When Your Body Needs More Care

A Practical Guide to Hypermobility, Connective Tissue Disorders, and Creating a Life That Works

AUTHOR

Maggie Buckley, MBA, BCPA

Board Certified Patient Advocate

FOREWORD & MEDICAL REVIEWER

Dacre Knight, MD, MS, FACP

Medical Director, EDS & Hypermobility Disorders Center
University of Virginia
Chief Medical Officer, The Ehlers-Danlos Society

PUBLISHED BY

EDS CONNECTIVE™

When Your Body Needs More Care
A Practical Guide to Hypermobility, Connective Tissue Disorders, and Creating a Life That Works

Written by Maggie Buckley, MBA, BCPA
Published by EDS Connective
edsconnective.com

ISBN: 979-8-9963001-0-5
First published June 2026

Disclosure: This guide was authored by Maggie Buckley, MBA, BCPA, and medically reviewed by Dr. Dacre Knight, MD, MS, FACP; both serve as advisors to EDS Connective and may receive compensation or travel reimbursement. Additional contributions were provided by EDS Connective advisors Dr. Alan Hakim and Jeannie Di Bon. In addition to her advisory role, Jeannie Di Bon maintains a business relationship with EDS Connective via The Zebra Club. Dr. Melissa Koehl maintains a business relationship with EDS Connective via Chimera Health. These financial and business relationships are disclosed in accordance with the FTC Endorsement Guides. The views expressed are those of the individual contributors and do not necessarily reflect the official positions of EDS Connective.

This publication is for informational and educational purposes only.

The content in *When Your Body Needs More Care: A Practical Guide to Hypermobility, Connective Tissue Disorders, and Creating a Life That Works* is intended to provide general health education and awareness. It is not intended as, and shall not be construed as, medical advice, diagnosis, treatment, or a substitute for professional medical care.

About the author.

This guide was written by Maggie Buckley, MBA, BCPA, a board-certified patient advocate. Ms. Buckley is not a licensed healthcare provider. The content reflects her professional experience in patient advocacy and health education, not clinical guidance.

About the contributing providers and medical reviewer.

This guide contains contributions from physicians and healthcare providers and has been reviewed for medical accuracy by Dacre Knight, MD, MS, FACP. All provider contributions and Dr. Knight's review are limited to general educational content. They do not constitute individualized medical advice, do not create a provider-patient relationship with any reader, and do not constitute an endorsement of EDS Connective, its platform, or its commercial services. Any personal experiences, observations, opinions, or perspectives shared by contributors reflect their individual professional and/or lived experiences and should not be interpreted as guarantees of any particular health outcome.

About the publisher.

This guide is published by EDS Connective, LLC, a virtual health platform facilitating access to online hEDS and HSD diagnostic evaluation by independent physicians in all 50 states. EDS Connective is not a healthcare provider and does not render medical diagnoses, provide treatment, or practice medicine.

No guaranteed outcomes.

No representation is made that following any suggestion, recommendation, or information in this guide will produce any particular health outcome, improvement, or result. Every individual's health circumstances are unique. What is informative for one reader may not be appropriate for another.

Consult your healthcare provider.

Always seek the advice of your physician or other qualified healthcare provider before making changes to your healthcare, treatment plan, physical activity, diet, or medications. Never disregard professional medical advice or delay seeking it because of information you have read in this publication.

If you are experiencing a medical emergency, call 911 or your local emergency services immediately.

"Maggie brings lived experience and wisdom to navigate the unique challenges of life with a connective tissue disorder. Using a 'Whole Health' perspective, she explains the importance of an integrated approach to reducing the impacts of pain. She points to tools and actions that, day by day, help cultivate control over one's body and life. ***This is foundational reading for those wishing to live better with hypermobility."***

— Beth Darnall
PhD, Professor, Anesthesiology, Perioperative and Pain Medicine
Director, Stanford Pain Relief Innovations Lab
Stanford University School of Medicine

When I first began caring for patients with Ehlers-Danlos syndromes, hypermobility, and related connective tissue disorders, I quickly realized that the challenges patients face extend far beyond diagnosis itself. While obtaining an accurate diagnosis is often a long-awaited and deeply validating milestone, it is hardly ever the end of the journey. More often, it is the beginning of a new set of questions. These may include: What does this mean for my future? How do I manage my symptoms? Who can help me? How do I continue building a meaningful life? None are simple questions, and they are questions that medicine alone cannot fully answer.

Throughout my career in medicine, including my years leading the EDS Clinic at Mayo Clinic and now serving as Medical Director of the University of Virginia EDS & Hypermobility Disorders Center, I have had the privilege of meeting thousands of individuals living with hypermobility and connective tissue disorders. Their stories have taught me so much. Among the most important lessons is this: while clinical expertise and multidisciplinary care are essential, they are only part of the equation. Patients also need practical guidance, a community, validation, and tools that help them navigate daily life. That is precisely what this book provides.

One of the greatest strengths of this book is its emphasis on empowerment rather than fear. A diagnosis of EDS, HSD, or another connective tissue disorder can feel overwhelming at first. The internet often presents a confusing mixture of information, personal experiences, and worst-case scenarios. Maggie instead offers a grounded and balanced perspective. She encourages readers to move forward thoughtfully, focusing on what can be controlled, what can be strengthened, and what supports can be built over time. This is the Serenity Prayer in book form.

I am particularly pleased to see the emphasis on whole-person health. The management of connective tissue disorders extends beyond joints, skin, blood vessels, and diagnostic criteria. It includes movement, nutrition, hydration, sleep, mental health, relationships, purpose, and environment. These factors may not eliminate disease, but they often have a profound influence on quality of life. The most successful patients I have cared for are those who gradually develop a collection of sustainable strategies that help them live well despite ongoing challenges. More importantly, the book reinforces the truth that a diagnosis does not define a person. My patients with connective tissue disorders are incredibly talented and strong. They are students, professionals, athletes, artists, caregivers, leaders, and

friends. They are people with dreams, talents, and aspirations that extend far beyond their medical conditions.

Whether you are newly diagnosed or have been navigating this path for many years, it is my wish that this book helps you find clarity and hope. You may not have chosen this journey, but you do not have to travel it alone. Within these pages, you will find knowledge, perspective, and encouragement from someone who understands the entire experience.

I am grateful to Maggie Buckley for sharing her wisdom and expertise so generously. It is my privilege to introduce this important work, and I hope it serves as a trusted resource for many years to come.

Dacre Knight, MD, MS, FACP

Medical Director, EDS & Hypermobility Disorders Center, University of Virginia
Chief Medical Officer, The Ehlers-Danlos Society

EDS Connective

> *EDS Connective is a virtual health platform facilitating access to online hEDS and HSD diagnostic evaluation by independently licensed providers in all 50 states, no referral needed.*

If you're here, we know you've probably already been through a lot. People with hEDS and HSD typically spend years—even decades*—navigating complex, multi-systemic symptoms, and seeing specialist after specialist.

Founded by an hEDS patient who waited 15 years for her own diagnosis, we understand what it means to finally get answers. We work with leading experts in the Ehlers-Danlos Syndromes and hypermobility to help you get the evaluation you've been looking for in as little as days, not decades.

Our platform connects patients with independently licensed providers trained through EDS ECHO, the Ehlers-Danlos Society's specialized clinical training program for connective tissue disorders—online, available in all 50 states.

As the exclusive Diamond Sponsor of the Ehlers-Danlos Society, EDS Connective supports the global organization dedicated to EDS research, education, and patient support. Learn more at **edsconnective.com**.

AT A GLANCE

- Independently licensed providers trained through the EDS ECHO program of the Ehlers-Danlos Society
- Online and available in all 50 states
- No referrals needed
- Founded, owned & operated by an hEDS patient

** Daylor et al., J Clin Med (2025)*

Author

Maggie Buckley, MBA, BCPA

Advocacy Advisor & Patient Representative

Ms. Buckley has been a Health/Patient Advocate for over three decades while living with a chronic pain condition. She works with individuals, their families, and caregivers to access appropriate healthcare services to address their most pressing needs, and maintains a robust network with other Health Advocates to refer clients to specialist advocates.

She currently volunteers in many roles for the Ehlers-Danlos Society, the Loeys-Dietz Syndrome Foundation Canada, and the Loeys-Dietz Foundation (a division of the Marfan Foundation USA). She has also represented the voices of lived experience on research projects covering connective tissue disorders, pain management, and other health topics.

With an undergraduate degree in Social Work and an MBA in Accounting, Maggie became a Board Certified Patient Advocate in 2019. She is active in legislative and regulatory advocacy, has testified at policy hearings, has spoken at conferences and in the media, written articles, and coached hundreds to self-advocate for better care.

Instagram: @FriendofFred | LinkedIn: Maggie Buckley, MBA, BCPA

Medical Reviewer

Dacre Knight, MD, MS, FACP

Medical Director, EDS & Hypermobility Disorders Center, University of Virginia
Chief Medical Officer, The Ehlers-Danlos Society

Dr. Knight is the Medical Director of the EDS & Hypermobility Disorders Center at the University of Virginia, where he also serves as an Associate Professor of Medicine. He recently joined The Ehlers-Danlos Society as Chief Medical Officer. A board-certified internal medicine physician, he specializes in consultative and diagnostic medicine with a clinical focus on chronic disease, unresolved illness, and the coordinated care of patients with Ehlers-Danlos syndromes.

He earned his MD from St. George's University and a master's degree from George Mason University, followed by residency training at the University of Mississippi. Before joining UVA in late 2025, Dr. Knight founded and led the Mayo Clinic EDS Clinic for over six years, during which he was instrumental in securing the facility's recognition as an EDS Center of Excellence. He has also held faculty positions at Saint Louis University and served four years as a U.S. Air Force physician at Scott Air Force Base, including deployment to Afghanistan in support of NATO's Operation Resolute Support.

An active researcher and educator, he mentors medical students and residents in complex EDS cases and the application of machine learning and AI to diagnostic medicine. A former NCAA Division III soccer player, he brings a personal understanding of sports medicine and hypermobility to his work.

Expert Contributors

Lara Bloom

President & CEO, The Ehlers-Danlos Society · Academic Affiliate Professor of Practice in Patient Engagement and Global Collaboration, Penn State College of Medicine

Lara Bloom is President & CEO of The Ehlers-Danlos Society, leading global efforts to improve care, research, and outcomes for people living with Ehlers-Danlos syndromes and related conditions. Her work focuses on transforming fragmented health systems by embedding lived experience into research, policy, education, and service design.

She drives international collaboration across clinicians, researchers, policymakers, and industry to accelerate progress and advance equitable access to care. She serves in global leadership roles, publishes and speaks internationally, and advocates for inclusive, people-centered systems change.

Website: larabloom.com | Facebook: @larabloomeds | Instagram: @lara.bloom | YouTube: @larabloom

Dr. Linda Bluestein

MD · Board-Certified Anesthesiologist & Integrative Pain Medicine Physician

Dr. Bluestein is a board-certified anesthesiologist and integrative pain medicine physician. A former ballet dancer living with EDS herself, she is the founder of Hypermobility MD and Bendy Bodies, LLC, co-host of the podcast *Bendy Bodies with the Hypermobility MD*, and a contributor to the book *Disjointed: Navigating the Diagnosis and Management of Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders*. She serves on multiple advisory boards, including the EDS Research Foundation and the International Consortium on EDS and HSD.

Website: hypermobilitymd.com | Facebook, Instagram, and LinkedIn: @hypermobilitymd | Podcast: bendybodiespodcast.com

Jeannie Di Bon

MSc, MA · Movement Educator & Hypermobility Specialist · Founder, The Zebra Club & Integral Movement Method

Jeannie Di Bon is a movement therapist with over 17 years of clinical experience specializing in hypermobility, Ehlers-Danlos syndrome, and chronic pain. Living with hEDS, MCAS, POTS, and CFS herself, she is the creator of the Integral Movement Method, founder of The Zebra Club, and author of three books on hypermobility management, including *Hypermobility Without Tears* and *The Integral Movement Method for Hypermobility Management.*

Website: jeanniedibon.com | thezebra.club | Facebook: jeanniedb | Instagram: @jeannie_di | X: @jdibon | YouTube: @JeannieDiBonHypermobility

Dr. Irman Forghani

MD, FACMG · Director of Clinical Genetics and Genomics · Chief of RAD Center for Precision Medicine · Mount Sinai Medical Center

Dr. Forghani is a board-certified clinical geneticist specializing in hereditary connective tissue disorders, vascular malformations, and hereditary cancer syndromes. She founded and directed the Hereditary Connective Tissue Disorder Clinic at the University of Miami Miller School of Medicine, served as a co-investigator in the NIH-funded Undiagnosed Diseases Network, and is a member of the Ehlers-Danlos Society International Consortium Peer Review Panel.

Website: msmc.com/doctor/irman-forghani | Instagram: @dr_irman_genetics

Dr. Alan Hakim

MD, MA, FRCP(UK) · Medicine & Rheumatology · Hypermobility-Related Disorders · Principal Investigator Registry & Biobank, The Ehlers-Danlos Society

Dr. Alan Hakim is a consultant in Medicine and Rheumatology with over 25 years of experience in hypermobility-related disorders. He is Principal Investigator Registry & Biobank at The Ehlers-Danlos Society, Chair of the hEDS/HSD Working Group of the International Consortium on EDS and HSD, and a non-voting member of the Road to 2026 initiative reviewing the current classification criteria for EDS and HSD. He has published more than 150 scientific papers and articles and has led the internationally acclaimed EDS ECHO portfolio since its inception in 2019.

Shailavi Jain

RPh, BCPA · Registered Pharmacist & Board-Certified Patient Advocate

Shailavi Jain, RPh, BCPA, is a registered pharmacist and board-certified patient advocate specializing in supporting individuals with complex chronic illnesses. Through both her professional work and personal experience as a family caregiver, she understands the challenges of navigating complex healthcare systems. She is the founder of Your Health, Your Personal Advocate, where she helps patients and families organize complex medical information, identify knowledgeable providers, and become informed, confident advocates for their own care.

Website: yourhealthyourpersonaladvocate.com

Caroline Kim

BCPA, MSJ · Founder, Norbella Health Advocates

Caroline Kim, BCPA, is the founder of Norbella Health Advocates, an independent practice dedicated to helping patients access and understand quality medical care. Having lived with Ehlers-Danlos syndrome and multiple chronic conditions for over two decades, she pairs a deeply personal understanding of the healthcare maze with professional expertise. She holds a Patient Advocacy Certificate from UCLA, an ECHO certification from The Ehlers-Danlos Society, and a master's degree in journalism.

Website: norbellahealthadvocates.com | Facebook and Instagram: @norbellahealth | LinkedIn: Caroline Kim, BCPA

Dr. Melissa Koehl

Physical Therapist

Dr. Koehl is a Doctor of Physical Therapy living with hypermobile Ehlers-Danlos syndrome, a former nationally competitive gymnast, and the creator of ChimeraFit — a movement method that combines Pilates, yoga, and strength training, designed specifically for hypermobile bodies. She has been teaching safe, effective movement to people with hypermobility and joint pain for over 25 years.

Website: chimera-health.com | Instagram: @dr.melissakoehl.pt | YouTube: @chimerahealth-physicalther1354

Erin Kolb

MSN, FNP-C · Allergy & Immunology · Mast Cell Disease Specialist

Erin Kolb, MSN, FNP-C, is a board-certified family nurse practitioner specializing in allergy, immunology, and mast cell disease. She is the founder of Mast Cell Care, PLLC, and a TMS Project ECHO Certified Mast Cell Disease Provider. She serves on the Mast Cell Disorders Committee of the AAAAI and the Integrative Medicine Committee of the ACAAI. Drawing on her own lived experience with MCAS and dysautonomia, she is committed to helping patients navigate complex systemic illness with compassion and hope.

Website: mastcellcare.com

Dr. Denielle C. Medynski

DMD, Diplomate, American Board of Orofacial Pain

Dr. Medynski is a Clinical Dentist specializing in Orofacial Pain, which includes TMJ disorders, neuropathic pain, headaches, and sleep medicine. She graduated from the University of Medicine and Dentistry of New Jersey School of Dentistry in 2002 and completed advanced training in Orofacial Pain at the University of Kentucky. Board-certified in Orofacial Pain, she has served as an Assistant Clinical Professor at UCSF's Orofacial Pain Center. She currently has a private practice dedicated to orofacial pain in Walnut Creek, California.

