Common Questions about Hypermobility Conditions

Below is a list of common questions asked by people who have learned they have hypermobile-type Ehlers Danlos Syndrome (hEDS), and Hypermobility Spectrum Disorder (HSD): these are, by far, the most common hypermobility conditions. These terms are discussed in detail in other articles on this website, especially *Why the New EDS Classification Matters.* In this article, when I refer to "hypermobility conditions", I am referring mainly to hEDS and HSD. If you have another condition such as vEDS or Marfan syndrome, many of the statements below apply to you too; but you should check with your doctor to make sure which do and which don't.

What's my diagnosis?	If you have a number of joints that are "looser" than most people's, and if some of these are giving you trouble, then you very likely have a Hypermobility Spectrum Disorder (HSD), or the related condition, Hypermobile-type Ehlers Danlos Syndrome (hEDS). These new terms are part of a major revision of the names and definitions of inherited hypermobility conditions, published by an international committee in 2017. HSD and hEDS are by far the most common inherited conditions with "loose joints." Although they are are inherited conditions, they may occur in several family members, or just one. Different family members may have different patterns of symptoms. These diagnoses are based on the patient's medical history and findings on physical examination, using diagnostic criteria that have been agreed on by international expert committees. There are no blood tests, x-rays or scans that confirm HSD or hEDS. However, there are other kinds of EDS for which there *are* confirmatory tests. These tests should be done only in the few cases where the history and exam findings don't give a clear diagnosis.
Who can make the diagnosis?	Geneticists are trained to diagnose hEDS and HSD, and also the other, rarer kinds of EDS, and other inherited conditions that can cause joint hypermobility. Unfortunately however, they only do diagnosis, not treatment. Also, they tend to have waiting lists of many months, or even years. Moreover, geneticists at two institutions in North Carolina will not see people with hEDS and HSD even for diagnosis, on the ostensible grounds that these conditions don't require their special diagnostic skills. But no other specialists are currently trained to make these diagnoses. The result is that the remaining geneticists who <u>will</u> see patients to assess these two conditions, are now more overloaded than ever, so they have even longer waiting lists than before. That's why I wrote the article on my website, *Joint Hypermobility Diagnosis for Non-Specialists*. A family doctor, internist or pediatrician can make a diagnosis of the most common hypermobility syndromes by following the procedure given in that article.

Does having this diagnosis make any difference for me?	Sometimes patients have been told they "may have EDS" or they have "hypermobile joints" but that making a definite diagnosis has no practical implications. This is quite wrong. For one thing, some of the problems people with hEDS or HSD have, are *treated differently* if they are part of these conditions. Also, a number of other problems often go along with these conditions, but have often not been treated. Once they are recognized as real problems that are part of a hypermobility condition, they are much more likely to get treated, and treated properly. Finally, there are specific precautions that people with hypermobility conditions need to inform their doctors about, should they have surgery, or anesthesia. There's a handout on these precautions among the articles on this website.
What do hEDS and HSD affect?	Thes conditions affect the ligaments that hold joints together, which are loose or "hypermobile". They usually affect various other tissues and organs too. We don't know what the true underlying disorder is. It is likely to be some glitch in the chemical makeup of cells in several different organs and tissues, not just joints and not just "connective tissue". Hence the following problems: • Widespread pain, not only at loose joints. These other pains (outside joints) are often generated within the nervous system: they are called "neuropathic" pains. • Various abdominal complaints (stomach, bowels, pelvic organs). Sometimes no cause is found for these despite various special tests. This then contributes to the common misperception that people with hypermobility conditions are hypochondriacs. • Need for more sleep than most people, often needing naps during the day. • Exhaustion after limited exertion, sometimes with "brain fog", i.e. difficulty with paying attention, thinking, and/or memory. • Spells of dizziness or faintness. These are often due to an unstable pulse or low blood pressure, but sometimes the cause is unclear. • Excessive bruising and bleeding from minor injuries (or bruising from no apparent injury at all). • Slow skin healing; wounds and incisions may leave wide, thin scars. • Anxiety, panic attacks and/or compulsive behavior. • Crowded teeth, hence a need for braces and/or extractions. • Pain in the jaw joints ("TMJs"). • Headaches, often of several different kinds in the same person. Some are migraines; some come from the neck joints.

