

Common questions from people with H-EDS (Ehlers Danlos Syndrome, Hypermobility Type)

Below is a list of common questions asked by people who have learned they have Ehlers Danlos Syndrome, Hypermobility Type (H-EDS). ***They are also appropriate for people who think they may have such a condition, and want to help themselves before seeing a doctor who could confirm whether they have it or not.***

<p><i>What's my diagnosis?</i></p>	<p>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 Ehlers Danlos Syndrome, Hypermobility Type (H-EDS). This is not a blind guess, it’s based on the numbers: H-EDS is by far the commonest cause of having joint problems and number of joints that are obviously loose, or “hypermobile.”</p> <p>This is an inherited condition, that may occur in several family members, or just one. The diagnosis is based on the patient’s medical history and findings on examination, using diagnostic criteria that have been agreed on by international expert committees. There are no blood tests, x-rays or scans that confirm this diagnosis. However, there are other kinds of EDS and there <i>are</i> tests that can confirm them. These tests should be done only in the few cases where the history and exam findings don’t give a clear diagnosis.</p>
<p><i>Who can make the diagnosis?</i></p>	<p>Geneticists are trained to diagnose H-EDS, 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. Several major hospitals in North Carolina sometimes will not even make new patient appointments because they have such long waiting lists.</p>
<p><i>Does having this diagnosis make any difference for me?</i></p>	<p>Sometimes patients have been told they “may have EDS” or they have “hypermobile joints” but that such a diagnosis makes no difference to them, so it doesn’t need to be confirmed. This is quite wrong. For one things, many of the problems people with H-EDS have are <i>treated differently</i> if they are part of H-EDS, than they would be treated if the patient did not have it. Also, a number of other problems often go along with H-EDS, and often these are not being addressed. Once they are recognized as real problems, that are part of H-EDS, they are much more likely to get treated, and treated properly. Finally, there are specific precautions that people with H-EDS need to inform their doctors about, should they have surgery, or anesthesia.</p>
<p><i>What does H-EDS affect?</i></p>	<p>This condition affects the ligaments that hold joints together, which are loose or “hypermobile”. It also usually affects various other tissues and organs. 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</p>

	<p>different organs and tissues, not just joints and not just “connective tissue”. Hence the following problems:</p> <ul style="list-style-type: none"> • Widespread pain, not only at loose joints. These other pains (outside joints) are often generated within the nervous system: they are “neuropathic” pains. • Various abdominal complaints (stomach, bowels, pelvic organs). Sometimes no cause is found for these despite various special tests. This contributes to the common perception that H-EDS patients are hypochondriacs. They are not. • Need for more sleep than other people, often with sleepiness 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 unstable pulse or 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”). • Various other problems may be more common among people with H-EDS, but more research needs to be done to be sure of this. Some are mentioned in Dr Brad Tinkle’s book, <i>Joint Hypermobility Handbook</i>.
<p>What is the long term outcome (prognosis)?</p>	<p>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. Many patients eventually do get better from the <i>joint</i> problems, perhaps because joints tend to stiffen naturally with age.</p>
<p>Do medications help?</p>	<p>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 <u>minimum</u> 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.</p>

<p><i>Is exercise good or bad for EDS?</i></p>	<p>For most people with EDS the best therapy is gentle aerobic exercise and the best exercise is usually 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. Generally people with EDS quickly work out their own routines in the water, that they enjoy and that make them feel good.</p> <p>Another option for people with EDS is a recumbent exercise bicycle. These are available at some gyms (like <i>Planet Fitness</i> and at some physical therapists' offices.)</p>
<p><i>Should I have physical therapy?</i></p>	<p>This varies a lot from one person to another. The answer depends on the details of your condition so I can't give general advice on this. What I can say, however, is that anyone with hypermobile joints should seek a physical therapist who does full, 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. If I see a patient, I can provide specific instructions and handouts to help their physical therapist. See the article in this series, on <i>Physical Therapy and Exercise for EDS</i>.</p>
<p><i>Can my joints be fixed with surgery?</i></p>	<p>Most joint problems in EDS 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. If an operation is advised, the surgeon should discuss the pros and cons with a doctor knowledgeable about EDS. Also, the chapters on specific joints in <i>Joint Hypermobility Handbook</i> give useful information on this.</p>
<p><i>Can a podiatrist help?</i></p>	<p>A podiatrist may be able to help with foot problems. I strongly advise that before you see one, you copy Chapter 14 from the <i>Joint Hypermobility Handbook</i>, and give it to the podiatrist to study before treating you.</p>
<p><i>Can chiropractic help?</i></p>	<p>Sometimes a chiropractor can help a lot with short-term pain relief. But certain common chiropractic treatments can make problems in H-EDS very much worse. Specifically, <i>thrust-manipulations of the cervical spine (bones in the neck) should probably never be done.</i></p> <p>The sort of short-term pain relief treatments that chiropractors do should always be part of a <i>preventive</i> 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 <i>strengthen the muscles surrounding the loose joints.</i></p>

<p>Can acupuncture help?</p>	<p>Acupuncture can sometimes help with localized pains but it's quite hit-and-miss.</p>
<p>Should I see a hand therapist?</p>	<p>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.</p>
<p>Do nutritional supplements help?</p>	<p>There's no scientific evidence that supplements help pain in H-EDS. Nor is there any evidence that any supplements can tighten loose ligaments. But this does not 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.</p>
<p>Are pregnancy and childbirth safe for a woman with H-EDS?</p>	<p>This depends entirely on the <i>pattern and severity</i> of symptoms in each individual case. There is some information on this in <i>Joint Hypermobility Handbook</i>.</p>

Alan Spanos MD
AlanSpanosMD.com
Alan.spanos@yahoo.com
919 967 2927