Website: cafacialpain.com

Jesse Miller

MS, OTR/L · Occupational Therapist & Craniosacral Therapist · Founder, Conscious Connections OT

Jesse Miller is a licensed occupational therapist and craniosacral practitioner specializing in Ehlers-Danlos syndrome and hypermobility spectrum disorders. A graduate of The Ohio State University, she has attended the Global Ehlers-Danlos Conference since 2015 and is passionate about the mind-body connection and nervous system regulation in healing.

Website: consciousconnectionsot.com | Facebook: Conscious Connections OT | Instagram: @conscious.connections.ot

Dr. Jessica Pizano

DCN, CNS · Clinical Nutritionist & Exercise Specialist

Dr. Pizano earned her doctorate in clinical nutrition from Maryland University of Integrative Health and is widely recognized as a leading nutrition specialist in connective tissue disease and related diseases. She is an assistant professor at Notre Dame of Maryland's School of Integrative Health and has published book chapters and peer-reviewed articles on a variety of topics, including Ehlers-Danlos syndrome, metabolomics, nutritional genomics, and the microbiome. She specializes in supporting patients with connective tissue disorders and complex nutritional needs.

Website: mastcelladvanceddiagnostics.com | clinicalparadigms.com

Dr. Alan Pocinki

MD · General Internist

Dr. Pocinki recently retired after 35 years as a general internist, with a special interest in the joint hypermobility syndromes and related autonomic and sleep disorders. He has given dozens of lectures and webinars on these subjects and authored or co-authored numerous articles and book chapters. In 2020, he was honored with the Ehlers-Danlos Society's Lifetime Achievement Award for his contributions to the understanding and management of this condition.

Bridget Porter (Metz)

Loeys-Dietz Syndrome Advocate

Bridget Porter (Metz) is a patient advocate focused on early detection for those with rare heritable aortic health conditions, including vascular connective tissue disorders. Her passion is driven by the loss of her 13-year-old son, Connor, in 2020, to an aortic dissection resulting from undiagnosed Loeys-Dietz syndrome. She currently serves on the Board of the John Ritter Foundation for Aortic Health and the Loeys-Dietz Steering Committee of the Marfan Foundation. She is also partnering with the University of San Francisco School of Nursing on a program to train nursing students annually to identify and screen for rare aortic and cardiac events.

Dr. Chad Shepherd

Clinical Psychologist

Dr. Shepherd is a Chartered Clinical Psychologist with over eleven years of experience in Clinical Psychology services. He specializes in rheumatological conditions, particularly hEDS and HSD, and works with children, adolescents, and adults on chronic pain, fatigue, anxiety, and the psychological dimensions of living with complex chronic illness.

Website: drchadshepherd.com

Dr. Sarah Cohen Solomon

MD, FAAP · Pediatrician · Assistant Professor of Pediatrics, University of Virginia School of Medicine

Dr. Cohen Solomon is a board-certified pediatrician and Fellow of the American Academy of Pediatrics, specializing in hypermobile Ehlers-Danlos syndrome, POTS, and mast cell activation syndrome in children and young adults at the University of Virginia's EDS and Hypermobility Center. Living with hEDS herself, she brings both clinical expertise and lived experience to her practice.

Website: thebendypediatrician.com | Instagram & X: @TheBendyPediatrician

Sabrina Vaz

Second-Generation Pilates Instructor & Certified Somatic Practitioner

Sabrina discovered Pilates during her time at Laban Centre in London, England. She used the method to heal her own body after being injured in an automobile accident. In addition to Classical Pilates, she uses both the Gyrotonic and Gyrokinesis systems, along with many other modalities in which she holds certifications. She specializes in working with clients who have Ehlers-Danlos syndrome, Parkinson's, fibromyalgia, and patients recovering from strokes, as well as other special populations.

Website: beautifullybalancedcoaching.com | Facebook: Sabrina Vaz Barros Instagram, LinkedIn, and TikTok: The Real Sabrina Vaz

Inside This Book

Introduction

Finding Your Footing

> *You may feel as though this journey began the day someone finally named what was happening in your body, but in truth, you have already been at sea for a very long time. Long before there was a diagnosis, there was the work of staying afloat: noticing changes, adapting quietly, and learning what your body could and could not tolerate. A diagnosis can feel clarifying, but it does not hand you a complete map. It simply gives you a better starting point for understanding the body you are in and the care it may need. Throughout this book, I return to a simple image: the boat you are already in. What matters is not building the biggest boat or gathering the largest crew. It is steadying what you have, learning the waters you are in, thoughtfully adding support, and recognizing the care partners who are already alongside you. This book begins there—in the middle of the voyage, where you already are, learning how to steady the boat you have.*

I was diagnosed at age thirteen with a hypermobile connective tissue disorder by a compassionate orthopedist who not only understood the condition clinically, but also lived with hypermobility and chronic pain himself. In his white coat, he reviewed a long list of activities I should avoid—parachuting, bungee jumping, touch football, and many others. Then he took off the white coat and spoke to me as a person. He told me that I might never meet anyone else with this condition because it was considered so rare. He also told me something that stayed with me for decades: only I could learn where my limits were. If I wanted to try something, I should prepare for it, pay attention, and be willing to stop if it did not feel right. He referred me to what we would now call an integrative or multidisciplinary approach to care. That was in

1974. Since then, I have met and learned from tens of thousands of people walking similar paths.

My diagnostic label changed many times over the years. Every few years, a doctor would raise a different possibility—Marfan syndrome, fibromyalgia, arthritis, an autoimmune condition, Loeys-Dietz syndrome, or another connective tissue disorder—followed by exams, imaging, and testing, only to conclude that I did not fit neatly into any one category. For a long time, I carried an Ehlers-Danlos syndrome diagnosis because it served as a diagnosis of exclusion: other explanations had been ruled out, but the full picture was still unclear. I also took part in research and underwent multiple rounds of genetic testing over several decades. In 2023, that long process finally became clearer. Two previously uncertain genetic variants were reclassified as likely pathogenic, further exams and testing were completed, and my diagnosis was refined to an ultra-rare combination of a type of Loeys-Dietz syndrome and a type of Ehlers-Danlos syndrome.

If you have recently received a diagnosis, you may know the strange mix of relief and overwhelm that can come with finally having a name for what has been happening in your body. At first, it can feel like everything should get easier now that someone has connected the dots. Then reality sets in. The condition may be rare. The healthcare system may still be fragmented. You may find yourself explaining your symptoms, teaching people how to pronounce your diagnosis, and trying to figure out what to do next while your body is still asking for care. That is the gap this book is meant to help fill. It is here to help you catch your footing before you are pulled too far into confusion, exhaustion, or hopelessness.

What This Book Is Here to Offer

This is the book I wish had existed when I was first diagnosed. Between the ages of twelve and thirteen, I experienced repeated joint dislocations, chronic pain, and worsening headaches. Too often, I was made to feel weak, dramatic, or as though I were inventing symptoms to avoid school or activity. When that happens often enough, it can become easier to act like everything is fine than to keep risking dismissal. Over time, I realized that what many people need most after diagnosis is not only medical information. They also need practical ways to care for themselves, communicate clearly, make decisions, and build a life that does not revolve entirely around symptoms.

This book is grounded in what I think of as five core pillars of health: movement, hydration & nutrition, sleep, mental health, and surroundings. These pillars are not a cure, and they do not solve every problem. But they do offer a framework for building stability, reducing avoidable strain, and making day-to-day life more workable.

THE FIVE PILLARS OF HEALTH

- **Movement**
- **Hydration & Nutrition**
- **Sleep**
- **Mental Health**
- **Surroundings**

Throughout the chapters ahead, you will find practical guidance for navigating diagnosis, preparing for appointments, making healthcare decisions, pacing your energy, supporting your body in daily life, and building meaning, connection, and purpose beyond healthcare.

One of the most important lessons I learned early was that self-advocacy is not an optional extra. It is a practical skill. You learn the words. You learn the anatomy. You learn how to describe patterns clearly enough to be understood. You learn how to prepare for appointments, ask better questions, and recognize when a clinician is willing to work with you. I am deeply grateful to the mental health professionals, physical therapists, physicians, researchers, and patient communities that helped shape these lessons over time. I have carried them forward, refined them, and updated them as science has evolved and as others have shared their own stories with me.

Why This Guidance Reaches Beyond One Diagnosis

Over time, I learned that limiting myself only to people with one specific connective tissue diagnosis also limited what I could learn about care, adaptation, and survival inside an imperfect healthcare system. I broadened my circle to include people living with cancer, cystic fibrosis, sickle cell disease, arthritis, Sjögren's, chronic pain after injury, and other long-term conditions. The common denominator was clear: many people living with chronic illness are left to do far more of the coordination, explaining, adapting, and coping than the system was designed to support.

I have worked as a health and patient advocate for decades, and for even longer, people have sought me out informally because of my own experience navigating complex healthcare. Again and again, I was told that this guidance needed to be

written down so people would not have to wait for a chance encounter with an advocate to get practical help. That is part of why this book exists. Although it is written with heritable connective tissue disorders (HCTDs) and hypermobility in mind, much of what it offers applies more broadly to chronic illness: how to gather information, how to build support, how to make decisions, and how to live with more steadiness and direction.

My hope is that this book will be useful not only to patients and care partners but also to healthcare professionals who want a better sense of what life with a complex chronic condition actually asks of a person. Clinicians manage scans, procedures, medications, and surveillance. This book is meant to help fill the space around those things: the daily life of living in a body that needs more care, more planning, and more adaptation than most people can see. And because moving forward well rarely begins with speed, the first chapter starts where many people most need support: with calm, steadiness, and the kind of nervous-system regulation that makes it easier to think clearly, make decisions, and begin building from there.

PART I

Getting Oriented

Chapters 1 - 6

- Chapter 1: Calm Is the First Step Forward
- Chapter 2: What This Diagnosis Means for You
- Chapter 3: After Diagnosis: Relief, Grief, and What Comes Next
- Chapter 4: Building a System That Supports You
- Chapter 5: Making Decisions When Things Are Hard
- Chapter 6: What Integrative Care Looks Like in Real Life

The information in Part I is for educational purposes only and does not constitute medical advice. The contributors are sharing general health education, not providing individualized clinical guidance. Always consult your healthcare provider before acting on any information presented here.

01

Calm Is the First Step Forward

> *When fear first rises, it can feel as though the only sensible response is speed—more research, more appointments, more solutions, more effort. But a body already under strain rarely settles through force. Before you add more tasks, more information, or more urgency, it helps to begin by quieting the system enough to see what is actually happening. Calm is not passivity, denial, or weakness. It is the first practical step in building steadiness, because it helps you notice what is already supporting you and what needs attention first. Before you chart a new course, you steady the boat you are already in.*

This chapter is about helping your nervous system feel safer and steadier so you can build momentum. We'll talk about what stress does in the body, why getting stuck in "fight mode" can make symptoms louder and energy lower, and a few simple practices you can use anywhere to bring things down a notch.

If you're newly diagnosed, it can feel like you've been dropped into the middle of a storm: new terms, new appointments, new decisions—and a very real urge to fix everything right away. The frustrating truth is that lasting progress usually doesn't start with speed. It starts with steadiness. A more regulated nervous system gives your body and mind a better place to learn, heal, and make decisions.

> *"In order to heal, the body needs safety. Safety comes in many forms—a good night's sleep, rest, and connection with our values. In our modern lives, there are always ongoing challenges, particularly with chronic health problems. A good place to start is by calming the nervous system."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

From Fighting to Building

In healthcare, people often talk about illness like a battle: fight for your health, fight your body, fight the system. I understand why that language shows up. It can feel powerful in the moment. But it can also keep your body on high alert, as if danger is always present, even when the work in front of you is slow, steady, and deeply human.

If you're living with a heritable connective tissue disorder—or any chronic condition—this is not a short sprint. It is a long path with many chances to improve the quality of life. The community phrase "start low, go slow" exists for a reason: moving too fast can lead to burnout, symptom flares, and the discouraging feeling that nothing works.

SHIFTING YOUR MINDSET

WARRIOR MINDSET	BUILDER MINDSET
Fight for your health	Build skills that regulate symptoms
Push through	Create reliable strategies
Force progress	Grow a support network
Always on high alert	Work with your body

You don't need to prove you're tough. You're already strong: you've lived in this body for a long time, and you've found ways to cope. Nobody understands your day-to-day experience better than you do. That lived knowledge matters.

Calm Is a Skill

When clients come to me for patient advocacy, one of the first things we practice is nervous system regulation. Not because calm is simply "nice," but because calm is useful. It helps you think more clearly, communicate more effectively, and respond to symptoms based on what is really happening—not just what your brain fears might happen.

A simple place to start is a cleansing breath:

- **Breathe in slowly for a count of four.**
- **Exhale slowly for a count of four.**
- **Repeat 3–5 times.**

As you try this, notice what changes—your heart rate, muscle tension, and how clear your thinking feels. Even a few breaths can create just enough space to choose your next step rather than react on autopilot.

Use Transitions to Practice Regulation

One of the easiest ways to build this habit is to pair it with transitions you already do every day:

- **Room-to-room transitions:** as you walk from the bedroom to the kitchen, take 2–3 slow breaths.
- **Before and after calls:** breathe before you dial; breathe again when you hang up to mark completion.
- **After any focused task:** take a few breaths before switching to the next thing.

Injury, Flare, or New Pain: Pause Before You Problem-Solve

When something suddenly hurts, your nervous system often hits the gas. That urgency is understandable—but it can also lead to mistakes: moving too quickly, grabbing the wrong support, using heat when ice would have helped (or vice versa), or spending energy chasing ten possibilities instead of the one you actually need.

If you can, try this sequence:

- **Stop for a moment.**
- **Take 2–4 slow breaths.**
- **Assess.** Is there bleeding? Swelling? A bruise forming? Are you dizzy? Is the pain changing as you breathe?
- **Respond appropriately.** Choose the simplest next right step (specific support, first aid, rest, or calling for help).

This pause is not "doing nothing." It's vagus-nerve-supported regulation—creating enough safety in the body to think clearly and conserve energy.

Why Fight-or-Flight Can Worsen Symptoms

YOUR AUTONOMIC NERVOUS SYSTEM

SYMPATHETIC (FIGHT/FLIGHT)	PARASYMPATHETIC (REST/DIGEST)
Mobilizes energy for immediate action	Supports digestion and recovery
Heart rate rises, muscles tense	Tissue repair and immune function
Digestion slows	Steady nutrient and hydration absorption
Attention narrows toward perceived threat	Rest and restoration

In the wild, fight-or-flight is usually short-lived: danger passes, and the body settles again. With chronic illness—and chronic stress—that "always ready" state can become the default. Over time, constant muscle tension can lead to pain, and slower digestion can worsen GI symptoms and make it harder for your body to absorb the nutrients and hydration it needs for recovery and stability.

The goal is not to remove stress completely. The goal is flexibility: the ability to move out of fight-or-flight and back toward rest-and-digest when your body is safe enough to do that.

A Toolkit for Cultivating Calm

Regulation starts with noticing. That is the first skill. Pay attention to the early signs that your system is revving up—racing thoughts, a tight jaw, clenched muscles, shallow breathing, or a sense of urgency—and then choose one tool that fits the moment.

— Breathing (fastest access)

Return to the 4-count inhale/4-count exhale, or simply make your exhale slightly longer than your inhale.

> *"As a DPT living with hEDS, I've learned that nervous system regulation is essential for managing fatigue, pain, dysautonomia, GI symptoms, and mast cell issues. Meditation can be helpful for many people, but for me, it often worsens fatigue. For many of my patients and clients, especially those with autism or ADHD, the act of sitting quietly can actually feel more dysregulating or anxiety-producing. Instead, things like gentle movement, vagus nerve stimulation through vocalizing or humming, and short breathing exercises (even just one slow exhale) can be much more effective and efficient ways to help the nervous system feel safe and regulated. The beauty of this approach is that it can be sprinkled in several times over the course of a day, which also feels more manageable."*
>
> **— Dr. Melissa Koehl, PT**

— Visualization (building understanding and compassion)

Gently focus attention on the body area that feels "loud." The aim is not to judge or panic, but to understand what you're sensing and to separate *threats* from *familiar sensations* that are common for your body.

> *"The brain and nervous system love visualization. We can create sensations through imagined or emotionally associated experiences. In persistent pain states, the nervous system can become highly protective and sensitized. Gentle visualization can help shift the body from a state of threat toward one of safety and regulation. Calming imagery, positive sensory focus, and feelings of safety can influence breathing, muscle tension, stress hormones, and pain responses."*
>
> **— Jeannie Di Bon, MSc, MA, Movement Educator & Hypermobility Specialist**

— Guided imagery (finding safety through the senses)

If you like scripts or audio guidance, try a simple image such as a leaf on a branch. Imagine being that leaf: supported, connected, and anchored. Notice sensory details—warm/cool air, distant sounds, nearby smells. This kind of sensory refocus can help your nervous system return to the present moment.

