What are

SEDS

Joint Hypermobility Syndromes/ Ehlers-Danlos Syndromes and Symptomatic Hypermobility?

Joint Hypermobility syndromes JHS and Ehlers-Danlos Syndromes EDS and symptomatic hypermobility. These names might change in the future.

EDS/JHS are multi systemic connective tissue disorders. Children can be hypermobile with no symptoms, but for some they may have symptomatic hypermobility. These children commonly have symptoms with tiredness, strength, posture, dizziness, headaches, allergies, stomach pain, reflux, bowel/bladder issues, skin differences; sometimes thin skin with bruising and poor wound healing, sometimes thick velvety skin. Other effects are palpitations, dizziness, fainting, headaches and gastro intestinal issues. It sometimes co-occurs with other diagnoses such as autism, ADHD and dyspraxia (DCD)

Children with EDS/JHS or symptomatic hypermobility will need personalised needs identified and sometimes followed through by physio or occupational therapy at school. Due to differences in emotional processing their senses, they might not realise they are in pain until it overwhelms them or tired.

They will need break out times, movement time, toilet passes, food/drink passes and sometimes somewhere where they 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 more help with adaptive equipment such as cushions, chairs, writing slopes, special adapted pencils, pens or laptops. PE will need careful consideration not to over extend range of limbs even for asymptomatic hypermobility or do too much or too little.

They need to know their options and that it is okay to do this without singling them out. Some might need extra medication during the day.

More on the symptomatic hypermobility can be obtained at www.sussexeds.com
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My name

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