

Joint Hypermobility and Ehlers-Danlos Syndrome

The classic sign of joint hypermobility — a thumb that can bend back towards the forearm.

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What you're feeling

You may have always been the “double-jointed” one, able to bend your thumb back to your forearm, hyperextend your elbows, or fold yourself into shapes that make other people wince. For many people that flexibility is simply a harmless quirk and causes no trouble at all.

For some, though, it comes at a cost. The joints that move beyond the normal range can also ache, especially after activity or at the end of the day. You might notice that some joints click, clunk or feel loose, as if they could slip out of place, and sometimes they do. The shoulder, the small finger joints and the base of the thumb are common culprits in the upper limb: a shoulder that partially slides out (a subluxation) or fully dislocates, fingers that bend the wrong way, a thumb joint that gives way when you pinch or grip. Injuries can seem to take longer to settle than you'd expect, and the same joint may keep letting you down.

Hypermobility often travels with other features. Some people have soft or stretchy skin and bruise easily. Many describe fatigue that is out of proportion to what they've done, dizziness or a racing heart on standing, and digestive symptoms like bloating or reflux. Not everyone has all of this, but if several of these ring true alongside your loose joints, they may be connected.

What's actually happening

Your joints are held together and supported by **connective tissue** (ligaments, tendons and the capsule around each joint), and a key building block of that tissue is a protein called **collagen**. In people with hypermobility, the collagen and connective tissue are a little **stretchier and more elastic** than usual. The supporting structures give a bit more, so joints can travel further than the normal range allows.

This sits on a **spectrum**. At one end is simple **joint hypermobility** that never causes a problem. When loose joints start to produce pain, instability or repeated injuries, doctors call it a **hypermobility spectrum disorder**. At the far end is **hypermobile Ehlers-Danlos syndrome (hEDS)**, where the stretchier connective tissue is

more pronounced and more likely to come with the wider, whole-body features (skin, bruising, fatigue, gut and dizziness/autonomic symptoms). The lines between these are not sharp, and where you sit can shift over time. To help map this out, doctors often use a simple set of bend tests called the **Beighton score**, alongside your full history.

The reason all this matters for your joints comes down to one idea: if the passive supports (the ligaments and capsule) hold a joint less firmly, the joint has to rely much more on the muscles around it for stability. When those muscles are strong and well-coordinated, the joint stays put. When they tire or aren't conditioned for the job, the joint slips, aches, and over many years may wear a little faster than it otherwise would.

There's one pattern worth knowing about in the shoulder. Where a single injury can knock a normal shoulder out in one direction, a loose shoulder often feels unstable in several directions at once, sliding forwards, backwards or downwards. Doctors call this **multidirectional instability**. It also means these shoulders tend to **partly slip and self-correct (subluxate)** more often than they fully dislocate. This matters because it is exactly the kind of instability that responds best to building muscle control, and least well to an operation alone.

What we can do about it

The most important message is this: hypermobility and hEDS are **not curable, but they are very manageable**, and the cornerstone of management is not a tablet or an operation. It is **building the muscles that stabilise your joints**.

Physiotherapy and targeted strengthening are the mainstay. A physiotherapist who understands hypermobility will work with you to build control and strength around the joints that trouble you most. For the upper limb, that often means the shoulder blade and rotator cuff muscles, and the small muscles that control the thumb and fingers. The aim is to train your muscles to do the steadying work that your ligaments do less of. This is a gradual, ongoing programme rather than a quick fix, but it is what changes things for most people.

Around that core, several other measures help:

- **Pacing and joint protection:** spreading activity through the day, avoiding the end-of-range positions that strain loose joints, and adapting how you do demanding or repetitive tasks.
- **Bracing and taping:** used selectively to support a joint while you build strength or get through a flare, not as a permanent crutch.
- **Pain management:** simple strategies, sometimes medication, and attention to sleep, fatigue and the other body-wide symptoms, because these all feed into how your joints feel.