— Body scans (information without judgment)

With a steady breath (3–4 counts in, 3–4 counts out), slowly scan from the top of your head down to your toes. Notice sensations and alignment. Make small adjustments toward neutral, comfortable positions. Over time, this builds body knowledge: what needs support, what needs movement, and what needs rest.

These are accessible, self-directed practices. The more you practice when things are *not* urgent, the easier it becomes to use them when you really need them.

Conclusion

MINDFULNESS FOR CHRONIC PAIN

- Train a different response when pain arises
- Practice observing sensations without judging them
- Notice impermanence: sensations change over time

When you have more tools in your toolkit, the jumble of symptoms can feel less scary and less overwhelming because you have options. Each time you use a tool, and it helps, you give your brain evidence that you can handle what is happening. That sense of control can calm the nervous system and help create a steadier, less reactive cycle. In time, that steadiness becomes part of how you keep your footing when the water changes.

WHAT TO REMEMBER:

- Calm is a foundation for clear thinking, better decisions, and sustainable progress.
- Regulation is practice-based: small reps throughout the day add up.
- Shifting toward rest-and-digest supports digestion, recovery, and energy.

PRACTICE PROMPT (2 MINUTES)

- Put one hand on your chest and one on your belly (or just rest your hands wherever is comfortable).
- Inhale gently through your nose for a count of four.
- Exhale slowly for a count of six (or simply make your exhale a little longer than your inhale).
- Do 5 rounds. If your mind wanders, that's normal—just come back to counting.

Make it yours: If counting feels stressful, drop the numbers and just slow the exhale. If breathing through your nose is hard, breathe through your mouth. If sitting still isn't supportive, try this while walking slowly, rocking gently, or lying down with your knees supported. The goal is not perfection—it's giving your nervous system a clear signal: *right now, I'm safe*.

02

What This Diagnosis Means for You

> *A diagnosis does not tell you everything, but it can begin to explain what kind of body you are living in. It can help make sense of why the same demands may feel different for you than they do for someone else, and why your body may need more support, more recovery, or a different way of moving through the world. Learning about connective tissue is not only about anatomy. It is also about recognition: understanding the structure you are working with, where it is resilient, and where it may need more protection. In that way, diagnosis is less a destination than the first clear look at the boat you are learning to navigate—and the waters it has already been carrying you through.*

With a calmer view, you can start gathering the knowledge and skills that help you live well with a heritable connective tissue disorder. In this chapter, you will look at what "heritable connective tissue disorder" means, how these diagnoses are made, and why hypermobility can appear across several different conditions. Some people are hypermobile and never become symptomatic. For others, the same trait is part of a broader pattern that affects how the body functions and what kinds of support it needs. In simple terms, an HCTD is a broad label for a group of genetic conditions that affect connective tissue. When connective tissue is altered, it can lead to structural and functional changes throughout the body. One way to picture it is the story of *The Three Little Pigs*: the houses may look similar from the outside, but the building materials matter, and weaker materials change how the structure holds up.

The phrase "heritable disorder of connective tissue" is often traced back to Victor McKusick's 1955 article, "The Cardiovascular Aspects of Marfan's Syndrome: A Heritable Disorder of Connective Tissue." In 1956, the first edition of McKusick's *Heritable Disorders of Connective Tissue* discussed conditions including Marfan Syndrome (MFS), Ehlers-Danlos syndrome (EDS), osteogenesis imperfecta (OI), pseudoxanthoma elasticum, and Morquio syndrome. In later editions (including the 2002 version), the connective tissue disorder landscape expanded and was organized to include conditions such as the following:

Connective Tissue Disorder Landscape

- Osteogenesis Imperfecta (OI)
- Ehlers-Danlos Syndromes (EDS)
- Marfan Syndrome (MFS) and Microfibrillar Disorders
- Cutis Laxa, Pseudoxanthoma Elasticum, and Homocystinurias
- Menkes Disease and Occipital Horn Syndrome
- Epidermolysis Bullosa (EB)
- Various metabolic, bone, and skin disorders (e.g., Alkaptonuria, Osteopetrosis)

That list—plus Loeys-Dietz syndrome (LDS) and Stickler syndrome—represents some of the differential diagnoses a clinician may consider when you show up with hypermobile joints and related musculoskeletal and skin concerns. I'm sharing this with you for one reason: to help you see why identifying a specific subtype is rarely quick or simple.

What Is Connective Tissue?

When you hear the words "connective tissue," you might immediately think of tendons and ligaments—the bands that connect muscle to bone and help your joints work smoothly. But connective tissue is much bigger than that. It is everywhere: in your bones and muscles, in your skin, and in fascia, the web-like layer under your skin that wraps and supports muscles and other structures.

When you talk about HCTDs, you are talking about conditions you are born with that affect how your body builds connective tissue. One simple way to picture this is that your body's "recipe" for making things like collagen varies. Different conditions can affect different parts of your body, and sometimes more than one at once. To sort out

what is going on, your healthcare professional usually combines your symptoms, your medical and family history, and what they can observe on an exam.

That exam may include checking how far your joints move, seeing how your skin stretches and bounces back, and looking for certain eye features. For example, you might have a bluish tint to the whites of your eyes, sometimes called blue sclera. That can be seen in osteogenesis imperfecta, but it can also appear in other connective tissue conditions.

If you're hypermobile, it can feel like you're always trying to find a steady footing—like standing on a moving boat. When a joint moves more than it's built to, your body often recruits different muscles to jump in and "hold things together." Over time, that extra work can add to soreness or pain. You might also deal with subluxations (partial slips) or dislocations.

Connective tissue is one of your body's main support systems. It helps hold structures in place so your muscles and bones can move safely. It cushions your organs, helps protect and insulate you, and connects your skin to the layers underneath so your skin can sit smoothly. Even your blood vessels rely on connective tissue for strength and support.

Collagen is a major building block of connective tissue—often described as your body's "glue." Joint looseness can become more noticeable during childhood and growth spurts, when your body is changing quickly. One way to picture it is this: as your bones get longer, your tendons and ligaments ideally act a bit like rubber bands, taking up slack while everything adjusts. If your connective tissue is stretchier, or if it does not "spring back" in the usual way, your joints can start to feel wobbly or unstable as your muscles catch up to the bones. And because your muscles also contain connective tissue, building and maintaining muscle tone for extra support can take more effort than for someone with more stable connective tissue.

Depending on the specific condition you have, differences in connective tissue can affect how strong, stretchy, or repairable your tissues are. That is one reason symptoms can show up in different parts of your body. You might notice mostly joint issues, or you might also have skin differences, digestive symptoms, or blood-vessel-related concerns.

"Connective tissue is the body's structural framework—the material that gives strength, support, and flexibility to nearly every organ system. It is composed of proteins like collagen and elastin, which function like cables and elastic bands, holding tissues together while allowing resilience and movement. But connective tissue is more than scaffolding. It is a dynamic, living environment that surrounds cells, blood vessels, and nerves, enabling communication and coordinating processes such as healing and inflammation.

"Because it is present throughout the body, disruptions in connective tissue can have widespread effects, involving the joints, skin, cardiovascular system, eyes, digestive tract, and nervous system. Symptoms that may seem unrelated are often linked by a shared underlying issue. In heritable connective tissue disorders, genetic changes affecting these structural components or their regulation alter tissue integrity and signaling, leading to the diverse clinical features we observe in practice."

— Irman Forghani, MD, FACMG

When your joints feel unstable, they may move past their usual safe range. That can contribute to repeated joint slips, subluxations, dislocations, and ongoing pain. Your skin can be part of the picture too. You might notice very soft or stretchy skin, easy bruising, or scars that heal differently, such as thin, papery scars or sunken scars. Stretch marks can also appear even without major weight changes. And because your pelvis supports many organs and tissues, issues such as hernias or prolapse can occur in some connective tissue conditions.

Connective tissue can be hard to "see" in regular medical care because it touches so many parts of your body. Specialists often focus on one system at a time—heart, digestion, joints, feet, or nerves. If connective tissue is the common thread for you, your symptoms can feel scattered, and it can take time to connect the dots and build a care team that looks at the whole picture.

If looseness and instability are part of your life, it can help to focus on support and control rather than flexibility. Many people begin with physical therapy, not just for injury, but to learn safer joint mechanics, alignment, and how to move within a more controlled range. Occupational therapy can help you solve day-to-day problems, such as finding braces, splints, and tools that make tasks easier on your joints.

For exercise, many people do best with a gentle, steady approach that builds strength slowly over time. Options can include swimming, resistance bands, modified yoga or Pilates, and carefully progressed strength training. This is where the "start low, go slow" rule matters: your body often responds better to gradual, repeatable progress than to pushing hard and paying for it later.

You might use braces for certain activities to reduce strain, and regular movement breaks can be easier on your body than staying in one position for too long. You may also hear about proprioception, which is your body's sense of where it is in space. Practicing neutral positions while lying down, sitting, standing, and moving between positions can help improve that awareness. Posture work is usually a full-body project—head and shoulders, ribs, hips, knees, ankles, and feet. The goal is to learn what "neutral" feels like in your body without locking or over-straightening your joints, and from there to build the kind of functional strength that makes your joints feel more supported.

Day-to-day symptom management is often a mix of strategies: hydration, nutrition, pacing, and working with allied health professionals, such as physical therapists, occupational therapists, and registered dietitians or nutritionists, to address pain and function. You might try an anti-inflammatory eating style or follow a specific plan, such as a Mediterranean-style approach, while aiming for enough variety to support overall health and address nutritional deficiencies. If you are considering supplements or new routines, it is worth checking with a clinician or pharmacist first—especially if you take other medications or have other health conditions.

As you understand more about connective tissue and the role it plays in your body, it becomes easier to put words to the different kinds of discomfort you might feel. Joint pain may come from repeated strain or joints moving more than they should. Muscle pain can come from muscles working overtime to stabilize you, sometimes staying tight for long periods. Nerve-related pain can happen when nearby nerves become irritated. Skin discomfort may be related to bruising or the way your skin heals. When you can describe these patterns clearly, it becomes easier to explain what you are experiencing and to work with your care team to determine what supports you best.

Here is a more technical way to describe what you have been reading so far—without losing the main point. Connective tissue is the material that supports, protects, and gives structure to many other tissues and organs throughout your body. There are many kinds of connective tissue, but most consist of relatively few cells plus an extracellular matrix, the material outside the cells. That matrix is usually composed of

collagen fibers, elastic fibers, proteoglycans, and non-fibrous material collectively called the "ground substance."

When people talk about connective tissue, they are often referring to structures such as tendons, ligaments, fascia, and dura, the tissue that surrounds and protects your central nervous system. Connective tissue also includes bone and cartilage. Collagen is the most abundant protein in your body and one of the main proteins in connective tissue. It gives tissue much of its strength, flexibility, and resilience. There are many types of collagen, and many of the Ehlers-Danlos syndromes involve changes in what are called fibrillar collagens.

Collagen also matters for proprioception, which is your body's sense of where it is in space. The connective tissue around your joints plays a major role in helping you detect where a limb is, how it is moving, and how your body is positioned relative to the world around you. When connective tissue is lax because of collagen differences, proprioception may be less reliable. That can show up as poor coordination or a feeling of clumsiness. You might bump into walls or door frames, struggle more on stairs, or have a harder time navigating uneven ground because it is harder to tell exactly where your body needs to land.

If your body does not make enough collagen, or if the collagen is structurally different, poorly organized, or unable to assemble into fibrils in the usual way, connective tissue can lose some of its mechanical integrity. In practical terms, your tendons and ligaments may not do their jobs as effectively. Because collagen's role is largely structural, changes in collagen can reduce tensile strength, which may contribute to joint instability, subluxations, and dislocations. Collagen also helps maintain your skin's strength and elasticity. When collagen structure is altered, and the collagen fibrils in the skin are disorganized, this can contribute to the hyperextensibility seen in some HCTDs, as well as to skin fragility, such as skin that tears more easily or heals in unusual ways.

How Connective Tissue Diagnoses Happen

Getting a connective tissue–related diagnosis can feel both clarifying and incomplete, especially when your symptoms involve more than one body system. A label such as Joint Hypermobility Syndrome may accurately describe loose joints, pain, partial slips, or full dislocations that affect function. But it can still miss the bigger picture if your other symptoms and body systems were not fully considered at the time. Even so, diagnosis matters. It can connect you to information, resources, and the right kinds of clinicians. It can guide what symptoms need monitoring or

treatment, highlight medication, anesthesia, or surgical issues that affect safety, and point you toward strategies that might otherwise be overlooked.

If you are still waiting for a diagnosis, it is reasonable to care for your body as though any of the HCTDs could still be possible. In practical terms, that means focusing on stability, strength, and safer movement while also paying attention to patterns that may suggest common co-occurring conditions, such as dysautonomia, mast cell activation, or cardiovascular concerns.

> *"Many face years—sometimes decades—without a diagnosis, navigating a system that overlooks or misunderstands their symptoms. Even with a diagnosis, access to knowledgeable healthcare professionals and coordinated multidisciplinary care remains limited in most parts of the world."*
>
> **— Lara Bloom, President & CEO, The Ehlers-Danlos Society**

It also helps to know that diagnostic best practices change over time. For example, someone diagnosed with Ehlers-Danlos syndrome, Hypermobility Type in 2001 under the 1997 Villefranche Nosology—which described six EDS types—might later be reclassified as having hypermobile Ehlers-Danlos syndrome under the 2017 criteria. Another person with overlapping features might have been diagnosed with EDS Type III in 1993, only to be later reclassified into a type of Loeys-Dietz syndrome or another connective tissue disorder as research sharpens the distinctions between conditions and genetic testing becomes more accessible. In other words, a diagnosis can change not because your symptoms were imagined, but because science, diagnostic tools, and classification systems keep evolving. See Appendix A for a fuller history of how Ehlers-Danlos syndrome subtypes have changed over time.[1]

It can also help to picture what is happening on your clinician's side of the table. To reach a diagnosis, they review your medical history, examine your body, study prior records, and compare your symptoms and physical findings against the criteria for many possible conditions. In some cases, that means narrowing the list from dozens—or even hundreds—of possibilities.

[1] *For similar classification histories of Marfan syndrome and Loeys-Dietz syndrome, see Appendices B and C.*

Genetic testing can be very helpful, but it works best when combined with your medical history, a careful clinical exam, and a detailed review of your records. It also has real limits. Test panels vary from one laboratory to another. Not all disease-causing variants are known yet. A result may identify a variant of uncertain significance, which means a change was found in the DNA, but researchers do not yet know whether it is actually linked to disease. Testing ordered without a proper medical evaluation is less reliable, and interpretation is most accurate when performed by someone with specialized genetics training.

> *"Diagnosing a connective tissue disorder is like assembling a puzzle—no single feature tells the whole story. It requires integrating a detailed personal and family history, careful physical examination, and often, genetic testing to identify the underlying cause. A comprehensive evaluation is essential because many of these conditions share overlapping, multisystem, and nonspecific features. A complete workup, including genetic testing, helps to confirm a diagnosis and distinguish between look-alike conditions with different risks and management implications.*
>
> *"Genetic testing plays a central role, particularly when the presentation suggests a recognizable syndrome. But the goal is not simply to assign a label—it is to guide surveillance, inform treatment decisions, clarify recurrence risk, and help patients and families better understand the road ahead."*
>
> **— Irman Forghani, MD, FACMG**

One reason genetic interpretation can be frustrating is that the reference range is still incomplete. Not everyone in the world has had their genome sequenced, and most people who have undergone testing are of European ancestry. That means the comparison data is uneven. When a rare variant is found, researchers may need more information from relatives or from people with similar ancestry to better understand what that change means. As more people participate in testing and research, the reference base grows, and future interpretations become stronger.

When your results come back, variants may be labeled pathogenic, likely pathogenic, or of uncertain significance. Those findings are then weighed alongside your symptoms, family history, and exam findings. Much of this work is based on educated guesses. Your data are compared with what is currently known, and patterns in the research are used to estimate which symptoms may appear and how much they may affect function. As the science improves, interpretation can too.

A practical question you may eventually ask is whether the right genetic test or panel was chosen in the first place. Hypermobility by itself can point to more than 200 different conditions, and not all of them are HCTDs, such as the Ehlers-Danlos syndromes, Loeys-Dietz syndromes, Marfan syndrome, osteogenesis imperfecta, or Stickler syndrome. Your clinician uses your records, history, and exam to narrow that list, often focusing on features such as family history, vascular signs, skin findings, skeletal characteristics, eye findings, and hearing-related features.

