



# **Exploring why autism/neurodivergence and hypermobility are 'double jeopardy' in education**

**Dr Eccles, Jane Green**





- Dr Jessica Eccles
- @BendyBrain
- Clinical Senior Lecturer in Psychiatry, BSMS
- Honorary Consultant Liaison Psychiatrist
- Co-lead SPFT Neurodivergent Brain Body Clinic



# Educationalist



- **Jane Green** ex Assistant Headteacher
- **MA Ed. (Leadership & Management) , Adv.Dip.Ed.(Child Dev.), PGCE QTS, BSc (HONS) Psych.**
- Email : [Chair@SEDsconnective.org](mailto:Chair@SEDsconnective.org)
- Twitter: @JGjanegreen
- Website: [www.sedsconnective.org](http://www.sedsconnective.org)
- LinkedIn: <https://bit.ly/2UZ9uC9>

# Outline and learning objectives

- 1. Learn how to 'spot' hypermobility
- 2. Learn about the impact of hypermobility on education
- 3. Understand the strengths and needs of hypermobile children and young people
- 4. Develop strategies to help hypermobile children attend school
- 5. Feedback experiences to facilitate group learning

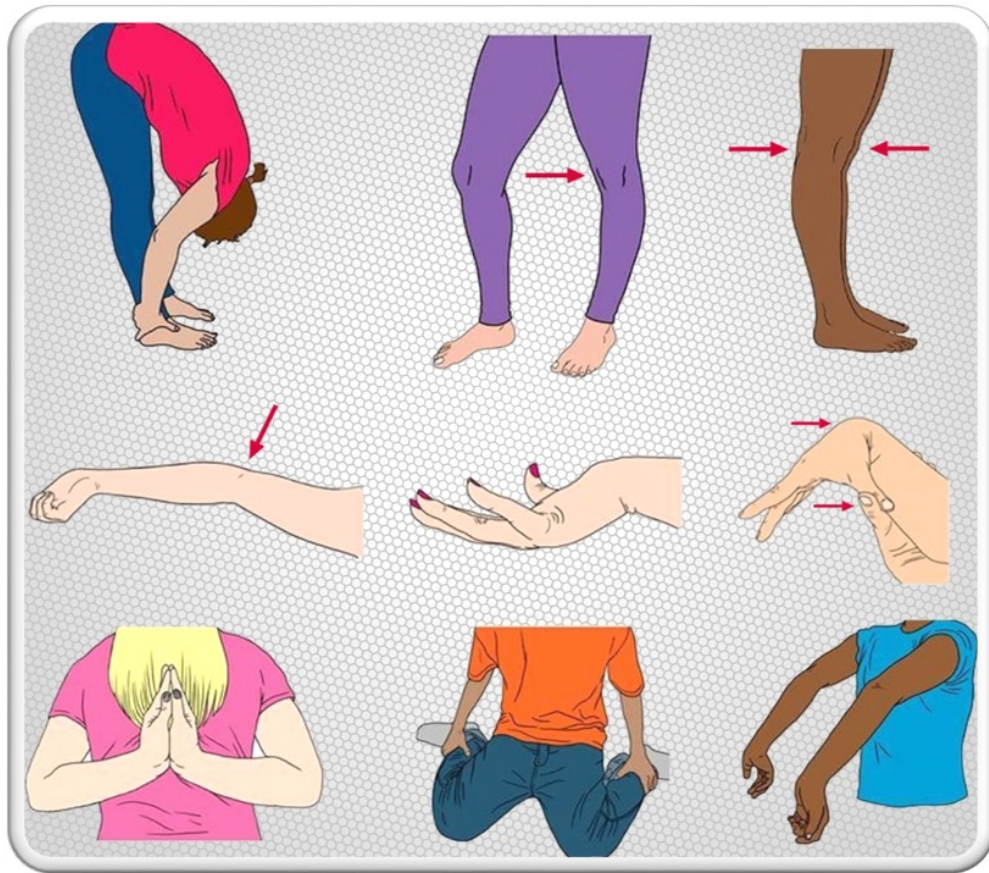


Possible clues

**Box 3: Common clues suggesting joint hypermobility syndrome (based on observations, expert opinion, and case series)**

**In children and adolescents**

- Coincidental congenital dislocation of the hip<sup>18</sup>
- Late walking, with bottom shuffling instead of crawling<sup>19</sup>
- Recurrent ankle sprains<sup>20</sup>
- Poor ball catching and handwriting skills<sup>21</sup>
- Tiring easily compared with peers
- So called growing pains or chronic widespread pain<sup>21</sup>
- Joint dislocations<sup>22</sup>



# What is hypermobility?

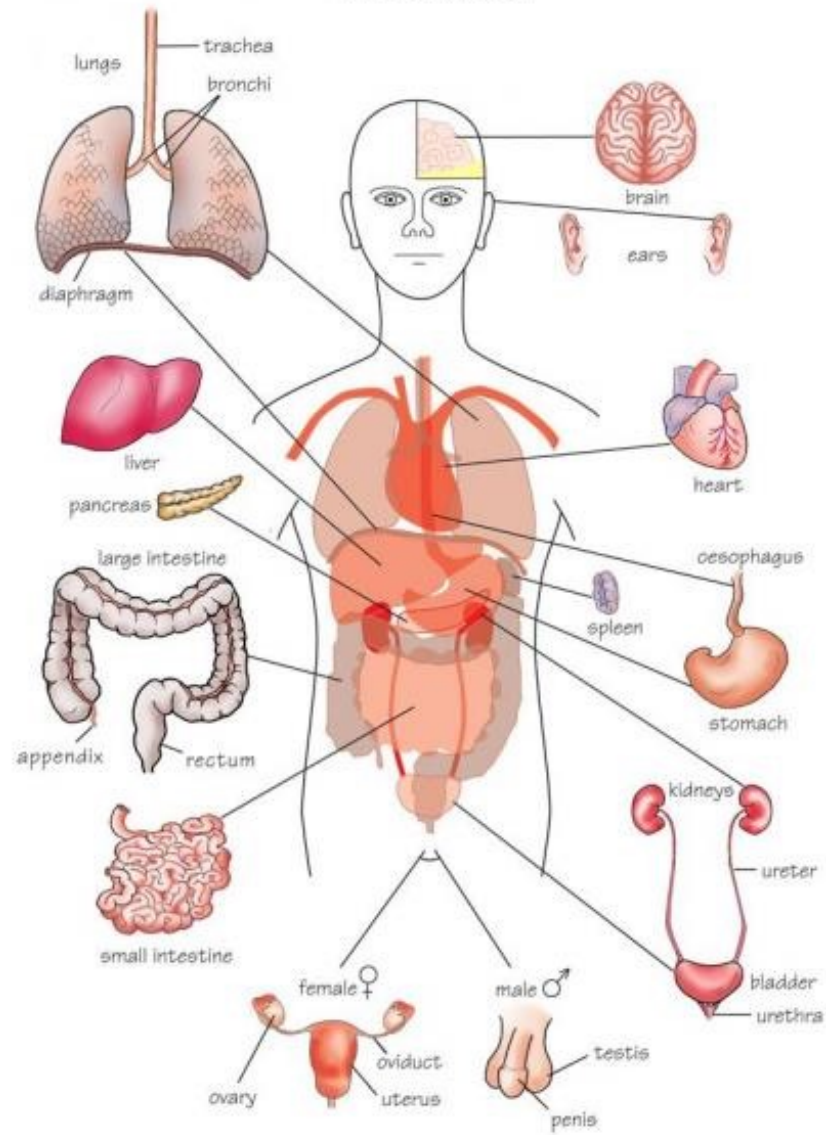
Hypermobility is more than just having flexible joints.

It can be advantageous but also can be linked to medical issues.

One in five children and young people are hypermobile.



