



The
**Ehlers
Danlos**
Society™

The Ehlers-Danlos Society

P.O. Box 87463 · Montgomery Village, MD 20886
USA

Phone: +1 410-670-7577

The Ehlers-Danlos Society - Europe

Office 7 · 35-37 Ludgate Hill · London EC4M 7JN
UK

Phone: +44 203 887 6132

DISLOCATION/SUBLUXATION MANAGEMENT

OR

“I’M JUST POPPING OUT FOR A WHILE!”

Jason Parry

Clinical Specialist Physiotherapist

Hypermobility/Extended Scope Physiotherapist

University College Hospital NHS Foundation Trust
London, England and

St John and St Elizabeth Hospital, Hypermobility Unit
London, England

One of the most common questions I get asked is how to manage dislocations and subluxations, which is weird if I happen to be out shopping at the time. However, in all seriousness, this really is one of the most frequent questions I face in clinic when treating many of my hypermobile patients and let's face it: it really is no laughing matter.

So where do I begin? Well, a good place is to first understand the difference between a dislocation and a subluxation.

A dislocation is defined as "displacement of a bone from its natural position in the joint". This is where the two bones that form a joint fully separate from each other. If we consider a shoulder for example, which is a ball and socket joint, a dislocation occurs when the ball (which forms the top of the arm bone) slips entirely out of the socket it should sit in within the shoulder. This can happen in any direction, but the main point is that the two bones completely separate. Ouch!

A subluxation is basically defined as "a partial dislocation". It can be no less painful than a full dislocation, but the two bones that form the joint are still partially in contact with each other. So once again, if we consider the shoulder joint as an example, the ball which completely came out of the socket in the dislocation example above would still be partially sitting in the socket in a subluxation.

These events can happen in almost any joint, but some are more commonly involved than others, with shoulders, knees, thumbs, and ankles seemingly the most prevalent.

Both dislocations and subluxations can be painful, irritating, infuriating, and occasionally debilitating problems. However, they don't need to ruin your life and can – with patience, effort, trust, and time – be managed. Not necessarily completely eliminated, but managed.

Let's first look at the reasons why dislocation or subluxation happens with a quick anatomy lesson. The main reason is abnormal collagen composition. Collagen – primarily Type 1 collagen – is the main structural protein of the various connective tissues in the body. It is found in ligaments, tendons, and joint capsules and makes ligaments and tendons strong like little "guy ropes". What do ligaments, tendons, and joint capsules do? Ligaments connect bone to bone, tendons connect muscles to bone, and joint capsules are like envelopes of tissue that surround a moveable (synovial) joint. All of these structures tighten up under tension and act to stop the two bones that form a joint moving too far apart from each other. So we can

see that these ligaments, tendons and joint capsules play an important role in giving a moveable joint its stability.

Let us now consider hypermobile Ehlers-Danlos Syndrome (hEDS according to the 2017 International Classification, formerly known as EDS hypermobile type or EDS Type III). This is a heritable disorder of connective tissue (HDCT) which makes the ligaments and tendons stretchier (more lax). This means that joints are potentially less stable – hence greater propensity for subluxations and dislocations. Makes sense?

There are other reasons for dislocations and subluxations:

- **Altered muscle tone:** This can often account for dislocations. Inappropriate muscle patterning, in which certain muscles around a joint “switch on” when they shouldn’t and then inappropriately work way too hard, can often pull a joint out of place. The joint is also easier to slip out, of course, if it is more lax in the first place. Muscle fatigue, spasms and stress can all play a part in this too.
- **Impaired proprioception:** Proprioception is the body’s ability to sense position and movement within joints and enables us to know where our limbs are in space without us looking. It relates to coordination. Impaired joint position sense can cause joints to slip out of place.
- **Repeated overstretching:** Otherwise known as too many “party tricks”. I know many of you guys have the capacity to amaze people with your ability to wrap yourselves into weird and wonderful positions that the rest of us gawp at. You know, those tricks you did as kids, popping your shoulders in and out of joint, or folding your legs over your head? Well, stop – it’s no good for you! Repeated overstretching to that degree will only exacerbate the laxity and the chances of the joints slipping out of place. I’m certainly not saying that you should never do stretches, but I am saying give up the party tricks and don’t stretch your joints way beyond normal range. So please think twice about that career as a contortionist.
- **The shape of your joint surfaces:** Some of you may be born with shallow-shaped joint sockets or other bony shaped anomalies that predispose a joint to possibly slipping out of position more easily. Unfortunately, that just may happen to be the shape of your skeleton.
- **Traumatic incident:** The most common reasons for a joint to come out of place

for those of us without hEDS. Traumatic incidents can happen to anyone, but your extra joint laxity may actually work a little in your favor with this one; it may prevent you damaging some of your ligaments and tissues in the way that a non-hypermobility person who suffered a traumatic dislocation probably would.

