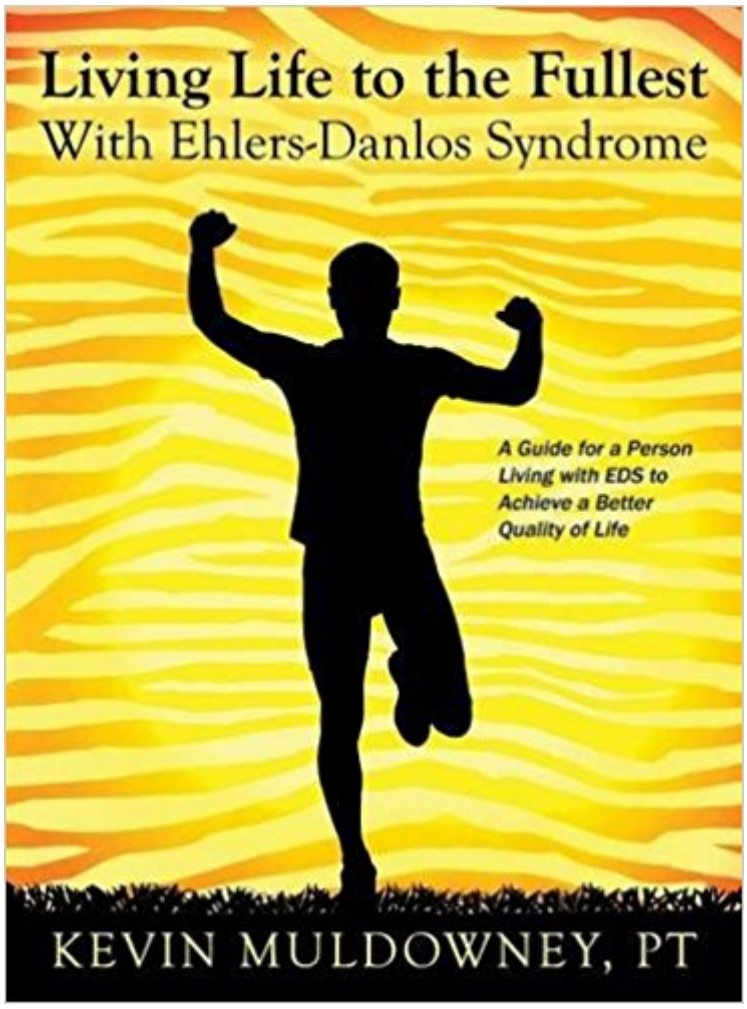
Living Life To The Fullest With Ehlers-Danlos Syndrome: Guide To Living A Better Quality Of Life While Having EDS



Synopsis

Kevin Muldowney, MsPT has been treating people with Ehlers-Danlos Syndrome since 2005. As a physical therapist, he has developed an exercise protocol to help stabilized the many joint subluxations/dislocations associated with this genetic disorder. This book is intended for the person diagnosed with EDS to both inform them about the healthcare team needed to properly treat them as well as to guide both the physical therapist and their patient with EDS through the Muldowney exercise protocol. This book will cover such topics as: how joints sublux in this population, how to find the right physical therapist, how to exercise without injury and what physical therapy techniques works best. By the end of this protocol people with EDS should be better informed about what is going on with their body and how to make it better.

Book Information

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Customer Reviews

I have had problems with joint pain / multiple dislocations and subluxations for years. I've been in PT mulitple times and it has never been particularly helpful - in fact, I usually wind up more injured than when I first started. About a year ago I had a doctor insist that I needed to go back to PT with the purpose of developing and implementing a full-body strengthening program. I begrudgingly went because he wouldn't drop it and lucked into seeing someone who understands connective tissue disorders and how to go about treating them. It has been life changing. Unfortunately, we haven't been able to work on a full body preventative strengthening program because we have been dealing with multiple injuries. I bought this book to see what I could do at home to augment what my PT is

