The Intersection of Neurodivergence and Chronic Illness

Bianca Comfort



www.comfortpsychology.com bianca@comfortpsychology.com

Acknowledgement

I respectfully acknowledge the Yugambeh people as the Traditional Owners of the land we are meeting on today. I would like to pay my respect to the people, cultures and Elders past and present.

Housekeeping











Bianca Comfort

Clinical Psychologist

Bianca is an AuDHD Clinical Psychologist from Melbourne, and is the Director of Comfort Psychology, a telehealth practice focused on chronic illness and neurodivergence.

She is also the Vice President of the Australian Psychological Society, and Co-Chair of the Australian EDS & HSD Network.

Bianca's expertise lies in the intersection between neurodivergence and chronic illnesses such as EDS, POTS, and MCAS. Drawing from both her professional and lived experience, Bianca is a passionate advocate and educator.

Agenda

- Key terms neurodivergence
- 2 Common co-occuring physical health conditions
- The links between ND and EDS, POTS, MCAS etc.
- 4 Unique considerations & relevance to practice



NEURODIVERGENT

A descriptor for an <u>individual</u> who has different neurology than the 'typical'.

NEURODIVERSITY

A fact of natural variation in brain neurotypes across the population. Diversity = diverse.

NEURODIVERSITY PARADIGM

A way of thinking and acting about neurodivergence.

NEURODIVERSE

A descriptor for a group of people with different neurotypes: a mix of NT / ND.

NEURODIVERSITY MOVEMENT

A social justice movement challenging societal norms and deficit-based thinking.

PREFERRED LANGUAGE

Autistic person / ADHDer. Autism & ADHD instead of 'ASD' (removes term 'disorder').

Co-occuring Health Conditions

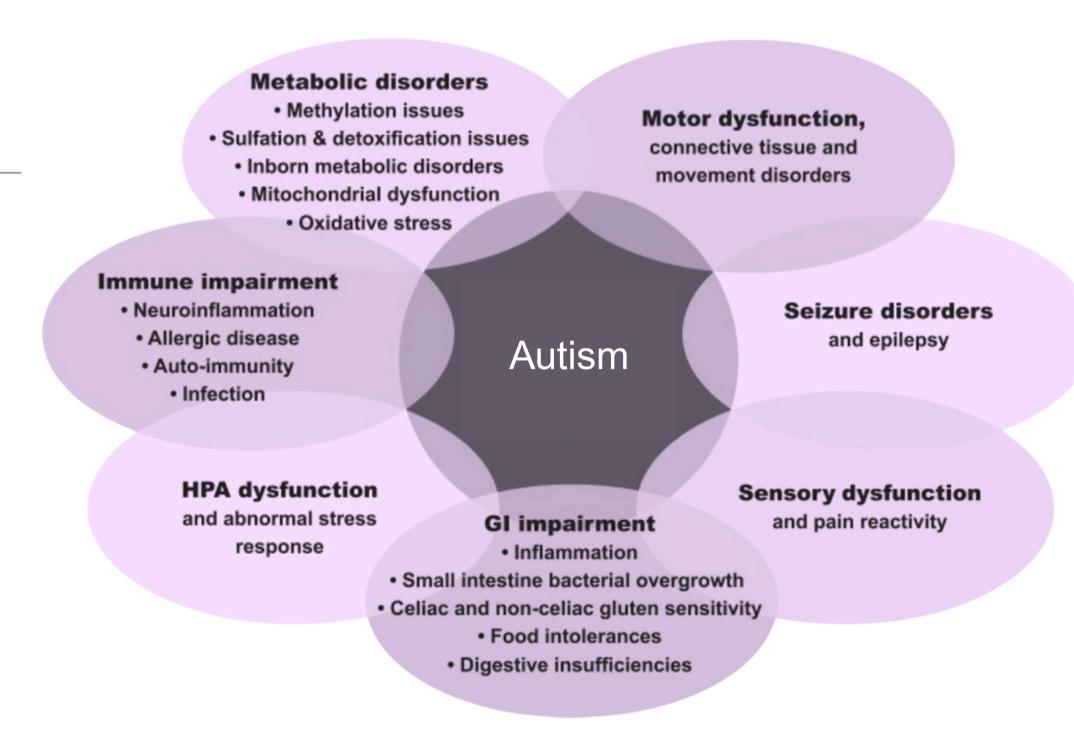
Common Conditions



Australian
Journal of
General
Practice

Box 1. A non-exhaustive list of medical conditions that commonly co-occur with autism