How often can these subluxations/dislocations happen? The answer to that is different for different people. Some people get them maybe just once or twice a year, others once a month. Some people get them once a week and others once a day. Some people get them repeatedly throughout the day and in some people they never seem to stop. Either way, we need to try to reduce the frequency if we can, and manage them when they do happen.

In some people, the joint just finds its own way back in to place, and phew, what a relief. But in others, once the joint slips out, it won't go back in again. The pain kicks in (often big time) and the most common and perfectly understandable reaction is... PANIC! At this point, some people pick up the phone and call for an ambulance – well actually they don't; they're often writhing in agony or they can't actually pick up the phone, especially if it's their shoulder or wrist out of place, but someone else does – and off to the emergency room they go.

Panic causes more stress and more muscle spasms. Stress and muscle spasms cause more pain, and less chance of resolving the dislocation. Easy for me to say, I know, sitting here with my joints all lovely and located without the associated agony. But trust me, if you want to start managing this situation and taking control, then this is what you're going to have to begin to practice. Because what happens in the ER? Well, if they aren't already fed up with you turning up 100 times a month and starting to get all ratty towards you – not fair I know – they will often give you pain relief of some sort (perhaps Entonox, an NSAID) or they may go the whole hog and give you a general anaesthetic. Then they'll yank your joint back into place. All good, right? Not so, because often, maybe within minutes, the joint will pull itself back out of place again because of the muscles still spasming around the joint, and you're back to where you started.

So what else do our ER docs then sometimes do? They stick you in an orthopedic cast to hold the joint in place. Imagine, then, the battle going on underneath it: your joint trying to pull itself back out of position again while being forcibly held in place by the cast. Sounds painful to me, and often is; and when then do you take the cast off? This doesn't sound like a viable management solution to me or a good way of life for you.

So what should you do if your joint comes out? Here are the six key principles that I suggest you start incorporating to begin to get a grip on managing this situation, as opposed to this situation managing you. The main aims are to stay calm, keep on top of the pain, and allow the muscles to relax. It takes lots of practice and patience, but it can be done.

- 1. Breathe:** Use slow deep, relaxed breaths. Try using some relaxation techniques, there are lots of different ones out there. As painful as it is, and as difficult as it may sound, you need to start to try to take control of this situation. So start to learn how to breathe through it.
- 2. Use painkillers:** Take some appropriate painkillers (analgesia) if you have some. However, note the word “appropriate”. You should only ever take analgesia according to the dosage indicated by your prescriber. Never take more than the suggested dose. You might feel like it may not be enough at the time, but if it can take some of the edge off, then that’s a great start. Please don’t ever overdose.
- 3. Support the joint:** You need to try to make yourself as comfortable as possible (I know it’s not easy). Use pillows or a sling if you have one. Find a comfortable resting position as much as possible. This allows the muscles to relax and stop spasming.
- 4. Try heat:** Hot water bottles, wheat bags, and a warm bath can all help to relax spasming, overactive muscles.
- 5. Distraction:** Try to take your focus away from the pain and the situation. Listen to music, watch a movie if you can, talk to friends/family, try a relaxation CD/MP3. This can be helpful as a short-term pain relieving strategy. Again it can help muscles relax.
- 6. Gentle massage:** Sometimes gentle massage around the joint can help relax the muscles enough to be able to gently relocate the joint or for the joint to just slip back into place by itself.

What if it doesn’t go back? Don’t expect the joint to go straight back in. It is often not unusual for joints to remain out of place for hours or even days. But once it’s out, it’s out. It’s not going out even more, so try not to panic.

Is it dangerous? Am I damaging my joint if it comes out? It is highly unlikely. Your joint laxity allows for your ligaments and capsules to stretch. It is mostly just distressing as opposed to damaging.

When should you go to hospital or get help? If the limb starts to change color due to a lack of blood supply. If your limb goes completely numb. If you have tried strategies 1 through 6 above, have waited a reasonable amount of time, and are still desperately struggling.

But as mentioned earlier, it is not unusual for ER to relocate your joint only for it to pop straight out again or when the anaesthetic wears off. Therefore you need to learn to stay calm and to start to self-manage.

One of the most valuable things you can do after a subluxation/dislocation is to reflect on the event once you have had a chance to calm down. Were you moving in a way that normally causes the joint to dislocate? Did you move without thinking? What was your posture like? Were you tired or overdoing it? Were you stressed about something? It is so valuable to look for triggers as to why the event may have happened. It may have been none of these reasons, but if it was, then you can hopefully learn to avoid repeating them in the future.

Finally, prevention is better than cure! It is obviously better if we can prevent these situations occurring in the first place as opposed to having to deal with them. To that end, the following can hopefully help to reduce the frequency of such occurrences:

- Physical therapy to learn to control the muscles around joints and to use the right ones;
- Rehab to improve proprioception;
- The possible use of supports/braces if required;
- Trying to manage stress and anxieties.

But ultimately, stay calm! The more you stay calm when these events happen and manage it yourself, the easier it should get each time.