

P-06-1348 Commission suitable NHS services in Wales for people with EDS or hypermobility spectrum disorders

This petition was submitted by Natasha Evans-Jones, having collected a total of 1,125 signatures.

Text of Petition:

Historically those showing signs of Ehlers-Danlos syndromes (EDS) or HSD have been referred to rheumatology departments. In 2021, they were directed to stop seeing these patients in favour of their diagnosis and management in primary care, which is not currently equipped for this role. A unique tertiary service in England has also closed to out of area patients. This situation has led to inequalities in access to healthcare for those with EDS and HSD in Wales resulting in unacceptable suffering.

Additional Information:

Ehlers-Danlos syndromes are genetic connective tissue disorders with body-wide symptoms which can be disabling, affecting all aspects of life. One type is life-threatening. Symptoms of most types include musculoskeletal problems, chronic pain and fatigue, gastrointestinal disturbance, fragile skin, pelvic and bladder problems, autonomic dysfunction and anxiety. Twelve of the 13 classified types can be diagnosed via genetic testing. There is no single test for the most common type (hEDS) or for the related hypermobility spectrum disorders (HSD) which makes diagnosis challenging. Together, hEDS and HSD are fairly common. A study in 2019 using data from Welsh hospitals and GP records found that 1 in 500 people are affected (Demmler et al, <https://bmjopen.bmj.com/content/9/11/e031365>).

The situation in Wales is causing suffering for those waiting for diagnosis, those on inappropriate treatment pathways, and their families.

Senedd Constituency and Region

- Vale of Clwyd
- North Wales