# THE HUMAN BODY





**Table 3**

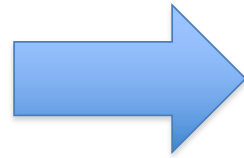
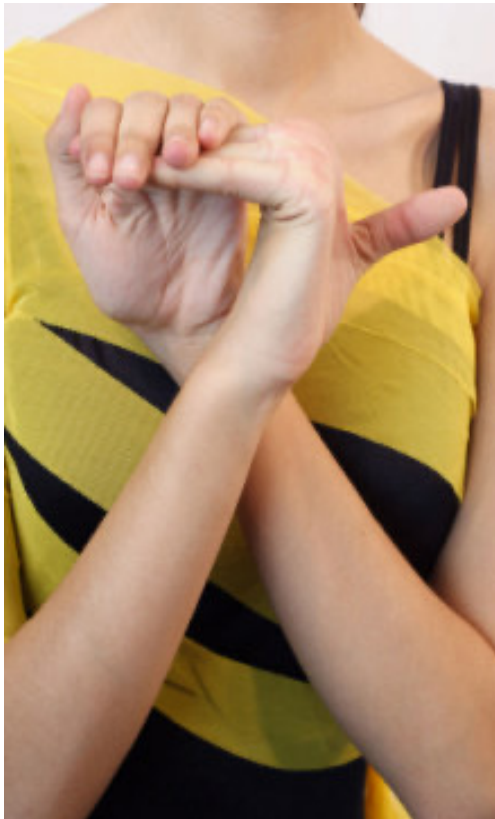
Clinical Spectrum of EDS-HT/JHS (Hamonet et al., 2014; Colombi et al., 2015).

---

Osteoarticular	i.e. mild scoliosis, flat foot, lumbar hyperlordosis, joint hypermobility
Muscular	i.e. hypotonia, fibromyalgia, recurrent myalgias and cramps, dystonia
Mucocutaneous	i.e. mildly hyperextensible skin, velvety/silky/soft skin texture, striae rubrae and/or distensae in young age, small or post-surgical atrophic scars, Keratosis pilaris, hernias, light blue sclerae, gingival inflammation/recessions, hypoplastic lingual frenulum, easy bruising, resistance to local anaesthetic drugs
Gastrointestinal	i.e. dysphagia, dysphonia, reflux gastroesophageal, gastritis, unexplained abdominal pain, food intolerances
Cardiovascular	i.e. varicose veins, low progressive aortic root dilatation, pseudo-Raynaud's phenomenon, mitral valve prolapse
Urogynaecological	i.e. dyspareunia, dysmenorrhea, urinary stress incontinence, meno/metrorrhagia.
Ocular	i.e. myopia, strabismus, palpebral ptosis.
Dental	i.e. dental neuralgia, gingivitis, temporo mandibular joint pain, dental pains to cold/warm.
Neuropsychiatric	i.e. dysautonomia, clumsiness, proprioceptive dysfunction, paresthesia, headache, fatigue, sleep disturbances, cognitive impairment, anxiety, hyperaesthesia, hyperosmia, hyperacusis.

---

# From connective tissue to crisis...





# BJP The British Journal of Psychiatry **Psych**

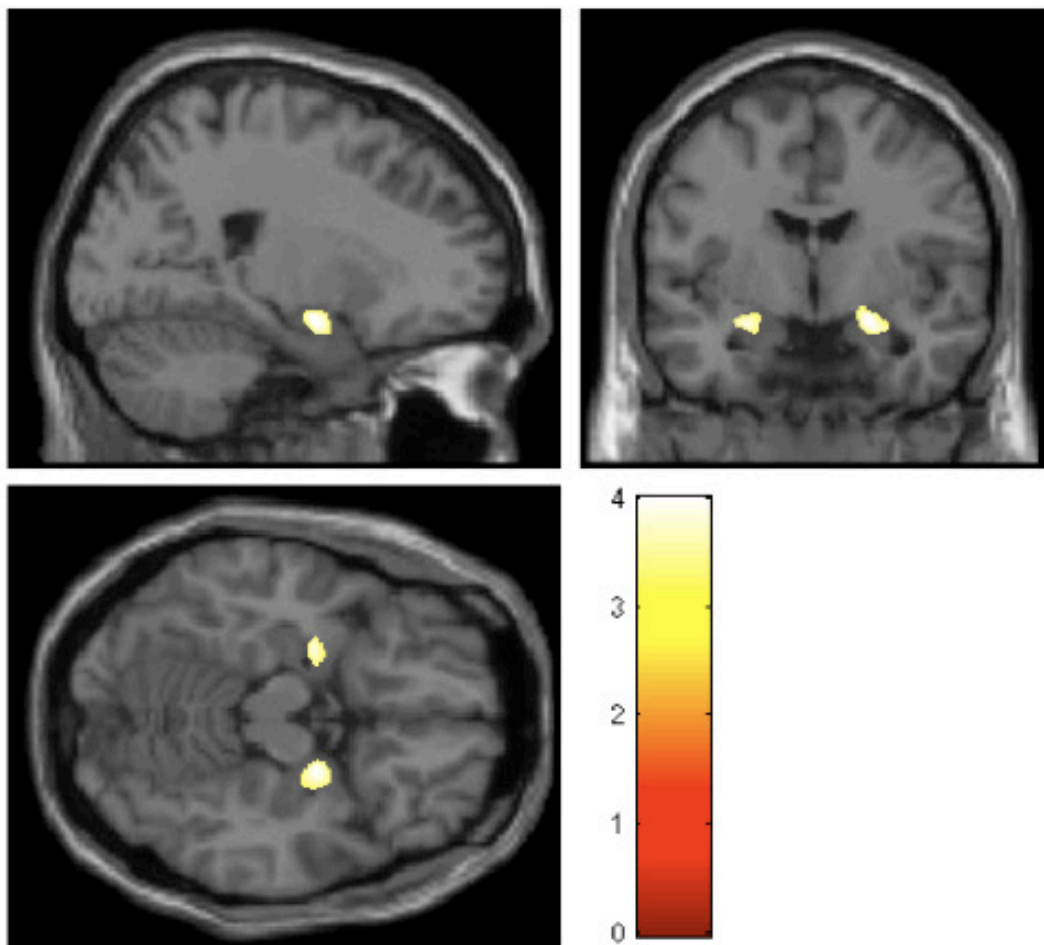
## **Brain structure and joint hypermobility: relevance to the expression of psychiatric symptoms**

Jessica A. Eccles, Felix D. C. Beacher, Marcus A. Gray, Catherine L. Jones, Ludovico Minati, Neil A. Harrison and Hugo D. Critchley

*BJP* 2012, 200:508-509.

Access the most recent version at DOI: [10.1192/bjp.bp.111.092460](https://doi.org/10.1192/bjp.bp.111.092460)





# Proprioception

Child Care Health Dev. 2007 Sep;33(5):513-9.

## **Developmental Coordination Disorder and Joint Hypermobility Syndrome--overlapping disorders? Implications for research and clinical practice.**

Kirby A, Davies R.

The Dyscovery Centre, Cardiff, UK. amanda.kirby@btinternet.com

### **Abstract**

**BACKGROUND:** Joint Hypermobility Syndrome (JHS) and Developmental Coordination Disorder (DCD) are two childhood disorders usually identified separately. DCD is a heterogeneous condition with little known of the underlying aetiology of the disorder. This paper examines the potential overlap between DCD and JHS and examines children with DCD for symptoms which may be consistent with a diagnosis of JHS. Implications for research and clinical practice are considered.

**METHODS:** A questionnaire covering a range of symptoms consistent with a diagnosis of JHS and related autonomic nervous systemic symptoms was completed by parents from 27 children with DCD and compared with responses from parents of 27 typically developing children.

