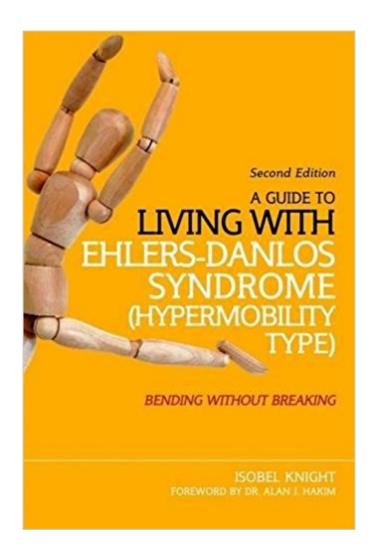


## The book was found

# A Guide To Living With Ehlers-Danlos Syndrome (Hypermobility Type): Bending Without Breaking (2nd Edition)





## Synopsis

Covering everything from recognising symptoms and obtaining initial diagnosis to living with the condition on a daily basis, this complete guide to living with and managing Ehlers-Danlos Syndrome (Hypermobility Type - formerly known as Type III) has been revised and fully-updated in this accessible new edition. The author, who has the condition, looks at how it affects children and adolescents and explores pain management, pregnancy, physical and psychological aspects, and how it widely affects dancers and other performance artists. New material includes: changes in terminology information on how osteopathy and nutrition can help psychological approaches beyond CBT how to deal with professionals what to expect from support groups and rehabilitation programmesThis new edition will be a must for anybody who suffers, or suspects they might be suffering from, Ehlers-Danlos Syndrome (Hypermobility Type) and provides everything needed to enjoy a fulfilling life with this complex condition. It will also be of interest to their families and friends, and professionals working with Hypermobility Type EDS.

## Book Information

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Without having to worry about medical jargon, this is a book for anyone (layperson or professional) who wants to understand the personal impact of, and wants to be up to date with the clinical presentation and management of Ehlers-Danlos Syndrome - Hypermobility Type. --from the foreword by Dr Alan J. Hakim MA FRCP, Consultant Rheumatologist and Acute Physician, Barts Health NHS Trust and Board Non-executive, CWHHE Clinical Commissioning Collaborative, North

## West London

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Newly diagnosed and this book is giving me insight to facing this challenge.

very informative, really helps to navigate this rare illness

## Excellent info

PLEASE FIND A BOOK BY A MEDICAL AUTHORITY TO LEARN ABOUT EDS! This has to be one of the dumbest books that I have ever had the displeasure of reading.NOT A GUIDE TO LIVING WITH EDS!!!! It's a story from some woman who thinks that she is an expert on EDS. This whole book seems to be devoted to the author's poetry and person stories. If you don't know anything about EDS, then maybe up to chapter 8 would be useful, but again IF YOU HAD NO KNOWLEDGE OF EDS. Most of us have a lot of knowledge, before we start looking for books to read. This book is not the most accurate, so please FIND SOMETHING ELSE. The author chooses instead of giving information about associated conditions, to talk about her experiences with the conditions. This is not a GUIDE!!DO NOT LISTEN TO THIS WOMAN ABOUT STRETCHING!!!!! If you speak with your (educated) rheumatologist, they will tell yoga (and most will also include pilates) should be avoided. This woman advocates pilates for EDS people. She also talks about circuit training----running stairs?! EDS people should not be doing any exercises that put strain on your joints. Exercises for EDS people need to be for strengthening muscles, without putting strain (or as little strain as possible more accurately). These exercises may include swimming (avoid over the head work especially if you had difficulties with your shoulders), walking, and perhaps light cardio, such as using ellipticals. Speak with a doctor, not this quack who has obviously not done any real research. LIGHT weight training is also recommended. Ballet is TERRIBLE for EDS. For correcting posture and learning sense of your body, yes, BUT NOT AS PUTTING STRAIN ON JOINTS!!! You

go to a physical therapist, not a ballet instructor to fix these issues. Her desire to blame everything on EDS is out of control. Trying to blame EDS for cognitive problems, without recognizing that depression and fatigue can cause the cognitive problems . . . she really has no idea what she is talking about.

Having recently been diagnosed with EDS I found great comfort and help in this book by someone who herself has the syndrome. It was encouraging and full of great information and advice. There may be other more helpful books out there but I ended up buying this after first reading it through an interlibrary loan. The only point worth making is that the author is British and terminology and treatment approaches are somewhat different there. However, that does not diminish the content of the book concerning EDS and I actually appreciated learning what England has to offer those afflicted with this. My son shows signs of EDS and I am planning on passing this on to him once my husband reads it and I reread it.

This book, while having a lot of good information, and even including facts about the relationship between hormones and EDS that I wasn't aware of, still doesn't quite present a full, organized picture of EDS, and its treatment. While there are a lot of suggestions for potential therapies that might help with pain, fatigue, or mental health, most of the recommendations seem to be based in either the author's personal experience or in anecdotal recommendations by people she knows. While presenting case studies and true life experiences with the elements being reviewed in the book is interesting, and usually helpful, I feel that this book is too slanted to the author's personal experience, rather than an objective review of the syndrome and proven therapies and and treatments. Most people with EDS are not dancers, and this book has dancing liberally sprinkled throughout - almost like Dancing with EDS was the book the author really wanted to write. Also, much of what she says regarding healthcare and support systems only applies in the UK, which isn't very helpful for readers in the United States.

More autobiographical than informative. Wish I had gotten a different book.

This is a great book for anyone both newly diagnosed and those who have had a diagnosis a while..

The book is written with knowledge of the problems we suffer from. Myself and my 19 year old daughter have Ehlers Danlos Syndrome Hypermobility Type so I know how useful this book is first hand, it should be read by all Doctors, Gps, Nurses, Physiotherapists etc. This book is informative,

factual, written in terms that a "normal" "non medical" person can easily understand. It answers the questions that a person with this syndrome asks, but may not receive forthcoming answers from the medical profession around them..

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