

FACTSHEET



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Joint hypermobility syndrome

Children and adolescents with “joint hypermobility” have joints which move beyond the normal limits. Many famous gymnasts, musicians, trapeze artists and dancers have been able to achieve fame due to the flexibility of their joints.

Generalised Joint Hypermobility is where multiple joints in the body are affected, and this is normally something an individual is born with. Most children and adolescents with flexible joints do not have any symptoms, but some individuals may need to take additional care to protect their joints from injury. Sometimes people with flexible joints can have soft tissue injuries, joint subluxations (slipping out slightly) or dislocations (slipping out completely), and they are more susceptible to sport injuries (strains and sprains).

Occasionally people with joint hypermobility can develop recurring pain in multiple joints, pain in muscles, or fatigue, which can limit their ability to participate in daily activities like attending school or doing sport and physical activity. This pattern of symptoms is sometimes called “Joint Hypermobility Syndrome” (JHS) which is the same as Ehlers-Danlos Syndrome (Hypermobility type). JHS is treated with a rehabilitation program comprised of physical strengthening and reconditioning and a program to manage pain including psychological therapies. For people with hypermobile joints, the task of looking after their joints and the task of maintaining their physical fitness needs to be integrated into their lifestyle, so that they can maintain a healthy lifestyle in the long term.

Genetics and Joint Hypermobility

Most people with Joint Hypermobility can identify other family members who are ‘flexible’, as the condition runs in families. Joint hypermobility is more common in females than males. Some genetic syndromes such as Down syndrome or Marfan syndrome, can be associated with hypermobility, so it is important that everyone with hypermobility in four or more joints is seen for an evaluation by a geneticist, or other specialist in hypermobility. In the vast majority of people with hypermobility a genetic cause will not be identified.

Joint Hypermobility and Musculoskeletal Injury

Joint instability and injury can occur more often in people with joint hypermobility, with the knee, ankle and shoulder being the most commonly affected joints. Joint injuries are more likely in individuals who do not exercise, as the strength to support and protect joints adequately is not maintained. Recovery from injury can take longer in individuals with hypermobile joints, particularly the recovery of muscular strength and endurance. If injuries occur frequently, they should be treated promptly by a physiotherapist and, if needed, a doctor who has expertise in managing children with paediatric sports injuries. Rest or immobilisation after injury should be kept to a minimum to prevent further weakening of the muscles that serve to protect the joint. Gentle mobilisation using water or land based activities can often be started early but should always be done under physiotherapy guidance.

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Musculoskeletal and Joint Pain

Some children and adolescents with hypermobile joints may experience joint pain. Most commonly, this happens during and after physical activity. Typically this pain will subside, however, for a small number of individuals exercise-induced joint pain may become a more chronic problem. For individuals where pain is ongoing or frequent, therapy involves improving joint strength and stability, and preventing strain that leads to pain symptoms. Physiotherapy with a particular focus on core and postural muscles helps protect joints and prevent pain symptoms. Because joints support our bodies, individuals who are overweight suffer from increased joint pain, so a healthy diet is important. A 6-8 week physiotherapy exercise programme is effective in reducing chronic joint pain by 30-40%. Passive treatments such as ice, massage, electrotherapies, bracing and splinting may be useful at times of pain exacerbation but should be avoided as long-term strategies.

Management of complex chronic joint pain should include a multidisciplinary approach including physiotherapy and psychology for pain-focused cognitive-behavioural therapy (see complex pain factsheet). Complex pain clinics are available in all three children's hospitals in NSW.

Hand function and Handwriting

Handwriting is not usually a major problem for most children and adolescents with hypermobile joints. However, difficulties in keeping up with classmates during written tasks at school are reported in up to 40% of students with JHS. Because handwriting difficulties can affect academic performance, learning and self-esteem, an occupational therapy assessment can be useful.

Gastrointestinal and Urinary Symptoms

Chronic constipation, gastro-oesophageal reflux, chronic abdominal pain, irritable bowel syndrome and urinary tract symptoms are reported by a small number of children and adolescents with hypermobility. The gut, like joints, is largely made of connective tissue, and the current understanding is that gut symptoms occur because the connective tissue of individuals with hypermobility is more flexible, making it more difficult to manipulate food and push it through the gastrointestinal tract. Gut problems typically get better with plenty of water, physical activity and a high fibre whole food diet which make the stool soft and larger and easier for the gut to push. Occasionally laxatives may be needed under medical supervision. Probiotics can be useful for

cramping and gas. A very small number of children with joint hypermobility report symptoms consistent with stress incontinence where a little bit of urine leaks when coughing, jumping or sneezing. This is also due to the differences in connective tissue and can be treated by targeted physiotherapy.

Fatigue

Although most children and adolescents with joint hypermobility have normal levels of energy, fatigue can be a problem for some individuals, and is more common in children and adolescents with JHS. The cause of fatigue is thought to be multifactorial in nature. Fatigue and physical deconditioning is associated with poor sleep, muscle weakness, low aerobic fitness and dizziness in children and adolescents with joint hypermobility. Fatigue symptoms can be helped by increasing physical fitness, psychological interventions which strengthen emotional resilience, and education on pacing. The goal of pacing interventions is to avoid “boom and bust” cycles where periods of excessive activity result in worsening musculoskeletal symptoms and are followed by periods of inactivity which in turn, worsen fatigue and dizziness symptoms.

Anxiety

Children and adolescents with joint hypermobility have an increased incidence of anxiety, panic attacks and depression, all of which can be effectively treated with psychological interventions and promoting physical wellbeing.

Physical Activity

Physical activity is important for the health and wellbeing of all children and adolescents, including those with hypermobile joints. Pacing of activity levels—both at home and at school—is important if children are experiencing pain or fatigue, and some sports may need to be modified if they cause frequent injuries. Advice about specific sports and physical activities for you/your child should be discussed with your physiotherapist or doctor. Care should be taken with contact sports, which should be avoided if the child is hypermobile in their cervical spine (extension range 90 degrees or more). Swimming, pilates, bike riding, walking and other water based activities are excellent activities to increase physical strength and joint stability.

Remember:

If you have concerns about your child please discuss them first with your GP or Paediatrician. Specialist advice on hypermobility can usually be obtained from regional Paediatric Rheumatologists or Paediatric Rehabilitation specialists. Most public hospitals have a genetics clinic which provides consultation on diagnosis and the three NSW children's hospitals all have complex pain clinics.