- Anxiety^{10,11}
- Depression^{10,11}
- Attention deficit hyperactivity disorder^{10,11,13}
- Migraine with aura²⁶
- Eating disorder or food sensitivities¹⁰
- Post-traumatic stress disorder²⁷
- Sleep apnoea^{10,12}
- Gastrointestinal disorders^{10–12}
- Epilepsy^{11,26}
- Hypermobility spectrum disorders/Ehlers-Danlos syndromes¹⁰
- Fibromyalgia¹⁰
- Obsessive-compulsive disorder¹¹
- Autonomic dysfunction²⁸



Physical Health

ND people experience significantly higher rates of health conditions

(Croen et al., 2015; Forde et al., 2022).

Autistic people have a **life expectancy 20–36 years shorter**than the general population, with over **two times the mortality rate**(Select Committee on Autism,
Parliament of Australia, 2022).

Autistic people &
ADHDers have a higher
prevalence of HSD/EDS
& comorbidities
(Kindgren, Quiñones Perez,
& Knez, 2021).

Hypermobility

Hypermobility is excessive joint flexibility beyond 'normal' range.

- Also known as "double jointedness"
- Affects 20% of the population
- Often advantageous for athletes and performers



Ehlers-Danlos Syndrome

Ehlers-Danlos Syndrome (EDS) is a group of genetic connective tissue disorders characterised by:

- Joint hypermobility
- Skin hyperextensibility
- Tissue fragility

There **are 14 subtypes**, most are rare.

Hypermobile EDS (**hEDS**) is the most common subtype, affecting 1 in 3,100–5,000 people.

Symptoms generally include:

- Joint instability
- Joint dislocations/subluxations
- Pain and fatigue
- Easy bruising
- Poor wound healing
- Velvety skin
- Impaired propioception
- Multi-systemic impacts (e.g., GI issues, dysautonomia, inflammation, etc.)

THE HSD SPECTRUM

THE HYPERMOBILITY SPECTRUM DISORDERS
DO NOT EXIST ON A LINEAR SPECTRUM LIKE THIS:

HOW PEOPLE THINK THE HSD SPECTRUM LOOKS

MILD HSD

MODERATE HSD

SEVERE HSD

EACH PERSON'S EXPERIENCE IS A COMBINATION OF THE SPECIFIC SYMPTOMS THAT AFFECT THEM. THE SPECTRUM LOOKS MORE LIKE THIS

WHAT THE HSD SPECTRUM REALLY LOOKS LIKE

INSTABILITY

MAST CELL ACTIVATION SYNDROME

PAIN

FATIG

SSUES DYSAU

DYSAUTONOMIA

HEADACHES

ANYIETY





Hypermobilty Spectrum Disorder (HSD)

is a condition of symptomatic joint hypermobility that does not meet criteria for a connective tissue disorder like EDS.

It should not be considered less 'severe' than hEDS as it causes significant pain, fatigue, and functional impairment.

ND x Hypermobility

Individuals with EDS are **7.4x more likely to be autistic** and **5.4x more likely to to have ADHD** (*Cederlöf et al., 2016*)