Surgery is approached cautiously. For an upper-limb surgeon this is a genuinely important point. When a joint (most often the shoulder) dislocates repeatedly despite good rehabilitation, an operation to stabilise it can be considered. But the same stretchy tissue that loosened the joint in the first place also holds surgical repairs less reliably and can heal differently, so standard stabilising operations carry a higher chance of stretching out or failing over time. Because of this, surgery is reserved for carefully selected problems, planned with your hypermobility firmly in mind, and always paired with a strengthening programme before and after. The rehabilitation is what protects the result.

What to expect

Hypermobility is part of how your body is built, so it doesn't go away, but its impact can change enormously with the right management. Many people who commit to a strengthening programme find their joints become far more stable, their pain settles, and the slips and dislocations become much less frequent. Progress tends to be steady rather than sudden, measured over months, and the gains are best held by keeping the muscles conditioned for the long term rather than stopping once things improve.

It helps to think of this as a long-term partnership with your body rather than a problem to be fixed once. Flares can still happen, especially after illness, a growth spurt, or a period of less activity, and you'll get better at reading the early signs and heading them off. Where the wider features are present (fatigue, dizziness, gut symptoms), looking after those alongside your joints usually makes everything more manageable. With a sensible plan, most people stay active and do the things that matter to them.

When to see someone

- A joint that **dislocates or partly slips out repeatedly**, particularly the shoulder, or a first dislocation that won't settle.
- **Pain that is disabling** or steadily getting worse despite rest and your usual measures.
- **Instability that interferes with daily life:** struggling to grip, lift, work or sleep because a joint keeps letting you down.
- A new or rapidly worsening joint problem, or **numbness, tingling or weakness** in the arm or hand.
- If you suspect a **hypermobility spectrum disorder or hEDS** and want it properly assessed (especially when loose joints come together with skin, bruising, fatigue, dizziness or gut symptoms), it's worth seeking a considered review so the right plan can be put in place.

In more depth

This section goes further than you need for your own treatment decisions. Hypermobility is worth the extra reading because the confident story – loose joints are a collagen gene problem, and a lax joint can simply be tightened surgically – does not survive contact with the evidence on either count.

THE MOST COMMON TYPE HAS NO KNOWN GENETIC CAUSE

The 2017 international classification recognises **13** types of Ehlers-Danlos syndrome. Twelve of them are caused by variants in **20** identified genes, and for those twelve a definite diagnosis requires molecular confirmation [1].

The thirteenth is hypermobile EDS – by a wide margin the most common – and its molecular basis **remains unknown** [1]. There is no gene test for it. It is the one type diagnosed purely on clinical criteria, which is why the diagnosis can feel frustratingly subjective compared with conditions that end in a laboratory result.

This matters for how the condition is explained. Saying that hypermobility “comes down to inherited differences in collagen genes” is accurate for classical and vascular EDS, where the causative variants are known. For hypermobile EDS it is a plausible assumption rather than a demonstrated fact. The honest position is that we can describe the tissue behaviour reliably and cannot yet name the molecular cause.

THE BEIGHTON SCORE IS MORE RELIABLE THAN ITS REPUTATION

The nine-point Beighton score is often dismissed as crude and examiner-dependent. That criticism is not supported. A systematic review of **1,333** participants found the score shows **substantial to excellent** inter-rater and intra-rater reliability, and that this held across raters of varying background and experience [2].

So the measurement is sound. The genuine limitation is different: the score samples the little fingers, thumbs, elbows, knees and spine, and a good score tells you about *generalised* laxity – it was never designed to grade the stability of one shoulder in front of you.

WHAT HYPERMOBILITY ACTUALLY PREDICTS FOR THE UPPER LIMB

This is the number that matters in a shoulder clinic. A systematic review and meta-analysis of **2,335** athletes found that joint hypermobility was associated with a **threefold higher odds of shoulder injury** [3]. The authors are appropriately cautious about the quality of the underlying evidence, but the direction and size are hard to ignore.