Historically, research and diagnostic protocols focused most heavily on conditions associated with life-threatening vascular problems or visible structural differences, largely because they were the most urgent to identify. One benefit of that focus is that it gradually produced better descriptions of subtypes and a clearer picture of the wider range of symptoms people with HCTDs can experience. Each new study, each refinement of diagnostic criteria, and each improvement in testing gives clinicians more tools to confirm or rule out conditions that fit your history, symptoms, family pattern, and exam findings. That process can feel slow on the patient's side, but over time, it makes diagnosis more accurate and care more targeted.

Co-occurring Conditions

Because collagen is found throughout the body, it is common for more than one body system to be involved in a heritable connective tissue disorder. That is one reason you may hear people use shorthand phrases such as "EDS plus the Trifecta." At first, that phrase can be confusing. In practice, it grew out of patient experience: people noticed certain patterns showing up together, compared notes, and then brought those observations back to clinicians and researchers.

> *"If you ask a general doctor on the street what EDS is, you're more likely to get 'I don't know.' But if they do know, they'll probably say it's something about joints and something about skin. Well, it's an awful lot more than that—ocular, dental, neurological, gastrointestinal, pulmonary, cardiovascular, musculoskeletal, bladder. Every single system is involved."*
>
> **— Dr. Alan Hakim, MD, MA, FRCP(UK)**

Originally, the "Trifecta" usually referred to three commonly discussed conditions: dysautonomia, mast cell activation syndrome (MCAS), and EDS. As clinicians and researchers looked more intentionally beyond the core joint, skin, and vascular

findings that were emphasized in earlier descriptions of HCTDs, they began to recognize more overlapping conditions and symptom patterns that warrant additional scrutiny and research. Over time, the conversation widened.

Co-occurring Conditions

- Cardiovascular: mitral valve prolapse, aortic root dilation, arterial fragility
- Chronic fatigue
- Chronic pain
- Dental issues: Temporomandibular Joint (TMJ) dysfunction, fragile gums, dry mouth, high arched palate, narrow jaw, crowded teeth, enamel defects
- Dysautonomia: Postural Orthostatic Tachycardia Syndrome (POTS), vasovagal syncope, orthostatic hypotension (OH), inappropriate sinus tachycardia (IST), to name a few types
- Early onset osteoarthritis
- Eye issues: detached retina, blue sclerae, lens dislocation, eye misalignment, double vision
- Gastrointestinal (GI): gastroparesis, motility dysfunction, altered intestinal permeability, malabsorption, nutritional deficiencies
- Lipedema
- Mast Cell Activation Syndrome (MCAS): allergic-type reactions
- Neurodivergence: Attention Deficit Hyperactivity Disorder (ADHD), autism, depression, anxiety
- Neurological: headaches, craniocervical instability, cognitive dysfunction ("brain fog"), Chiari malformation, tethered cord, spinal cord compression, Functional Neurologic Disorder (FND)
- Respiratory: breathing pattern disorders, restrictive lung disease, spontaneous pneumothorax
- Sleep disorders: sleep apnea, airway collapse, disrupted sleep patterns

Many of these conditions overlap, which is one reason the overall picture can feel confusing. For example, chronic pain may show up alongside dysautonomia, MCAS, sleep disorders, neurological issues, or gastrointestinal problems. Sleep problems may also be linked to chronic pain, dysautonomia, neurological symptoms, or GI symptoms. In real life, these systems often affect each other rather than staying neatly separate.

Research is still ongoing to understand how often these conditions occur in people with different types of HCTDs and which combinations tend to cluster together most

often under which type or subtype diagnosis. What matters most for you, though, is what you are actually experiencing. This list is not a checklist of expected features, and it does not mean you will develop every condition on it. It is also not a reason to rush toward invasive testing or treatment without careful evaluation. Just as diagnosing an HCTD can take time, diagnosing co-occurring conditions may also take time and may involve several specialists. To protect your energy and mental health, focus first on the symptoms you have now. Then decide which ones most need evaluation, with the practical goal of finding symptom management that helps you live as fully and steadily as possible. You do not need to read the whole horizon at once; you only need the next clear marker in the water. One of the conditions people often hear about early is mast cell activation syndrome, or MCAS.

— Mast Cell Activation Syndrome (MCAS)

MCAS is one of the co-occurring conditions that people with hypermobility, heritable connective tissue disorders, and a range of other chronic conditions may hear about early on. While it frequently appears alongside HCTDs, it is not exclusive to them—MCAS occurs across many diagnoses and is increasingly recognized as part of a broader pattern of immune dysregulation. Mast cells are part of the immune system. They help the body respond to infection, allergens, and injury by releasing chemicals such as histamine and tryptase. When that release happens too strongly or at the wrong time, it can lead to symptoms such as flushing, itching, hives, swelling, stomach pain, diarrhea, congestion, dizziness, rapid heart rate, or, in some cases, anaphylaxis. Because mast cells are present in many tissues, symptoms can involve more than one body system at once.

Diagnosis can be frustrating because MCAS is not confirmed by one simple test. Doctors usually look for repeated episodes affecting more than one body system, improvement with medicines that target mast cell mediators, and laboratory evidence of mast cell activation collected during or near a flare. Timing matters, and normal results between flares do not always settle the question. Treatment usually focuses on reducing triggers when possible, using medicines such as antihistamines and other mast cell–targeted therapies, and having an emergency plan in place if severe reactions are a risk. The practical goal is to notice patterns, document what happens, and work with a knowledgeable clinician to sort out what is contributing to your symptoms.[2]

[2] For a fuller overview of MCAS classification and diagnostic frameworks, including the difference between Consensus 1 and Consensus 2 criteria, see Appendix D.

— Dysautonomia

Dysautonomia is a broad term for conditions that affect the autonomic nervous system, which controls automatic functions such as heart rate, blood pressure, sweating, digestion, temperature regulation, and the body's response to standing upright. It is one of the co-occurring conditions that people with hypermobility, heritable connective tissue disorders, Long COVID, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), migraine, autoimmune illness, diabetes, and other chronic conditions may hear about early on. One common pattern is *orthostatic intolerance*, which means symptoms happen or worsen when a person is standing or sitting upright and often improve when lying down. Symptoms can include dizziness, lightheadedness, shakiness, fatigue, nausea, feeling overheated, a racing heart, headaches, brain fog, stomach problems, exercise intolerance, trouble standing for long periods, and fainting or near-fainting. Because the autonomic nervous system affects many body systems at once, symptoms can feel wide-ranging and difficult to connect at first.[3]

POTS is one type of dysautonomia, but it is not the same as dysautonomia as a whole. In simple terms, all POTS is dysautonomia, but not all dysautonomia is POTS. Diagnosis can take time because symptoms often overlap with many other conditions and may change depending on hydration, illness, hormones, heat, activity, or recovery from infection. Doctors often start by listening closely to symptom patterns and checking heart rate and blood pressure while lying down and standing, and some people may need additional autonomic testing. Treatment depends on the person, but may include fluids, salt when appropriate, compression garments, pacing, activity changes, and medication. The practical goal is to notice patterns, document what happens, and work with a knowledgeable clinician to better understand what is driving your symptoms and build a treatment plan that feels realistic and supportive.

As a diagnosis like this begins to make more sense, the picture often becomes both clearer and more complex. You may start to see how connective tissue, the nervous system, the immune system, pain, sleep, digestion, and daily function affect one another in ways that were not obvious before. That does not mean you need to solve everything at once. It means you can begin to notice patterns, name what is happening more clearly, and decide what needs attention first. And once a diagnosis starts to make more sense in the body, it often changes how it feels in the heart and mind as well. That is where we turn next.

[3] *For a fuller overview of dysautonomia and orthostatic intolerance, see Appendix E.*

03

After Diagnosis: Relief, Grief, and What Comes Next

> *For many people, diagnosis brings relief first: a name, an explanation, a sense that the confusion may finally start to lift. But that relief is often followed by something more complicated. A diagnosis may answer an important question, while also introducing grief, uncertainty, and the realization that care may still be difficult to access and coordinate. Knowing what is happening does not end the work. It changes the work. You are no longer drifting without a name, but you are still learning how to travel these waters with more clarity and steadiness.*

This chapter explores the emotional whiplash of diagnosis, why care rarely gets easier overnight, how identity can shift, how to tell friends, family, and coworkers without overwhelming them, and practical strategies for navigating a healthcare system that was not designed for complex chronic conditions.

The Emotional Whiplash of Diagnosis

Getting a name for what's been happening to your body can feel like relief—finally, a label that explains your symptoms. But that relief can quickly collide with reality: care may still be slow, confusing, and fragmented, and you may realize you're being asked to rebuild parts of your life around a condition that isn't going away.

You have a label, and you may still wonder whether it's the right one. That shadow of doubt is reasonable, considering how long you've been telling doctors about your symptoms and hoping they can identify the cause—and help you live well and participate fully in life.

Identity Shift After Diagnosis

Diagnosis doesn't just change your medical chart—it can change your story about who you are. Productivity, goals, hobbies, and even the way you measure "a good day" might need to be renegotiated. That can bring up frustration, anxiety, grief, and deep exhaustion—not because you're failing, but because you're adapting.

For some people, the identity shift is obvious. If you've built your sense of self around contact sports, being told to avoid them can feel like someone pulled the floor out from under you. If you were "the flexible one" who got praised for dancing or gymnastics, learning that hypermobility is part of a broader condition can be both validating and unsettling: it explains the talent *and* the injuries.

The goal isn't to erase the old identity—it's to translate it. A stage performer might become an instructor, a choreographer, a photographer, a writer, or a clinician who understands dancers because you've lived it. What you've learned about pain, recovery, pacing, and persistence is real expertise. The hard part is giving yourself permission to let life look different.

Another surprise: once the "fight" to be believed is over, your body may finally drop out of fight-or-flight. People often describe a crash—like they can't hold themselves together anymore. That's not weakness. That's your nervous system coming up for air after years of bracing, pushing through, and trying to prove you weren't imagining it.

> *"Grief—coming to terms with the loss of something important, such as a particular identity—can be an ongoing process. At some point, we move into waves of acceptance. From here, the next part of the journey can begin. It's useful to start from an informed position. Gathering information from different sources is crucial; however, not all sources of information are helpful. Care must be taken in which pieces of information you use to begin the journey towards effectively managing chronic illness."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

How to Talk About Your Diagnosis

It's natural to want to unload everything at once—years of symptoms, dismissals, and finally the moment someone put a name to it. But most people can't take in the full lecture on day one. A better approach is to invite them into the process.

- **Start with the headline.** "I got a diagnosis. It's called Ehlers-Danlos syndrome (your type)—a hypermobility-related connective tissue disorder. I'm still learning what it means."
- **Let them set the pace.** Give space for questions. Some people need small pieces over time.
- **Expect repetition.** If they ask the same question again, it may be how they're processing—not a sign they don't care. Try a new explanation each time.
- **Offer a role.** Most people want to help but don't know how. Give concrete options: rides, pharmacy pickup, help carrying things, meal prep, or simply checking in.
- **Protect your energy.** You don't owe anyone the entire diagnostic criteria or your full medical history.

Coworkers are a special case. There is no legal requirement to disclose your full diagnosis label(s) or share your medical records. If you can reliably and predictably show up and perform your job duties and meet goals, there may not be a reason to disclose anything. If you choose to disclose, keep the focus on what helps you do your job well: ergonomic equipment, a modified schedule, the ability to take short rest breaks, or a work-from-home/hybrid setup. The size and structure of your employer will shape who you need to talk to about modifications and accommodations. In a large company with a Human Resources department, start there. Your employee handbook should explain the formal process and the right person to contact. Supervisors or managers in charge of scheduling are the people to talk to if you need a schedule change or time off for medical reasons. A coworker you trust may become an ally if you let them know there is a medical reason you do certain things, such as:

- Taking a few minutes longer for bathroom breaks.
- Keeping a yoga mat on hand to lie down for a few minutes during breaks.
- Using a seat cushion you brought from home.

Start these discussions before a problem arises or your performance slips. Documentation for all of these interactions is important over the long run. Use email to create a dated record of meeting requests and follow up after meetings with your understanding of what was discussed and decided. Keep these messages somewhere you can access if you lose work email access—for example, by forwarding them to your personal address, BCC'ing yourself, or printing hard copies. When asking for accommodations, frame the request as: "To do this part of my job efficiently and effectively, I need [specific accommodations]."

Examples:

- The bus schedule gets me to the office at 7:30 a.m. or 8:25 a.m. Is it possible to change my start time from 8:00 a.m.?
- The mouse/trackpad makes my hands numb. Is it possible for the company to provide an upright ergonomic mouse?

You can be truthful without giving details that could be misunderstood or used against you. Frame requests as supports that improve reliability and performance.

Navigating Rare or Poorly Understood Conditions

Here's the part nobody tells you: a diagnosis doesn't automatically unlock care. At first, it can feel like a golden ticket—*Now that you know what it is, surely everything gets fixed, right?*

It makes sense to expect that. Many people spend years (sometimes decades) trying to explain symptoms, being dismissed, and slowly becoming sensitive to rejection from the healthcare system. So when the label finally arrives, you hope the rejection ends. You show up thinking, *Great—now you can write the referrals, treat the symptoms, and I can get my life back.*

And then reality sets in: the system may still move slowly; clinicians may still disagree; and there may not be one clear pathway. It can take years to get a diagnosis—and it can also take time to build a treatment plan that actually works for *your* body.

On top of that, the years you spent undiagnosed often left behind protective habits that were understandable at the time, but may backfire now. If you avoided activity to prevent pain or injury, deconditioning can make symptoms worse. Rebuilding strength—safely—takes time and the right support. And emotionally, rebuilding trust after being ignored or harmed by previous care takes time, too.

This is why mental health support isn't "extra." It's a core part of the care plan. If you can access a therapist, that's ideal. Group support can help too—especially when it's well moderated (the goal is shared problem-solving and normalization, not a spiral of doom). Things to look for in a support group:

- Clear rules
- Trained facilitators/moderators
- Crisis resources
- Consistent enforcement of no medical misinformation guidelines
- Boundaries around graphic symptom sharing

If cost or insurance limits your options, ask local mental health clinicians directly about sliding scale fees and consider alternatives that still provide safe support: community mental health clinics, short-term counseling programs, vetted peer support groups, clergy (if that's a fit for you), or even structured journaling to organize and release the thoughts that otherwise loop endlessly.

Structured journaling is a framework for journaling that combines the therapeutic power of journaling with an intentional pathway supported by prompts or a template with a form you complete each day that leads into free writing. There is no right way to do this. The path is your own. Here is a sample set of writing prompts:

- How would you describe yourself at age 12? How would you describe yourself now? What changed and why? Do you like the changes?
- What is important to you? What do you enjoy? Where do you find peace?
- Each day, record 3 things that gave you joy, 2 things that you would change if you did them again, and 1 thing you consider a success. Then reflect on those things and finish with lessons learned and plans for the future.

There are many journaling and writing prompts available. Ask other people in your life whether they journal and how they do it. Try out different frameworks to find one that is supportive and helps you move forward in life, rather than being stuck in negative muck.

One more thing: if you can't find a group specific to your exact diagnosis, don't assume support groups for other chronic illnesses are irrelevant. People navigating the same specialists, the same referral bottlenecks, and the same disbelief can become valuable allies.

> *"In the wake of losing our 13-year-old son, Connor, due to an aortic dissection resulting from undiagnosed Loeys-Dietz syndrome, we quickly realized the importance of knowledge and community. Because Loeys-Dietz syndrome is rare, it is often misdiagnosed or undiagnosed and shares many common traits with hypermobile Ehlers-Danlos syndrome (hEDS). This is why community building across HSD, EDS, and vascular connective tissue disorder groups is more than just support—it is a critical survival mechanism. When we share our experiences and expertise, we create a network of vigilance that can save lives, ensuring that no family is left to navigate the complexities of these conditions in isolation."*
>
> **— Bridget Porter (Metz), Loeys-Dietz Syndrome Advocate**

Building Your Care Team

A multidisciplinary team usually starts with one key person: a primary care clinician who is compassionate, curious, and humble enough to say, "I don't know—yet." That kind of clinician is gold, because you need someone who will partner with you instead of performing certainty.

