

The best first step you can take is finding a GP who is willing to listen and learn with you.

## CONTACT US

✉ [contact@ehlers-danlos.org.nz](mailto:contact@ehlers-danlos.org.nz)

🌐 [www.ehlers-danlos.org.nz](http://www.ehlers-danlos.org.nz)

🏠 [www.facebook.com/groups/LooselySpeakingNZ](https://www.facebook.com/groups/LooselySpeakingNZ)

**Ehlers-Danlos Syndromes**  
New Zealand



## OUR CONDITION IS OFTEN ASSOCIATED WITH OTHER CONDITIONS

Here are some of our most commonly associated conditions:

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Autonomic Dysfunction
- Mast Cell Activation Disorders (MCAD)
- Chiari Malformation (CM)
- Scoliosis
- Small Fibre Neuropathy
- Sleep Disorders
- Mental Health
- Chronic Fatigue (CFS/ME)
- Neuro Divergence

# EHLERS-DANLOS SYNDROMES



# HYPERMOBILITY SPECTRUM DISORDERS

[WWW.EHLERS-DANLOS.ORG.NZ](http://WWW.EHLERS-DANLOS.ORG.NZ)

# WHAT IS EDS & HSD



Ehlers-Danlos Syndrome (EDS) and Hypermobility spectrum disorder (HSD) are a group of connective tissue disorders that are generally inherited and are varied both in their genetic causes and how they affect the body.

**0** Age symptoms can start



**10**

Average age of when symptoms start to have a daily impact



**32**

Average age of diagnosis

**13 SUBTYPES**

Hypermobile most common type  
1:3100-5000 prevalence\*

\*www.ehlers-danlos.com/what-is-eds/

## WHAT ARE THE MAIN SYMPTOMS OF EDS & HSD?

**THE HALLMARK CLINICAL MANIFESTATIONS ARE MOST OFTEN JOINT AND SKIN RELATED AND CAN INCLUDE**

- Joint hypermobility (they move beyond the joint's normal range)
- Dislocations / subluxations
- Soft velvety-like skin; stretchy skin, fragile skin that tears or bruises easily, unusual scarring, slow and poor wound healing
- Chronic, debilitating musculoskeletal (joint and muscle) pain
- fatigue/tiredness
- gastrointestinal problems
- bladder issues
- poor response to local anaesthetic
- .....and more

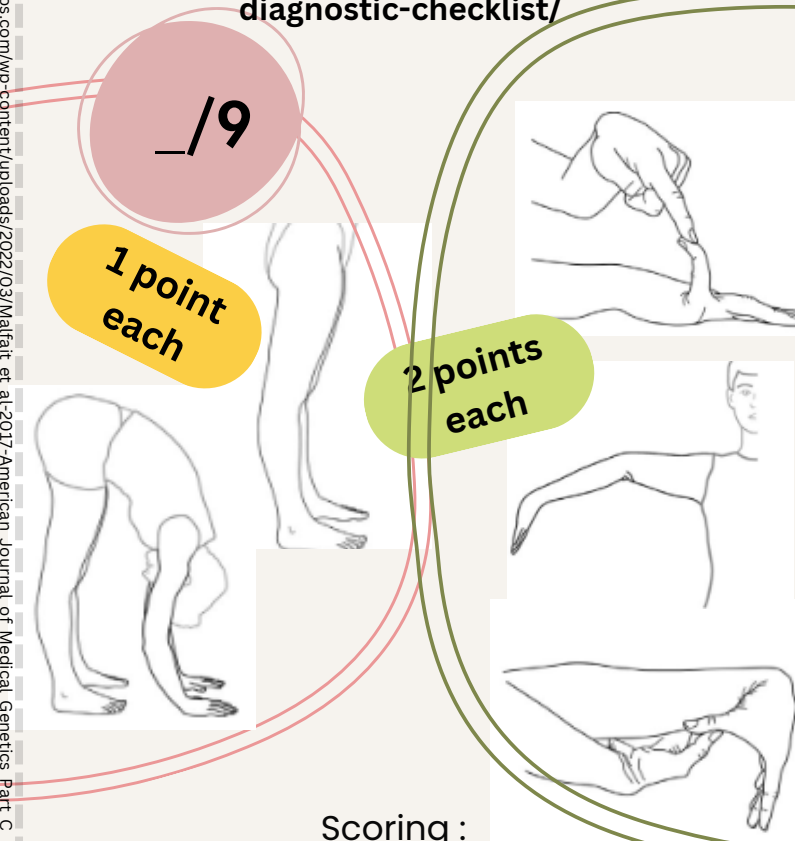
**THINK THIS SOUNDS FAMILIAR? TALK TO YOUR TRUSTED MEDICAL PROFESSIONAL**

## HOW IS IT DIAGNOSED?

There are clear guidelines that any medical professional can use to diagnose

<https://www.ehlers-danlos.com/heds-diagnostic-checklist/>

https://www.ehlers-danlos.com/wp-content/uploads/2022/03/Malfait\_et\_al\_2017\_American\_Journal\_of\_Medical\_Genetics\_Part\_C\_Seminars\_in\_Medical\_Genetics.pdf



Scoring :

- >6 Pre-pubertal children and adolescents
- >5 Pubertal men and woman to age 50
- >4 Men and woman over the age of 50

“Can you now, or could you ever”  
Did you amuse your friends by contorting your body?