Co-occurring Health Challenges for Autistic People and those with Learning disabilities

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Why both Autism , Learning disabilities and symptomatic hypermobility?

Why is this connection needed or important ?

Why is it relevant for autistic individuals and those with learning disabilities

Is it only being double jointed?

Where do we go next?

How do we find out more ?

Some common conditions/symptoms of symptomatic hypermobility

Often seen as.....

PAIN

CFS/M.E.

Headaches/ Migraines/TMJ

Dizziness/Tiredness/Worried
Difficulty Concentrating
Brain Fog/'Blankness'

Autonomic Nervous System/ Palpitations
Vascular differences
pseudoAsthma, anxiety

Shakiness
Weakness
Sweating
Shallow breathing

Stomach Pain
Reflux /Gut
Bowel issues,
Bloating , IBS

Stomach pains, spasms
Vomiting, Burning pain.
Refusing food
Toiletting issues

Thick,
velvety silky
skin or
Thin Skin,
scarring

Eczema,Scars
Bruises
Raynaud's

Soft tissue
injuries, sprains
Joint dislocations
Fibre tears

Fidgeting - Moving - Slumping
Juddering or falling
Limping
Sensitivity to touch
Clumsiness

Allergies//MCAS/IBS

Scratching
Hot
Irritable

Autism/ Dyspraxia/ ADHD/ Tourettes'

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Interoception

our 8th sense and one of our inner senses

Skin

Not knowing if you are in pain or just have an itch!

stomach

Hunger/thirst Too much Too little

breathing

shallow breathing, yawning

Self-regulation/ emotional regulation

Not knowing if we are tired

heart

Not knowing how hard your heart is working

bladder/ bowels

Not knowing if you need to go to the toilet

Too low or high PAIN sensitivity

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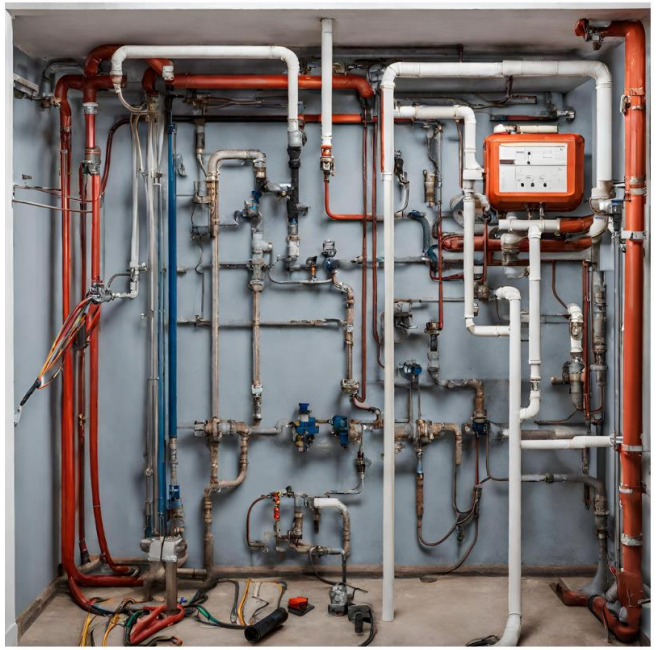
The issue with connective tissues

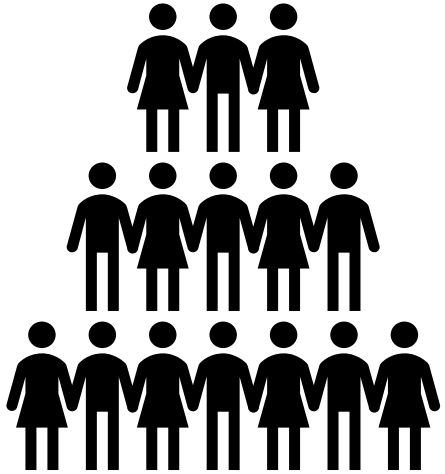
Heritable-



Medically Unexplained symptoms MUS educational/health bias!

