

Physical Therapy & Exercise for People with EDS

The advice below is for people with Ehlers Danlos Syndrome, but is also applicable for those with other hypermobility conditions. Even if you are still awaiting a definite diagnosis, it should still be relevant. Note that it does not deal with braces for loose joints, because these are the subject of a separate article. Also, note that the video lectures referred to were still online in March 2016 but may later be withdrawn. In that case, try searching on the name of the lecturer in case a similar lecture has been posted later.

Section 1: For Patients

If you have Ehlers Danlos Syndrome (EDS), then a good physical therapist may be your most important medical team member. Here are some tips on how to find a good one, and some resources to learn about how physical therapy can help you. Also, I've added remarks about exercise that you can do on your own, as a crucial accompaniment to physical therapy. Then, there's a section for the physical therapist, so you should copy this whole file, give it to your PT and direct their attention to the last section, on the third page.

How to find the right physical therapist

To help people with EDS (or "Joint Hypermobility Syndrome", which is now thought to be the same thing as Type III, or Hypermobility-EDS), a physical therapist should meet two main criteria:

1. Have a major interest in **manual therapy**. This means, being good with one's hands to feel what is going on in joints, and to work on the joints by hand to improve how they function. If your therapist doesn't do much manual therapy, then ask him or her to refer you to a therapist who does.
2. The therapist must be able to **work one-one-one with clients for the full time of each therapy session**. This is because the response to physical therapy of EDS patients is complex and often surprising. So, for instance, things don't go well if such patients are given standardized exercises or treatments to be supervised by an assistant: the physical therapist needs to be there the whole time.

Phone the PT office you're interested in, and ask to speak to the physical therapist in charge. Explain that your doctor told you to check a few things with the therapist to see if they can help you, and that you have Ehlers Danlos Syndrome. Then ask "Do you do manual therapy? Do you work one-on-one with patients for the whole appointment?" If you're happy with the answers, then tell the PT that you can email him or her some study materials from me. **Have the physical therapist email me at alan.spanos@yahoo.com** (the dot between my names is important) and I'll send my most up-to-date package of information to the therapist. Also at your first appointment, **give the therapist this 3-page handout to study**.

How physical therapy can help you

There are at least three ways physical therapy can help you if you are an "EDSer." First, the therapist can help you learn **ways to move** with more ease, more comfort and less tendency to throw your joints out of place. Second, the therapist can direct you through a strengthening program **to help muscles to work better with ligaments** to support joints and keep them safe. Third, the therapist can help you with a long term program of **whole-body aerobic exercise** to reduce pain, improve sleep, improve mood, increase energy and stamina, and help keep your weight down.

An important warning: things a therapist does *to relieve pain* should only be done *together with an exercise routine to strengthen muscles*. Otherwise, the pain will promptly come back, and likely be worse than before because pain relief usually goes with more relaxed muscles, whereas you want the muscles to be working to control your joints. So don't put up with pain treatments from PTs (or chiropractors) who are not working on a strengthening program as their main focus: they are a revolving door with no long-term benefit.

The following three websites were online, as of October 23, 2015, and each depicts rather different approaches for physical therapy for people with EDS. But there's one big common thread - that EDSers can get to do more, and often a lot more, activities that they previously couldn't, physical therapy and a home exercise program. I suggest you watch each of these over several days and discuss what you learn with your physical therapist.

Eric and Nicole Canavan. Eric and Nicole are both physical therapists, and Nicole has EDS so Eric is her PT, and they have both become very expert in what helps people with EDS: <https://vimeo.com/58504462>.

Mark Lavallee. Mark stresses exercise for people with EDS who would like to be as fit as possible. Dr Lavallee himself is both a person with severe EDS (Classic Type) and also a competitive athlete and sports medicine specialist: www.youtube.com/watch?v=CU327_4F92A&feature=youtu.be.

Jan Dammerholt. Jan is a nationally-known teacher of advanced physical therapy techniques: <http://www.chronicpainpartners.com/physical-therapy-ehlers-danlos-by-jan-dommerholt/>.

Exercise you can do on your own

Physical therapists prescribe very specific exercises to strengthen muscles or help improve body movements. But you should also develop a home exercise program of **whole body, aerobic exercise**: exercise that works all four limbs and your trunk muscles, with easy, repetitive moves. This has a great many benefits. It reduces sensitivity to pain; it builds energy and stamina; it improves sleep; it improves your mood; it helps keep weight down; it improves the health of your heart and other organs; and it helps preserve your brain power as you age.

