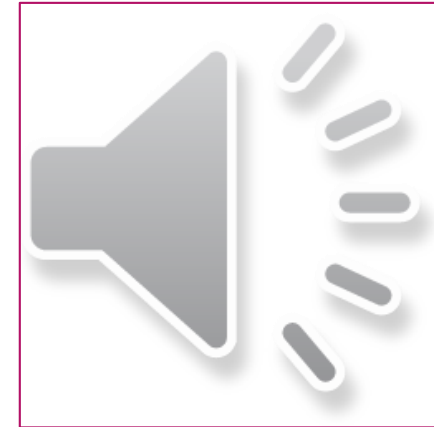
10

When I was young,  
I stuck out my tongue,  
Cheeky and smart,  
This was the start,  
Of watching people's faces,  
Before I could tie shoelaces,  
To see how they felt,  
And what I should say.

Found my peers too loud,  
Adverse to crowds,  
Shop lights, too bright,  
Discomfort out of sight,  
Shaking and tense,  
I got the sense,  
I should hide how I felt,  
And who I was.

Didn't want to get in trouble,  
Or cause a kerfuffle,  
I misunderstood,  
As little as I could,  
No one said what they meant,  
So all my energy was spent,  
Trying to work out,  
How to reply.

Sung and danced,  
Easily entranced,  
I was often pensive,  
My efforts extensive,  
To bond with friends,  
Then make amends,  
Careful and perceptive,  
Except to myself.



# Labels and DSM

Autism is characterised by...

- ‘Persistent **deficits** in social communication and social interaction across multiple contexts’ such as ‘**failure** of normal back-and-forth conversation’ and ‘**failure** to initiate or respond to social interactions’.
- Autistic people have ‘**deficits** in developing, maintaining, and understanding relationships’.

(DSM-5 by American Psychiatric Association, 2013: 50-51)

I have definitely had struggles with understanding friendships (such as when I lost a friend due to not laughing at her joke) and can struggle with communication confusion (such as when I take instructions literally) but I think these are **differences, not deficits**.

Advantages: e.g. I feel my direct, literal communication was an asset as an International Buddy

‘Autistic traits have moderate to high **heritability**’ (Lundqvist and Lindner, 2017: 2080)

**I share many traits with family** e.g. being highly organised, honest, pedantic and assertive, with intense/obsessive interests.

How much to include this?

# Self-diagnosis

/Self-realised/ self-actualized/ self-identified/ self-determined

- ▶ **Price** (2022: 43-45)
- ▶ Learning you are autistic = a journey of self-acceptance, community building and growing self-advocacy and you might not need or want a diagnosis to go down that path
- ▶ I firmly support self-determination
- ▶ I prefer the term self-determination or self-realisation to self-diagnosis because I believe it's more sensible to view autistic identity through a social lens than a strictly medical one
- ▶ Diagnosis is a gatekeeping process and it slams its heavy bars in the face of anyone who is too poor, too busy, too Black, too feminine, too queer and too gender nonconforming
- ▶ The autistics who lack access to fair diagnosis need solidarity and justice the most desperately out of all of us and we can't just shut them out
- ▶ For many autistic parents, it's the diagnosis of their children that kicks off their own exploration of autistic identity

For me, I am self-diagnosed but feel a bit conflicted on these terminology decisions

1. You shouldn't say self-diagnosed because then you're supporting the medical model and ableism

2. If you support self-diagnosis of autism (or ADHD) you're basically supporting self-diagnosis of all health conditions

3. Self-diagnosis is valid as not everyone can afford to get an assessment (£££) so it is classist to invalidate it

4. If you self-diagnose, you might take all the resources from the people who need them more than you

5. Autistic people with low support needs (LSN) need to always state that they have LSN so that they are not speaking on behalf of the whole community

6. Low support need (LSN) autistics should not drone on about being LSN because they are trying to distance themselves from HSN autistics, which is ableist