**RESULTS:** Children with DCD showed a significant difference from the group of typically developing children on questions regarding hypermobility, pain and autonomic nervous system symptoms, typifying JHS.

**CONCLUSIONS:** This study has shown a similarity in symptoms seen in some DCD children to those with a diagnosis of JHS. In addition, children are also presenting with multi-system symptomatology including those involving the autonomic nervous system. This study reinforces other recent work showing the reverse pattern of JHS children showing similar functional similarities to DCD children. This has implications for future research in DCD in order to understand the underlying aetiology of this complex disorder. In addition, it is important for clinicians to be aware of these findings in order to provide appropriate and tailored support and treatment for children presenting with differing patterns of co-ordination difficulties. Children with DCD and JHS may require appropriate podiatry as well as recognition of their symptoms of pain and how this may affect participation in physical activity.

> [Am J Med Genet C Semin Med Genet](#). 2021 Dec;187(4):500-509. doi: 10.1002/ajmg.c.31957.  
Epub 2021 Nov 22.

## Variant connective tissue (joint hypermobility) and dysautonomia are associated with multimorbidity at the intersection between physical and psychological health

Jenny L L Csecs<sup>1 2</sup>, Nicholas G Dowell<sup>1</sup>, Georgia K Savage<sup>1 2</sup>, Valeria Iodice<sup>3 4</sup>,  
Christopher J Mathias<sup>3 4 5</sup>, Hugo D Critchley<sup>1 2</sup>, Jessica A Eccles<sup>1 2</sup>

Affiliations + expand

PMID: 34806825 DOI: [10.1002/ajmg.c.31957](#)

### Abstract

The symptoms of joint hypermobility extend beyond articular pain. Hypermobile people commonly experience autonomic symptoms (dysautonomia), and anxiety or related psychological issues. We tested whether dysautonomia might mediate the association between hypermobility and anxiety in adults diagnosed with mental health disorders and/or neurodevelopmental conditions (hereon referred to as patients), by quantifying joint hypermobility and symptoms of autonomic dysfunction. Prevalence of generalized joint laxity (hypermobility) in 377 individuals with diagnoses of mental health disorders and/or neurodevelopmental conditions was compared to prevalence recorded in the general population. Autonomic symptom burden was compared between hypermobile and non-hypermobile patients. Mediation analysis explored relationships between hypermobility, autonomic dysfunction, and anxiety. Patient participants had elevated prevalence of generalized joint laxity (38% compared to the general population rate of 19% (odds ratio: 2.54 [95% confidence interval: 2.05, 3.16]). Hypermobile participants reported significantly more autonomic symptoms. Symptoms of orthostatic intolerance mediated the relationship between hypermobility and diagnosis of an anxiety disorder. Patients with mental health disorders and/or neurodevelopmental conditions have high rates of joint hypermobility. Accompanying autonomic dysfunction mediates the association between joint hypermobility and clinical anxiety status. Increased recognition of this association can enhance mechanistic understanding and improve the management of multimorbidity expressed in physical symptoms and mental health difficulties.

**Keywords:** anxiety; autonomic dysfunction; joint hypermobility; multimorbidity.





**The big idea**  
Health, mind and  
body books

# The big idea: should we drop the distinction between mental and physical health?

The current false dichotomy holds back research and stigmatises patients

---

---

---

**Edward  
Bullmore**

Mon 12 Sep 2022 12.30  
BST



## Our study

- Looks across ND groups
- Compares HM to general population
- Specifically assesses relationship with physical health concerns

ORIGINAL RESEARCH article

Front. Psychiatry. 02 February 2022 | <https://doi.org/10.3389/fpsy.2021.786916>

## Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain

 Jenny L. L. Csecs<sup>1,2\*</sup>,  Valeria Iodice<sup>3,4†</sup>,  Charlotte L. Rae<sup>5</sup>,  Alice Brooke<sup>1,2</sup>,  Rebecca Simmons<sup>6</sup>,  Lisa Quad<sup>1,2</sup>,  
 Georgia K. Savage<sup>1,2</sup>,  Nicholas G. Dowell<sup>1,7</sup>,  Fenella Prowse<sup>1,8</sup>,  Kristy Themelis<sup>1,9</sup>,  Christopher J. Mathias<sup>3,4,10</sup>,  
Hugo D. Critchley<sup>1,2,6</sup> and  Jessica A. Eccles<sup>1,2,6\*</sup>



22,829

TOTAL VIEWS



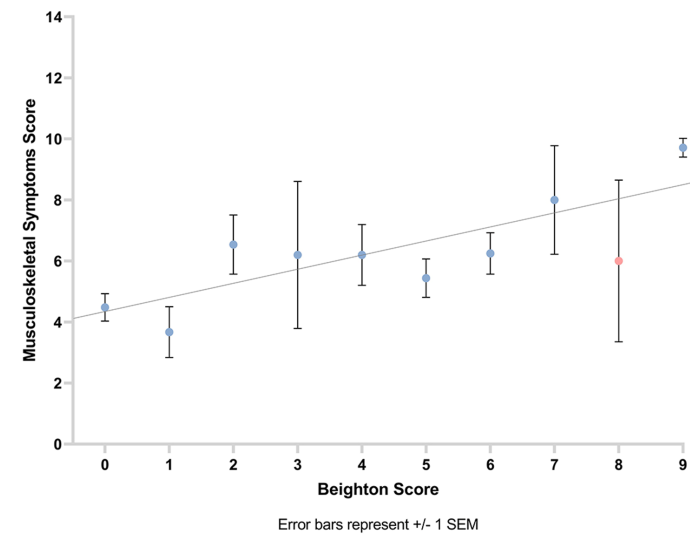
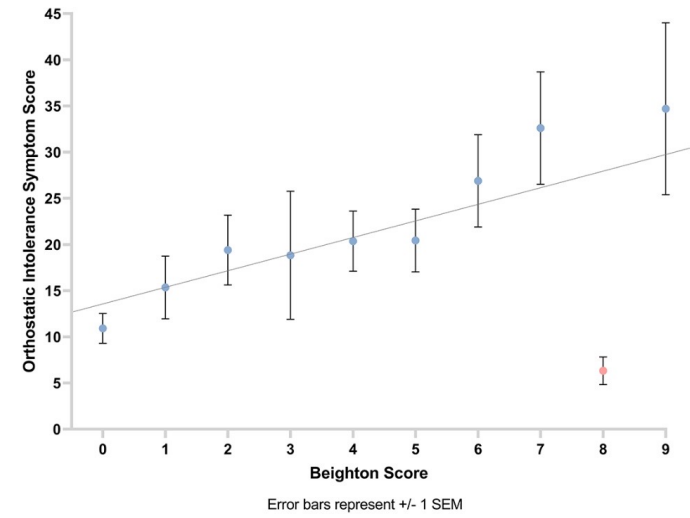
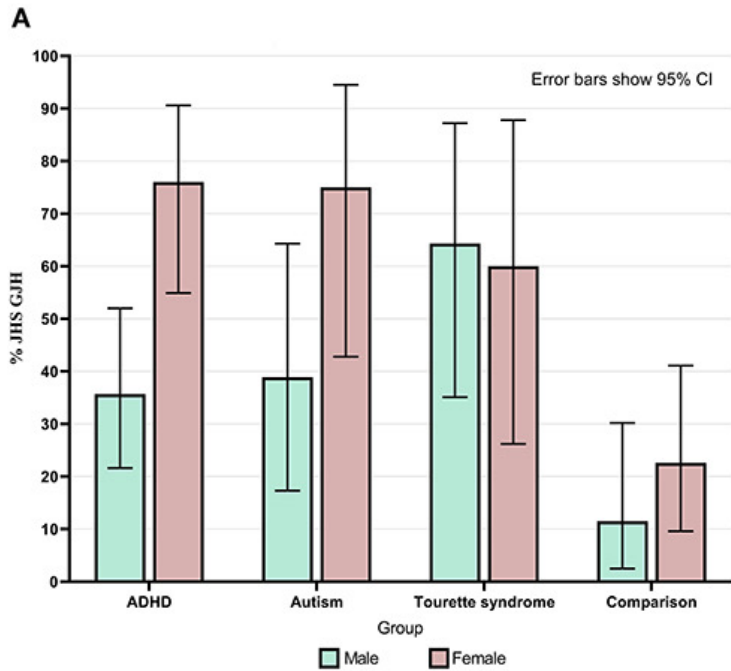
206

