

# Benign 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 marked flexibility of their joints which can be a useful advantage..

Generalised joint hypermobility is where multiple joints in the body are affected. This is normally something a child is born with and part of an individual's make up. **Most children and adolescents with flexible joints do not have any adverse symptoms**, but some individuals may need to take extra care to protect their joints from injury. Sometimes people with flexible joints can have soft tissue injuries (muscle tendon or ligament tears), joint subluxations (slipping out of place slightly) or dislocations (slipping out completely). People with flexible joints are also more likely to have injuries such as strains and sprains during sports or in activities where they don't have full control of how their body moves e.g. trampolining.

Some people with joint hypermobility can develop recurring pain in multiple joints, pain in muscles, or fatigue. Pain can limit their ability to participate in daily activities like school or doing sport and physical activity. This pattern of symptoms is sometimes called "Joint hypermobility syndrome" (JHS) and can include a diagnosis of Hypermobile type Ehlers-Danlos Syndrome (h-EDS).

Joint hypermobility is treated with a rehabilitation programme of physical strengthening and reconditioning in conjunction with pain management psychological strategies to help children and young people deal with stress and anxiety. People with hypermobile joints, need to protect their joints with healthy muscle maintained through physical fitness. Maintaining movement and great nutrition needs to become priorities in life to minimize injury and disability.

## Genetics and joint hypermobility

Most people with Joint Hypermobility can think of other family members who are 'flexible', because 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 linked with hypermobility, so it is important that people with hypermobility in four or more joints talk to their doctor about their hypermobility. **Most people with hypermobility will not find a genetic cause** but early identification means that steps can be taken to minimise injury.

## Joint hypermobility and musculoskeletal injury

Joint instability and injury is more common in people with joint hypermobility. The knee, ankle and shoulder are the most commonly affected joints in children. Joint injuries are more likely in individuals who do not exercise, because the strength to support and protect joints adequately is reduced if muscles are not maintained. Recovery from injury can take longer in individuals with hypermobile joints, particularly the recovery of muscular strength and endurance. If injuries happen often, 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. **Talk to your child's GP about an Enhanced Primary Care Package to help with the cost of 10 Allied Health sessions/year.**

## Musculoskeletal and joint pain

Some children and adolescents with hypermobile joints may have pain. Often this happens during and after physical activity. Typically this pain will subside, however, for a small number of individuals exercise-induced joint or muscle 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 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 published study demonstrated that a 6-8 week physiotherapy exercise program 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 and specialists in musculoskeletal disease (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, up to 40% of children with small joint hypermobility will have trouble keeping up with classmates during written tasks at school. Because handwriting difficulties can affect academic performance, learning and self-esteem, a paediatric 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 often get better with plenty of water, physical activity and a high fibre whole food diet. These changes 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

While 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 hEDS. The cause of fatigue is thought to be multifactorial in nature. Fatigue and physical deconditioning is linked with poor sleep, muscle weakness, low aerobic fitness and dizziness in children and adolescents with joint hypermobility. Fatigue symptoms can be helped by gradually increasing physical fitness, psychological interventions which strengthen emotional resilience, and education on pacing activities to avoid overdoing it on one day and doing nothing the next.

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, make fatigue and dizziness symptoms worse.

## Anxiety

Children and adolescents with joint hypermobility have an increased incidence of anxiety, panic attacks and depression. All of these issues can be effectively treated with psychological interventions and promoting physical wellbeing. **Listening to your child and understanding his/her condition, whilst maintaining an optimistic and hopeful view of the future will you're your child to stay confident.**

## 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 or avoided 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 and trampolines, which should be avoided if the child is hypermobile in their neck (cervical spine extension range 90 degrees+). **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. Advice on hypermobility can be obtained from Paediatric Rheumatologists or Paediatric Rehabilitation specialists.
- Most public hospitals have a genetics clinic which provides consultation on diagnosis of the rarer connective tissue disorders and the three NSW children's hospitals have complex pain clinics.

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Modified from fact sheets :

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