7. You can be self-diagnosed but only if you don't say 'I'm autistic'; you must always say the 'self-diagnosed' part

8. It's invalidating to self-diagnosed people to say 'they are self-diagnosed' or 'I am self-diagnosed' because you are implying it's not valid

9. If you talk about the positives of autism/call it a superpower/say it's not a deficit (whether you are self- or formally diagnosed), you're basically saying there are no challenges which is invalidating to people who feel there are challenges

# Evolving Diagnostic Labels (confusing)

ASD

Level 1-3 (most  
to least  
independent)

- ▶ Neurodivergent
- ▶ ND
- ▶ On the spectrum → it's seen more as a pie chart than a spectrum
- ▶ Autistic person → Person with autism → autistic person
- ▶ Capital letter for the 'A': Autistic
- ▶ Asperger's/ Aspie / Aspergirl → autistic (Level 1)
- ▶ High functioning → Low support needs/high masking
- ▶ Low functioning → High support needs/low masking
- ▶ AuDHD (Autistic and ADHDer)
- ▶ Deficit/disorder vs difference/neurotype
- ▶ Acoustic, Neurospicy, 'Tism, Touch of the 'Tism, 'Tism Rizz, #actuallyautistic



# Autism Spectrum

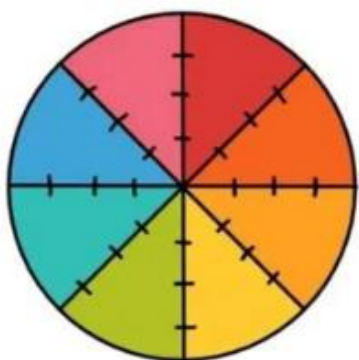
The Autism Spectrum is NOT linear



less autistic

very autistic

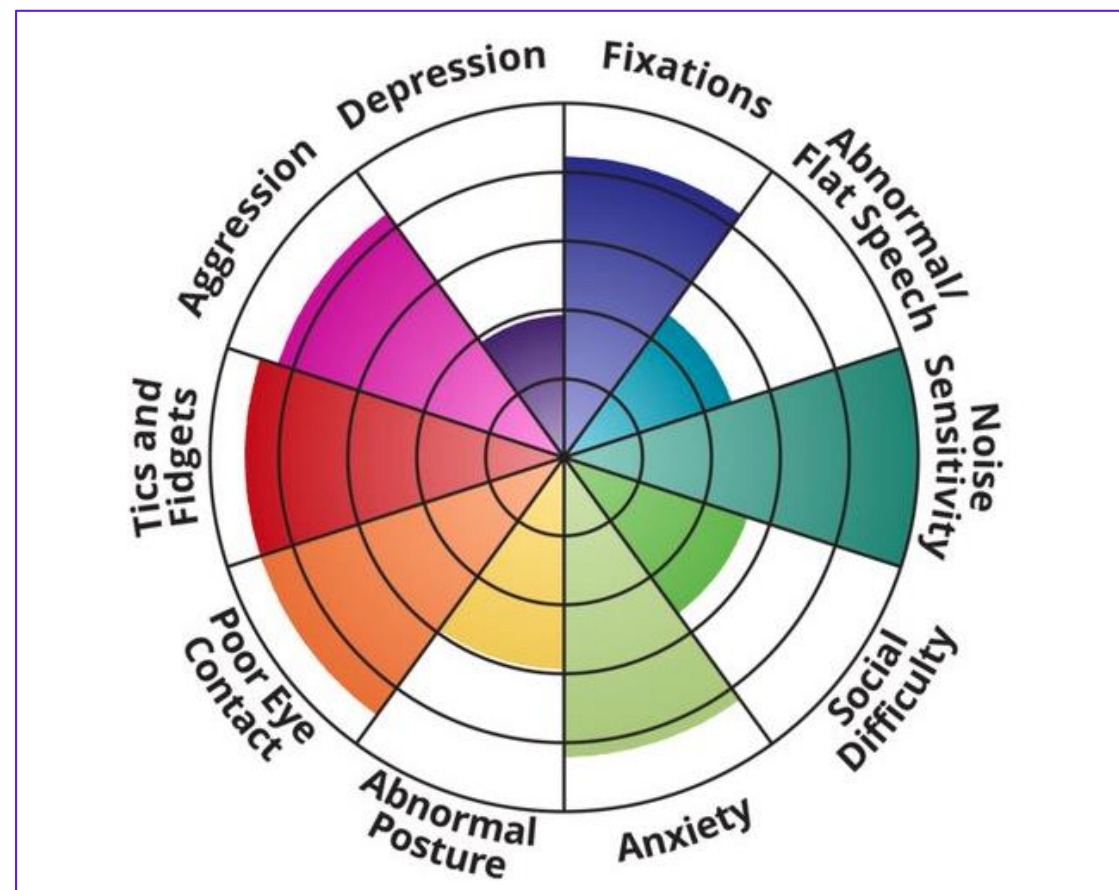
The Autism Spectrum looks more like:



- Social differences
- Interests
- Repetitions
- Sensory sensitivities
- Emotional regulation
- Perception
- Executive functioning
- Other

Terms like "high functioning", "low functioning" are harmful and outdated.

Autism\_sketches



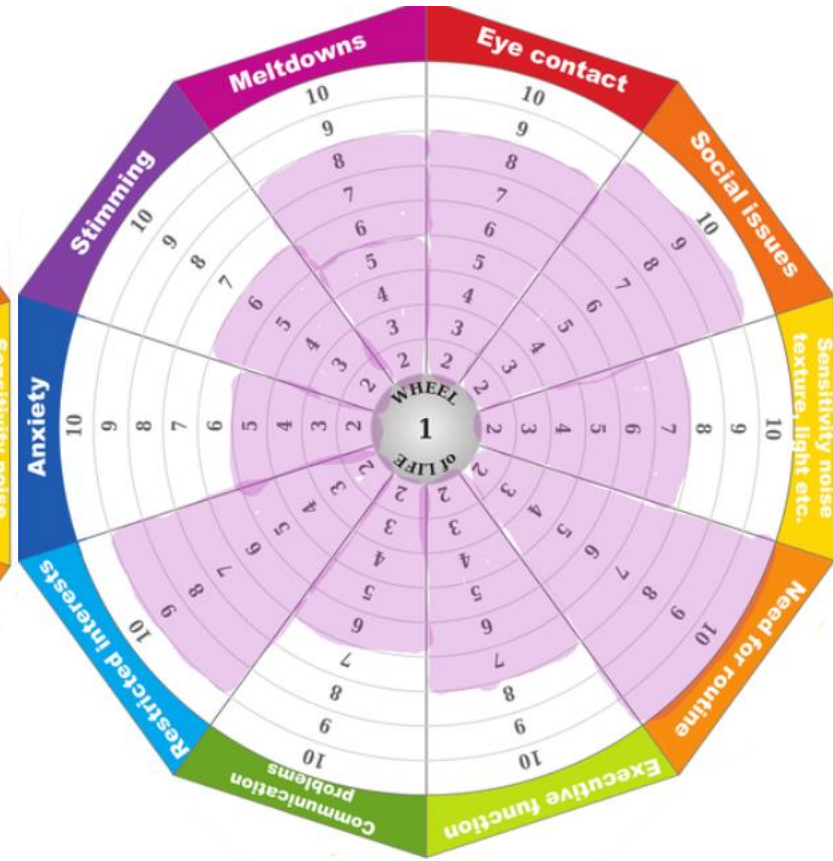
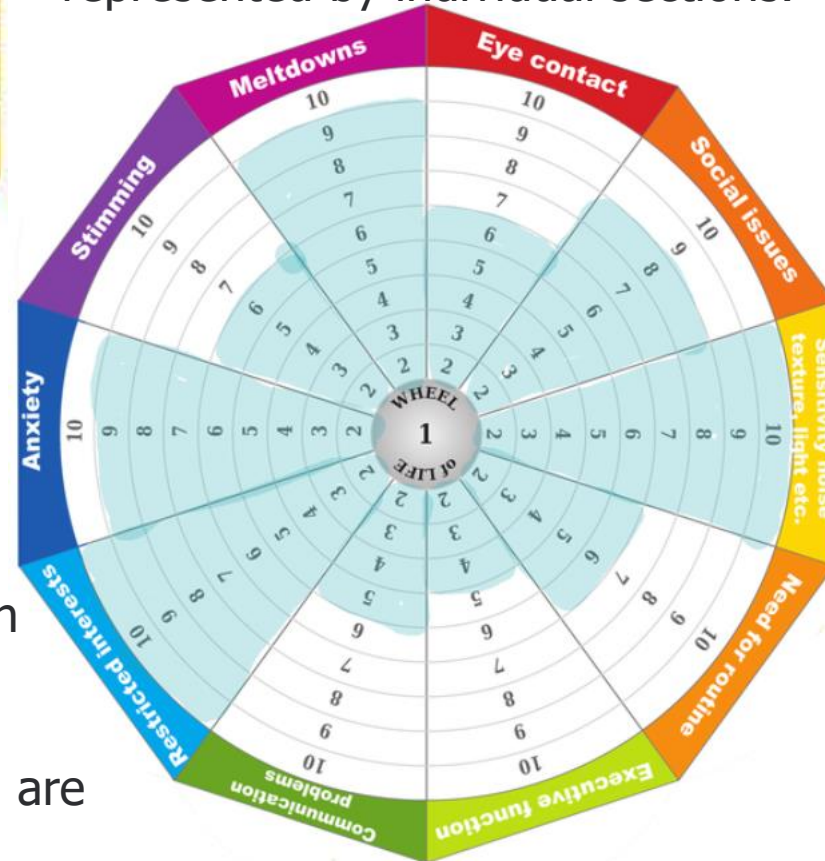