That risk is not confined to the upper limb. Generalised joint laxity is associated with **increased graft failure and inferior outcomes** after anterior cruciate ligament reconstruction [4] – the same tissue behaving the same way in a different joint.

SURGERY WORKS LESS WELL, AND THE NUMBERS ARE SPECIFIC

This is the least comfortable part of the literature and the most useful.

A systematic review and meta-analysis of **1,769** patients found that people with Ehlers-Danlos syndrome undergoing total joint arthroplasty were at significantly increased risk of **all-cause revision, instability, aseptic loosening and wound complications** [5]. A separate review of orthopaedic surgical outcomes across the Ehlers-Danlos syndromes reached the same conclusion: outcomes are worse than in the general population, and complications occur more frequently [6].

None of that says surgery is wrong. It says the expected benefit is smaller and the expected complication rate higher than the figures quoted for the general population, and that the threshold for operating should move accordingly. If you have hypermobile tissue, published success rates for an operation were mostly not measured on people like you.

FOR AN UNSTABLE SHOULDER, REHABILITATION IS NOT THE CONSOLATION PRIZE

Multidirectional instability – a shoulder that is loose in several directions rather than having been dislocated out of one – is the classic hypermobile shoulder problem, and it is the clearest example of the point above.

Where surgery is needed after rehabilitation has genuinely failed, arthroscopic capsular plication and open capsular shift produce **comparable** rates of recurrent instability, return to sport and complications [7][8], with

CQ HAND + UPPER LIMB

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the arthroscopic approach causing less postoperative stiffness [9]. One historical technique, thermal capsular shrinkage, performed poorly enough that the meta-analysis advises against it [9].

The ordering is the message. Every one of those reviews frames surgery as what follows failed rehabilitation, not as an alternative to it – because tightening a capsule does not change the tissue it is made from, and the muscles remain the only part of the system that can be strengthened.

REFERENCES

1. Malfait F, Francomano C, Byers P, Belmont J, Berglund B, Black J, et al. The 2017 international classification of the Ehlers-Danlos syndromes. *Am J Med Genet C Semin Med Genet.* 2017;175(1):8-26.
2. Bockhorn LN, Vera AM, Dong D, Delgado DA, Varner KE, Harris JD. Interrater and intrarater reliability of the Beighton score: a systematic review. *Orthop J Sports Med.* 2021;9(1).
3. Liaghat B, Pedersen JR, Young JJ, Thorlund JB, Juul-Kristensen B, Juhl CB. Joint hypermobility in athletes is associated with shoulder injuries: a systematic review and meta-analysis. *BMC Musculoskelet Disord.* 2021;22(1).
4. Krebs NM, Barber-Westin S, Noyes FR. Generalized joint laxity is associated with increased failure rates of primary anterior cruciate ligament reconstructions: a systematic review. *Arthroscopy.* 2021;37(7):2337-47.
5. Subramanian T, Uzzo RN, Lama J, Mazzucco M, Ortiz S, Gausden EB. Outcomes of total joint arthroplasty in patients who have Ehlers-Danlos syndrome: a systematic review and meta-analysis. *J Arthroplasty.* 2025;40(8):2186-95.e1.
6. Yonko EA, LoTurco HM, Carter EM, Raggio CL. Orthopedic considerations and surgical outcomes in Ehlers-Danlos syndromes. *Am J Med Genet C Semin Med Genet.* 2021;187(4):458-65.
7. Longo UG, Rizzello G, Loppini M, Locher J, Buchmann S, Maffulli N, et al. Multidirectional instability of the shoulder: a systematic review. *Arthroscopy.* 2015;31(12):2431-43.
8. Jacobson ME, Rigganbach M, Wooldridge AN, Bishop JY. Open capsular shift and arthroscopic capsular plication for treatment of multidirectional instability. *Arthroscopy.* 2012;28(7):1010-17.
9. Chen D, Goldberg J, Herald J, Critchley I, Barmore A. Effects of surgical management on multidirectional instability of the shoulder: a meta-analysis. *Knee Surg Sports Traumatol Arthrosc.* 2015;24(2):630-9.