"I think I may have EDS"
(Ehlers Danlos Syndrome)

Many people think they have Ehlers Danlos Syndrome (EDS). Some have medical problems that resemble those of a relative who has EDS, so they wonder if they do too. Or, they've been surfing the web to learn more about some ailment, and they find it can be part of EDS, and then they read a description of EDS and it all seems to fit them. Or, they see a doctor who notices they have some loose joints and wonders aloud about EDS.

If you are one of these, you will have discovered that the next step – seeing a doctor who can make a firm diagnosis, and tell you what to do about it – is quite frustrating. Generally, the only specialists who claim to be able to diagnose EDS are geneticists (the specialists in inherited diseases). But there are very few of them, and they typically have waiting times of many months, or even a year or more. Moreover, while geneticists can *diagnose* EDS, almost none of them *treat* it: they see their job as diagnosis only.

If you ask, say, an orthopedist or a rheumatologist if they can tell you if you have EDS, and if so what to do about it, you are likely to get a version of one of the following responses:

"It's just a name, don't worry about it."
"It's inherited, so there's nothing you can do about it."
"See a geneticist."

None of these is very helpful, if you are hurting and tired all the time, and getting worse. So, this article aims to tell you what to do while you are waiting to see someone who can diagnose your condition, and what you can do about it yourself.

Making the diagnosis yourself

The most important thing to know about the diagnosis of EDS is that if you have done some homework on EDS, and you still think you have it, then *you almost certainly do have it.* This is one of the medical conditions that you can diagnose with a high degree of confidence on your own. In my practice, the number of people who see me because they think they have EDS, and are wrong, is less than one in fifty. What's the homework to enable you to do this? Get Brad Tinkle's excellent book, *Joint Hypermobility Handbook*. If it's out of stock at Amazon, try Barnes & Noble, or the publisher. It costs about $25. Read the first section, then browse the rest looking for chapters on specific medical problems that you have: there's a chapter on foot and ankle problems, one on the spine, and many others. *If you "find yourself" on many of the pages in this book, then you almost certainly have EDS.*

You can be reassured that Dr Tinkle has the authority to write such a book. He is one of the world authorities on Ehlers Danlos Syndrome, and was largely responsible for the move, in 2010, to abolish the distinction between EDS and "benign joint hypermobility syndrome or BJHS". This means that a huge number of people who had been felt to be too mildly affected to warrant the EDS diagnosis, and were labelled as having BJHS, now were acknowledged to have H-EDS. Once looked at that way, many turned out to have more medical problems than had been previously addressed. We have Dr Tinkle and a few of his colleagues to thank for this realization. It has meant that we now perceive EDS, Hypermobility Type as a far commoner condition than in the past: it's now clear that its prevalence is not the one in five thousand previously talked of, but more like one in five hundred *or even much less.* A French paper recently proposed that some features of H-EDS may be present in as many as one person in forty! An international conference in New York, in May 2016, will address this and try to come up with clear criteria to help us identify EDS better. For most, this will not be by special "genetic tests". The reason is that for H-EDS, *we have no genetic tests* and probably will not for a long time. So the diagnosis rests on the patient's symptoms, and findings on physical examination, often supported by information about other members of the family.

H-EDS is one of three main types of EDS, and is by far the most common of them. So if you think you have EDS based on browsing in Tinkle's book, then you probably have EDS "Hypermobility Type" or H-EDS. (This was previously called "Type Three.")

The other two main types of EDS are "Classic Type" (previously called "Type One"), and "Vascular Type" (previously called "Type Four"). The Classic Type is distinguished by more fragile, stretchy skin than the others. The Vascular Type is associated with major risks due to rupture of internal organs. For both of these, unlike the Hypermobility Type, there are special tests than can help confirm the diagnosis, that can be done by geneticists. *If you, or your doctor, think you may have one of these types, then you could ask your primary care practitioner to try to get you seen more promptly than usual by a geneticist.* Geneticists will often oblige, if there is a specific concern about one of these two types of EDS.

If you are waiting to see someone who can make a firm diagnosis of EDS (or of some other condition that resembles it), then Tinkle's book is only the first place to learn about your condition. Also, go to *EDSNF.org*, the website of the Ehlers Danlos National Foundation. It has lots of helpful resources. And check out *EDSAwareness.com*, whose resources include a series of online lectures by EDS specialists, some of which are very, very good. Both these websites can help you connect with other people with EDS, and so can *Inspire.com.*

Educating your doctors

Managing your medical problems before you are diagnosed with EDS can be improved with a few straightforward tactics. First, copy the relevant section from Tinkle's book and take it to each appointment with a doctor or therapist about the problems for which you are seeing them. For instance, if you have a foot problem, copy the four pages on "foot and ankle problems" in the book and take them to your appointment. Make sure the doctor reads it, or at least promises to. If he or she won't do that, then maybe this is not a doctor you should be seeing.

Physical Therapy and Exercise

Physical therapy is helpful for some specific problems that come with EDS, but not with others. The same goes for exercise. For information on these topics, see the separate article on them in this website.

Braces

People with painful joints are often offered braces to hold them steady. But doctors, physical therapists and chiropractors routinely get these wrong if the patient has EDS. Most braces are not well designed for people with EDS, and many don't work at all for them. Also, many braces are designed for men, and don't fit women. For people with EDS, a brace often needs to be customized (altered) to do its job properly. And finally, many braces have protruberances and seams on the inside that can damage the fragile skin that many people with EDS have. This is why my practice is collaborating with *Better Bracing NC*, a specialist company that will deal specifically with fitting braces for people with EDS. Its two founders are women who themselves have EDS and use both their own experience, and those of the large community of EDS patients online, to select the best braces and, even more importantly, to fit and adjust them accurately for each individual patient. The company expects to launch in May 2016.

Surgery and anesthesia

If you have loose joints, and you are to have surgery of any kind – or even a test like colonoscopy that requires an *anesthetic*, then go to the section on surgery and anesthesia in this website, print it out and follow the instructions. They will help ensure your safety, if you have EDS or any other condition in which joints are loose.

Not just joints

Doctors used to think EDS is only a condition of loose joints, and perhaps fragile skin. But for people with EDS, there may be other problems that loom just as large, or larger than these. These may include:

- Pain in places other than from joints.
- Migraines and other kinds of headaches
- Being tired all the time.
- Sleeping too long, or not sleeping well.
- Trouble concentrating and thinking clearly ("brain fog").
- Stomach and bowel problems including nausea, abdominal pain, severe constipation and hemorrhoids.
- Pelvic pain.
- Dizziness or faintness, if your are on your feet for a while. This is called "orthostatic intolerance" or OI.
- Chronic anxiety, sometimes with panic attacks.

People with EDS are often reluctant to mention some these problems to their doctors, fearing they will seem to be hypochondriacs. But each of the problems listed above (and some less common ones) are part of EDS, and they deserve to be properly assessed, and treated. I plan to put summaries of them in other articles on this website.

****

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