Pie chart = similar to the wheel of life used by some life coaches

The "pie chart" or "autism wheel" model = advocated by researchers who regard the linear model as static and limited.

In the pie chart model, individual autism traits are represented by individual sections.

(Jack, 2022)



See examples from source's clients, both diagnosed as autistic

Neither is "more" or "less" autistic. Both are autistic.

# Formal Diagnosis ?



Price (2022: 43-35): Self DX = valid

- ▶ Being identified formally as disabled is very much a double-edged sword
- ▶ A diagnosis can even be used against people in divorce proceedings or child custody cases or to force a legal adult under a financial conservatorship
- ▶ Unfortunately, diagnosis is not a guarantee that you will receive support anyway

Middleton (2023: audiobook): Self DX = valid

- Human rights vs support (if you even receive support anyway?)
- Misdiagnosis in formal assessments
- Waiting lists and £ to go private
- Diagnostic assessment: infantilizing and exhausting + can cause immigration discrimination

My main reason for not seeking a formal diagnosis (yet?):

Anxiety on my medical record since teens (regret)

'Waiting for autism assessment' on my medical record

My fears of it being on the system = not getting referrals that I want/need e.g. to see neuro. Previously being removed from lists

## *'I Feel Bad'*

I feel bad I spoke too much,  
I feel bad I don't like touch,  
I feel bad I thought you were joking,  
I feel bad now for moping.

I feel bad for being oblivious,  
And for being too serious,  
For failing to notice,  
And struggling to focus.

I feel bad I left early,  
And that you thought I looked surly,  
I didn't mean to cause hurt,  
I didn't know you were trying to flirt.

