



Supporting and working with community groups and clubs to promote a deeper understanding of local health and care needs and experiences

## Spotlight on Sussex Ehlers-Danlos Syndromes and Hypermobility support (SEDS)

Ehlers-Danlos Syndrome (EDS) including hypermobility spectrum disorder (HSD) is a complex, heritable, connective tissue disease. Although it is considered rare 1/3-5000 it is feared there could be many more undiagnosed or misdiagnosed sufferers and so it may only be rare due to lack of knowledge and awareness and lack of diagnosis. For those with a diagnosis in South East Surrey and Sussex there is a voluntary community support group offering help to those in need.

EDS is a heritable disease and 13 types can be identified by testing but the most common hEDS and HSD are diagnosed by examination, family history and specific criteria. Connective tissue lies between other tissues and organs, keeping them separate yet connecting to them. In EDS a gene mutation causes certain parts of the connective tissue, usually the collagen, to be extra stretchy or fragile. Collagen is present throughout the body. It is considered an invisible disability and you don't have to have stretchy or bruised skin, in fact sometimes the opposite.

Common symptoms are sprains, dislocations, chronic fatigue, acute pain, chronic persistent pain like fibromyalgia, nerve pain, arthritis, organ issues, brain, heart, stomach, bowel and bladder issues, prolapses. Also, sufferers can have severe dizziness, palpitations, body regulation issues, severe intolerance/allergies and autism. The presentation of symptoms varies significantly, and sufferers are very much individual in this respect. In some cases, it is life-limiting particularly Vascular EDS (vEDS) or where the neck ligaments give way.

The Sussex Ehlers-Danlos Syndromes and Hypermobility Support (SEDS) voluntary community group supports sufferers of all ages and family/carers with EDS or suspected symptoms; as it is so difficult to get a diagnosis. They provide active support, awareness in the local area to sufferers, to organisations, businesses, transportation, education and social and health departments. They can signpost people to further advice, to the national EDS UK Support Charity, other support groups and activities.

As part of a Community Fund Grant project, insight from members was collated and anonymised and forms part of the insight and evidence that Healthwatch gather to identify common themes around what works and doesn't work for local people.

**This insight is used to influence services development and can feed into:**

- West Sussex Health and Wellbeing Board
- HASC - Health and Adult Social Care Select Committee
- WSCC Joint Strategic Needs Assessment
- Safeguarding Adult Board
- The Developing Integrated Care System for Sussex.

Healthwatch West Sussex also share reports with the Care Quality Commission (who are responsible for the registration and inspection of services which deliver regulated activities) and to Healthwatch England to form part of the national picture used to influence national developments, such as the NHS70 10 year forward plan.

---

**To contact Sussex Ehlers-Danlos Syndrome (SEDS)**

Email: [admin@infosussexeds.org.uk](mailto:admin@infosussexeds.org.uk)

Via Facebook: Sussex Ehlers-Danlos Syndromes (SEDS) for members, or Sussex EDS & HSD Support

Website coming soon at: [www.infosussexeds.org.uk](http://www.infosussexeds.org.uk)



The National charity for EDS, which SEDS has links to in Sussex, is EDS UK Support.

---



Not only do we collect the experiences of local people, but we can also provide free information and guidance just call: **0300 012 0122**.

Email [helpdesk@healthwatchwestsussex.co.uk](mailto:helpdesk@healthwatchwestsussex.co.uk),

Website [www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk).

**healthwatch**  
West Sussex

You can also follow our social media channels:

Facebook [@healthwatchwestsussex](https://www.facebook.com/healthwatchwestsussex)

Twitter [@healthwatchws](https://twitter.com/healthwatchws)

If you are setting up or would like to share news of a similar project we would be interested to hear from you. Please contact Cheryl Berry, Community Partnership Co-ordinator, email: [cheryl.berry@healthwatchwestsussex.co.uk](mailto:cheryl.berry@healthwatchwestsussex.co.uk)