It's tempting to spend all your energy hunting for *the* famous specialist with the longest publication list. Sometimes specialty clinics are important, especially for diagnostic confirmation or complex complications. Most of these clinics do not become your new main doctor. Instead, they handle diagnosis and symptom collation, then send you home with treatment and surveillance suggestions for you to work on with the care team you have at home. Be prepared to encounter waiting lists and out-of-pocket expenses (fees not covered by insurance, travel expenses, etc.). See Chapter 4, *Building a System That Supports You*, to learn how to prepare for appointments and what to bring with you.

For most day-to-day realities, your best progress comes from a respectful partnership with primary care—someone who will listen, help you prioritize, write appropriate referrals, and advocate within the system you actually have access to.

Humility matters because science is moving. Many connective tissue disorders were first described in the late 1800s and early 1900s, and classifications and criteria continue to evolve. So even a well-intentioned clinician may be out of date. The right question isn't "Do you already know everything about my condition?" It's "Are you willing to learn alongside me, and help me navigate the system?"

Common barriers are real—and not your fault:

- **Being passed between providers.** When nobody "owns" the big picture, you can end up bouncing from specialty to specialty.
- **Feeling dismissed.** Time limits, bias from prior difficult encounters, or simple unfamiliarity can lead to minimization.
- **Scarcity and waitlists.** Even large cities may have few clinicians comfortable with hypermobility-related conditions.
- **Insurance and geography.** Network restrictions, travel distance, and state licensing rules can all limit who you can see.

It can help to remember what the emergency department is built to do: stabilize emergencies, not coordinate chronic care. If something isn't immediately life-threatening, they'll often tell you to follow up with primary care—because primary care is the gateway to referrals, longitudinal planning, and coordination.

Over time, your team can grow beyond physicians to include physical and occupational therapists, mental health clinicians, dietitians, orthotists, wound care, and sometimes complementary providers you trust (for example, massage or acupuncture). The point isn't to collect providers—it's to build a network that keeps you functional, safe, and supported.

As you build that network, communicate in ways that make it easier for busy clinicians to help you: be concise, show patterns, prioritize the top issues for each visit, and ask for the *next* best step instead of trying to solve everything at once.

Conclusion: A Name, Not a Finish Line

You may have hoped that a diagnosis would be a finish line. More often, it's a starting point: a new language for what you've been living with, and a map that's still missing a few roads. If you feel relief and grief at the same time, you're not doing it wrong—you're responding to a big shift.

As your identity adjusts, try to measure progress differently. You're not just "giving things up." You're learning how to translate who you are into a life that protects your body and still reflects your values. That translation takes time, and it's allowed to be messy.

When you tell other people, you don't have to deliver the story in one sitting. Start with the headline, share in layers, and protect your energy. The right people will learn with you—and the ones who can't may still care, even if they don't understand yet.

Finally, remember that you don't need a perfect team to start getting better support—you need the next helpful step. A humble primary care clinician, a skilled therapist, one good referral, and a reasonable accommodation at work. Those pieces add up. You're building a system around you, even if the larger system wasn't built for you.

04

Building a System That Supports You

> *A good system becomes most valuable on the days when your energy is low, your symptoms are louder, or your words are harder to find. Preparation is not overthinking. It is a practical form of self-support. When appointments, records, medications, symptoms, and decisions start to pile up, even a few organized tools can reduce stress and help you communicate more clearly. This chapter is about building that kind of structure—not perfection, but enough order to make the next step easier. A well-packed boat handles rough water with less panic.*

You're about to walk into appointments that can shape your quality of life. If you live with a heritable connective tissue disorder—or you suspect you do—you may already know how exhausting it can be to explain yourself again and again. Symptoms can be inconsistent, your body can feel different from one day to the next, and when hypermobility is part of the picture, more than one body system is often involved. That can make your story hard to tell in a short visit. Most appointments focus on one main concern. Everything else gets squeezed into the last few minutes, or it does not get addressed at all. Many important conversations simply do not fit into a standard visit—not because they are unimportant, but because they take time. If you've ever left an appointment wishing you could have asked one more question, that's a sign that more time might help.

And for complex, multi-system conditions like HCTDs, that is where the real problem begins. Your symptoms do not fit neatly into one system, and your appointments are often not designed to capture the full picture you need to share.

This chapter is here to make that part easier. You're going to build a simple, repeatable system—one that works even when your energy is low—so you can show up prepared, communicate clearly, and spend appointment time on decisions instead of re-telling your entire history. You don't have to do it perfectly. You just have to do it in small steps that add up.

Remember: With hypermobility, it's normal to build your systems on good days so they can support you on hard days. Updating your summary, refilling your folder, or jotting a few symptom notes isn't overthinking—it's pacing, and it's a form of care.

Start with Your Records

Before you can advocate for yourself, you need your information in one place—especially when your symptoms fluctuate, and it's hard to remember what happened on which day. If you've ever tried to answer intake questions while you're anxious, in pain, lightheaded, or simply running out of stamina, you already know how easy it is to forget details or minimize what you've been dealing with. A record system doesn't need to be fancy; it just needs to be kind to your real life.

Start by requesting and downloading—or printing—your medical records from every place you've received care: primary care, specialists, urgent care, hospital visits, imaging centers, labs, physical therapy, and so on. Then organize them in a way that makes sense to *you*: by date, clinic, body system, or diagnosis. If you like using apps, tools such as Primary Record or Guava can help you store and search documents, but a simple folder system can work just as well.

> *"An organized patient is an empowered patient. Gathering your health story is often the first step toward advocating for yourself."*
>
> **— Shailavi Jain, RPh, BCPA**

Create a Medical Summary

Once you have the records, turn them into a summary you can keep up to date. Think of it as your "low-energy mode" tool: when brain fog hits, or a new clinician asks you to start from the beginning, you can hand them a clear snapshot instead of trying to perform perfect recall. Aim for **one page, double-sided** (or two pages total). Make **both** a digital version you can send and a printable version you can carry.

Include identifying and contact details at the top: your full name, date of birth, address, phone, email, medical record number (if you have one), primary/secondary insurance details, and an emergency contact. Add your primary care clinician and any specialist you've seen more than twice in the last year.

Then add the clinical basics in a clean, scannable format:

- **Diagnoses:** List your diagnoses (alphabetical is often easiest), the year they first appeared in your record, and—if relevant—the year they were confirmed again. Include key treatments linked to each diagnosis.
- **Medications:** Include prescriptions, over-the-counter medications, and supplements. For each one, note the dose, schedule, and who prescribed or recommended it.
- **Allergies and intolerances:** Include drug allergies and intolerances, food allergies and intolerances, and environmental allergies. When possible, note when each one was identified, whether it was confirmed, and any treatments or precautions that go with it.

This summary becomes your cheat sheet for intake forms and new visits, and it can save appointment time because your clinician can scan it and quickly decide what to dig into in the full chart. It also narrows the "scrolling problem"—the more dates and specifics you provide, the less time they spend hunting.

Make it an emergency tool, too. Keep a printed copy somewhere that first responders are trained to look, such as on the refrigerator or inside a front door. Consider keeping a copy in your bag or wallet as well. Many people assume, "It's in my phone," but in a real emergency, a phone may be locked, dead, lost, or not clearly associated with the right person. Paper is still one of the fastest ways to get critical information to an emergency room.

Set a reminder to update this summary whenever you start, stop, or change a medication or supplement, or whenever your diagnoses change.

Build a Running List of Symptoms and Concerns

Next, give yourself permission to do this in stages. Open a notes app, a notebook, or a simple spreadsheet. For one to two weeks, every time you notice a symptom, a concern, or a question you want answered, add it to the list. If you're hypermobile, you may notice that your symptoms don't stay neatly in one category—pain, fatigue, GI issues, dizziness, headaches, skin changes, and joint instability can overlap. That doesn't mean you're "too complicated." It means your body is asking for a clearer map.

Once you have a long list (and you probably will), sort it in a way that helps you think and communicate:

- **Group by body system:** When you can, sort symptoms into categories such as GI, respiratory, neurological, musculoskeletal, or skin.
- **Duplicate cross-system items:** If one issue spans multiple systems—for example, an allergy issue that affects skin, breathing, and digestion—list it in more than one place and add a note so you remember it is the same underlying concern.

Prioritize What Matters Most Right Now

Now ask yourself a practical question: *Which issues are most disruptive to my life—or most concerning to me?* Impact matters. Fear matters. Function matters. And it's okay if your answer changes from month to month; with chronic conditions, your priorities can shift as your body shifts.

Choose your **top 10 concerns** and treat them as your agenda for the next year of care. Then, for your next appointment, pick the **top three**. This helps you show up with focus while still communicating that there's a bigger picture.

When you share your top items, you're doing something important: you're signaling that you want a collaborative relationship over time. You're also "planting seeds" so your clinician can start thinking, researching, or noticing patterns between visits. And you're keeping expectations realistic—most appointments can truly address only one or two issues well.

Also include routine health maintenance on your list (vaccines, annual labs, screenings such as mammograms, etc.). It helps your clinician see that you're approaching your health as a whole person—not only as a single chronic condition.

Track Symptoms Clearly

It's hard for anyone to act on a vague report like "my leg hurts." What helps is a short, specific description: what happens, when it happens, what makes it better or worse, and how it affects your life. This is especially true with hypermobility, where pain may move around, joints may feel unstable, and symptoms can flare after activity that looks "normal" on the outside. You don't need perfect data—you just need enough detail to make your experience easier to understand.

Pick a method you can actually sustain: a paper journal, a calendar, a notes app, or a symptom-tracking app. Wearables and phone apps can also be useful if they capture data that relates to your experience (sleep, activity, heart rate, blood pressure, etc.). You're not trying to become your own clinician—you're trying to show patterns.

When you're tracking pain or other fluctuating symptoms, consider logging:

- **Intensity:** Note the intensity of the symptom, whether that is pain, fatigue, dizziness, or another measure that makes sense to you.
- **Location:** Record where it happens and whether it moves around.
- **Activity beforehand:** Write down what you were doing before it started or worsened, including activities that may seem small.
- **Instability sensations:** Note any feelings of giving way, slipping, popping, or subluxation-like movement.
- **What you tried:** Record what you used in response, such as rest, heat or ice, medication, bracing or tape, position changes, pacing, or gentle movement.
- **What changed:** Note what made it better or worse and how long it took to settle.

Over time, this gives you something powerful: a way to describe frequency, triggers, persistence, and what you've already tried—without relying on memory in the exam room.

Prepare for Appointments

Before an appointment, choose your top three issues from your list. For each one, plan a **two-sentence summary** that includes the pattern and the impact. Then bring your supporting details from your journal if your clinician asks. Write down your **top three concerns in order of priority** before you go. Do not wait and hope the clinician will naturally get to the issues that matter most to you. If you know what you need to cover, say it early. It also helps to track your symptoms in advance, especially patterns in timing, triggers, and what makes things better or worse. A short written

summary is often much more useful than trying to explain everything out loud in the moment. You should also bring an updated list of your medications and supplements, including doses, so you do not have to rely on memory during the visit.

You do not need to arrive with binders full of evidence. If you have tracked your symptoms, noted the patterns, and prepared your two-sentence summary, you already have what you need. The summary is your headline, and everything you have documented is there to support it if your clinician asks for more detail.

"In the last 30 days, my knee felt like it was giving way nine times while walking. If I stop and sit down, the sensation and pain usually resolve within about 30 minutes; straightening the knee and rubbing the painful area helps. This is interfering with my ability to take care of myself and is eroding my confidence about leaving the house safely. Will you help me figure out why this is happening so frequently?"

When you answer questions during an appointment, try to be as honest and specific as you can. The clearer and more concrete your explanation is, the easier it is for your clinician to understand what's happening and build a plan that actually fits your life.

— Scheduling the Appointment

When you make the appointment, ask whether you can send a concise note in advance that lists your top three concerns. If your situation is complex, ask whether longer appointments are available. If you plan to bring a care partner or support person to help you take notes, let the office know ahead of time.

— During the appointment

During the visit, state your agenda early. You can say something simple like, *"I have three things I need to cover today."* That helps set expectations and keeps the conversation focused. If something is not clear, ask for an explanation in plain language. You have every right to ask, *"What does this mean for my daily life?"* or *"Can we look at the actual numbers, not just whether this is normal?"* If it fits your situation, you can also ask, *"Could this be related to dysautonomia or connective tissue issues?"* or *"What is the next step if this does not improve?"*

If it would help, bring someone with you to take notes and give them a copy of your priorities list ahead of time. At the beginning of the appointment, share your list with the doctor so your main concerns are visible from the start. Before you leave, repeat back the plan in your own words and ask whether you understood it correctly. This is especially helpful because miscommunication is common at the end of rushed visits.

As you review the plan, make sure you understand the important next steps. That may include whether a diagnosis was confirmed, whether a new diagnosis is being considered, what treatment options were discussed, whether a new medication was prescribed and why, how and when to take it, what side effects to watch for, and who to contact if those side effects become concerning. You may also want to confirm which pharmacy the prescription was sent to, when your next appointment should be, and whether any referrals were made. If referrals were placed, ask whether the office will contact you or whether you need to call and schedule those appointments.

— Following up after the visit

After the visit, review your encounter note through the patient portal, if available. If something still feels unresolved, send a brief follow-up message or schedule another appointment focused on that concern. If you felt dismissed or misunderstood, it is reasonable to bring that up directly at your next visit. You can also ask when you should expect results, how long follow-up may take, and when you are supposed to come back. When you use the portal, keep your message concise and focus on one clear question at a time.

> *"Whether you're managing your healthcare journey independently or with the help of an advocate, keeping your records organized and staying on top of your appointment summaries is essential. Regularly reviewing these summaries allows you to catch errors early and ensure your doctor accurately documents your concerns. Remember: if the record is incorrect, you have the power to request changes."*
>
> **— Caroline Kim, BCPA, MSJ**

Use Home Tracking to Support Care

If you've lived with chronic symptoms for a while, you may have had visits where you left feeling unheard or oversimplified. That experience is real—and it can make it hard to trust the process. At the same time, many clinicians start with the basics because they're trying to rule out common contributors and keep you safe.

When it makes sense—and only to the extent you have capacity—document the basics you've already worked on. Track hydration for a week. Keep a brief food note. Write down what helped your sleep, what worsened it, and what changed when you paced your day differently. This isn't about proving you "deserve" care. It's about

giving your clinician a clearer starting point so you can move faster toward the next useful step—testing, referrals (like physical therapy with hypermobility-informed clinicians), supports, and treatment options.

Healthcare decisions are some of the hardest decisions you will ever make, especially when your condition is lifelong, complex, or still being figured out. Preparation does not guarantee perfect care, but it does increase the odds that you will be heard, believed, and helped. And on the days you can only do a little, that still counts. One updated line in your summary, one week of notes, or one clear question can build real momentum.

Self-Advocacy Without Extra Overwhelm

Everything you have done so far—collecting records, building a summary, prioritizing symptoms, and tracking patterns—is self-advocacy. If you live in a hypermobile body, you have probably already spent years adapting, compensating, and pushing through. This chapter is about turning that hard-earned knowledge into something the medical system can quickly understand. The goal is simple: make it easier for a clinician to see the full picture and for you to hold on to your voice during the visit.

— Your medical summary is your foundation

If you only do one thing from this chapter, make it the medical summary. See the Prepare for Appointments section above for everything you need to get started.

As you move forward, remember what you are really building: a shared language with your care team. When you can summarize your history, name your priorities, and describe your symptoms with specifics, you give your clinician something they can work with—and you give yourself more stability in a process that often feels uncertain. You do not have to do everything at once. You can build this system on your good days and let it carry you on the hard days. You are not "too much." You are doing your best in a body that asks for creativity and care.

You Do Not Have to Do This Alone

If this chapter brought up a lot, please know this: you are not alone, and you are not expected to carry all of this by yourself. It is okay if the process feels like a lot. Building systems for your care is something you can do slowly, gently, and with support. You do not have to do everything at once, and you do not have to do it

perfectly for it to help. Support can come from a trusted friend, family member, care partner, or a professional advocate who can stand beside you as you organize records, prepare for appointments, track symptoms, and communicate with your care team.

The best advocates do not start only with your diagnosis or what is written in your chart. They start with your full story. That includes your living situation, what matters most to you, your goals, your day-to-day responsibilities, and the resources you have available. When someone understands that bigger picture, they can help you formulate better questions, connect symptoms across multiple systems, and think through next steps that actually fit your life.

If you need more structured guidance, a Board Certified Patient Advocate (BCPA) can help with everything described in this chapter—and often more. A BCPA can help you organize records, prepare for appointments, track symptoms, clarify your concerns, identify support services, explore accommodations at work or school, and connect with community resources that fit your needs and circumstances. In other words, they can help you build the kind of support system this chapter describes and strengthen it in ways that make moving forward feel more possible.