Gender, medical and research bias

- **Girls/Women/Non-binary**
- Misdiagnosed /undiagnosed
- Diagnostic overshadowing
- Autistic/ ADHD/ Dyspraxic diagnosed/misdiagnosed



Heritable Connective Tissue Disorders

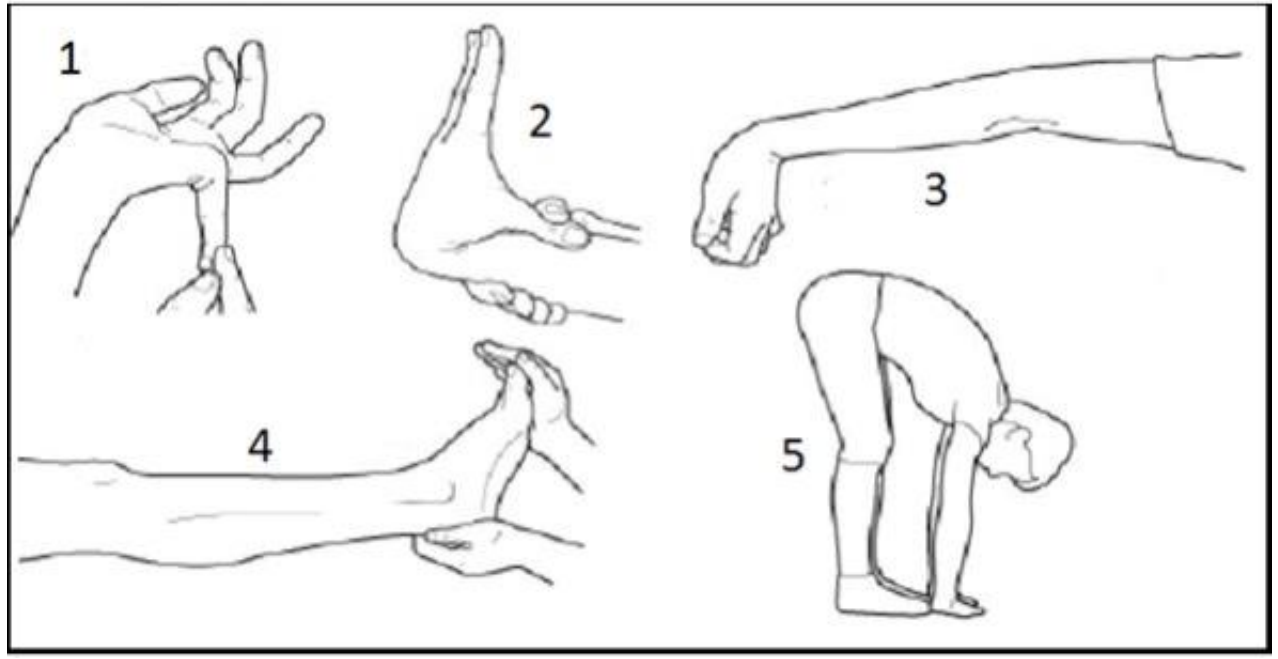
Ehlers-Danlos syndromes (EDS) 13 named
hEDS most common (adults)

