**Introduction to Hypermobility**

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| **Slide number** | **Text** |
| 2 | Thank you for choosing to watch this webinar. My name is Jo Lambert and I will be taking you through the slides today. I hope that by the end of the webinar, you will feel more confident in meeting the needs of children and young people with hypermobility and will know where to find additional support if needed. We will cover the following topics: What is hypermobility? What causes hypermobility? Common difficulties; educational implications; ordinarily available; strategies; useful links and resources; and finally where to get help. |
| 3 | Joint hypermobility means that **some or all of a person's joints have an unusually large range of movement**. People with hypermobility are particularly supple and able to move their limbs into positions others find impossible. Contrary to some perceptions that this ability is some kind of party trick or unique talent, having hypermobile joints can be severely debilitating to the person experiencing this condition. |
| 4 | Joint hypermobility syndrome is often genetic and it cannot be prevented.Hypermobility is characterised by loose and stretchy ligaments, which make the joints weaker rather than stronger.The weakness is attributed to the fact that a person with Hypermobility has different collagen to other people. Collagen strengthens the ligaments Most experts agree that joint hypermobility syndrome is part of a spectrum of hypermobility disorders which includes [Ehlers-Danlos syndrome](https://www.nhs.uk/conditions/ehlers-danlos-syndromes/). Some people with hypermobility spectrum disorders do not have symptoms.There is not usually one diagnostic test but diagnosis is made based on the range of symptoms a person is experiencing. There is a lot of information online regarding EDS specifically, should you wish to further develop your awareness. |
| 5 | On this slide we look at the common difficulties associated with hypermobility. These can include pain and stiffness in the joints and muscles; dizziness and fainting; digestive problems such as constipation and irritable bowel syndrome; fatigue; joints that dislocate; recurrent injuries; and comorbidity or coexistence with other conditions such as ADHD and dyspraxia. Before moving onto the next slide, pause for a moment to think about the educational implications of these symptoms and difficulties. What could they mean for the child or young person what they mean for your staff in your school? |
| 6 | Hopefully you thought of at least some of the following: * Pain and fatigue impacting on ability to focus, record work, socialise etc.
* Difficulties accessing P.E and using practical equipment
* Difficulties with dressing and undressing
* Bowel and bladder issues impacting on independence with toileting
* Frequent absences from school for medical appointments and as a result of illness/fatigue
* Mental health difficulties with regard to managing and coming to terms with their condition.
* Difficulties accessing extracurricular activities and off site visits.
* Frequent injuries and damage to skin and joints, making the child more vulnerable to infection.
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| 7 | Before we go on to talk about strategies and adaptations to try in your educational setting, please refer to the new ordinarily available document as this contains some useful strategies that can be tried before you reach for external input from other sources. I will briefly talk through some of these strategies here, however you can access the ordinarily available documents online, and refer to the PNI page on the Essex Schools Infolink for further information. * Be mindful of fatigue levels and the need for rest and/or changes in positioning.
* Draw up a daily health care plan to cover any medication toileting eating and drinking and physio needs for example. This should be created in conjunction with parents and any relevant health professionals.
* Consider using alternative means of recording work, especially when a child is experiencing high levels of pain and/or fatigue
* Develop effective home/school communication so that all concerns and important information shared.
* Ensure that all furniture is the correct height and size so that the pupil can sit comfortably with their peers.
* Plan any school trips well in advance so that any adjustments necessary can be made for the pupil to fully access them.
* Use a whole school approach to disability awareness and inclusion e.g. books, assemblies and charity events to raise awareness/funding. Ensure all staff are aware of the child's needs.
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| 8 | Hopefully you will already be aware of the term reasonable adjustments. All employers and education settings are expected to make reasonable adjustments to help meet the needs of their employees and/or students. You can find out more about reasonable adjustments by looking it up online. Here we will focus on some strategies and adaptations you can try to support pupils with hypermobility without necessarily requiring the help of external professionals.**Sitting –** discourage W sitting. Provide alternatives, such as bean bags and encourage frequent changes of position. For older children, ensure they can move around frequently to maintain comfort and focus.**Break times and moving around –** allow the pupil to leave lessons 5 mins early; have a carry buddy; issue a lift pass, minimise the distance travelled.**Reading, writing and exams** – apply for access arrangements well in advance; use a variety of means for the child to record their learning including use of technology, scribing and ergonomic tools where appropriate. |
| 9 | **Using the toilet –** allow the child to go to the toilet when they need to with minimal attention and fuss! The child may need a grab rail which you should have in your accessible W/C anyway. If the child needs assistance, it is NOT necessary to have 2 staff members present.**Attendance -** do not penalise the child for poor attendance but do be clear about how this is evidenced, recorded and supported. Consider ways they can stay in touch, catch up and join in social occasions.**The sensory environment –** some pupils with hypermobility will present as more anxious than other children and may have difficulties regulating their temperature and other senses. Try to foster a calm environment with minimal background noise and visual clutter. |
| 10 | **School uniform** – consider allowing the child to come in wearing their P.E kit on P.E days; allow some flexibility with footwear and clothing with tricker fastenings.**School trips –** plan and risk assess well in advance; provide alternative activities if there are things the child cannot access (document on planning school trips available on the Essex Schools Infolink PNI Page)**Managing pain –** create a pain management plan for the CYP; do not expect them to ‘ride out the pain’ or assume they are faking it; allow access to the medical room when needed; consider use of a pain scale  |
| 11 | **Pacing –** Try dividing activities into three categories depending on the level of energy they take to create a ‘traffic light system’.  Green is for easier tasks, such as eating lunch.  Amber are tasks which take a bit more physical or mental energy, for example writing for a long time. Red tasks take a lot of energy, such as a PE lesson.  These tasks are very personal to each individual.  There should only be one red task a day as these need time to recover from.**Physical education –** usually some sport or exercise is considered beneficial for people with Hypermobility but recommendations will depend on the individual. Incorporate rest breaks, a chair to sit on and a variety of balls etc. See next slide for PNI “Adapting P.E” course details. |
| 12 | If you wish to deepen your knowledge and awareness of hypermobility or simply want to find sources of information and support, you may wish to refer to some of the organisations and resources listed on this slide. |
| 13 | If you have tried all the suggestions made previously and are still finding it hard to meet the child’s needs, you can seek advice from the child and their family as to how best to meet the child’s needs; you can seek help from the Occupational and/or Physiotherapist or you can ask the school nurse if you have access to one. You can refer to the PNI team for further advice by completing the online referral form on the Essex Schools Infolink. The PNI Specialist Teaching Team does not always accept referrals for children and young people with Hypermobility, unless it is especially severe and adaptations need to be made that are beyond that which is Ordinarily Available, but we will look at requests and decide on an individual basis whether to become involved. |
| 14 | We have now come to the end of this webinar. Thank you for listening. I hope you found it useful and if you have any questions please do not hesitate to contact us at education.psi@essex.gov.uk |