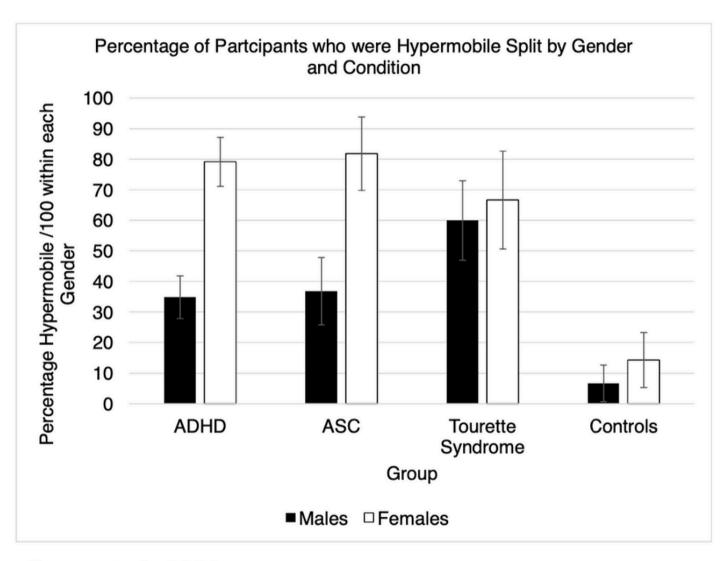
32% - 74% of ADHDers have EDS

(Dogan et al., 2011; Shiari et al., 2013)

13% - 53% of Autistic people have EDS

(Csecs et al., 2020, Eccles, 2016)

More common in females/AFAB



Csecs et al., 2020

Chronic Pain

ND individuals experience **higher levels of musculoskeletal pain** (*Csecs et al., 2020*).

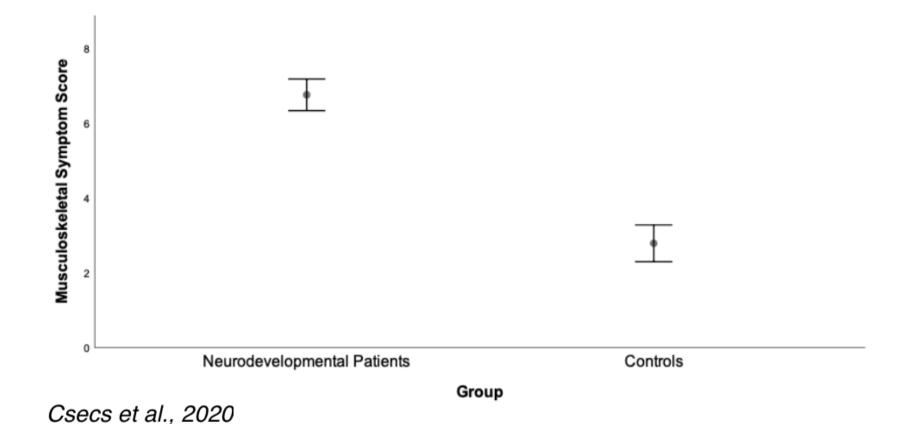
Positive correlation between **Beighton score** and pain (*Csecs et al., 2020*).

ND folk often experience **other chronic health conditions that can cause pain**.

Hypo- and hyper- sensitivity to pain.

Communication & appearance differences.

Musculoskeletal symptom score was significantly higher in patients (Mdn = 6) compared to controls (Mdn = 3), U = 1811.5, z = 4.95, r = 0.48 p < 0.001, (Figure 5).



POTS / Dysautonomia

POTS is a condition where the **autonomic nervous system** doesn't regulate blood flow and heart rate properly when a person stands up.

This causes an abnormally fast heart rate (**tachycardia**) and dizziness or lightheadedness due to blood pooling in the lower body, reducing blood flow to the brain.

Can present like anxiety/panic attack

Common symptoms include:

- Heart palpitations
- Dizziness or fainting upon standing
- Fatigue
- Brain fog
- & Multi-systemic impacts...