Hypermobility Spectrum Disorders (HSD) closely related

For children younger people
pgHSD pgJH

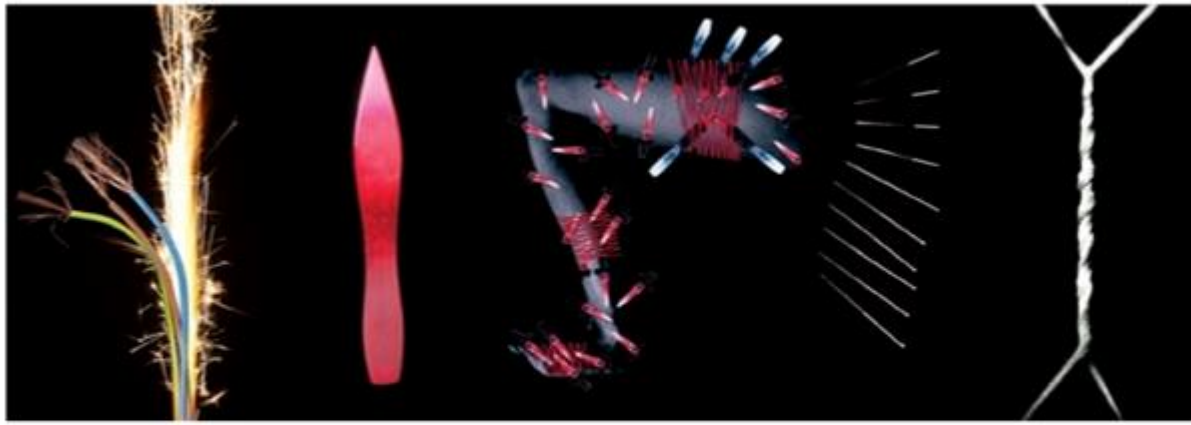
Symptomatic Hypermobility (SH) in lieu

Part of the diagnostic criteria Beighton scale – 9 points dependent on age



https://www.physio-pedia.com/Beighton_score

Reporting/Masking Pain



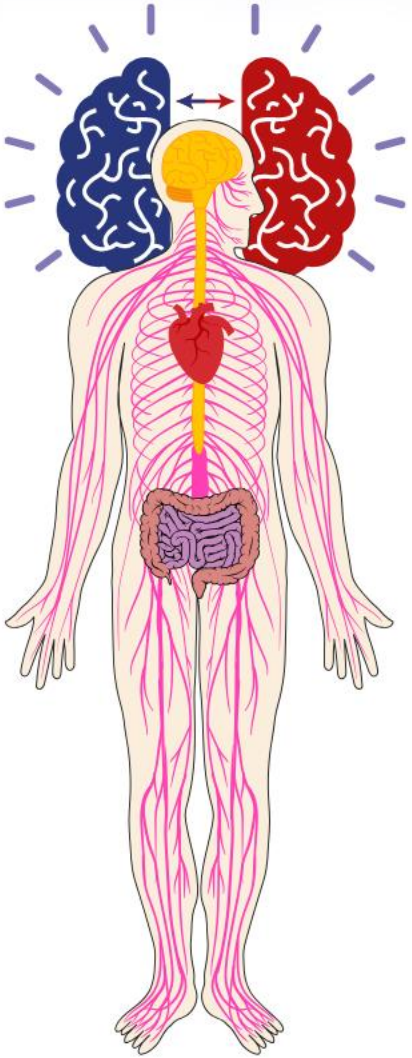
ıre 3 Cards selected by this patient to take into her consultation. All images co-created by the Deborah Padfield with patients with chronic

DYSAUTONOMIA

AUTONOMIC NERVOUS SYSTEM (ANS)

Controls unconscious bodily functions such as heart rate, digestion, blood pressure

Parasympathetic Nervous System (PNS)



- *Involuntary*
- *Useful in emergencies*

Sympathetic Nervous System (SNS)

POTS - BLOOD FLOW

- Some POTS symptoms are due to abnormal blood flow within the body
- Blood is not properly distributed throughout the body forcing the blood downwards
- Standing up & exercise may be difficult The heart beats faster & blood pressure increases for some & drops for others
- Laying down may help relieve these symptoms by increasing the blood flow to the heart and brain

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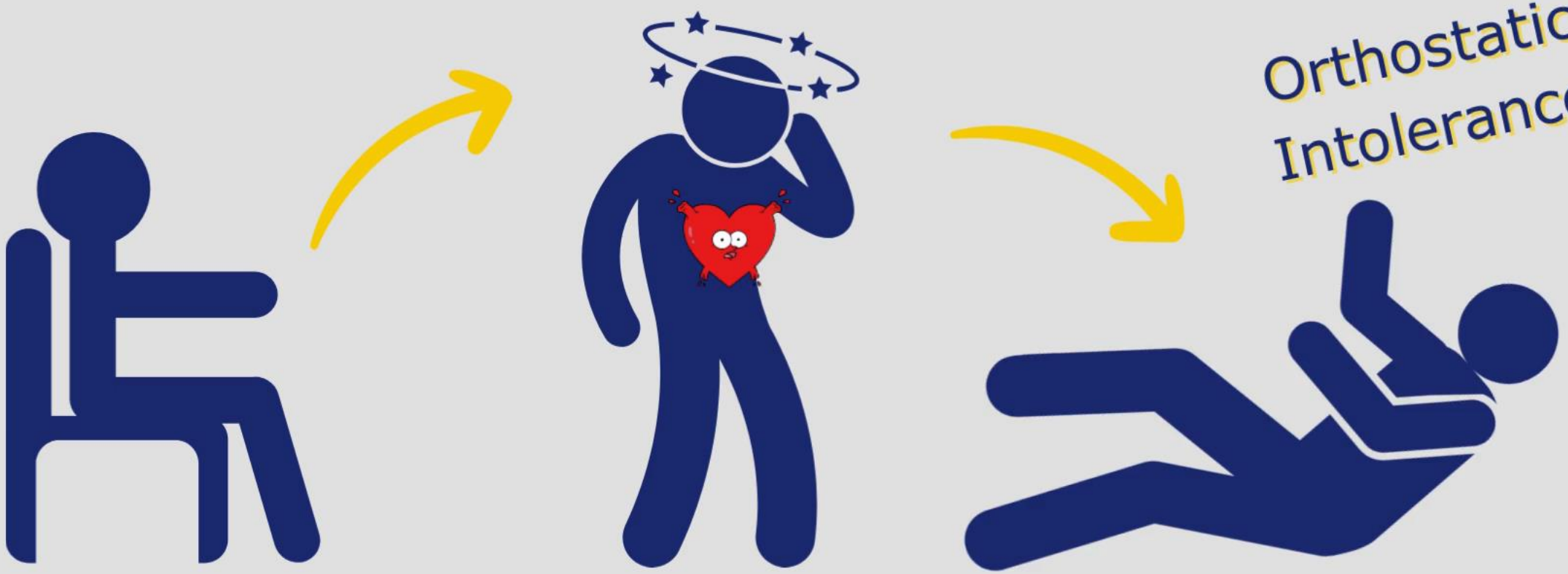
Dysautonomia