> *"Hiring a professional patient advocate isn't a sign of defeat; it's a strategic choice to clear the hurdles in your way. Whether you need an expert to manage the heavy lifting of a medical records request, a guide to decode complex treatment options, or a bridge to the right care providers, an advocate is a powerful ally. They ensure your voice is heard today, while building the foundation you need to confidently stand up for your own health tomorrow."*
>
> **— Caroline Kim, BCPA, MSJ**

Tips for Hiring the Right Patient Advocate

Look for someone who listens before offering solutions. A good advocate should take the time to understand your story, goals, concerns, and priorities before recommending next steps.

Find someone who sees the whole picture. EDS rarely travels alone. Look for an advocate who understands common related conditions such as POTS, MCAS, gastrointestinal issues, chronic pain, and fatigue, and who can help connect the dots across multiple providers.

Ask about their training and scope of services. Advocacy is a broad field. Make sure you understand what services they provide, whether they have specialized training related to EDS or chronic illness, and how they can support you.

Choose someone whose approach aligns with your values. Whether you prefer a conventional, holistic, or blended approach to healthcare, your advocate should respect your preferences and support informed decision-making.

Consider whether lived experience matters to you. While not required, personal experience with chronic illness or caregiving can bring a level of empathy, patience, and practical understanding that is difficult to teach.

Pay attention to how you feel after speaking with them. The right advocate should help you feel less overwhelmed, more informed, and better prepared to move forward.

— Shailavi Jain, RPh, BCPA

Conclusion: Building a System That Supports You

You do not need a perfect body—or a perfect explanation—to deserve good care. If you live with hypermobility and chronic symptoms, your experience can be real even when it is variable, hard to measure, or difficult to fit into a single box. What you are doing here is practical and brave: you are turning a complicated lived experience into a clear story that someone else can understand and act on. And you are doing it in a way that respects your energy.

Use this checklist to keep it simple. Think in short horizons—what you can do today, what you can do this week, and what to prepare right before your next appointment.

— Today (10 minutes counts)

- **Start a running note:** Open a note titled "Symptoms + Questions" and add three to five bullets—anything you do not want to forget.
- **Create a folder:** Make one digital folder or one physical binder labeled "Medical Records."
- **Write your one-sentence why:** Add a line at the top of your note: "Right now, I most need help with [your most pressing symptom or concern] because [how it is affecting your daily life]."

— This week (one small task on a good day)

- **Request records:** Ask for records from the key places involved in your care, starting with the last 12 to 24 months: primary care, top specialists, imaging, labs, the ER or urgent care, and physical therapy.
- **Draft your one- to two-page medical summary:** Include identifying information, insurance, an emergency contact, your care team, diagnoses with dates, key treatments, medications, and supplements, and allergies or intolerances.
- **Choose your tracking method:** Pick one tool you will actually use, such as a calendar, notes app, or journal, and log symptoms for seven days.
- **Sort your symptom list:** Group symptoms by body system and duplicate cross-system issues so they do not disappear.

— Before your next appointment (the day before or the morning of)

- **Pick your top three:** Choose the three issues you most want addressed at this visit.
- **Write two sentences for each:** Use one sentence for the pattern—how often it happens, when it happens, or what triggers it—and one sentence for the impact—what it stops you from doing.
- **Bring one clear ask:** End with the kind of help you want, such as an evaluation, a referral, treatment options, or the next step.
- **Make it portable:** Bring or attach your medical summary and any key results, and keep a printed copy accessible at home for emergencies.

— Ongoing: When meds/supplements or diagnoses change, update your summary—one line at a time. Small updates keep your system seaworthy.

05

Making Decisions When Things Are Hard

> *Not every symptom, recommendation, or decision carries the same weight. Some situations are urgent, some are important, and some can safely wait until you have more information and more steadiness. When you live with a chronic condition, decision-making is rarely simple, and pressure can make everything feel equally immediate. This chapter is about learning how to sort urgency from noise, ask better questions, and make choices that are safer, more sustainable, and more aligned with the life you are actually living. Good navigation is not only about moving forward; it is about knowing when to hold your course, when to anchor, and when to wait for clearer weather.*

This chapter is about how to make difficult healthcare decisions. It covers due diligence, how to find reliable sources, when and how to seek second opinions, understanding that it is okay to say no to a treatment or procedure, recognizing that "let's wait and see" can be a valid choice, and knowing when it may be appropriate to take an intentional break from healthcare to recover emotionally and physically.

Living with a heritable connective tissue disorder, a hypermobility spectrum disorder, or another chronic illness can turn you into an expert decision-maker—sometimes earlier than anyone should have to. Here's the thing: when your body is unpredictable, choices show up faster than clarity does. This chapter invites you to slow the moment down, take a breath, sort urgency from importance, and choose next steps that fit your life—not just your diagnosis.

Start with Priorities

When symptoms stack up, it can feel like every problem is equally loud. Quick reality check: they're not. Some issues are urgent, some are important, and some are "real, but not first." If you can, start by asking, "What keeps you safe and alive? What preserves function? What supports work, caregiving, relationships, and joy?" Prioritizing like this isn't giving up—it's how you keep moving.

> *"The difference between body awareness and fixation is often a fine line. Decision trees can be helpful here; start with simple questions with simple solutions. 'I feel yucky. Am I thirsty? Have a drink. Am I hungry? Have a snack. Am I tired? Take a short rest.' This helps to review both common causes of feeling unwell and more specific symptoms. The goal is to be able to identify urgency—does this symptom need a doctor right away, or is it okay to monitor and wait—without your life being ruled by body scans, symptom checks, and wellness apps. It's too much noise—it's exhausting and overwhelming—and leaves no room for anything else. I want my patients LIVING with chronic illness, not constantly fighting it."*
>
> **— Dr. Sarah Cohen Solomon, MD, FAAP, Pediatrician**

Then there's the practical side—because your life is part of the equation. What insurance do you have, and what does it actually cover? What specialists are within driving distance? What are the out-of-pocket costs—money, time off work, transportation, childcare, energy? You're not "being difficult" for factoring that in. You're being realistic.

One more helpful frame: clinicians see problems through the lens of their training. A surgeon is trained to solve problems surgically. A specialist may size everything up by asking themselves, "Is this a candidate for what I do?" That doesn't make them wrong. It just means you may need more than one lens—and you're allowed to collect them.

Vetting Providers (and Knowing When to Walk Away)

You're allowed to interview your clinicians. Truly. Think of it less like "being picky" and more like building a team—especially when your body is complex, and recovery may be slower or less predictable.

- **Experience and comfort:** How familiar is your clinician with hypermobility/HCTDs? If they're not familiar, are they willing to learn and collaborate?
- **Communication:** Do they explain options, risks, and uncertainty in plain language? Do they welcome questions?
- **Shared decision-making:** Do they ask what matters most to you (function, pain control, stability, stamina, work, caregiving)?
- **Coordination:** Are they willing to communicate with PT, primary care, and other specialists?
- **Recovery realism:** Do they discuss recovery timelines and accommodations—not just the procedure itself?

Red flags that often justify a pause—or a clean exit—include: If your gut says, "Something is off here," you can take that seriously.

- Dismissing symptoms as anxiety, deconditioning, or "normal," without an evaluation.
- Refusing to explain risks, alternatives, or expected recovery.
- Pressure to decide quickly when the situation is not urgent.
- Shaming language (e.g., blaming the patient for being "too complicated" or "noncompliant").
- Unwillingness to document concerns, review records, or coordinate care.

It's really common to explain new symptoms as "just part of the condition." Sometimes that's true. But sometimes it can delay the diagnosis of something separate and treatable. So if something is new, changing, or feels meaningfully different from your baseline, you're not overreacting by getting it checked. Chronic illness is not a blanket explanation for everything.

In plain terms, you can ask: Is this an emergency (risk to life, limb, eyesight, breathing, severe neurological change, uncontrolled bleeding, sudden severe pain unlike your baseline)? Is it urgent (needs treatment within 24–72 hours)? Or is it appropriate for primary care/specialty follow-up? You don't have to get this perfect—you just have to make the safest call you can with the information you have. It can also help to keep a short "what's normal for me" list—baseline vitals, typical pain patterns, known

dislocations/subluxations, usual migraine features—so you're not trying to remember everything while stressed.

Choosing the Safest Path You Can

With connective tissue conditions, the same intervention can carry a different risk profile than it does for the general population—sometimes because of tissue fragility, autonomic issues, bleeding tendencies, medication sensitivities, or past anesthesia reactions. Those risks can also differ meaningfully between connective tissue conditions themselves. In some disorders, such as Marfan syndrome, vascular Ehlers-Danlos syndrome (vEDS), or Loeys-Dietz syndrome (LDS), surgery may carry a greater risk or become more time-sensitive than it would in hEDS or HSD. So, unless it is an emergency, when someone recommends a medication, procedure, or surgery, it is fair to slow it down and ask for a clearer picture of the risks and benefits: What is the benefit? What is the most likely downside? What is the worst-case scenario? What would make this unsafe for your body?

- **Medications:** potential side effects and any condition-specific cautions to discuss with the prescribing clinician.
- **Procedures and injections:** what tissues are involved, what nerves could be irritated, and what supports recovery.
- **Surgery and anesthesia:** prior reactions, airway and positioning considerations, and post-op pain control plans.
- **Activities:** identifying what is higher risk for you (falls, impact, heavy lifting, extremes of flexibility) and what safer substitutions exist.

> *"When trying to make a decision but you can't see the forest for the trees, or you're overwhelmed by choices, try shifting your perspective. Ask yourself: if this decision were about someone I cared deeply about, what would I advise them to do?"*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

Second Opinions and the Right to Say "Not Yet"

When a procedure is recommended, you're allowed to do due diligence. You also don't have to decide on the spot (unless it's truly an emergency). Wherever possible, gather more than one option, because a single opinion is still just one viewpoint. Getting a second opinion isn't disloyal—it's a normal part of responsible care,

especially when the decision is elective, expensive, irreversible, or likely to require a long recovery.

If you can, look beyond the first few weeks. What happens a year, three years, or ten years later? When you ask others about a surgery or procedure, try listening for patterns: Would they do it again? What complications showed up later? What helped? What do they wish they'd known before?

Questions that support informed consent include:

- How many times have you performed this procedure?
- How many times have you performed it on someone with hypermobility or a connective tissue disorder?
- What is the typical healing time in the general population—and what adjustments do you recommend for my history?
- What are the non-surgical or less invasive alternatives?
- What does rehab usually involve (PT frequency, bracing, activity restrictions), and what happens if flare-ups delay rehab?
- Could changing one joint or structure create problems upstream or downstream (compensation, instability, nerve irritation)?
- What are the signs that should prompt urgent follow-up after the procedure?

Most importantly, remember you have the right to decline. You don't have to pursue a treatment simply because it's popular in a support group or because a clinician is confident. It's okay to say, "I'm not ready," or "I want to try conservative options first," or "I need another opinion." "That helped someone else" is useful information—but it is not a mandate.

"Wait and See" Can Be an Active Choice

If the situation is not life-, limb-, or eyesight-threatening, delaying a decision can be wise. But that threshold is not the same across all connective tissue conditions: what may be reasonable to monitor in hEDS or HSD may require faster action in vEDS or LDS. In Marfan syndrome, vEDS, and LDS, aortic or arterial surveillance—and timely intervention when indicated—can be life-preserving and not safely deferrable. Waiting can create space to collect records, consult another specialist, trial conservative care, or simply see whether symptoms settle. In chronic illness, timing is part of treatment—and "wait and see" can be a plan, not a shrug.

Defining Recovery Periods (and Protecting the Rest of the Body)

Recovery is rarely just "healing the site." It's also preventing deconditioning, managing pain, protecting joints from compensation patterns, and keeping your nervous system as steady as possible. Many hypermobile bodies lose strength quickly with inactivity, so it can help to ask your physical therapist, "What can I safely keep moving while this area rests?"

And yes—this is where the connective-tissue mantra comes in: start low and go slow. You may need longer timelines than the "average patient," because collagen differences, autonomic symptoms, and flare cycles can change the pace. That isn't a personal failure. It's just data.

One more thing to keep in mind: anything invasive—needles, incisions, implants—can irritate nerves and tissues. Most of the time, your body adapts. Still, it helps to ask ahead of time what sensations are expected, what would be concerning, and what the plan is if nerve symptoms show up.

> *"While one area of the body rests or recovers, it can be helpful to continue moving safely in other ways if possible. Gentle movement and breathwork can support circulation, reduce deconditioning, maintain confidence, and help regulate the nervous system. This does not mean pushing through pain or ignoring warning signs. Instead, focus on adapting movements to your current capacity rather than stopping completely. This may mean breathing practices, meditation, or gentle movements you can do in bed."*
>
> **— Jeannie Di Bon, MSc, MA, Movement Educator & Hypermobility Specialist**

Taking Intentional Breaks from Healthcare

After enough appointments, tests, and phone calls, you might hit medical fatigue. That's not weakness—it's a normal response to a high-demand reality. If it's safe, an intentional break can be a legitimate health choice. It gives you space to be more than a patient: to rest your mind, reconnect socially, and make room for meaning and pleasure. The break isn't denial; it's pacing. (Emergencies, rapidly changing symptoms, and recommended vascular surveillance should not be delayed and still deserve prompt attention. See Appendix C for urgent-care warning signs.)

Conclusion

QUICK RESET CHECKLIST

- **Name the priority:** What is urgent vs. important vs. "real, but not first"?
- **Take inventory:** Insurance coverage, distance to care, money/time/energy costs, support needs.
- **Remember the lens:** What is this clinician trained to do—and what other perspective is missing?
- **Vet the provider:** Experience with hypermobility/HCTDs, communication style, coordination, recovery realism.
- **Watch for red flags:** Dismissal, pressure, shaming, refusal to explain risks/alternatives, poor coordination.
- **Choose the right setting:** Emergency vs. urgent vs. primary/specialty follow-up.
- **Don't blame everything on the diagnosis:** New or changing symptoms still deserve assessment.
- **Ask for risk stratification:** Benefit, likely downsides, worst case, and what would make it unsafe for your body.
- **Get a second opinion when it matters:** Especially for elective, expensive, irreversible, or long-recovery choices.
- **Use informed-consent questions:** Clinician experience, alternatives, realistic timeline, rehab demands, downstream effects, warning signs.
- **Claim the right to "not yet":** Declining or delaying can be a valid decision.
- **Make "wait and see" active:** Gather records, try conservative care, track patterns.
- **Plan recovery as a whole-body event:** Prevent deconditioning, protect other joints, start low and go slow.
- **Take intentional breaks when safe:** Pacing includes rest from appointments, calls, and medical decision load.

If you live with hypermobility or a heritable connective tissue disorder, decision-making isn't a single moment—it's a long practice. Some days you'll feel clear; other days you'll feel flooded. Either way, you can return to the basics: separate urgency from noise, ask for the information you deserve, and choose the path that protects function and quality of life. When a choice is hard, it doesn't mean you're failing. It usually means the situation is complex, and your care requires nuance.

Over time, the focus shifts less from finding the "perfect" answer and more toward taking the next right step with the best available knowledge—then checking in again without shame. You can seek second opinions, say "not yet," ask for safer alternatives, and take breaks when your nervous system is tapped out. And if something is new, severe, or rapidly changing, it is reasonable to treat it as real and worthy of prompt medical attention. In the end, informed care isn't only about what is done to your body; it's also about how well you're listened to along the way. Good decision-making is part of learning when to sail, when to anchor, and when to wait for clearer weather.

06

What Integrative Care Looks Like in Real Life

> *When symptoms involve more than one body system, care often works best when multiple kinds of expertise are involved. Integrative care is not about collecting the largest possible team. It is about building a workable support structure where different people and strategies can contribute without pulling in opposite directions. For many people with connective tissue disorders or hypermobility, that kind of care does not happen automatically. This chapter is about what integrative care means, why it matters, and how to build it even when the system around you is fragmented. What matters is not the biggest boat. It is the right crew for the waters you are in.*

You've probably noticed that living with chronic illness, a connective tissue disorder, or hypermobility rarely fits into neat medical boxes. Symptoms overlap, flare patterns change, and your body can respond to stress, movement, hormones, sleep, and nutrition in ways that feel hard to predict.