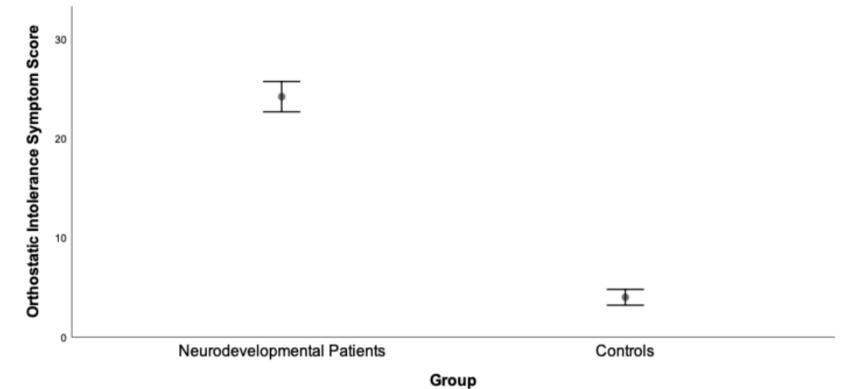
ND x POTS

OI conditions such as **POTS are more common** in ND individuals (*Owens, Mathias, & Iodice, 2021*).

POTS is also more common in people with EDS/HSD, and research has found **positive correlation between Beighton score and OI** (*Csecs et al., 2020*).

ND people can have **unique challenges in managing POTS** - e.g., sensory, capacity, memory.

Orthostatic intolerance symptom score in patients was significantly higher (Mdn = 21.5) compared to controls (Mdn = 3), U = 2829.5, z = 7.21, r = 0.63, p < 0.001, (Figure 3).



Csecs et al., 2020

ME/CFS

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, chronic illness characterised by:

- Disabling fatigue and post-exertional malaise (PEM) that doesn't improve with rest
- Sleep dysfunction
- Pain
- Cognitive difficulties
- Sensitivity to noise, light, food, medications and/or chemicals
- Light-headedness and/or dizziness (POTS-like Sx)
- Gastrointestinal issues
- Flu-like symptoms
- Problems with temperature regulation

ME/CFS

What causes it?

- Viruses/infection (e.g., Epstein-Barr virus)
- Environmental toxins
- Physical trauma (such as surgery or car accident)
- Physical, mental or emotional stress
- Genetic predisposition (runs in families)

The World Health Organisation (WHO) classifies ME/CFS as a neurological disorder.

Prevalence

- 75-80% of people with ME/CFS are female or AFAB.
- 25% of people with ME/CFS experience severe symptoms
- 0.4-1% of the Australian population has ME/CFS (~250,000 people)

(EMERGE, 2025)

Long COVID

Long COVID is post-viral condition characterised by a range of symptoms persisting for at least **three months*** following a COVID-19 infection:

- Fatigue that doesn't improve with rest
- Brain fog (difficulty concentrating, memory issues)
- Shortness of breath
- Joint pain and muscle aches
- Sleep disturbances
- Headaches
- Dizziness or POTS-like symptoms

ND x ME/CFS

Autistic & ADHD individuals are more likely to experience ME/CFS & Long-Covid (Raw et al., 2023).

Recent data from Dr Jessica Eccles (*paper under review, 2025*) suggests up to **80%** of people with **ME/CFS** and/or **fibromyalgia** are **autistic**.

Children with **autistic/ADHD** traits (screening) are **twice** as likely to experience 'chronic disabling fatigue' by age 18 (*Quadt et al., 2024*).

People with **hEDS/HSD** are also more likely to experience ME/CFS & Long-Covid (*Quadt et al., 2025*).

Impact on practice

Impact on practice

Why is this stuff important to know?

