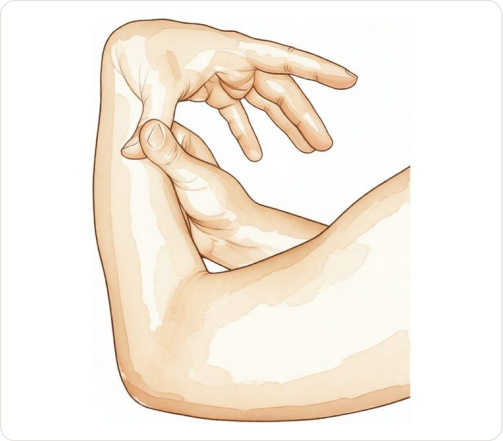
CQ HAND + UPPER LIMB
SPECIALIST ORTHOPAEDIC SURGEON

PATIENT INFORMATION — IN DEPTH

Joint Hypermobility and Ehlers-Danlos Syndrome



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

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

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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.

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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 steps up to a more detailed, student-level explanation. It isn't needed to manage hypermobility, but if you're curious about *why* the joints are loose and the tissues behave as they do, read on.

IT COMES DOWN TO COLLAGEN

Collagen is the body's main structural protein: the tough scaffold inside bone, tendon, ligament and skin (see those pages). In joint hypermobility and the Ehlers-Danlos syndromes (EDS), inherited differences in the genes that build or process collagen make it slightly weaker or stretchier than usual. Because collagen is *everywhere*, a small change in it shows up throughout the body.

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WHY JOINTS ARE LOOSE AND TISSUES FRAGILE

Stretchier ligaments and joint capsules let joints move beyond the normal range (hypermobility), dislocate or sublux more easily, and provide less reliable position-sense, so joints can feel unstable. The same collagen difference often makes skin soft and stretchy and prone to bruising, and, in some types, makes other tissues more fragile.

The Beighton manoeuvres used to score joint hypermobility — lax ligaments let joints bend well beyond the usual range.
Rollcloud, Wikimedia Commons, CC0

A SPECTRUM, AND WHY TYPING MATTERS

This runs from common, benign joint hypermobility through to the defined Ehlers-Danlos syndromes. Most types are managed conservatively and are not dangerous. But a few rarer types, particularly **vascular EDS**, affect blood vessels and hollow organs and need specialist care. That is exactly why an accurate diagnosis and type matters: most people simply need good joint management, but a minority need closer surveillance.

WHY STRENGTH AND PROPRIOCEPTION ARE THE TREATMENT

You can't change the collagen you were born with, so management works *around* it: building the muscles that stabilise lax joints, and retraining **position-sense (proprioception)** so the body protects its own joints. This, not bracing everything, is what keeps hypermobile joints healthy.

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