I feel bad I don't see you enough,  
I'm always tired and it's tough,  
I feel bad for not looking,  
And for cancelling our booking.

I feel bad I told your secret,  
I didn't know I was meant to keep it,  
I feel bad when I open presents,  
Or look withdrawn at big events,

I feel bad, it must be draining,  
To listen to me complaining,  
Didn't realise the guilt I had,  
About always feeling I am bad.



# Fluctuating Feelings

- ▶ Sobriety: Felt grateful for it but have lately struggled with it. My senses have been more reactive (again) since Covid 3.0 so currently, I do wish I could have a drink to help me ease this overload
- ▶ Menstrual Cycle: Pre = feeling sensitive, sad, grief. After = Feeling grateful, wouldn't change a thing etc
- ▶ How does it feel to share what I have so far of my auto/bio lit review? The short answer is it varies.
- ▶ How can I be sure I do that thing for that reason? I can't
- ▶ I want to come out and unmask vs I want an easy life & to be employable (Brady (2023: audiobook) discusses this in terms of needing to pay for housing/food)

What if it's found that HSPs are not autistic?

I developed **CVS** in childhood, which I was told was due to hormonal changes (but can also be due to light sensitivity and/or emotional stress)

CVS was **reclassified as a migraine**, which confuses me

## *'Thanks a Lot, Covid'*

*'Thank you Covid,  
My life has exploded.  
Never ached so much,  
Legs tender to touch.  
Drowsy from exhaustion,  
I approach stairs with caution.  
Two red lines,  
Affecting all this time.  
It's been a year already,  
I can only move steadily.  
But thank you Covid,  
For I have noticed.  
Being tired brings clarity,  
Of who I am and want to be.  
I realise things I've been hiding,  
On the hamster wheel, abiding.  
I'm bi, introverted,*

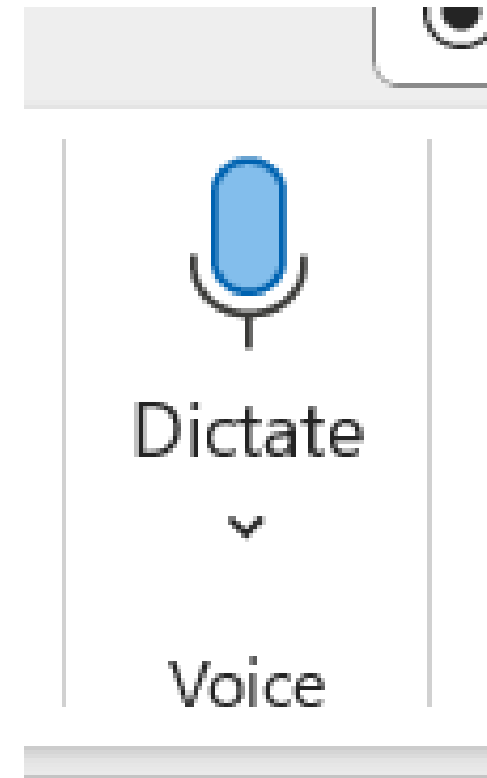
*Neurodivergent.  
The friendships worth keeping,  
Hold rewards I am reaping.  
For our connections are stronger,  
Now I am no longer a fawner.  
No longer feel obliged,  
To keep it all inside.  
When socialising for hours,  
Tiredness overpowered.  
Faking a smile,  
In case people ran a mile.  
I no longer subscribe,  
To masking all the time.  
Covid, you made me start fresh,  
Stop, think and reassess.  
What I wish to spend time on,  
Now I can't stand for as long'.*





# Free Speaking

- ▶ I find free writing hard and free speaking easier
- ▶ I tend to record voice memos on the iPhone voice memo app
- ▶ Then, I use Dictate on Word or Power Point to type these up for me
- ▶ I might record one after reading something that resonates with me or record one when I think of/remember an anecdote that I might want to draw on
- ▶ This works well for me, as it helps me to process my thoughts, emotions and ideas