[View Article Impact](#)

Frontiers

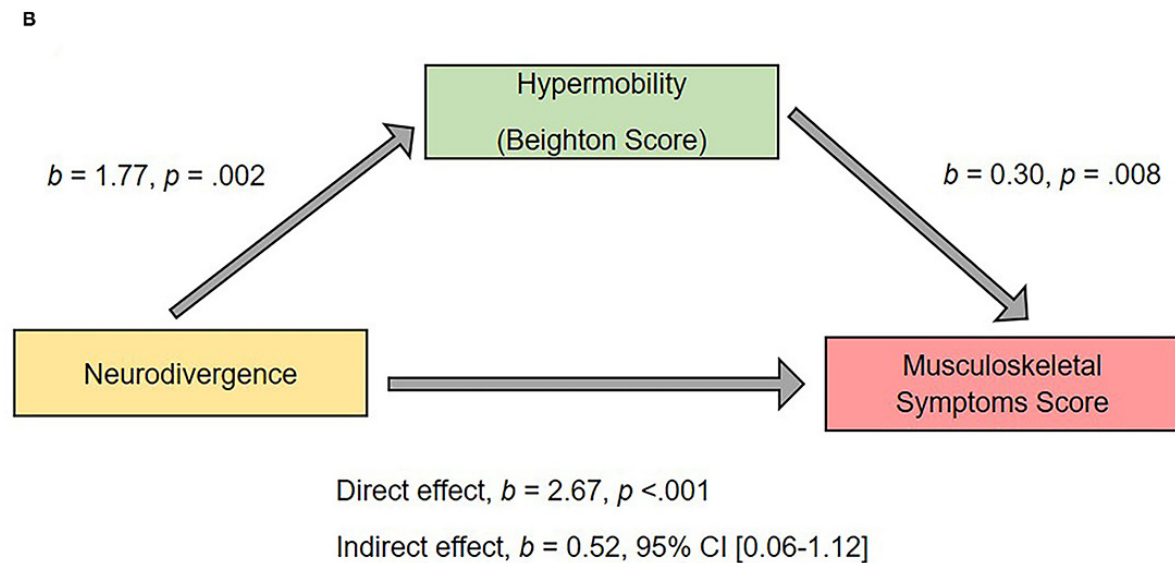
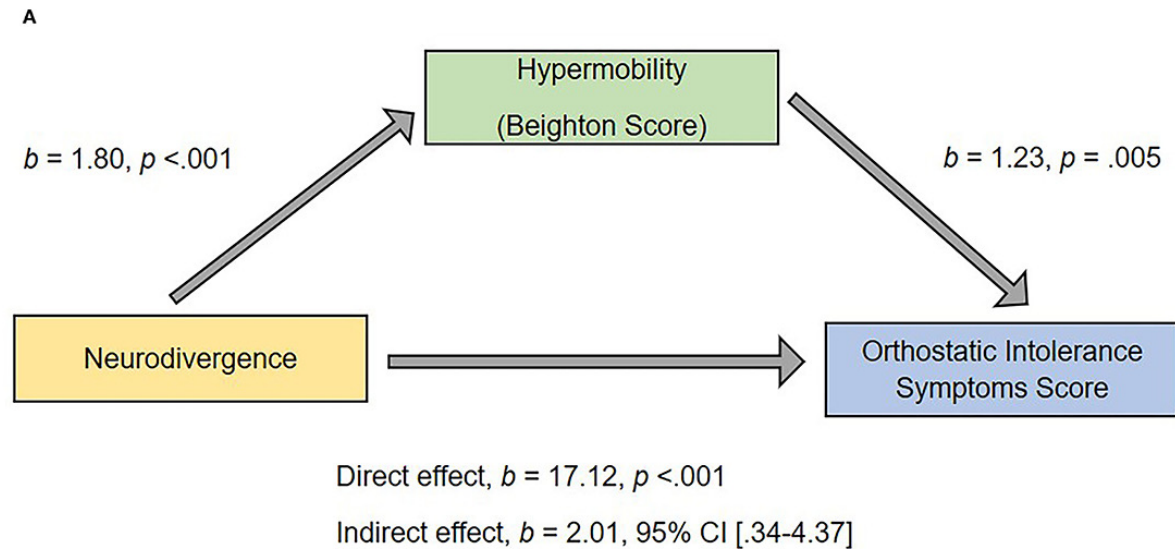


# Findings



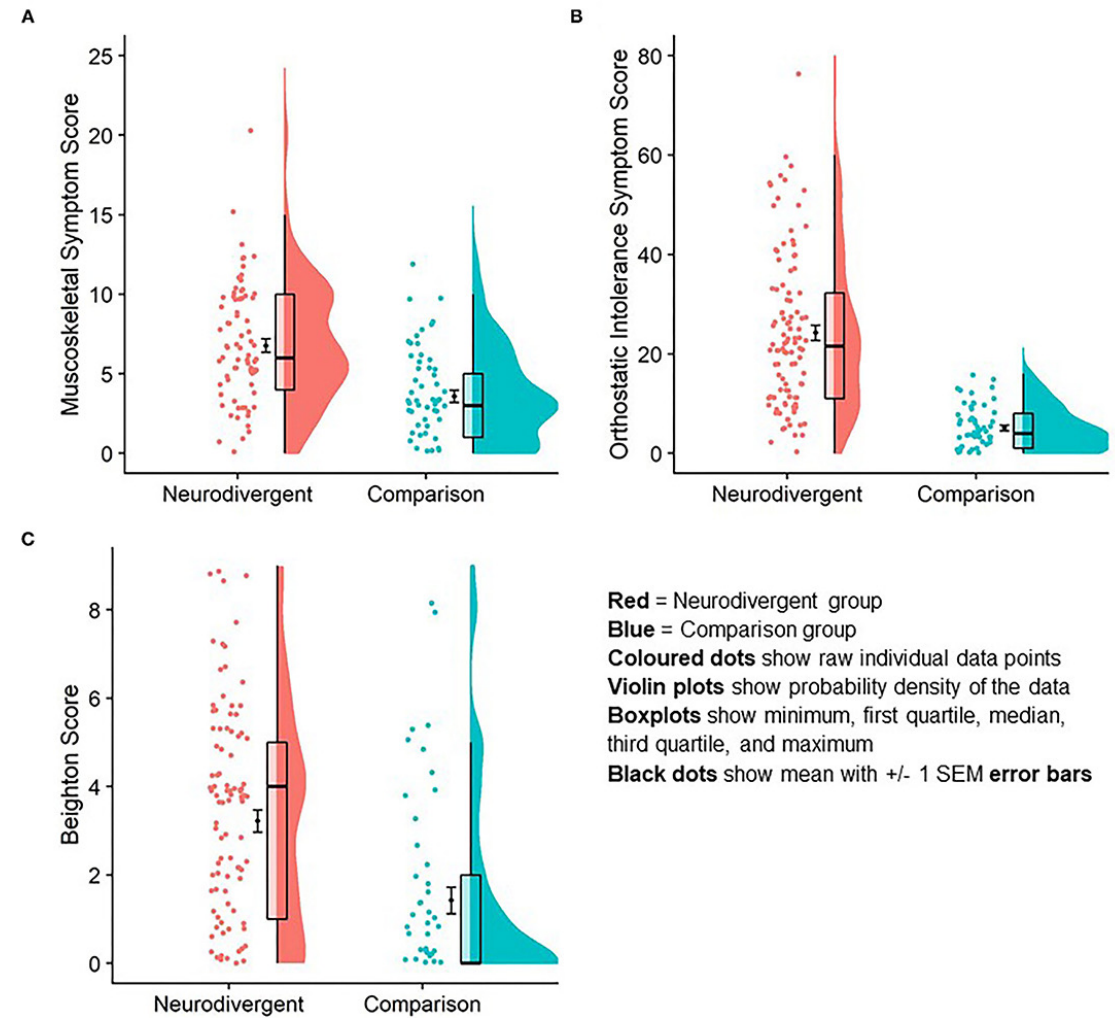
## Implications

- Increased awareness
- Think JH in ND
- Think ND in JH
- Service provision and strategies – ND/JH friendly and accessible?