Postural Tachycardia Syndrome

Syncope

Dysautonomia is a disorder of autonomic nervous system (ANS) function



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Connective Tissue

Neurodivergence

Symptomatic Hypermobility

PAIN

AUTISM ADHD

Dyspraxia DCD

TOURETTES' TS

Dyscalculia

Dyslexia

Dysgraphia

Bipolar

OCD

EU/BPD

Plus more- AN

EDS HSD

Dysautonomia

MCAS pgJH/HSD

MSK

ME/CFS

POTS

GI

IBS

Migraines

CCI/AAI

Anxiety

Fibromyalgia

Plus more

Key

EDS Ehlers-Danlos syndromes
HSD Hypermobility Spectrum Disorders
pgJH paediatric generalised joint hypermobility
pgHSD paediatric generalised HSD
CCI AAI Craniocervial instability Atlantoaxial instabilty
CFS Chronic Fatigue syndrome
EU/BPD Borderline Personality Disorder
DCD Developmental Coordination Disorder
GI GastroIntestinall
IBS Irritable Bowel Syndrom
MCAS Mast Cell Activation Disorder
M.E.-Myalgic Encephalomyelitis
MSK Muscular Skeletal
POTS Postural Orthostatic Tachycardia syndrome
TS Tourettes/ Tics
AN-Acquired Neurodivergence

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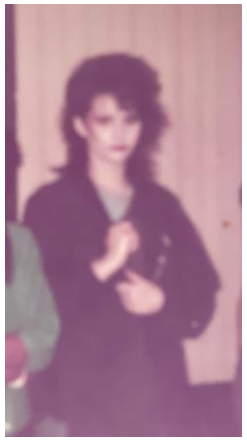
My story:



‘Maybe it’s the bendiness in my brain that makes me really creative and not something to be cured. As well as a weakness in my body there’s a real strength in my brain’
Jane Green MBE

Transformational change in Health Education Social Care and employment

SEDSConnective / Symptomatic Hypermobility Neurodivergent Charity

What is it?

There is no cure for symptomatic hypermobility or if diagnosed EDS HSD JH pgHSD pgJH. Our CONNECTIVE tissues found throughout the body/head are different. The main protein collagen is weaker/more elastic and affected by hormones/chemicals as well as the social emotional and mental environments

Why and How ?

www.sedsconnective.org

> I left school early, considered dim and a hypochondriac. I was often unexplainably unwell and injured but learnt to hide, mask my pain and injuries. I selfstudied late, degrees and national career helping students but knew there was something missing in our training and research. Eventually I lost my career due to stereotypical research and HPC bias. Medically retired in 2015. At the age of 53/ 54 and 61 received my hEDS and neurodivergent diagnoses but no care pathway. I knew there would be others like me out there with no support, knowledge or understanding & joy.

In 2018 I started a small, voluntary community group actively funding when possible and advocating in the areas above. It started in 3 villages but soon grew now with global reach

"I am more than my disability but SEDSConnective provides me with a community that believes me about my conditions, educates me, and most importantly accepts me and my family to grow" Member

What have been the challenges?