# Collage: 'Sensitive'





# Final Comments

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- In this paper, I evaluated how it feels to be writing my PhD's literature review auto/biographically
- I have faced many dilemmas and decisions so far, often experiencing fluctuations in the labels I might want to use
- My PhD seems to be evolving/changing more than past work I have completed, which I find challenging, as it feels like I am not properly ticking tasks off and being able to mentally move on from them. I seem to be going down many reading rabbit holes

- ▶ I enjoy writing about my experiences but find it emotional and more time-consuming (and dare I say spoon-heavy) than writing without 'I'
- ▶ I find voice memos the easiest way to reflect on my experiences and anecdotes
- ▶ I feel I have poor introspection skills in terms of struggling to 'read' what my body needs from me so reflecting and writing auto/biographically is helpful for that, as I am becoming more self-aware of patterns of overwhelm, spoon usage and social withdrawal

How much to talk about/include health/menstruation/family/personal details?

- ❖ American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition. DSM-5*. Arlington: American Psychiatric Association.
- ❖ Bedrossian, L. (2019). Understand how autism presents differently in women than men. *Disability Compliance for Higher Education*, 24(7): 6.
- ❖ Bennie, M. (2023). *Under-Responsive / Seeking Sensory Input* [online] Autism Awareness Centre. Available at: <https://autismawarenesscentre.com/under-responsive-seeking-sensory-input/>
- ❖ Brady, F. (2023). *Strong Female Character* [audiobook] Octopus Publishing Group.
- ❖ Chapman, L., Rose, K., Hull, L and Mandy, W. (2022). “I want to fit in... but I don’t want to change myself fundamentally”: A qualitative exploration of the relationship between masking and mental health for autistic teenagers [online] *Research in Autism Spectrum Disorders*, 99: 1-18.
- ❖ Davies, P. (2012). ‘Me’, ‘Me’, ‘Me’: The Use of the First Person in Academic Writing and Some Reflections on Subjective Analyses of Personal Experiences. *Sociology*, 0(0) 1-9.
- ❖ Garvey, N. (2023). *Looking After Your Autistic Self* [audiobook] John Murray.
- ❖ Hayden, C. (2022). *Different, Not Less* [audiobook] AudioStudios. Available at: <https://www.audible.co.uk/pd/Different-Not-Less-Audiobook/B0BFFWGSL1>
- ❖ Hovet, K. (2019). Opinion: Highly Sensitive Person (HSP) and Female Autism Are the Same In Some Cases [online] Medium. Available at: <https://medium.com/the-shadow/opinion-highly-sensitive-person-hsp-and-high-functioning-autism-are-the-same-in-some-cases-842821a4eb73>
- ❖ Jack, C. (2022). From Autistic Linear Spectrum to Pie Chart Spectrum [online] Psychology Today. Available at: <https://www.psychologytoday.com/gb/blog/women-autism-spectrum-disorder/202208/autistic-linear-spectrum-pie-chart-spectrum>
- ❖ James, L. (2017). *Odd Girl Out: An Autistic Woman in a Neurotypical World*. London: Bluebird.
- ❖ Kok, FM., Groen, Y., Becke, M., Fuermaier, ABM and Tucha, O. (2016). Self-reported empathy in adult women with autism spectrum disorders – A systematic mini review. *PLoS One*, 11(3): 1-13.
- ❖ Middleton, E. (2023). *Unmasked* [audiobook] Penguin Audio.
- ❖ Miller, D., Rees, J. and Pearson, A. (2021). "Masking Is Life": Experiences of Masking in Autistic and Nonautistic Adults [online] *Autism in adulthood: challenges and management*, 3(4): 330-338.
- ❖ Neufeld, J., Taylor, MJ., Lundin Remnélius, K., Isaksson, J., Lichtenstein, P and Bölte, S. (2021). A co-twin-control study of altered sensory processing in autism [online] *Autism: the international journal of research and practice*, 25(5): 1422-1432.
- ❖ Price, D. (2022). *Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity*. London: Octopus Publishing Group.