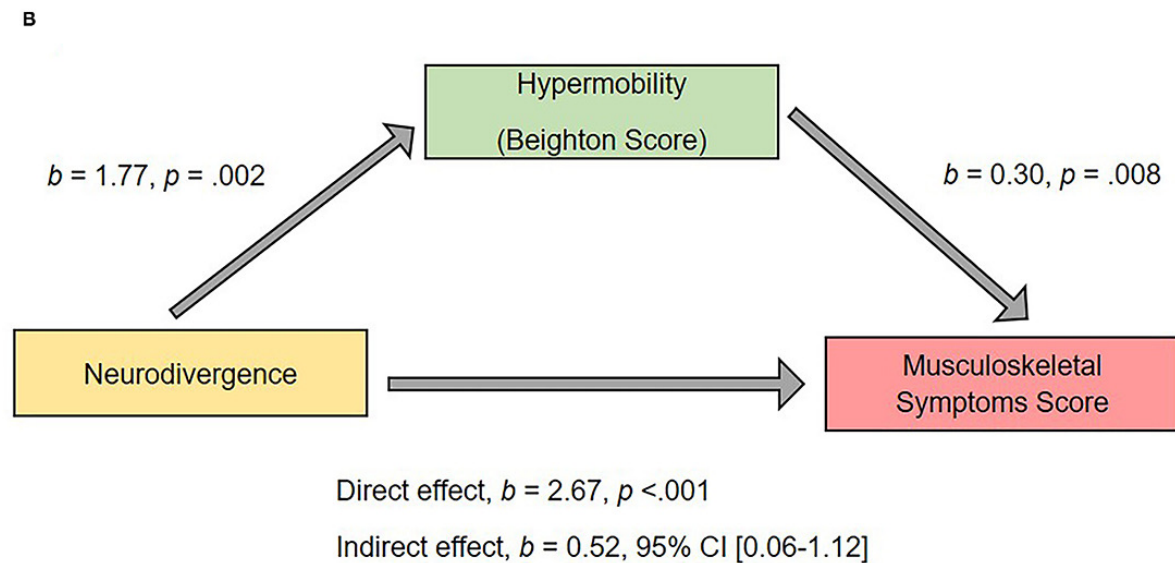
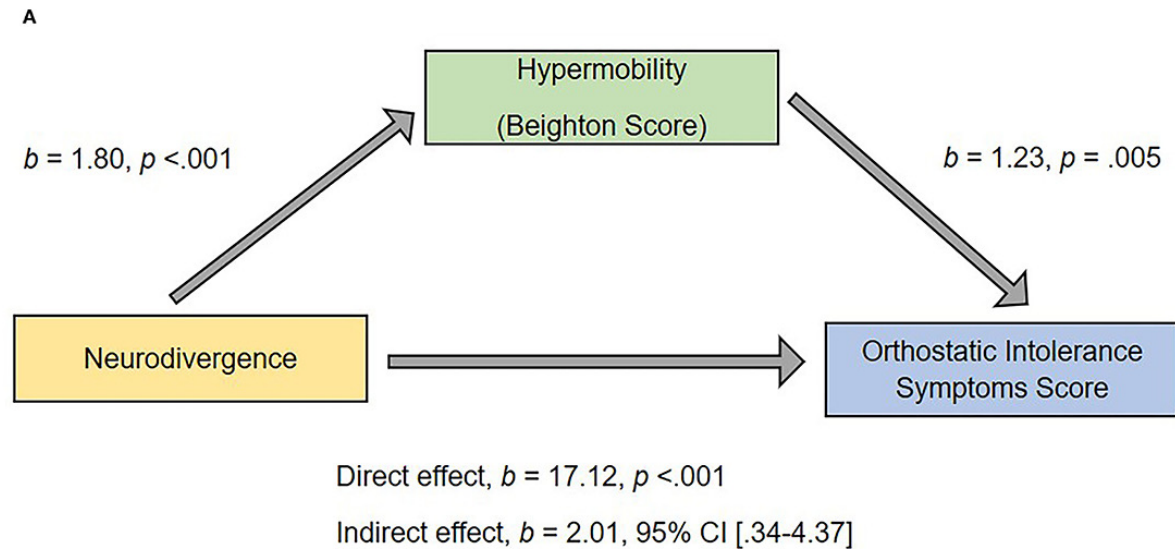
## Findings

- OR HM in ND 4.51 (95% CI 2.17–9.37) c.f general population
- ND greater orthostatic intolerance and musculoskeletal skeletal pain
- HM mediates this link



## Implications

- Increased awareness
- Think JH in ND
- Think ND in JH
- Service provision and strategies – ND/JH friendly and accessible?



# Attainment and Attendance



All school current models/approaches to autism  
ADHD dyspraxic education training =  
mental/emotional/sensory but not physical?

Are we missing health  
symptoms/conditions due to  
disconnection brain/body?

# Some common conditions/symptoms of symptomatic hypermobility

## Seen As....

P  
A  
I  
N

CFS/M.E.

Anxiety /  
migraines

Autonomic Nervous  
System  
Vascular differences

Stomach Pain  
Reflux /Gut  
Bowel issues,  
Bloating , IBS

Thick,  
velvety silky  
skin or  
Thin Skin,  
scarring

Soft tissue  
injuries, sprains  
Joint dislocations  
Fibre tears  
Trigger points

Allergies

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

Shakiness  
Weakness  
Sweating  
Shallow breathing

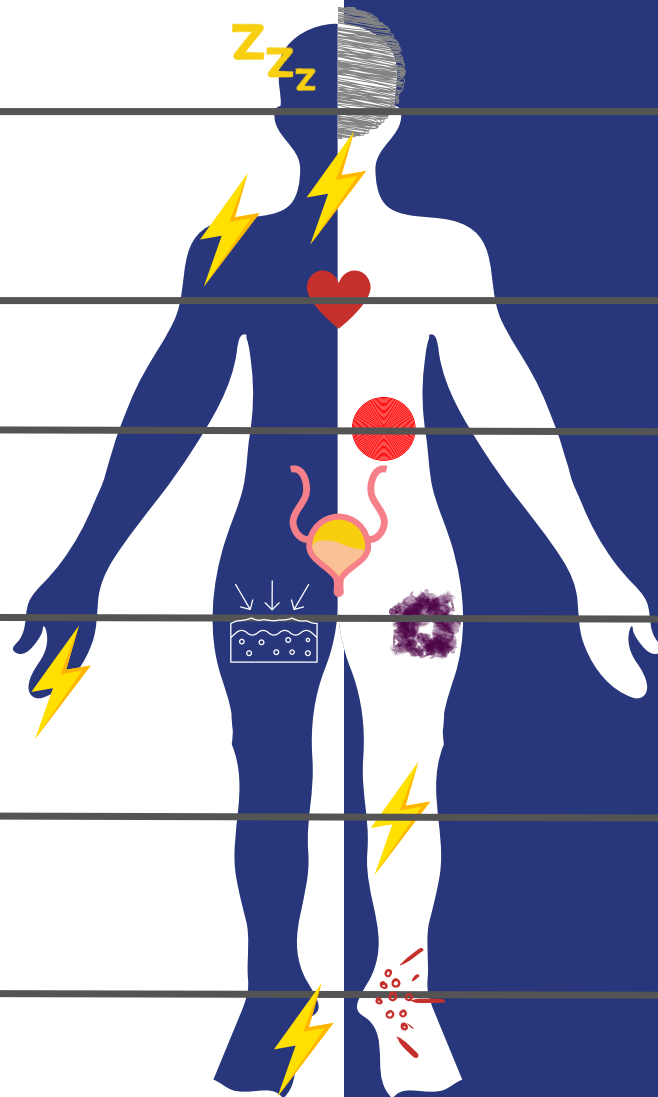
Stomach pains, spasms  
Vomiting, Burning pain.  
Refusing food  
Toileting issues