SEDSConnective have had to take risks and be innovative in unrecognised and protective arenas

Ill/disabled voluntary community user led and many also sandwich carers

The pressures to secure funding have been extremely difficult with no formal connections or assets

What have been the benefits?

- Helping save lives, being believed, valued = JOY
- Empowering the most disenfranchised by health, society, employment, life, generational
- By us for us - CommunityVoice
- Active specialised support for members not available elsewhere
- Raising awareness public domain and allied professionals
- Writing, publicising, researching as equals

What does the future hold?

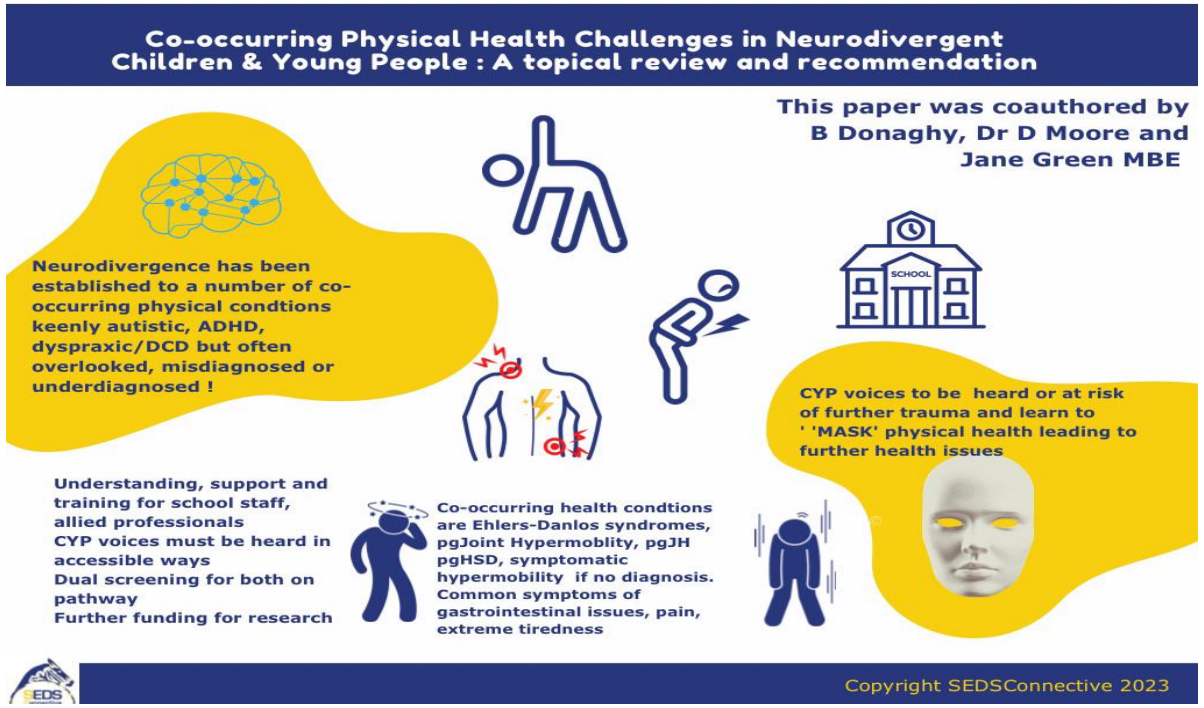
WE envisage a time when neurodivergent health, care education and employments are accepted and supported equally and equitably.

We envisage a time when the shift of conversation in models and approaches is unifying

We are leading this path but always open to join up with others.

“Sadness and anger are examples of emotional displays for symptoms a subsequent symptomatic distress (Ruscheweyhin in Donaghy, Moore, Green)”

“For example, when a CYP joints hurt, they may feel sad, from or cry and as this pain turn to fatigue they may feel angry”



Bethany Donaghy, David Moore & Jane Green (2023) Co-Occurring Physical Health Challenges in Neurodivergent Children and Young People: A Topical Review and Recommendation, Child Care in Practice, 29:1, 3-21,
DOI: 10.1080/13575279.2022.2149471

Education/Health/ Care

Can we unify and connect the dots? Health is a concept is as equality and equity. The models are incomplete and needs a balancing, UNIFYING new model or theory

“If you can’t connect the issues, think Connective tissues”

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