# Images and Video

## Images:

- ▶ Shutterstock blonde stressed child: [https://www.shutterstock.com/search/blonde-cartoon-girl-sad?image\\_type=vector](https://www.shutterstock.com/search/blonde-cartoon-girl-sad?image_type=vector)
- ▶ Lightbulb: <https://psmag.com/health-and-behavior/how-to-inspire-creative-thinking-details-details>
- ▶ FreePik spoon: [https://www.freepik.com/free-vector/sticker-spoon-kitchenware-white-background\\_18554385.htm#query=spoon%20cartoon&position=0&from\\_view=keyword&track=ais&uuid=5ec317ae-0367-4fa9-804c-56dd57c16d1d](https://www.freepik.com/free-vector/sticker-spoon-kitchenware-white-background_18554385.htm#query=spoon%20cartoon&position=0&from_view=keyword&track=ais&uuid=5ec317ae-0367-4fa9-804c-56dd57c16d1d)
- ▶ HSP: [https://www.reddit.com/r/hsp/comments/rm4m7o/traits\\_of\\_the\\_highly\\_sensitive\\_person\\_by/](https://www.reddit.com/r/hsp/comments/rm4m7o/traits_of_the_highly_sensitive_person_by/)
- ▶ Woman with 3 faces/emotions: [https://www.self.com/story/emotional-regulation-skills?fbclid=IwAR1sKUI3csNveP8XRJuyo6HDAKfRC1bT4PvVSsp\\_N8ye5Z63Dq9srQ7UXmU](https://www.self.com/story/emotional-regulation-skills?fbclid=IwAR1sKUI3csNveP8XRJuyo6HDAKfRC1bT4PvVSsp_N8ye5Z63Dq9srQ7UXmU)
- ▶ Colours: <https://pixabay.com/photos/art-multicoloured-to-dye-abstract-2369664/>
- ▶ Covid Earth: <https://pixabay.com/illustrations/covid-corona-coronavirus-virus-4948866/>
- ▶ Stairs: <https://www.pinterest.nz/pin/649925789974595993/>
- ▶ Paint and Paper: <https://pixabay.com/photos/art-watercolors-arts-and-crafts-1851483/>
- ▶ Autism Infinity: [https://www.freepik.com/premium-vector/infinity-rainbow-sign-vector-illustration-autism-new-symbol-neurodiversity-conceptxdxa\\_25493979.htm](https://www.freepik.com/premium-vector/infinity-rainbow-sign-vector-illustration-autism-new-symbol-neurodiversity-conceptxdxa_25493979.htm)
- ▶ Autism not a linear spectrum: <https://www.facebook.com/theicannetwork/photos/a.278436099008274/2251518355033362/?type=3>
- ▶ Not a linear spectrum Image 2: <https://priscillastuckey.com/nature-spirit/being-autistic/>
- ▶ Image 3 pie chart, not linear: <https://www.psychologytoday.com/gb/blog/women-autism-spectrum-disorder/202208/autistic-linear-spectrum-pie-chart-spectrum>
- ▶ Any other images e.g. Question Mark or Top Hat: Power Point's 'Icons' feature

## Video:

- ▶ <https://www.bbc.co.uk/ideas/videos/im-autistic-heres-why-i-decided-to-stop-masking/p0gffmp8?playlist=my-autistic-self>



A watercolor palette with various colors and several brushes are scattered on a dark wooden surface. The palette is white with many small wells of paint in shades of blue, green, yellow, orange, red, and purple. The brushes have wooden handles and metal ferrules, with some having dark bristles and others having lighter, more natural-looking bristles.

*Thank you  
for  
Listening!*