already having me do. It is a great book, and the only one of its kind (that I am aware of, at least). I do have some quibbles with it, though.Negative:* The author makes it clear in his introduction that you are to use this book with a physical therapist. He says this will take 2-3 visits a week for 6-12 months. I don't think this is practical for most people. My insurance pays for 20 PT visits a year. After that the cash pay price for my PT is $75 a visit. We can swing 1 visit a week paying cash because PT allows me to function. $225 a week for PT is not in our budget.* He is also adamant that you need to follow the protocol of progression of exercises exactly, without skipping around to address things that hurt NOW (chronic injuries). On some level I understand this reasoning because dealing with a long string of chronic and new injuries is what has prevented me from figuring out a whole body program with my PT. However, I don't think a rigid approach is practical. For example, I injured my shoulder. It was so painful that I could not sleep. I couldn't lie down on my back because it hurt too much. I also couldn't raise my arm. This was not a brand new injury - it has been an issue for years. It never really healed after the first time I dislocated it, and then got worse and worse until I couldn't ignore it. If I had a PT tell me that they wouldn't help me with my shoulder until I had gone through back exercises for the sake of protocol / the larger picture, I would find a different PT. As a patient, I think there needs to be a balance between keeping the chronic injuries under control and working on the preventative.* I am disappointed by the pictures in the book. They aren't very high quality / resolution. I suspect that having better pictures would have dramatically increased the price of the book. (Which, by the way, I think is a fair price. This is basically a textbook for a physical therapist. To reach more people the author went through and also included a translation into normal person speak. The price is less than 1/2 what a typical medical textbook costs. It's comparable to a couple of co-pays, or less than one of my cash visits with my PT. You also have to think about what a narrow audience this book addresses. I don't see it hitting the NY Times best seller list.) In addition to the quality of the pictures, the model is wearing a baggy shirt and shorts that obscures his knees and elbows. I wish I could better see what his knees and arms are doing.* He states that you need to have a geneticist diagnose hypermobile EDS and then after the diagnosis you start the protocol and assemble your team. The problem with this is that the geneticists that *know* connective tissue disorders are swamped. Having to wait over a year to start to get things going is too long. My PCP diagnosed me, referred me to genetics to confirm and also sent me to several specialists (cardiology, GI, allergy, PT) to get the ball rolling while we waited for genetics to have an opening (which wound up being 18 months later). Those specialists did things and gave me information that immediately improved my quality of life. If I had to wait for genetics to confirm my diagnosis I would still be waiting.The positive:* This is a whole body program. Seriously. There are

face exercises. It is INCREDIBLY comprehensive and takes you slowly through different levels of exercises. He gives modifications and instructions on what to do if you can't tolerate something.* The author really and truly understands EDS. He acknowledges things that are unique to EDS, like coming out of PT more injured than when you started and the weird injuries that don't happen to typical people but are rampant in those with EDS. He gives instructions to the physical therapist on how they need to modify massage and mobilization techniques to avoid accidentally injuring you. He talks about POTS. He talks about who you need to have on your medical team and why. It's pretty incredible.* The non-medical speak explanations of the exercises are easily understood so that you can do this on your own (even though you aren't supposed to.). The medical speak is in there too and isn't inaccessible if you have a medical dictionary or google handy.* He includes a protocol on adding cardio to your activity. This is great for POTS and for people who have a hard time pacing themselves. I always feel great when I am exercising, decide to push myself a little bit harder, and then wind up feeling like I've been hit by a bus a few hours later.* There are lists of what you need to do each day when you are working through the protocol and for when you have worked through all the exercises.It's a great book. My issues with it are pretty picky. I wish allowed half stars because I would give it a 4-1/2. I am planning on using the book mostly on my own to augment my current PT program. I am going to have my PT double check my form on the exercises before I start doing them at home and I do plan to work through the protocol as it is written. For me this is a reasonable approach, although it is not exactly what the author recommends.

Giving hope to EDS patients all around the globe. Easy step-by-step instructions with photographs for therapists and patients to follow. Even backed up by a Facebook page where you or your therapist can ask Kevin Muldowney questions. Thank you Kevin from NZ.

I have been following this protocol for over a year and a half and at the age of 65, the time I have put into it has been totally worth it. On my good days, the sacrum holds and the up slips have gone away. It takes time, determination and commitment to follow up and do the exercises but they are not hard and do in time strengthen your muscles, thus allowing you to hold better. This book is not meant for you to take home and do yourself. You need to find a willing PT that will use the book as the guide and watch you try each new step and then check your body to be sure you held while doing the workout. It is safe, gentle, must be geared to your body and it's needs. I am thrilled with my results and love that this is allowing me to be proactive with my life!!!

so informative, really helps to navigate this illness and the therapy that can change your life

Very helpful on levels of physical therapy exercises you are able to do at home with the aid of pictures of actual people performing them. Most items necessary are one who have attended PT before probably already have or can obtain at a minimal cost.

We bought 2 copies of this book, one for us and one for my daughter's PT. It has only been 2 weeks but I think it is helping. Her PT is following it exactly, and said it is one of the best thought out programs he has seen. For the first time, physical therapy is helping, not hurting my daughter!

Really will help.

So glad to have this book! I don't have anyone in my area familiar with EDS and can't afford PT on a regular basis. Because I have a medical background, I don't have a problem doing these exercises by myself, with someone to correct my form until I have it down.

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