	• Bladder problems of various sorts. • Unusually severe menstral pain. • Various other problems may be more common among people with hypermobility conditions, but more research needs to be done to be sure of this.
What is the long term outcome (prognosis)?	Any of the individual problems with EDS may get better or worse over time, or go through slow swings towards better, then worse, then back again. Some patients eventually find their *joint* problems improve, perhaps because joints tend to stiffen naturally with age.
Do medications help?	Medications often help pain and may also improve other symptoms. Each one only helps certain patients and we can't predict which one will help which patient. Therefore it makes sense to try <u>several</u> of them, one at a time, using each for a test period, for the minimum amount of time needed to see if it helps. It typically takes about two or three months to test all the main options. This requires a lot of communication between doctor and patient during those months. A doctor who won't do brief follow-ups by phone, or can't see patients except at wide intervals, will have difficulty getting the patient on the best medication regimen for their particular case.
Is exercise good or bad for EDS?	For most people with a hypermobility condition, the best therapy is gentle aerobic exercise and the best exercise is often in water. For them, it's ideal if they can find a pool, comfortably warm, where they can swim or just move around in the water for at least half an hour, at least three times a week. Joining an exercise class for people with arthritis or spinal problems is a good way to do this. People with hypermobility conditions quickly work out their own routines in the water, that they enjoy and that make them feel good. Another option for people with EDS is a recumbent exercise bicycle. These are available at some gyms, and at some physical therapists' offices. See the article on this website, *Physical Therapy, Exercise and Braces for People with EDS,* for more on this.
Should I have physical therapy?	Physical therapy by a skilled therapist helps many people with hypermobility conditions. A lot depends on the therapist. Anyone with hypermobile joints seeking a physical therapist should find one who does long, one-on-one visits and does "manual therapy", rather than treating mainly by supervising an exercise program being done by several patients at the same time. See the article accompanying this one, on *Physical Therapy, Exercise and Braces for Hypermobility Conditions.*

Can my joints be fixed with surgery?	Many joint problems in hypermobility conditions can <u>not</u> be helped by surgery, because ligaments that have been tightened surgically soon get loose again. But in a few cases, surgery can and should be considered. A recent review of orthopedic surgery for hypermobility conditions is available. It can be obtained online by searching for *Orthopaedic management of the Ehlers–Danlos syndromes. Am J Med Genet Part C Semin Med Genet 175C*. (There is a fee to download or print it.) I recommend that patients make a copy of this and ask their orthopedist to read it, if surgery is to be considered. A summary of the article, for patients, is on this website (*AlanSpanosMD.com*). See also my article, *EDS: What the Specialist Needs to Know.*
Can a podiatrist help?	A podiatrist may be able to help with foot problems. Chapter 14 of Brad Tinkle's useful book, *Joint Hypermobility Handbook*, describes foot problems and their treatments.
Can chiropractic help?	Sometimes a chiropractor can help a lot with short-term pain relief. But certain common chiropractic treatments can make problems in hypermobile conditions very much worse. Specifically, *thrust-manipulations of the cervical spine (bones in the neck) should never be done: they can cause <u>permanent and painful joint damage</u>* in patients with any form of EDS or HSD. The sort of short-term pain relief treatments that chiropractors do should always be part of a *preventive* program to stabilize the joints through exercise, otherwise the treatments have to be repeated for ever. Most physical therapists believe such treatment has to include a serious exercise program to *strengthen the muscles surrounding the loose joints.* Some chiropractors include this in their treatment plans; others don't.
Can acupuncture help?	Acupuncture sometimes helps with localized pains but it's quite hit-and-miss. In some States, physical therapists are allowed to do a specialized form of acupuncture, called "dry needling". This is sometimes quite helpful.
Should I see a hand therapist?	A hand therapist is a physical therapist (PT) <u>or</u> occupational therapist (OT) who specializes in treating problems of the hand and arm (all the way up to, and including, the shoulder). They can sometimes be very helpful if you have difficulties with tasks done with the hands. The Silver Ring Splint website shows examples of splints that sometimes help painful fingers a lot.
Do nutritional supplements help?	There's no published scientific evidence that supplements help pain or tighten loose ligaments in hypermobility conditions. If any of them helped much, this should be clear from multiple reports from patients on online support group sites; but I don't see such reports. However, this doesn't prevent the purveyors of such supplements from making big claims about them. They often make sciencey-sounding arguments for their products, but

	this is salesmanship, not science. I advise you to steer clear of all this merchandise, until it's supported by something better than smart sales-talk.
Are pregnancy and childbirth safe for a woman with hEDS or HSD?	This is a really, really difficult question. If you have vascular EDS, then pregnancy carries a major risk of catastrophic bleeding in pregnancy, with the possibility of a fatal outcome. But if you have the much more common hypermobile type (hEDS), or a hypermobile spectrum disorder (HSD), then the outcome of pregnancy can be extremely variable. The answer to this question is necessarily connected with the related question of what might be the risk of having a child with more severe features of a hypermobility syndrome than does the mother. These questions need to be dealt with on an individual basis with each patient, preferably with a geneticist.

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