Scars, Bruises

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

Scratching  
Hot  
Irritable

Autism. ADHD or Dyspraxia +





# Activity- What are the 4 key areas of difference that need to be taken into account in the education of students with EDS JHS or Symptomatic Hypermobility?

?

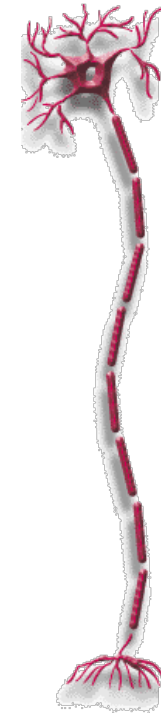
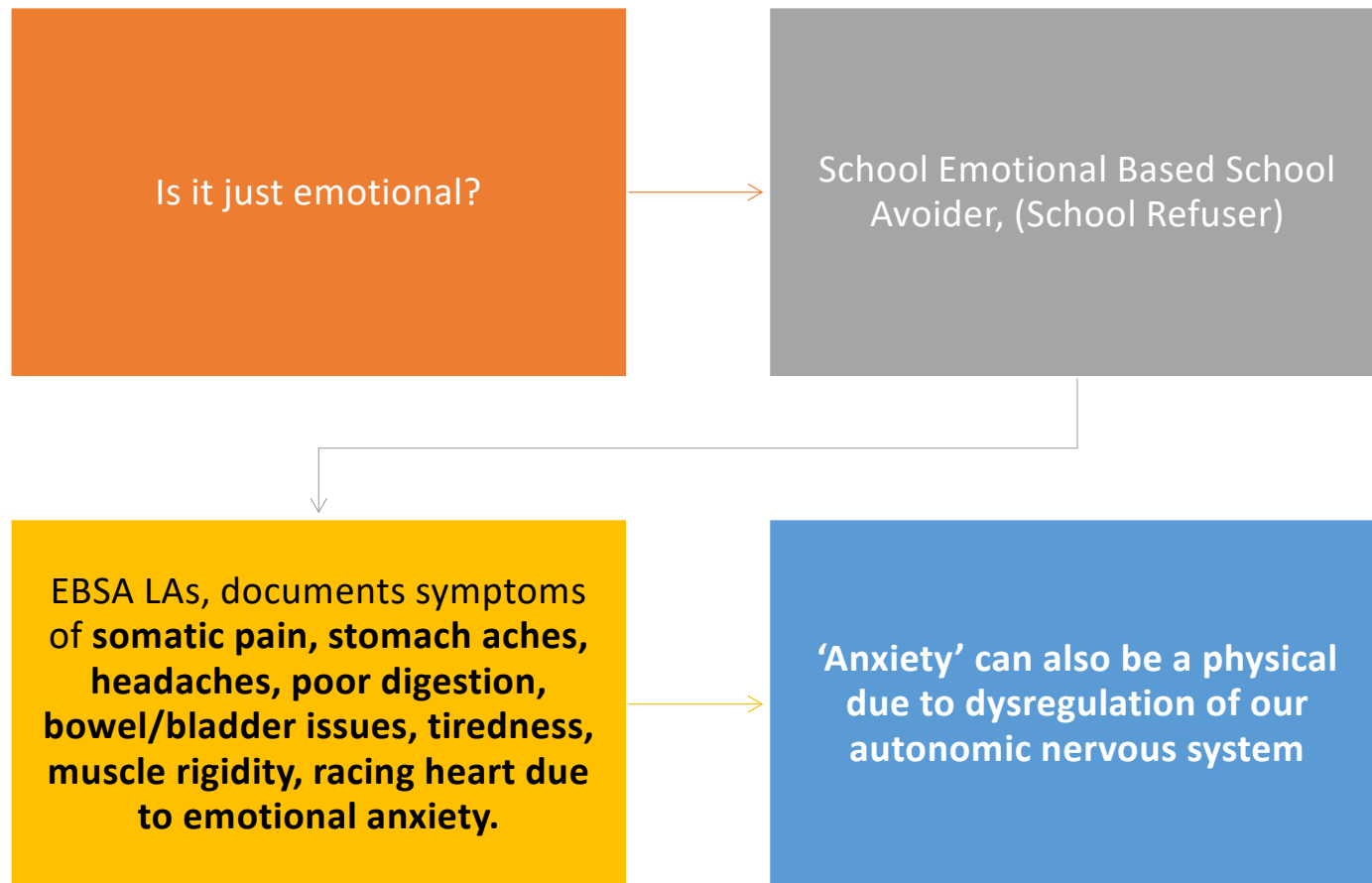


?

?

?

# Emotional Based School Avoidance EBSA





J Green

High Health Issues

Low Health Issues

High  
Educational  
Demand

Poor Outcomes:  
- Low Attendance  
- Less Attainment

Excellent Outcomes:  
- High Attendance  
- High Attainment

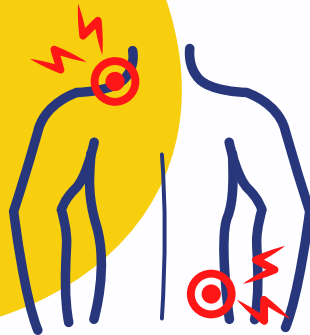
Low  
Educational  
Demand

Low Outcomes:  
- Low Attendance  
- Less Attainment

Low Outcomes:  
- Low Attendance  
- Less Attainment

# Research Shows - Neurodivergent people more than 2 x likely to be hypermobile

Neurodivergent people are more than twice as likely to have **hypermobile joints** and are far more likely to experience **pain** on a regular basis



Research was led by **Dr J. Eccles BSMS** & funded by **MRC, MQ Mental Health** and **Versus Arthritis**

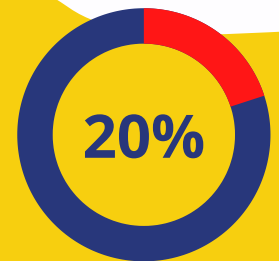
More than **50%** participants had **autistic, ADHD** or **TS Disorder** diagnosis & demonstrated higher levels of **hypermobility**



Neurodivergent participants also reported much higher symptoms of **pain, dysautonomia & dizziness**



This is compared to just **20%** of the **general population**



# Activity- What are the four key features of a good school for students with symptomatic hypermobility

Staff

Outcomes



Communication

Plus

WHAT it feels like

How it appears

# Iceberg Symptomatic hypermobile

Ehlers-Danlos Syndromes  
EDS, JHS, Symptomatic  
Hypermobility

Pain  
Tired  
Clumsy  
Different  
Racing Heart  
Itchy

withdrawn  
Not believed

Social-Wants to do what his/her peers are doing  
Tired-Inflammation in body leads to extreme tiredness  
Confused- 'brain fog' and confusion  
Uncoordinated-Cannot even use muscles in arms to handwrite  
Pain- stomach spasms

Withdrawn  
floppy  
Sensitised / Traumatised  
Seems Tired  
Seems super active  
Anxious  
hyperfocussed  
Confused

# **Activity - Why are these students not attending school consistently?**

Discussion-

What would you do?



