

# Double Jeopardy

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# My story:

- **Education re qualifications/ unusual background**
- **6 schools before the age of 10 in different countries. I returned to**
- **Became a wandering passive nomad around the world**
- **Had children both medical issues**



**single Parent/carer**





**BLADE RUNNER**

Surreal –  
passive-  
dreamlike-  
strange

# First activism

- Birth/Eldest significant health issues allergy risks
- Advice- Watch Eastenders!
- Eldest no sleep 4 years, night terrors- I didn't know how to ask for help and accused of being a 'bad' mother
- Children had increasing health issues/ skin/asthma, allergies, hospitals
- Eldest dx autistic age 3 ½ - no support for us
- I activated a SEN on my own, not that difficult but...
- I couldn't understand all the terminology so...



# First activism cont.

- My eldest needed support and understanding so I decided to learn to help others teach-terminology
- Education-Degrees starting with BSc. (HONS) Psych. OU
- (homeless)
- Won awards / asked to do first carer conference as a speaker AOUG and OU awards
- No money, holidays, heating and little food
- Slightly battled and bruised re my eldest, residential school, various agencies and no communication or belief 😞😞



# Medical issues cont.

- Literal and don't question
- D.Ed Psych. had to decline- health issues
- Carried on outstanding teaching advisory teacher then lead nationally
- Literal, symptoms were in my **'head'**.
- No in my ankles, toes, knees, hips, tendons, back, shoulders, stomach, skin, muscles, ribs, mouth, nose and more



- PGCE Sec., Specialist SEND teacher, post grads. MA Ed.
- Autism advisory teacher for council-2010 redundant
- Steering committee at AET
- National Lead educationalist -
- DfE AET



- Repeated illnesses, injuries
- Redundancy
- I used to travel to work on crutches, made up splints, same shoes for 10 years
- Rest of time recovering for next day-Pain
- No pain killers –
- did the WRONG thing



# Discombobulation 1



- Professional autism conferences
- ‘ Who is the autistic speaker? they asked  
Me??
- No, you don't have blue hair
- No, you're a professional
- No, you don't like data enough
- Redundancy – first one devastating....
- Mentored and trained young autistic people and adult to become speakers
- They were all young adults







- Retired- physically and mentally
- 2015 finally diagnosed Ehlers-Danlos syndromes and not 'bendy'
- But immediately discharged- No diagnostic pathway
- I did not partake in the world for a couple of years
- I had to buy my practitioners a book on EDS and I had no money
- 9 months prone -I couldn't think clearly as a carer, or for myself
- Limited recovery followed by:



# Surreal passive burnt out....

- Life threatening illness – food issues GI-, vomiting, respiratory issues, allergies, fornication parathesis, dermatographia.....

**Mum – are you dying ?**

**Am I dying?**

Not rhetorical

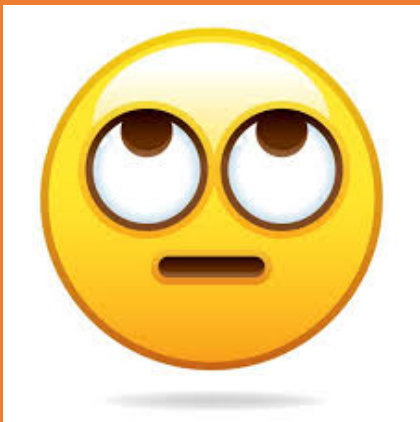
# In 2016 I had my autism dx

In my autism assessment I was asked why I didn't present an  
anxious

Says who, says I



# Medically unexplained symptoms

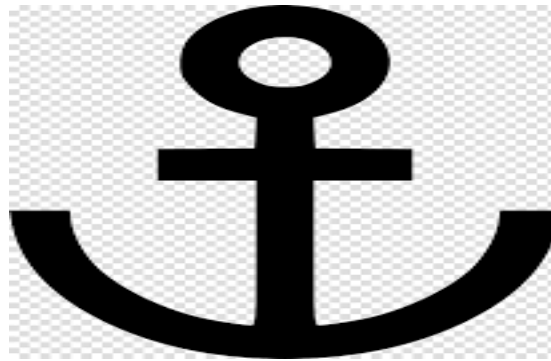


- Too many times I have asked for health advice and either dismissed:
- Told to take lots of drugs but not treat me
- Actual harmful advice that made my condition worse
- That it was all in my head
- Why are you here- didn't I like my job?
- We all get aches and pains at our ages
- Psychogenic in origin
- Hormonal (yes to an extent)
- Come back when you're not in pain
- You're just hypervigilant –Back pain (actually 2 prolapsed discs protruding on nerves plus spondylitic changes) letter



# Nowhere – now where? Discombobulation

- **Recombobulated**
- 'Imposter' in both



- Not accepted as 'neurotypical' or 'neurodivergent'
- Do not believe in masking as it was never intentional and for me a mask is an intent to protect or hide
- **No one should have to go through in the future what I have been through**
- I founded an active EDS support group in Sussex and advocate strongly to improve our life in education, health, social care and transport. Both autism and EDS/HDS all other co-occurring conditions

# Who is missed out?

- There is little support for others who are 'managing'
  - No overt support for professionals or late diagnosed
  - No joining up of health issues/ symptoms from allergies, joint
  - Symptom pain, tiredness, GI issues etc.
- 
- No money
  - Yet we are equally at risk of burn out
  - We are seen as troublesome and troublemakers



# Spectrum bias

- So in health, education, social care, and employment I believe that I (and others) have been subject to spectrum bias
- Practitioners see one end of the spectrum or age ie children or those with mental health disorders
- Professional presentation, qualified, age, articulate in different forms of communication (most of the time)
- And age (you can't be this age and not known/diagnosed)
- Language used with 'articulate' autistic people and responses times (spiky profile)

# Autism Spectrum bias

- In secondary or tertiary patients the specialists see those patients who are from a limited portion of the patient spectrum (Willis, 2008,2013)
- Bias and assessment is :
- Gender biased
- Age biased
- Presentation biased- if professional, trained in presenting ?
- Ethnicity
- How to help – unconscious bias training?



# Autism is something that has 'everyone throwing everything at it all the time'

- Despite largely high formal qualifications, the clinically mostly late-diagnosed adults with ASD represented in our sample are disadvantaged regarding their participation in the German labour market, especially with respect to rates of unemployment, early retirement and overeducation
- Consequently, there are high rates of unemployment and early retirement for health reasons represented in our sample. Furthermore, adults with ASD seem to struggle to maintain professional positions that are appropriate to their formal qualifications and are often inadequately employed in terms of overeducation (Frank, 2018)

*‘Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will be best at any given moment?’*

Harvey Blume *‘The Atlantic’* (1998)

**“In forests and tide pools, the value of biological diversity is resilience: the ability to withstand shifting conditions and resist attacks from predators. In a world changing faster than ever, honoring and nurturing neurodiversity is civilization’s best chance to thrive in an uncertain future.”**

S Silberman (2013)



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