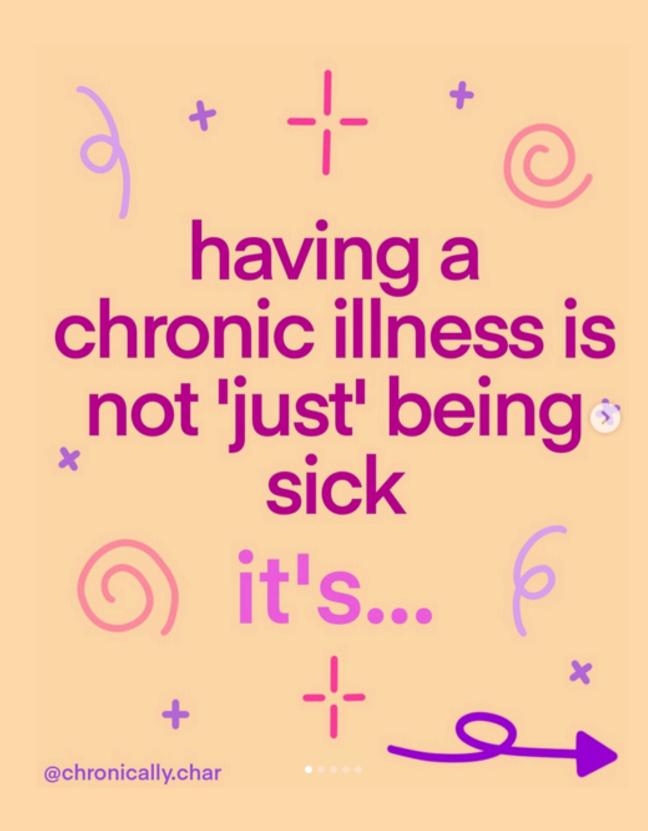
- Increased awareness = more accurate and timely diagnoses (we can screen!)
- Avoiding diagnostic overshadowing
- Recognising increased burden on QoL, social isolation, impact on work/study and relationships
- Chronic illness/pain can worsen sensory + executive functioning difficulties for autistic & ADHD folk.

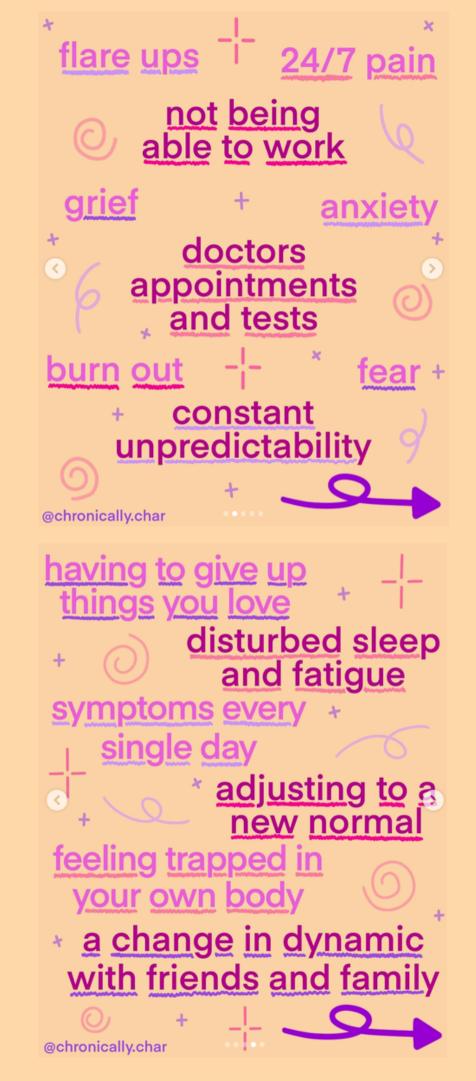
Can help work through barriers to medical care / diagnosis / supports.

Anxiety & depression

- Rates of mental health difficulties are **higher in all of these populations** (ND, EDS, POTS, MCAS) (*Bulbena et al., 2017, Slepian et al., 2025*).
- These conditions can *cause* a person to feel anxious or depressed thus important differentials for cause of distress.
- Examples of mechamisms of this (to name a few) are:
 - **EDS:** Proprioceptive difficulties, pain, fear of injury
 - POTS: Nervous system dysregulation
 - MCAS: Neuroinflammation











Misdiagnosis

POTS is often misdiagnosed as anxiety (Kesserwani, 2020).

Autism & ADHD can be **misdiagnosed as BPD/CPTSD** in women & genderqueer folk (*Weiner, Perroud, & Weibel, 2019; Dudas et al., 2017*).

Sensory sensitivities to food & ARFID are often **misdiagnosed as eating disorders** (*Young et al., 2022*).

Pain is often dismissed as "catastrophising" or "not visibly showing enough pain" in autistic folk - especially women.

Autism & ADHD are often missed in high masking / internalised presentations - more common in AFAB/women.