A word cloud of mental health conditions. The word 'ANXIETY' is the largest and most prominent, positioned in the upper left. Other large words include 'PAIN', 'IMMUNE-DYSFUNCTION', 'IBS', and 'SELF-HARM'. Smaller words are scattered around, including 'ALLERGY', 'AUTISM', 'FATIGUE', 'ADHD', 'MIGRAINE', 'ANOREXIA', 'DYSLEXIA', 'DYSAUTONOMIA', 'PSYCHOSIS', 'BRAIN-FOG', 'DYS CALCULIA', and 'DYS PRAXIA'. The words are in various orientations, some horizontal and some vertical.

ANXIETY

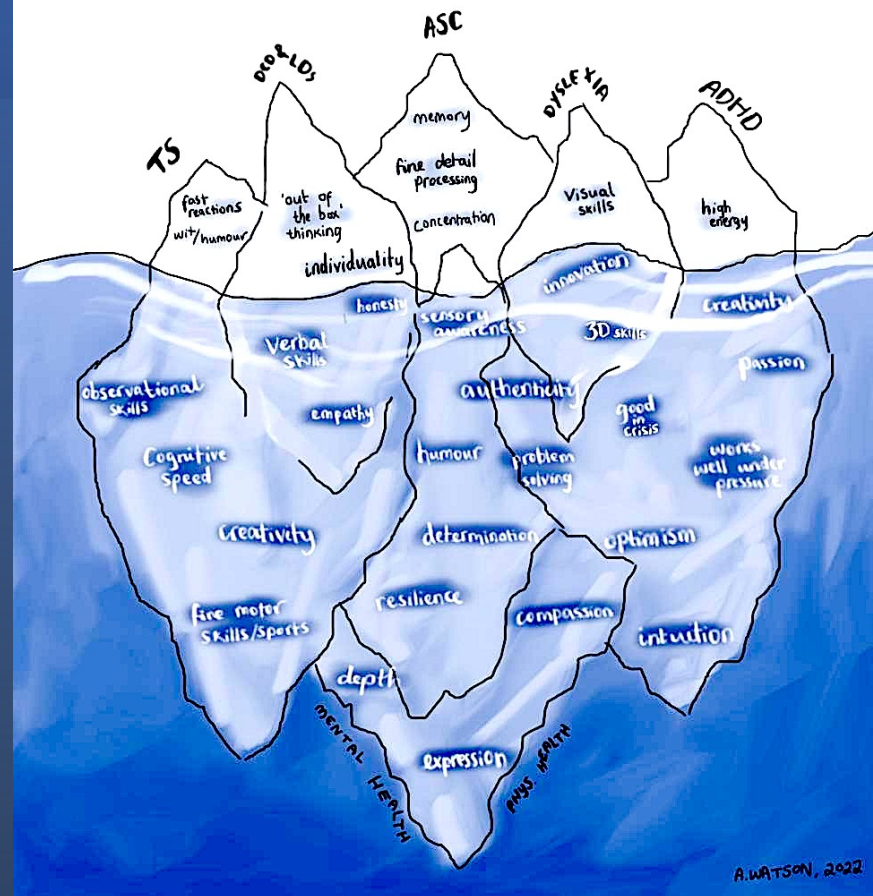
ALLERGY  
AUTISM  
FATIGUE  
ADHD  
MIGRAINE  
ANOREXIA

DYSLEXIA  
DYSAUTONOMIA  
PSYCHOSIS  
BRAIN-FOG  
IBS  
SELF-HARM  
DYS CALCULIA  
DYS PRAXIA

PAIN  
IMMUNE-DYSFUNCTION



# NEURODIVERGENT STRENGTHS



# Quotes

"Mum did an 'All About Me' profile page for her son – age 5, noting he had prominent veins on his face due to EDS, as Mum had hEDS. But they were worried, and it went to a safeguarding family support worker to check, as they thought he was abused at home. He was excluded due to having sensory meltdowns later on, and now attends a special autism school."

"No diagnosis meant no illness. I was threatened with a school fine. When I tried to explain in a TAF meeting, I was told..."*we don't have time for this...*"

"Teacher had told son's friends that there was nothing wrong with him, and that it was 'all in his head'"...

... "Our son was told he could only go back to 6<sup>th</sup> form if he was 100% well. He never went back to 6<sup>th</sup> Form."

# Quotes continued...

“When I was 12 years old, my substitute PE teacher ripped up my letter from hospital that said I was not to do PE – and made me do cross country, with disastrous results. After my parents complained, the school said there was nowhere else for me to go. The result – I never returned back to school on my GPs advice. I was very anxious and depressed, and my mum (a single parent) was fined £1000 as there was NO medical evidence. At the time I was also undiagnosed autistic”

“Daughter - 13, wishes all people understood that all her health conditions have an effect on each other. When she is in pain it makes her anxiety harder to cope with.”

Today's' disbelieved children in pain are the future's chronically ill & traumatised adults



# School Toolkit

FOR EDS AND JHS

[www.theschooltoolkit.org](http://www.theschooltoolkit.org)

---

Free online

---

Key take away points

---

Reasonable adjustments

---

Strategies/tips

---

Scenario plans

---

Resources – downloadable

---

Links to data and further resources

---

Content led by Jane Green funded by EDSUK plus

---

# Strengths of the hypermobile student- 'E' age 18years



GOOD PROBLEM SOLVER -  
ADAPTATION TO MAKE LIFE  
EASIER



GOOD PLANNING-  
THINKING AHEAD WHY SHE  
MIGHT NEED IN ADVANCE



THINKING 'SMARTER'



GOOD SWIMMER



FLEXIBLE DANCER



GOOD BASKETBALL PLAYER  
EXCEPT FOR HER FINGERS  
BENDING

# Strengths of the hypermobile student- 'D' age 16 years

GOOD PROBLEM  
SOLVER USING  
TECHNOLOGY TO  
HELP HIM

DETERMINED TO  
SUCCEED DESPITE  
HEALTH ISSUES

THINKING  
'SMARTER'

SELF TAUGHT

EXCELLENT  
MUSICIAN  
KEYBOARDS

COMPETITIVE

## Adjustments/Tips

W sitting is not recommended for CYP after 2 ½ years.

- **Foot Support** -
- **Sitting** –
- **“W” sitting** -



## What are...



# Ehlers-Danlos Syndromes/ EDS hEDS/HSD/JHS and Symptomatic Hypermobility?

Children and young people (CYP) can be hypermobile with no symptoms, but some may have symptomatic hypermobility. Most common symptoms seen are tiredness, anxiety, floppy posture, anxiety, dizziness, headaches, allergies, stomach pain, reflux, bowel/bladder issues, skin differences; sometimes thin skin with bruising and poor wound healing, sometimes thick, velvety skin. Other issues are racing hearts, fainting, brain fog, headaches and gastro-intestinal issues. The most common symptom is pain. It can co-occur with other diagnoses such as autism, ADHD and dyspraxia (DCD), Tourette's syndrome, possibly more.

CYP might need personalised needs identified and sometimes supported by allied professional in school or have outpatient appointments. Due to differences in emotional processing, alexythemia and interoception, they might not realise they are in pain until it overwhelms them or tired. They might mask pain as so used to it or feel they might be disbelieved. They might have poor fine and gross motor skills, it will take more time to work on clothes, laces, buttons, handwriting.

