

TOP TIPS to support pupils with EDS or JHS

The Ehlers-Danlos syndromes (EDS) are a group of genetic connective tissue disorders with symptoms affecting the whole body. It is more common for children and young people to be defined as having joint hypermobility syndrome (JHS) than EDS. Pupils with JHS can display similar symptoms to those with the most common type of EDS. Pupils affected by EDS may face challenges to their physical and mental health.

Adjustments



1 Pupils with JHS or EDS may have symptoms which affect them at school and vary greatly from day to day. The conditions affect individuals differently. Many of the adjustments which benefit pupils with JHS or EDS are simple and low cost.

2 Sitting



Pupils with the conditions may find it difficult to sit in a set position, especially for long periods. **Good posture is important.** Providing back support, cushions, beanbags, footrests or the option to stand can reduce discomfort and minimise fidgeting.

PE



3 Pupils are encouraged to take part in appropriate physical activity and sport to facilitate their physical development. This also helps keep joints in place and improves coordination, muscle strength and stamina. Contact sports are not advised for some pupils. Alternative activities and additional time to recover from injuries may be needed.

Attendance

4 Some pupils may have frequent medical appointments and/or may not cope with a full curriculum. Agree a way to keep in touch with pupils missing school for long periods (e.g. recording missed lessons). A part-time curriculum which includes some social interaction may be beneficial.



More information is available on our dedicated website for schools: theschooltoolkit.org or call The Ehlers-Danlos Support UK helpline **0800 907 8518**

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Visit: ehlers-danlos.org



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