When care is organized one specialty at a time, you can end up doing a lot of the "connecting the dots" yourself—simply because no single appointment is designed to hold the whole picture. Integrative care is one framework that tries to address that gap. In this chapter, you'll explore what integrative care means, why standard healthcare can feel especially mismatched for multi-system bodies, and what it can look like to build a workable network of support—whether or not you have access to a formal integrative clinic.

> *"Everything in the body is connected, but medicine is often taught and practiced in separate systems. In reality, sleep affects pain, pain affects the nervous system, the nervous system affects digestion, and digestion affects energy and nutrient status."*
>
> **— Dr. Linda Bluestein, MD, Integrative Pain Medicine Physician**

What Integrative Care Means

Integrative care is a way of approaching health where multiple specialties support you as a whole person—not as a collection of separate problems. In the best version of this model, you are at the center, and your care team communicates with one another so that treatment decisions are coordinated rather than conflicting.

For people with connective tissue disorders and hypermobility, this matters because symptoms often cross the boundaries of medical specialties. Your lived experience is inherently "integrated," even when the system around you isn't.

Sometimes integrative care happens in a dedicated clinic. You might move from one specialist's office to another in the same building, or you might stay in one room while different providers rotate in. In an ideal setup, the team shares notes, consults together, and includes you in shared decision-making—because you're the one living in your body every day.

Even when a clinic uses the word "integrative," the experience can vary. Some settings truly coordinate across specialties; others simply offer many services under one roof. Knowing that range can help you make sense of what you're being offered—and what still feels missing.

Why Standard Healthcare Models Can Feel Like They Don't Fit You

If you have a connective tissue disorder or hypermobility, you already know that symptoms can span multiple systems: joints, muscles, nerves, digestion, sleep, heart rate, pain processing, and mental health. Standard healthcare is often organized into "silos," where each specialty looks at one slice of the picture.

Siloed care can be useful for focused problems. But when your symptoms interact, it can create a familiar experience: you describe a pattern, and each provider can only

respond to the part that falls inside their lane. The result is that the overall story of your health can start to feel fragmented—like it belongs to no one.

This isn't a personal failure. It's largely a system design problem—one that wasn't built for complex, multi-system conditions. And it's why you may leave appointments thinking, *But no one is looking at the whole map.*

When You Become the Coordinator

Even in a formal integrative clinic, you may still need to coordinate parts of your care. And when an integrative clinic doesn't exist in your area—or your insurance doesn't cover the version you need—care can become a patchwork of local providers, hospital systems, and community resources.

That patchwork isn't a reflection of how "serious" your symptoms are. It's often just what's available. But it can be exhausting, especially when your energy and pain levels are already stretched thin.

In practice, that can mean you're the person doing the "in-between" work:

- Tracking symptoms over time (what's new, what's better, what's worse, and what seems connected)
- Keeping your records organized so you can share the right information with the right provider
- Asking providers to send notes or letters to each other (and following up when that doesn't happen)
- Bringing a clear "why I'm here today" to each visit so your limited appointment time goes further

If reading that list makes your shoulders tense, that makes sense. Coordinating care is real labor—often invisible, rarely reimbursed, and frequently done while you're symptomatic. The goal isn't to become perfect at it. The goal is to reduce avoidable stress, increase continuity, and help you feel more informed and less bounced around.

> *"It is an absolute must to understand that mind/brain and body are inextricably linked. They are all part of one system. Changing one thing in the system will affect other parts of the system. Reconnecting with values, changing mindsets, and feeling emotions can absolutely change the intensity of symptoms."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

What an Integrative Care Team Might Include

Your exact team will be unique to you. It can shift based on symptoms, testing, access, finances, and the season of life you're in. Many people with connective tissue variants end up drawing support from some combination of the following—not because they're "too complicated," but because their bodies involve multiple systems.

- **Primary care**: Someone who can hold the "big picture" and help with referrals
- **Genetics**: For evaluation, diagnosis, and documentation when needed
- **Orthopedics/sports medicine**: For joints, injuries, and structural issues
- **Podiatry**: For foot mechanics that affect your whole chain—ankles, knees, hips, back
- **Movement support:** Such as physical therapy and occupational therapy, and sometimes hypermobility-informed Pilates, yoga, or other modified movement
- **GI care:** Especially for motility and gut disorders
- **Neurology**: For headaches, neuropathic pain, autonomic symptoms, and sleep-related concerns
- **Cardiology**: For heart rate and blood pressure patterns, when relevant
- **Mental and emotional health support:** Therapy, support groups, skills-based programs, and community
- **Nutrition and hydration support**: Dietitian support, evaluation for deficiencies, and practical strategies you can actually sustain
- **Sleep evaluation**: Sometimes including a sleep study and treatment such as CPAP when appropriate

You do not need all of these at once. You might only need a few right now. You might also need breaks from appointments. An integrative approach can be built in layers, and it can change over time.

Integrative Care Includes Daily Supports

One reason integrative care can feel different is that it makes room for what happens outside the exam room. Your symptoms don't only show up during appointments, and your support plan can't only live there either. Often, what helps most is not a single dramatic intervention but a set of steady supports that make daily life a little more workable.

— Movement

With hypermobility, movement is often less about "pushing through" and more about stability, pacing, and injury prevention. Modified movement can be a form of protection—not a sign you're doing less. The right approach tends to respect pain, fatigue, and joint limits while gradually building support around vulnerable areas.

> *"When someone has a hypermobility disorder such as Ehlers-Danlos syndrome, movement is medicine. But the prescription has to be individualized—one built around training the deep muscles to support loose joints, calming the nervous system, and developing awareness of where the body is in space. And like any prescription, it is about consistency."*
>
> **— Sabrina Vaz, Pilates Instructor & Certified Somatic Practitioner**

— Mental and emotional health

Chronic illness is stressful. It can be isolating. It can also be deeply invalidating—especially when you're repeatedly misunderstood, minimized, or told to explain symptoms that don't fit tidy categories.

Mental health support isn't a statement that your symptoms are "in your head." It's an acknowledgment that your nervous system has been carrying a lot for a long time. Support can help with coping skills, grief, trauma responses, and the sheer ongoing effort of living in a body that needs more care than most people can see.

MENTAL HEALTH SUPPORT

Finding care is a crucial part of recovery. You are not alone, and support is available. For free and low-cost resources, including support groups and crisis hotlines, visit The Ehlers-Danlos Society's Mental Health Resources page. You can also access their comprehensive Mental Health Care Toolbox for further practical support.

— Nutrition

Nutrition guidance tends to work best when it's personalized and realistic—especially if you have GI symptoms, sensory needs, fatigue, or budget limits. For many people, the most helpful focus is steadier fuel, fewer avoidable flare triggers when possible, and targeted support for deficiencies that show up in lab results.

— Hydration

Hydration needs can be different when dizziness, temperature regulation issues, or autonomic symptoms are part of your baseline. It can help to know that "drink more water" isn't always sufficient—or even tolerated. Your care team can help you think through what hydration support means for you, and whether strategies like electrolytes are appropriate.

— Sleep

When sleep is disrupted, everything can get louder: pain, brain fog, reactivity, and fatigue. Sleep problems are also easy for systems to overlook—especially if the focus stays on daytime symptoms. If sleep is a persistent struggle, you deserve an evaluation, not just reminders to "sleep more." Sometimes a sleep study and targeted treatment can shift your baseline more than you'd expect.

Patient-Led Decision-Making

Integrative care is not just about having a list of providers. It's also about what happens when your real life meets the medical system: limited energy, limited time, financial constraints, and the emotional weight of repeated appointments. Your capacity matters. Your tolerance for medical logistics matters. Your priorities matter.

In other words, you are not only choosing treatments—you are choosing what you're willing (and able) to carry.

Some people find it grounding to return to a few gentle questions when decisions start to pile up:

- What is my biggest limiter this month—pain, fatigue, instability, sleep, GI symptoms, or something else?
- What is one change I could trial without destabilizing the rest of my life?
- Which treatments feel worth it, and which ones feel like too much right now?
- Do I want medications, devices, or evaluations (like a sleep study)—or do I need more information first?

You're allowed to pace your care. You're allowed to say, "Not yet." You're allowed to revisit decisions later with new information. Needing time doesn't mean you're failing—it often means you're responding wisely to a system that asks too much of you at once.

The Often-Missed Silo: Dental Care

Many people with connective tissue variants deal with dental and jaw issues, yet dental care is often separated from the rest of healthcare. That separation can create gaps—especially when decisions made by your dentist and your medical team affect each other.

People with HCTDs may have tooth, gum, and jaw symptoms related to their diagnosis. Regular cleanings and checkups can help catch problems before they become urgent or require more invasive treatment. A good dentist can watch for bruising, bleeding, and healing issues, and their team of hygienists and dental technicians has specialized training to help prevent infections that could spread and become bigger problems. They also offer various options for pain relief and comfort during cleanings and at-home care, which can make a real difference when your mouth, jaw, or body is more sensitive.

If dental care is part of your picture, you may find that you are the one acting as the bridge: sharing records, requesting letters, and helping your medical team understand what is happening on the dental side. If you have a care partner or advocate, this is one of those places where support can really matter—because it can be a lot to hold on your own.

Building Care Without an Integrative Clinic

If you don't have access to an integrative clinic, you can still build an integrative *approach*. For many people, the first real "integrative" support comes through community—learning from others with similar bodies, finding hypermobility-informed providers, and gathering language for what you're experiencing.

This isn't about doing medicine on your own. It's about not being alone as you navigate a system that often requires extra translation to address complex conditions.

As you build your network, one practical question matters more than almost anything else: **How willing is this provider to communicate and collaborate?** Coordinated care is not just a nice bonus; for multi-system bodies, it can be the difference between steady progress and constant backtracking.

And if you're starting from scratch: go gently. You're not behind. You're responding to a reality many people never have to see—that building care can be as demanding as receiving it.

Integrative care, at its heart, is a way of naming what you've known all along: your body doesn't divide itself into departments. You deserve care that recognizes patterns, supports your full life, and doesn't make you earn belief through exhaustion. Even small steps toward coordination—one collaborative provider, one clearer record, one daily support that steadies your baseline—can be meaningful. And you're allowed to build that kind of care slowly, in a way that honors your limits. Over time, the right crew makes the journey more workable.

PART II

Daily Life in a Real Body

Chapters 7 - 11

- Chapter 7: Listening to Pain, Building Support
- Chapter 8: When Rest Does Not Restore You
- Chapter 9: Rethinking Pacing
- Chapter 10: Practical Supports for Daily Life
- Chapter 11: Accessing Disability Services and Support

The information in Part II is for educational purposes only and does not constitute medical advice. The contributors are sharing general health education, not providing individualized clinical guidance. Always consult your healthcare provider before acting on any information presented here.

07

Listening to Pain, Building Support

> *Pain can come from many places in a hypermobile or connective tissue–affected body: unstable joints, overworked muscles, irritated nerves, poor sleep, stress, or the constant effort of holding things together. That complexity can make pain feel confusing, but it also means there are many ways to begin responding to it. This chapter is about learning to listen more closely, describe what you feel more clearly, and build support around the patterns your body is already showing you. The work here is not to fight every wave. It is to learn which signals require shelter, which require support, and which can be ridden out with more skill.*

How patients and care partners can respond to chronic pain in a hypermobile body with steadiness, skill, and hope.

It is early morning, and before the day has even begun, you are already taking inventory. How much did you sleep? Which joints feel steady enough to trust? What will the first few steps feel like when your feet touch the floor? If you are the one in pain, this quiet calculation may be so familiar that you hardly notice you are doing it. If you are a care partner, you may recognize it in the pause before someone stands, in the extra pillow tucked under an arm, in the way a plan is always being adjusted before breakfast. This is one of the hidden labors of chronic pain: the constant negotiation between what the day asks of you and what the body will allow. And yet, even here, there is room for skill, gentleness, and hope.

If you live with EDSs or a hypermobility spectrum disorder—or if you care for someone who does—you already know that pain is rarely simple. It can come from overworked muscles trying to stabilize loose joints, from irritated nerves, from poor sleep, from stress, or from the exhausting effort of holding everything together all day long. That complexity can feel overwhelming at first, but it also means there are many places to begin. Pain management is rarely about finding one perfect fix. More often, it is about learning your patterns, calming what can be calmed, and building enough support that your body does not have to fight so hard every moment of the day.

One of the most important things to remember is that pain is real, even when it is not coming from new damage. In a hypermobile body, pain often comes from instability, altered joint awareness, muscle guarding, and an over-alert nervous system. That changes how you approach treatment. Instead of assuming you must push harder or ignore what you feel, you can begin by asking a gentler and more useful question: What is your body trying to tell you right now?

When you understand that pain may be coming from instability rather than injury, movement, rehabilitation, and daily routines start to make more sense. The goal is not to frighten yourself into stillness. The goal is to create enough stability, support, and confidence to move more safely and recover more consistently.

When Stress Turns the Volume Up

Stress is not "just in your head." It is a full-body response to perceived threat. When your brain senses danger—whether that danger is physical, emotional, social, or simply the fear of worsening pain—it prepares you to respond. Hormones shift. Muscles tighten. Your heart rate changes. Your attention narrows. In the short term, that response is protective. But when stress becomes chronic, your nervous system can stay on high alert. Over time, that can make pain feel louder, sharper, and more persistent.

This is why mind-body tools matter. They do not deny pain, and they do not suggest that you can simply think your way out of a medical condition. What they do is help you influence the systems that shape the experience of pain. Breathing, guided imagery, meditation, gentle movement, journaling, and other grounding practices can lower your body's alarm level and make it easier to respond with intention rather than panic. It helps to practice these skills before you desperately need them, so they feel familiar when a flare arrives.

> *"Stress and pain are closely connected because the nervous system responds to both physical and emotional threats. When the body feels under pressure, the muscles may tighten, breathing can change, and the nervous system can become more protective and alert. Over time, this heightened state can amplify pain and make symptoms feel louder. Gentle regulation strategies such as breathing, grounding, pacing, and rest can help calm the nervous system."*
>
> **— Jeannie Di Bon, MSc, MA, Movement Educator & Hypermobility Specialist**

When pain spikes, one of the most useful things you can do is pause long enough to tap into a relaxation response. That may sound small, but it can change everything. Slowing your breathing helps settle the sympathetic nervous system so you can assess the moment more clearly. You may realize that you need support, a change in position, hydration, rest, heat, ice, or medical attention. Or you may realize that your body is sounding a loud alarm over something familiar and manageable. That pause gives you options, and options are powerful.

You do not need to be an expert meditator to benefit from mindfulness. You simply need a way to bring your attention gently back to the present. Guided imagery can be especially helpful during pain flares because it gives your mind somewhere steady to go. You might imagine clouds passing across the sky, waves moving in and out, or tension draining from a painful area with every exhale. Mindfulness can also be very ordinary: noticing the taste of a mint, the sound of rain, the feel of your feet on the floor, or the texture of a blanket in your hands. These practices are not about pretending the pain is gone. They are about giving your nervous system another signal to focus on, so pain is not the only thing filling the room.

Gentle movement practices such as modified yoga, tai chi, and carefully paced strengthening can also support pain management by combining breath, attention, and body awareness. For many people, massage—whether from a trusted professional, a care partner, or your own hands—can ease muscle tension and help you understand your pain more clearly. Even a few minutes of self-massage can teach you whether a spot feels burning, aching, tender, tight, or relieved by pressure. That kind of information can help you describe your experience more confidently to the people who are helping to care for you.

Sleep deserves special attention because it affects everything else. A difficult night can increase pain, stress, irritability, dizziness, and fatigue the next day. Yet sleep can

be complicated in a hypermobile body. You may unconsciously tighten muscles during the day to hold yourself together, and when you finally rest, those stabilizing patterns can relax in ways that leave joints feeling vulnerable. This is where experimenting kindly and patiently matters. Pillows under your knees, between your legs, across your chest, or under your arms may make the difference between waking up supported and waking up flared.

Good sleep hygiene does not have to be elaborate. What matters most is consistency. Try to build a predictable rhythm: dim the lights, reduce screens when you can, use a calming routine, and let your body learn what bedtime feels like. Some people find a body scan helpful, mentally checking in from head to toe and adjusting anything that feels strained or unsupported. Others prefer progressive muscle relaxation, gently tensing and releasing one area at a time. You do not need a perfect routine. You need a repeatable one that helps your body feel safer as it settles down.

Connection matters more than many people realize. When you are in pain, a calm voice, a familiar person, or a care partner who knows your usual coping tools can make a genuine difference. If you are a care partner, your presence can help the person in pain remember what has helped before: breathing, hydration, heat, ice, gentle movement, a brace, a quiet room, or a cup of tea. If you are the person in pain, it can help to make that list in advance so you do not have to invent a plan while overwhelmed.