Medical Trauma

ND folk are often misunderstood or misinterpreted in medical interactions - and experience higher rates of medical trauma as a result (*Baczewski, 2023*).

People with **EDS & POTS** also experience **higher rates of medical trauma** (*Halverson et al., 2021*).

This phenomenon has been recently coined as "clinician-associated traumatisation" (Halverson, Penwell, & Francomano, 2023). 85% of participants (EDS) had experienced this.

Marginalised groups have increased rates of these experiences - e.g., Indigenous, LGBTQIA+, low SES, CALD, etc. (*Baczewski, 2023*).



14th century doctors be like "i don't know what's wrong with you but you're a woman so i diagnose you with witchcraft"



19th century doctors be like "i don't know what's wrong with you but you're a woman so i diagnose you with hysteria"



21st century doctors be like "i don't know what's wrong with you but you're a woman so i don't believe anything is wrong with you and won't diagnose you"



That's not entirely fair. Sometimes they also diagnose you as "fat "

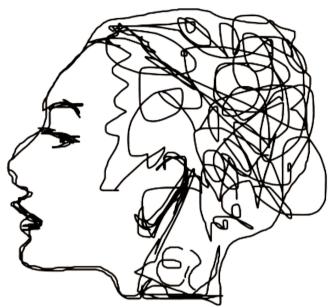
Communication

Double Empathy Problem

Crompton et al. (2021) found:

- No differences between autistic / autistic and allistic / allistic communication
- Difficulties arose within autistic / allistic communication
- Communication breakdowns between autistic and allistic people are a two-way issue, caused by both parties' difficulties in understanding.

Autistic people are information gatherers and sharers.



What professionals might term "rigidity" or "inflexibility" is, in all likelihood, an Autistic person's attempt to manage a chaotic world through controlling what is controllable.

© Reframing Autism, 2019.

Whole of Person Support

Encourage multidisciplinary care. Disciplines often needed include:

- **GP** coordination of care and medication management
- Physiotherapy injury prevention and management
- Exercise Physiology strength & conditioning
- Occupational Therapy modifications
- Psychology mental health support

Advocacy for our clients

- Writing to GPs / treaters
- Screening for these conditions
- Helping clients build self-advoacy skills

Screening Tools

Ask about **current & historical physical health** - fatigue, sleep, nausea, GI issues, pain, post-exertional malaise, brain fog, injuries, etc.

Remember high **pre-test reliability** - your clients are more likely to have these issues.

MCAS:

MCAS Screening Questionnaire

POTS:

NASA Lean Test

hEDS / HSD:

The Ehlers Danlos Society Website

The 5-part Questionnaire - Hakim & Grahame, 2003

Twelve Tips

- 1. Beware of assumptions and stereotypes
- 2. Replace labels with appropriate terminology
 - 3. Use inclusive language
 - 4. Ensure inclusivity in the physical space
- 5. Use inclusive and appropriate signs and symbols
- 6. Ensure appropriate communication methods
 - 7. Adopt a strength-based approach
 - 8. Ensure inclusivity in healthcare research
- 9. Expand the scope of inclusive healthcare delivery
- 10. Advocate for a more inclusive healthcare system
 - 11. Self-educate on diversity in all its forms
- 12. Build individual and institutional commitments

Diversity Equity Inclusion Intersectionality Strength-based approach



Marjadi et al., 2023

Resources

EDS

GP EDS Toolkit

The Ehlers-Danlos Society Website

<u>The Spider</u> (symptom measurement tool)

<u>Paediatric Diagnosis & Management in Aus</u>

The EDS Society Practitioner Database

Books: <u>Symptomatic</u> | <u>Disjointed</u>

POTS

The Australian POTS Foundation

Clinician Directory

MALMO Symptom Scale

MCAS

Podcast: <u>Mast Cell Matters</u>

MCAS Patient Guide/Overview

ME/CFS

Emerge Australia (resources, nurse hotline)

<u>Bateman Horne Center Resources</u>

<u>Information for Medical Practitioners</u>

Long COVID

RACGP Clinical Resources

<u>AU Resources (clinics, guidelines, apps)</u>

Long COVID weekly newsletter (research updates)

