TOP TIPS to support a friend or family member with EDS or HSD

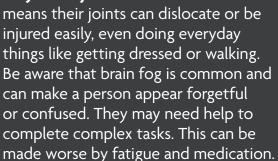
The Ehlers-Danlos syndromes (EDS) are a group of genetic connective tissue disorders with symptoms affecting the whole body. Hypermobility spectrum disorder (HSD) has similar symptoms to the most common type of EDS, the hypermobile type. Those affected by EDS or HSD may face challenges to their physical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



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.

Help

HSD and some types of EDS lead people to have very loose joints. This



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.

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

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