Initially, you should get help from your physical therapist to design a suitable aerobic exercise program. But you should soon be doing it all on your own. Here are a few tips that are specially relevant for people with EDS.

Exercise in water

For people with EDS, exercise in water is ideal. Many of them say they are more physically at ease in the water than they ever are on land. Some pools warm the water by an extra five degrees, for one or two sessions a week. Phone around to see if a swimming pool near you does this: with EDS, you are likely to be much more comfortable at the slightly warmer temperature. What you do in the water is much less important than just being there and moving around, so just do whatever feels good, working up to at least half an hour, at least twice a week. Be up to your neck in the water: that way you become weightless, the water supports you, and also the mild compression of the water helps with blood flow, which is often defective in EDS.

Note that a bathtub, jacuzzi or hot tub can't be made to provide this kind of benefit. There isn't enough room, the water is too hot, and it's not deep enough to let you float properly, or stand with the water up to your neck.

Check out recumbent stationary bicycles

Many EDSers have trouble exercising when upright. Sustained walking or running may cause too much pain in hips, knees and feet, or cause dizziness due to unstable blood circulation. So for many, the best exercise is on a recumbent stationary bicycle. In this, you can sit down, pedalling with your legs in front of you, but without

your weight going through them. Some also have handles so you can exercise your arms as well, which is ideal. You can see a wide variety by googling “recumbent exercise bicycles” or by searching for “recumbent exercise bikes” on the Walmart.com site. Prices start below \$100 and go up to several thousand, but there are always some models reduced to below half their original price. There’s no way to predict how any particular model will work for you. You absolutely have to try them in a store, not buy them blind. In the store, get one properly adjusted then exercise very gently for at least 10 minutes to see if it’s helping keep joints aligned or keeps pushing them out. You can sometimes find good examples in second-hand exercise shops. Get advice from your physical therapist on how to set the resistance (if that’s adjustable), and how to slowly build up both time and resistance. Then *Just Do It!*

Section 2: For Physical Therapists

“Ehlers Danlos Syndrome” refers to a group of hereditary conditions with the common factor of loose connective tissue, hence joints are hypermobile, so that only a little force can sublux and dislocate many of them. Such patients often have peculiar pain patterns, including painful neuropathies, whose cause is often unsure. Most have dysfunctional movement patterns. These may be due to pain. But sometimes they reflect defective proprioception, which is present to a greater or lesser degree in many “EDSers.”

Several physical therapists have proposed treatment protocols for EDS, using somewhat different approaches. There is no research that compares these for efficacy. However, they do share some basic principles:

1. EDS patients need to strengthen muscles, and use them to substitute, as far as possible, for ligaments in stabilizing loose joints.
2. Dysfunctional movement patterns should be corrected using any combination of techniques depending on the therapist’s training and experience.
3. Pain modalities are only used within a strengthening program, i.e. to permit performance of exercises. Manual therapy, dry needling, heat or electrotherapy may all meet this goal for some patients.
4. Treatment will likely take substantially longer than expected to reach goals. This is largely because new painful dysfunctions tend to surface as the first target areas are addressed. So all treatments should be one-on-one with the therapist, and several changes to the treatment plan can be anticipated.
5. The patient should also get direction on a slowly progressive home or gym-based aerobic exercise program. When convenient, pool exercises are ideal. A stationary recumbent bicycle is also helpful: not only in sparing weight-bearing on the legs, but also in mitigating orthostatic intolerance due to poor circulation, which is present in about two thirds of EDSers.

Resources for physical therapists

I can supply reprints of materials from textbooks on PT for EDS by Rosemary Keer, and from Kevin Muldoney. You can email me at alan.spanos@yahoo.com to request these. Also, lectures by well-known therapists specializing in EDS are available as videos online through the website, EDSawareness.com.

As of October 2015, the following three are available, and portray somewhat different approaches, that nonetheless share the same principles listed previously:

1. Eric and Nicole Canavan. Eric and Nicole are both physical therapists, and Nicole has EDS so Eric is her PT: <https://vimeo.com/58504462>.

2. Mark Lavallee. Mark stresses exercise as the main therapeutic tool for people with EDS, from his background as a patient with severe EDS who is also a competitive athlete and sports medicine specialist:
www.youtube.com/watch?v=CU327_4F92A&feature=youtu.be.

3. Jan Dammerholt. Jan is a nationally-known teacher of advanced physical therapy techniques:
<http://www.chronicpainpartners.com/physical-therapy-ehlers-danlos-by-jan-dommerholt/>.

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