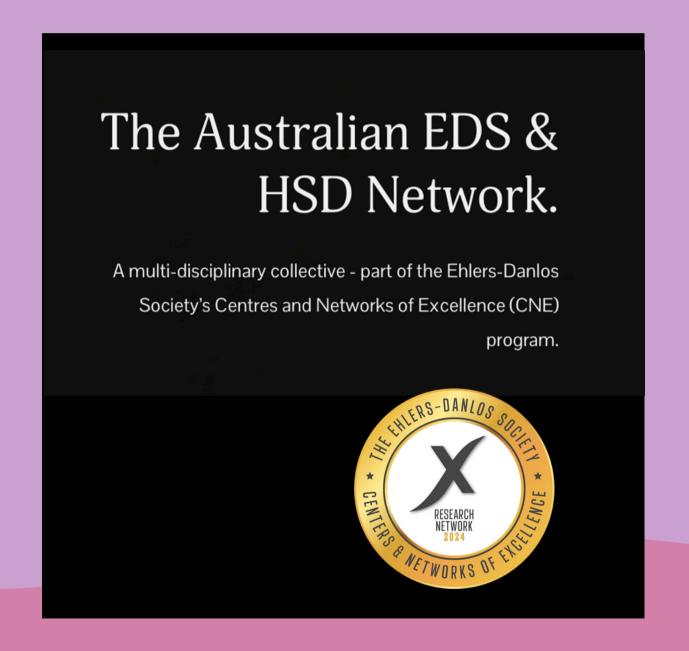
Questions?

More info & support

Webinars & future training



Referral pathways & support



www.comfortpsychology.com/training

www.EDSaustralia.com

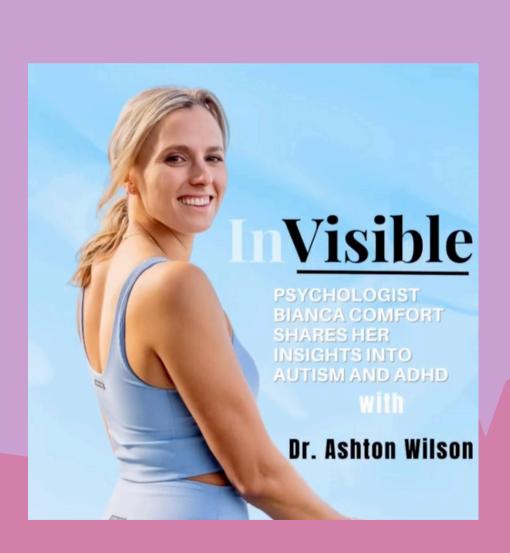
More Ramblings - Podcasts

The Neurodivergent Women

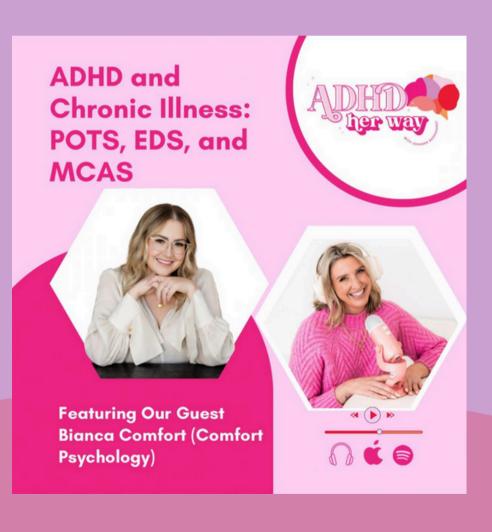
Coming 19 May 2025!



InVisible
Dr Ashton Wilson



ADHD Her Way
Dr Johanna Badenhorst





www.EDSaustralia.com

The Australian EDS & HSD Network.

A multi-disciplinary collective - part of the Ehlers-Danlos Society's Centres and Networks of Excellence (CNE) program.





Would love your feedback:)







bianca@comfortpsychology.com www.comfortpsychology.com