TIPS: Break out times, movement times, water toilet passes, food/drink passes and sometimes somewhere where they lie down for a few minutes. They might need more help with adaptive equipment such as cushions, chairs, writing slopes, special adapted pencils, pens or laptops. Also splints, supports and education for all.

Wheelchairs might be needed some or all of the time. Consider touch typing opportunities if possible. PE will need careful consideration not to over extend range of limbs even for asymptomatic hypermobility or do too much or too little. Communication and belief is key between pupil/parent/carer and school staff.

They need to know their options for support and that it is okay to do this without singling them out. This might be particularly key as they get older.

More on symptomatic hypermobility can be obtained at  
[www.SEDSconnective.org](http://www.SEDSconnective.org)  
Jane Green MA Ed.

© Copyright SEDSConnective  
2022



My name

---

Emergency contact name

---

---

I might have these differences:

---

---

---

This is what helps me.

---

---

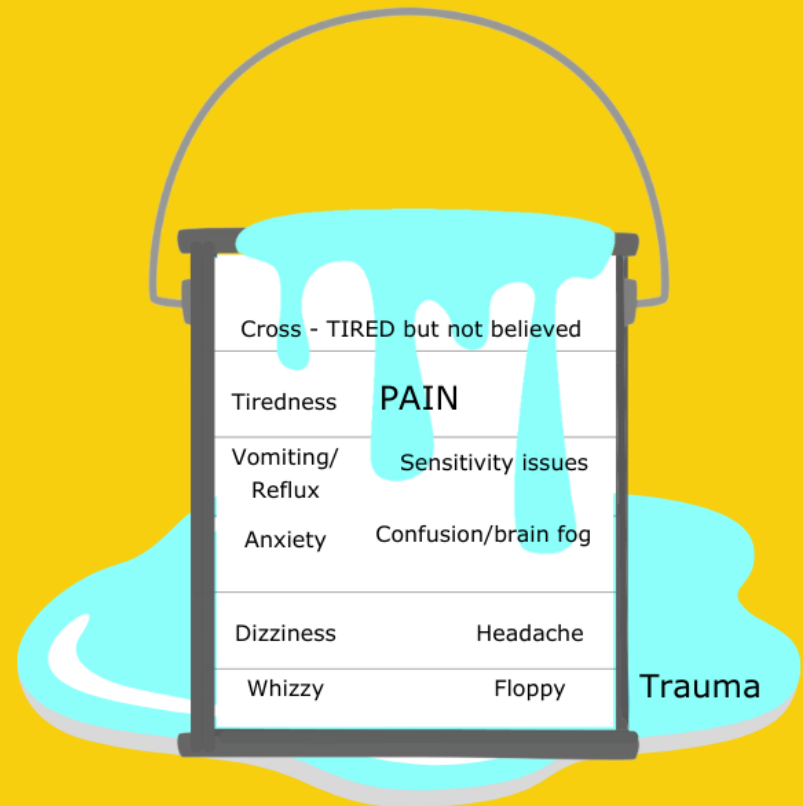
© Copyright SEDSConnective 2022





# E.B.S.A

## Emotional Based School Avoidance



Cross - TIRED but not believed	
Tiredness	<b>PAIN</b>
Vomiting/ Reflux	Sensitivity issues
Anxiety	Confusion/brain fog
Dizziness	Headache
Whizzy	Floppy

Trauma



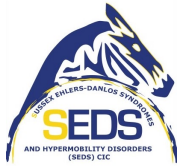
The background of the slide is dark grey with a central horizontal band of light grey. The light grey band contains the text. Above and below this band are three overlapping, semi-transparent blue circles that create a decorative pattern.

**‘If you can’t connect the issues think  
connective tissues’**

## Activity

# SOPHIE

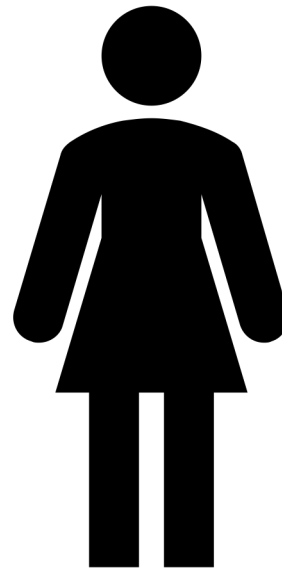
## Year 8



Quiet and passive  
anxious, has lots of  
headaches

Not reaching  
a sub level of  
progress each  
term

Marked low attendance  
in the past due to illness  
and appointments, now  
missing whole weeks

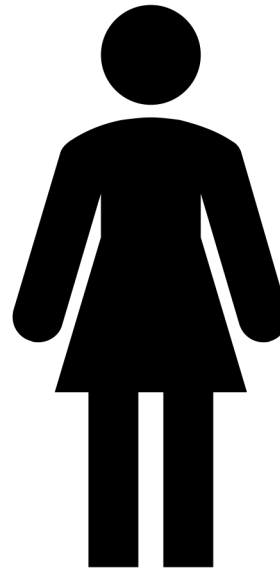


Has recently  
complained of pain in  
her shoulders & hips  
but excels in running  
sport events

Diagnosed autistic last year  
and had autism support from  
school specialist, EHCP put in  
place but still poor outcomes  
in attendance

# CLARA year 2

## 6/7 years



Used to complain about sitting still, likes to fidget, or flop on floor or chair . Social differences

Has been diagnosed dyspraxic as had trouble handwriting, tying laces

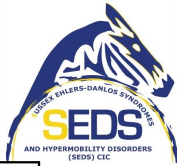
Very thin but often doesn't eat as resting during lunch hour, if not refuses to do anymore work

Appears with numerous bruises on legs and arms. Doesn't answer how they appeared

Seems unaware of when to access the toilet

Has 2 older siblings diagnosed autistic and home educated

# MATTIE year 11



Partial wheelchair user, likes to use manual wheelchair but is in large secondary site

Has a stoma bag.

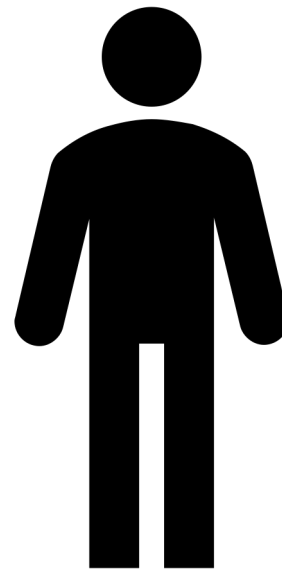


Popular and insightfully outspoken in class , rarely reflected in written work

Returns home very stressed most days

Incomplete homework is having an affect on attainment

# Arif Year 7 11/12 years



Has to wear splints on ankles when active, often gets injured

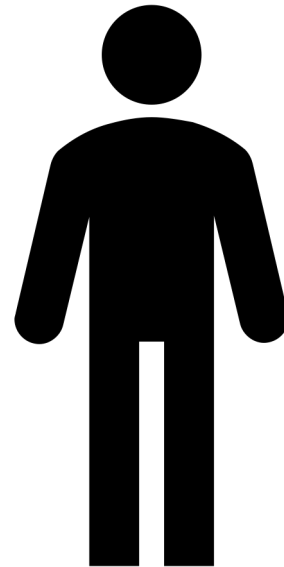
Hates handwriting

Often gets injured, told to wake up every afternoon is very tired literally every afternoon now can be days away

Has ADHD diagnosis. Started secondary school very well, excited can seem disruptive

Often observed with scratch marks on skin

# Hilary Year 9 14/15 years



Tends to eat lunch then immediately goes to toilet to vomit

1.73. cm tall but only 52 kg

Often asks to leave classroom to go to toilet

Now spending more time at home. Parents concerned, seen doctor but tests are negative

Has friends in school who like pop music and celebrities.



**Thank you**