Joint hypermobility syndrome and the Ehlers-Danlos syndromes

Symptomatic hypermobility

Hypermobility is the term used when people can extend their joints further than is usual. It is quite common in the general population, especially in children and alone, is not necessarily a problem. However, hypermobility can be associated with long-term, widespread pain, fatigue, frequent dislocations and damage to the tissues surrounding joints. When hypermobility comes with these problems it is called symptomatic hypermobility.

Joint hypermobility syndrome

Joint hypermobility syndrome (JHS) is a condition involving symptomatic hypermobility. People with JHS can display similar symptoms to people with some types of Ehlers-Danlos syndrome ((EDS) see below). The differences are not important from a school's perspective and we suggest pupils with symptomatic hypermobility, JHS and EDS be treated in the same way except for individual differences.

The Ehlers-Danlos syndromes (EDS)

EDS are a group of genetic (heritable) conditions affecting a type of connective tissue which is found throughout the body. This can cause widespread symptoms. The different types of EDS are distinct from each other. It is more common for children to be defined as having symptomatic hypermobility or JHS than the most common type of EDS (hEDS). Vascular EDS (vEDS) is different to the other types of EDS and can lead to sudden, life-threatening events.

Effects throughout the body

JHS and EDS are complex syndromes affecting many systems of the body. They are often invisible. As well as problems associated with symptomatic hypermobility, those affected may have skin which damages easily and is slow to heal or can be thick and velvety. They can also experience palpitations, dizziness, sweating, fainting, headaches and gut, bowel and bladder problems. Symptoms and their severity vary considerably from person to person. JHS and EDS may be associated with some other conditions but more research is needed.

Support at school

Children with JHS or EDS will need personalised needs identified and sometimes followed through by physio or occupational therapy at school. Due to differences in emotional processing they might not realise they are in pain until it overwhelms them or they are tired. Some might need medication during the day. They might need breakout times, movement times, toilet passes, food/drink passes and sometimes somewhere to lie down for a few minutes. They might have poor fine and gross motor skills - it will take more time to work on clothes, laces, buttons, handwriting. Sometimes they will need adaptive equipment such as cushions, chairs, writing slopes, special adapted pencils, laptops. PE will need consideration not to overextend range of limbs or do too much or too little. They need to know their options and that it is okay to do this without being singled out.

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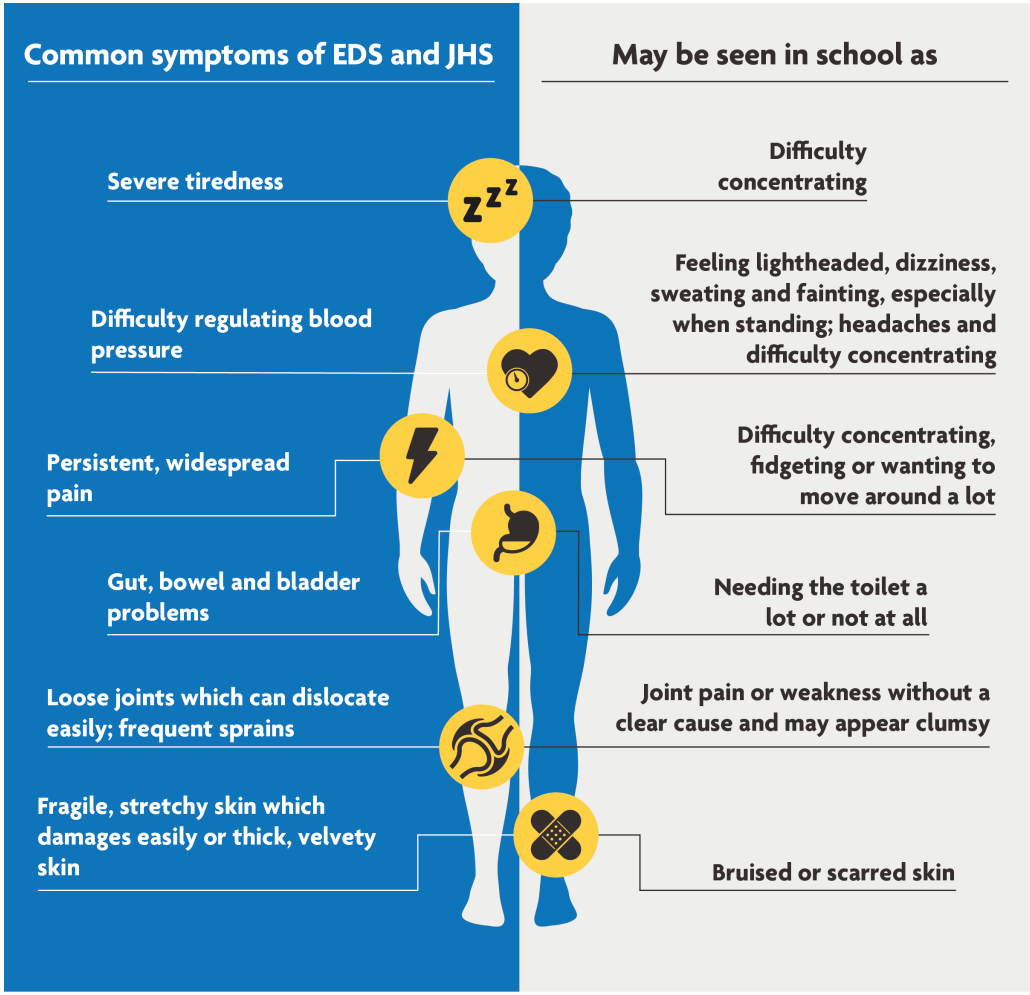

SchoolToolkit
FOR EDS AND JHS

For more information and resources to support children with EDS and JHS at school, please visit www.theschooltoolkit.org