

# Physical Therapy, Exercise and Braces for People with EDS or HSD

*The advice below is for people with an Ehlers Danlos Syndrome, or Hypermobility Spectrum Disorder. If your diagnosis is suspected, but not yet confirmed by a specialist, the material below should still be relevant for you.*

## Section 1: For Patients

If you have an Ehlers Danlos Syndrome, or the newly-termed “Hypermobility Spectrum Disorder (HSD), 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 comments 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, followed by a section on braces. I suggest you read all of this yourself, and make a copy to give to your physical therapist, who should read Sections 2 and 3.

### **How to find the right physical therapist**

To help people with EDS/HSD, a physical therapist should meet two main criteria:

1. They should 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 and muscles 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-on-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. The treatment often has to be changed as it goes along. So things don’t go well if such patients are given standardized exercises or treatments to be supervised by an assistant without reassessment by the PT at each session.

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, and make an appointment to see the therapist, then **give the therapist this 5-page handout to study**.

### **How physical therapy can help you**

There are at least three ways physical therapy can help you if you have EDS/HSD. 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** 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 you at a good weight.

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 may be worse than before, because pain relief usually goes with more relaxed muscles, whereas you want the muscles to be working (i.e. tensed) to control your joints. Pain treatments without strengthening can easily be a revolving door with no long-term benefit.

## **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, 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 maintain a good weight; 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. Below are a few tips that are specially relevant for people with EDS.

## **Exercise in water**

For people with EDS/HSD, 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, ideally three times 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 people with EDS 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 of place. You can sometimes find good machines 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.

## **Section 2: For Physical Therapists**

“Ehlers Danlos Syndrome (EDS)” and “Hypermobility Spectrum Disorder (HSD)” refer to a group of inherited conditions with the common factor of loose connective tissue, hence joints are hypermobile, so that 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 people with an EDS.

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 people with EDS. However, some patients may be unable to use these machines because they displace their joints.

### **Two books on physical therapy for EDS**

**Kevin Muldoney** is a physical therapist whose book, *Living Life to the Fullest with Ehlers Danlos Syndrome*, was published in 2015. He presents a program for EDS patients that is highly structured, intensive (two to three PT sessions per week) and very long (6 months to a year), developed out of his practice in Rhode Island, and for which he claims great success. The book became very widely read and used after he presented it at a national meeting, despite the fact that hardly anyone has the resources to do the whole program. Muldoney favors working with the lumbar spine and sacroiliac mechanics for a number of weeks before moving on to other body areas, in a structured and almost invariant sequence. The response of many physical therapists was to reject this rigorous sequence, in favor of a more flexible approach,

going straight to the book chapters most relevant for each patient. There are now accounts online of physical therapists who were able to help their EDS patients substantially by doing this. More interesting, some *patients* have reported they did better following the exercises in the book *without involvement of a physical therapist at all*. So, one apparently doesn't have to be slavish in following Muldowney's protocol. The book costs about \$60 from Amazon and is nicely set out with easily-copied pages to be used in the clinic, and by the patient at home.

**Rosemary Keer** is a leading physiotherapist in London who has for years collaborated with senior clinicians and researchers there. Her book is *Hypermobility Syndrome: Diagnosis and Management for Physiotherapists*, available at Amazon for about \$70. This has chapters on assessment of joint hypermobility in children, adolescents and adults, and describes treatment strategies that have found favor in favor in Britain. It is rather more of a textbook than a how-to manual as is Muldowney's book. My impression from physical therapists is that each of these books appeals to some therapists more than the other, depending largely on the therapists' training and temperament.

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### **Section 3: Braces for Joint Hypermobility**

Braces can be invaluable for people with EDS. They are seriously under-used for these patients, mainly because of the bias against braces when over-used for orthopedic injuries. That bias is based on two perceptions. One is that a brace contributes to weakness by reducing the need for muscular support of the braced joint. The other is that undue immobilization promotes stiffness due to soft tissue contractures. Both these are fatuous when applied to a patient with a joint that is *permanently and irredeemably loose* because of mechanical inadequacy of its supporting ligaments. The joint can't be used effectively at all, if it repeatedly displaces during movement. But with a brace, it becomes usable again, thereby giving the patient the ability to use the joint, hence to build up strength and prevent stiffness. The strategy is therefore quite different than that of using a brace to restrict movement in one plane, so tissues can heal after a sports injury. By contrast, in hypermobility syndromes the point of the brace is not to *restrict* active movement, but to *permit* it.

Brace fitting for EDS patients should not be left to professional orthotists, who are generally unaware of the special difficulties in fitting them for these patients. They also generally aren't aware of the best available braces for hypermobility conditions, especially because they typically act as distributors only for a few brace manufacturers. Patients do much better when the physical therapist has carefully assessed what's required in a brace, and collaborates with the orthotist to find one that meets these requirements. Patients themselves can generally perceive very well the pros and cons of different braces and their input should be encouraged.

## Brace needs and issues for people with hypermobile joints

- 1. Lightweight braces.** Since braces are for long term use in EDS, they need to be *lightweight*, but also *strong*, as they have to stabilise the joint in the face of often-complete mechanical failure of its ligaments.
- 2. Soft padding.** EDS patients have skin that is often thin, fragile and easily inflamed, and they bruise easily. So their braces should be *properly padded* on the inside, *without stitching* and other fixtures on the insides that could be abrasive, or chemically irritating.
- 3. Design for female patients.** The padding must reflect the patient's body contours. Many braces seem designed for thin men with no body fat, but most EDS patients are women, whose subcutaneous fat needs to be accommodated in the brace's design. This consideration can change the whole layout of a brace. They usually depend on three-point contact with hard tissues, typically bony prominences. But if one of these is overlaid with fat, the brace can have no "purchase" there, and a brace with a different mechanical design will have to be used. It's important when fitting a brace to feel all around its inner surface, to check where are the areas of poor contact, or no contact.
- 4. Adjustable braces.** Braces are preferable that are adjustable, and also can be modified – either by cutting parts down, or by building parts up with padding materials.
- 5. Unbraceable joints.** Some joints are difficult or impossible to brace properly without using braces so large and cumbersome that they impede more movements than they promote. These braces are during post-operative recuperation, but not in the long term when the patient is striving to manage normal daily activities. For this reason, I have never seen an EDS patient using braces for a shoulder or hip, in the long term.
- 6. Neck braces.** EDS patients often have chronic neck pain, with a feeling that their heads are too heavy. They may feel a need to support their chins in their hands when doing desk work for any length of time. Most neck braces don't work for them, but a Vista Aspen brace often does. It is available without a prescription for about \$60, and is adjustable with the help of the physical therapist. Patients should check the return policy before buying one. Unfortunately, more elaborate neck braces generally put pressure on the clavicles or upper ribs, and this causes pain and/or subluxations in people with EDS.
- 7. Finger splints.** Very effective, tiny splints are now available to stabilize loose interphalangeal joints in the hands. These are much better than the bulky, customized braces made by hand therapists for the larger hand joints. Some, like Silver Ring splints, are so minimalist as to be mistaken for jewelry. A hand therapist can select and fit them.
- 8. Brace manufacturers** tend to make products that vary greatly in their appropriateness for EDS patients. So one company may make excellent knee braces, but their ankle braces may fail by criteria 1 to 4, above. However, the Bauerfeind company has paid more attention than most, to the needs of people with permanently hypermobile joints. I recommend that EDS patients work only with orthotists who can obtain Bauerfeind splints (among others) and are familiar with them.

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