

# TOP TIPS

to support a friend or family member with EDS or HSD

The Ehlers-Danlos syndromes (EDS) are a group of genetic connective tissue disorders with symptoms affecting the whole body. Hypermobility spectrum disorder (HSD) has similar symptoms to the most common type of EDS, the hypermobile type. Those affected by EDS or HSD may face challenges to their physical and mental health.

## 1 Understand

**EDS and HSD are often invisible conditions.** People with them may look fine physically but could be experiencing a range of symptoms. These can vary widely from day to day. Making plans can be difficult when how you feel can change so quickly. Reassure them it is ok to rearrange and try to remain connected as social isolation and anxiety are common for people with EDS or HSD.



## 2 Help

**HSD and some types of EDS lead people to have very loose joints.** This means their joints can dislocate or be injured easily, even doing everyday things like getting dressed or walking. Be aware that brain fog is common and can make a person appear forgetful or confused. They may need help to complete complex tasks. This can be made worse by fatigue and medication.



## 3 Listen

**Active listening is very important.** People with EDS or HSD have often spent years trying to get an accurate diagnosis and treatment. This will have involved explaining what they are experiencing over and over again to many professionals. Try to avoid asking them to repeat this pattern. If someone appears to be struggling, ask them what they need. It could be something very simple. Don't assume you know what will help.



## 4 Empathise

**Living with chronic (long-term) pain affects all aspects of life – sleep, mood, self-image, confidence, activity levels and relationships.** Being in pain every day and not being able to do the things you want can cause strong emotions. Chronic pain is very difficult to treat and people may need to try a number of different options to find what works best for them.



More information is available from  
The Ehlers-Danlos Support UK helpline

**0800 907 8518**

helpline@ehlers-danlos.org

Visit: [ehlers-danlos.org](http://ehlers-danlos.org)



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