Journaling can also be a quiet form of care. You can use it to track symptoms, notice patterns, name emotions, or simply record what got you through the day. It can be as structured as a symptom log or as simple as writing down one thing that helped, one thing that hurt, and one thing that brought relief or comfort. Over time, that practice can shift your attention from helplessness toward knowledge, and knowledge is often the beginning of confidence.

The Background Noise of Pain

Here is something people without chronic pain often do not understand:

We ignore the pain so much because it's normal pain. There is pain from moving the wrong way, or pain from an injury, and there's a whole bunch of background stuff that we have gotten used to because we've been living in these unstable bodies. It's like, "Oh, that's a tweak, that's a twinge. Oh, I just need to change my position, and I can fix that."

It is only when pain spikes—to an 8 or 9—that we pause and reassess. These spikes can serve as valuable information. They prompt questions like, "Did I sleep? Am I hydrated? Did I eat enough? Did I overdo it—or not move enough? Am I stressed, lonely, or emotionally depleted?" Pain is not just a sensation; it is data.

The Many Layers of Pain

Pain in hereditary connective tissue disorders and hypermobility conditions is often layered. It may involve joints, muscles, nerves, digestion, sleep, circulation, stress, and the accumulated wear of compensating all day long. That is why pain care usually works best when you think in categories rather than miracles. Medication may help. Physical therapy may help. Better sleep, better pacing, braces, heat, counseling, hydration, assistive tools, or a carefully chosen movement practice may help, too. If you are a care partner, this layered picture matters to you as well, because it explains why support often needs to be flexible rather than one-size-fits-all.

> *"Having EDS means living with both acute and chronic pain. How you effectively address each will look very different."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

The more clearly you can identify which layer of pain you are dealing with, the easier it becomes to choose a response that is thoughtful, practical, and kind.

The rest of this chapter walks through those options—not as a checklist you must master all at once, but as a menu you can return to as your needs change.

Finding Words for Pain

One of the hardest parts of pain is describing it. Clinics often rely on a simple 0–10 scale, but that scale only becomes useful when it means something specific to you. If you are the person in pain, building your own pain vocabulary can help you communicate more clearly with clinicians, family members, and care partners. If you are a care partner, learning that vocabulary helps you recognize patterns and respond more effectively instead of guessing.

> *"There's no wrong way to describe pain. In fact, I encourage kids, teens, and families to find their own language rather than trying to use overly medical terminology. For many patients who have struggled so much to find appropriate care, the instinct is to use 'doctor language'—but that can backfire. Misuse or misunderstanding of medical terminology can lead down the wrong treatment path, or break down the communication and rapport with the medical team. Language matters! Use what works for you."*
>
> **— Dr. Sarah Cohen Solomon, MD, FAAP, Pediatrician**

— Create a Pain Scale That Belongs to You

Start with the usual anchors: 0 for no pain, 10 for the worst pain you can imagine or have experienced. Then make the scale real. In a notebook or notes app, give each number its own space and describe what that level feels like in your body. Use adjectives, metaphors, colors, sketches, or even sounds if that helps. The point is not to be medically impressive. The point is to be consistently understandable.

Over time, you will start to notice that some pain is sharp and alarming, some is dull and familiar, some responds to pressure, and some gets worse with touch or movement. That level of detail helps you advocate for yourself. It also helps the people around you understand when you need reassurance, when you need practical help, and when something feels different enough to deserve closer attention.

— Notice What Makes It Better, Worse, or Simply Different

Pain rarely shows up alone. It usually arrives with context. Paying attention to that context can turn pain from something mysterious into something more manageable.

A headache at a 5 might feel like pressure behind one eye, worsen when you stand up, and ease with hydration, quiet, or a warm drink. A shoulder pain at a 6 might flare after carrying groceries and settle with rest, support, and heat. The details matter because they help you respond sooner and explain your experience more clearly.

Keep notes about what was happening before the pain started, what you tried, and what changed next. Over time, these notes become a practical reference for both patients and care partners. They can reveal triggers, confirm what tends to help, and make medical appointments far more productive.

— Bring Useful Information to Appointments

For a week or so before an appointment, keep a short pain diary. You do not need to document every sensation. Just capture enough to show patterns. If a care partner is helping, they can help record timing, triggers, and what interventions seemed to change the situation.

- Date/time
- Pain score (0–10)
- Location
- Type (ache, sharp, throbbing, shooting, tingling, burning, etc.)
- What you were doing before it started
- What you tried (medication, rest, heat/ice, hydration, stretching, etc.)
- Duration
- Notes (where you were, temperature, posture, who was there, other symptoms)

Using Treatment Tools Thoughtfully

Medication can be one part of pain management, but it works best when it is matched to the likely source of pain and used with clear expectations. Some medications are aimed at inflammation, some at muscle spasm, some at nerve pain, and some at short-term symptom relief. If you are a patient, it helps to know what the medication is supposed to do, how long it should take to work, and what side effects to watch for. If you are a care partner, that same information helps you support safe use without taking over the person's autonomy.

Before starting a new medication, ask what benefit you are looking for, what counts as "not working," when to follow up, and whether there are interactions with other prescriptions, supplements, or over-the-counter remedies. Bringing all of that information into the conversation with your prescriber and pharmacist is part of good pain care.

The goal is not to be passive about medication. It is to be used thoughtfully and safely, as part of a larger plan.

Working with Your Body

— Physical Therapy Can Be Adjusted to Fit Real Life

Physical therapy is not a test of willpower. It is a process of learning how your body responds to load, repetition, alignment, and recovery. If a program makes you worse, that is not always a sign that you failed. It may be a sign that the dose, timing, or exercise choice needs to change. Patients need permission to say that out loud, and care partners can help by noticing patterns without pressuring them to perform.

You may not need to do every exercise in one long session. Sometimes a plan works better when it is broken into smaller pieces throughout the day or week. What matters is steady progress without constant flare-ups.

Physical therapy may also include practical guidance on bracing, body mechanics, heat or cold, transcutaneous electrical nerve stimulation (TENS), hands-on techniques, and daily movement habits. The best therapeutic relationship is one where you can be honest about your limits, your goals, and the fact that progress in a hypermobile body is often uneven.

— Occupational Therapy Can Make Daily Life Easier

Occupational therapy focuses on function. It can help you rethink how you dress, cook, work, write, carry, open containers, or move through the day with less strain. For care partners, OT can be especially useful because it offers concrete ways to support independence instead of stepping in for every task.

Assistive devices can be surprisingly simple: gripping gloves, jar openers, adaptive utensils, writing supports, reachers, or tools that reduce the effort required from unstable hands and joints. Small changes can protect energy and reduce pain more than many people expect.

"It's important to have a toolkit filled with devices and techniques you can utilize for the many activities you may encounter throughout your day. You may utilize finger splints to provide support during handwriting and typing at work or school. You may utilize various wrist supports if you are participating in a movement-based activity. You may learn some kinesiotaping techniques to provide proprioceptive feedback to your body for joint awareness. You may use compression or postural support garments if you need to stand for longer periods of the day. It can be empowering to know what tools best support your body—and to be able to utilize them to improve your participation in life."

— Jesse Miller, MS, OTR/L, Occupational Therapist & Craniosacral Therapist

— Massage and Touch Can Be Useful When They Are Gentle and Informed

Massage may ease muscle guarding and help you understand your pain more clearly. That might mean professional massage, careful self-massage, or a trusted care partner gently working on feet, hands, shoulders, or another tense area. The key is communication. If touch helps, say so. If pressure is too much, say so. In a body that is already working hard to stabilize itself, gentle and respectful usually works better than aggressive.

Calming the Nervous System

Pain is information, but the nervous system decides how loudly that information is broadcast. That is why mind-body skills belong in this chapter. They are not about pretending pain is imaginary. They are about helping you regain enough steadiness to notice, interpret, and respond to what your body is telling you. Care partners can support this process, too, by helping to create calm, reducing extra stimulation, and using familiar coping tools during a flare.

When pain is new or intense, it is natural to go on high alert. A useful skill is learning how to pause long enough to ask whether this feels dangerous, familiar, positional, inflammatory, muscular, or simply overwhelming. That pause does not erase pain, but it often changes what you do next.

Questions like these can help:

- Is this an injury or something familiar?
- Where is the pain, and what does it feel like?
- Would a small change in position, posture, or support help?

These skills get easier with practice when you are not in crisis. Gentle body scans, guided breathing, mindfulness, anatomy education, and simple check-ins can help you learn what your body usually feels like. The better you know that baseline, the easier it becomes to recognize when something is off. Care partners can learn these patterns too, which can be especially helpful when the person in pain is too overwhelmed or exhausted to explain much in the moment.

Mental health professionals can also be valuable members of a pain-care team. Counseling, cognitive behavioral therapy, group support, and other behavioral approaches can help you process grief, reduce fear, communicate more clearly, and build coping skills that make everyday pain less isolating. For care partners, self-care can also make the work of caring more sustainable.

Reducing the Load on a Sensitive System

By now, you have probably heard the phrase "manage your stress," and maybe you have wanted to throw something at whoever said it. That reaction makes sense. Stress advice can sound dismissive when you are dealing with a real medical condition. But stress still matters because it changes what your body has available for pain, recovery, digestion, sleep, and clear thinking. The goal is not to become perfectly calm. It is to lower the overall load wherever you can.

That might mean scheduling gentler movement, protecting recovery time, letting yourself enjoy music or comedy without guilt, asking for company, joining a support group, eating regularly, or keeping water and salt within reach if those are part of your care plan. For care partners, reducing stress may also mean taking breaks, sharing tasks, and recognizing that your nervous system needs support, too.

— Relaxation Is Easier to Use When You Practice It Ahead of Time

A simple place to start is slow breathing. Settle into a supported position, inhale gently, exhale fully, and let your attention rest on the sensation of breathing rather than on the goal of "doing it right." If thoughts intrude, that does not mean you failed. It means you are a person with a mind. Guided imagery, music, body scans, and short meditations work the same way: not as perfection, but as practice.

Exploring Complementary Approaches

Some people also benefit from approaches such as acupuncture, yoga, tai chi, or other gentle, body-aware practices. These are not magic answers, but they can support breathing, balance, body awareness, and nervous-system regulation. If you explore them, look for practitioners who are willing to work respectfully with chronic illness and hypermobility rather than pushing through pain for the sake of performance.

> *"Craniosacral therapy can be really helpful for patients with hypermobility and connective tissue disorders. The steady power of light touch can help to create an environment of safety within the body. When our bodies feel safe, they are more open to feeling supported—and when our bodies feel supported, our nervous system can move towards regulation."*
>
> **— Jesse Miller, MS, OTR/L, Occupational Therapist & Craniosacral Therapist**

Strengthening the Foundations

— Food and Hydration Affect Resilience

Food and hydration are not glamorous, but they matter. Inadequate fuel, dehydration, digestive issues, and nutritional deficiencies can all make pain, fatigue, dizziness, and recovery harder to manage. Because connective tissue disorders often affect digestion too, what works well may be highly individual. Paying attention to symptom patterns around meals, talking with your clinicians about possible deficiencies, and getting help from a dietitian when needed can make the basics feel more workable.

"I often tell patients that each positive change, even if it seems small, can add up to make a meaningful difference. Whether it comes from improving fluid volume, supporting good nutrition, finding a helpful medication, understanding triggers, or making other healthy adjustments, every piece matters.

"It is also important to remember that skipping meals or avoiding food in an effort to prevent or control symptoms can unintentionally worsen symptoms over time. Low blood sugar, dehydration, and poor nutrition can all cause symptoms of their own, both in the short term and in the long run."

— Erin Kolb, MSN, FNP-C

— Movement Works Best When It Is Steady and Respectful

Movement is often essential for a hypermobile body, but it usually requires more intention than people realize. Deconditioning can worsen pain and fatigue, yet pushing too hard can do the same. Think in terms of steadiness, alignment, and dosage. A short, well-supported walk, a few targeted exercises, or small movement breaks throughout the day may be more helpful than occasional heroic efforts. Care partners can support this by encouraging consistency, not overexertion.

"We hurt, so we stop exercising. Then we do not strengthen our bodies. We get weaker, and we end up relying even more on joints that are already hypermobile. It becomes a hard cycle to break."

— Jeannie Di Bon, MSc, MA, Movement Educator & Hypermobility Specialist

— Sleep Is Part of Pain Care, Not a Luxury

Pain disrupts sleep, and poor sleep makes pain harder to bear, so even modest improvements can matter. Supportive positioning, a repeatable wind-down routine, daytime light exposure, medication review, and a sleep environment that feels safe and comfortable can all help. If a care partner is involved, they can help protect bedtime routines and make small adjustments that reduce strain without making sleep feel like one more complicated task.

Using Information to Your Advantage

Digital tools can sometimes help you notice patterns you might otherwise miss. Wearables, heart-rate trackers, sleep monitors, and symptom apps can offer useful clues about exertion, rest, rhythm, and recovery. They are not a substitute for listening to your body, but they can add context—especially when you are trying to connect symptoms with sleep, stress, weather, or activity.

When the Weather Gets Involved

Many people with chronic pain notice that weather changes, especially quick drops in barometric pressure, seem to intensify symptoms. If that happens to you, it is worth tracking. Over time, you may notice patterns that help you plan rest, hydration, medication timing, or lower-demand days more intentionally. Sometimes simply knowing a difficult day has a pattern can make it feel less mysterious and less defeating.

Living with Pain Without Letting It Lead

— Let Hope and Grief Tell the Truth Together

Chronic pain can change the life you expected to live, and it is normal to grieve that. You may miss an earlier version of yourself, a sense of ease, or plans you thought would unfold differently. Making room for that grief is not the same as giving up. In fact, it is often what allows hope to become honest and durable. You do not have to pretend that this is easy to move forward.

You can be discouraged and still keep going. You can feel frustrated and still make progress. Healing in a chronic condition is rarely linear, and management is not the same thing as failure. It is a skill set. The more you learn about your body, your triggers, your supports, and your limits, the more capable you become of responding early and kindly instead of waiting until everything is in crisis.

— Build a Plan You Can Actually Live With

A workable pain plan is usually made of several smaller supports: movement, rest, physical therapy, medication, braces or tools, sleep routines, counseling, hydration, nutrition, and practices that calm your nervous system. You do not need every option, and you do not need them all at once. The right combination is the one that fits your body, your values, your resources, and the life you are actually living. Care partners

are part of that plan too, not just as helpers in emergencies but as partners in noticing patterns, protecting routines, and supporting autonomy.

Pacing is one of the kindest skills you can practice. When you have a little more energy, it is tempting to spend it all. But in a hypermobile or chronically painful body, that often leads to overdoing, flaring, recovering, and starting over. A steadier path is to stop before your body starts shouting and to trust that consistency will carry you farther than urgency.

— Practice Self-Compassion as a Daily Skill

There will be days when your body surprises you in good ways and days when it disappoints you. On both kinds of days, self-compassion matters. Naming what you feel, speaking to yourself with respect, and acknowledging the work it takes to live in this body are not indulgences. They are part of good care. If you are a care partner, that same principle applies to you, too. Supporting someone with chronic pain takes patience, flexibility, and emotional stamina, and your care counts as real work.

Most of all, remember this: you do not have to solve everything at once. Start with one useful change. Track one pattern. Practice one calming skill. Ask one better question at your next appointment. Add one support to your day. Small steps are not small when you repeat them. Over time, they become the structure that helps you live with more stability, more confidence, and more hope.

08

When Rest Does Not Restore You

> *Sleep is not a luxury for a body that already works hard to stay stable. It is one of the foundations supporting pain regulation, energy, healing, and daily functioning. Yet for many people with connective tissue disorders, hypermobility, or dysautonomia, sleep does not feel restorative. It may be shallow, interrupted, or simply unable to leave the body feeling repaired by morning. This chapter looks at why that happens and what may help. When rest is more reliable, the whole system moves more steadily.*

When Sleep Does Not Feel Restful

If you have EDS or another condition that makes your joints very loose, sleep may be hard for reasons that are not easy to see. It may be more than just not getting enough sleep. A body system called the autonomic nervous system may be part of the problem. This system helps control things like heart rate, blood pressure, digestion, and sleep. When it is out of balance, your body may stay too alert, even when you are trying to rest. If this is happening to you, please know that this is real and that you are not alone.

> *"Many patients are told to 'get more sleep.' But disrupted sleep architecture, pain, and autonomic dysfunction often make that difficult, even when you are in bed long enough."*
>
> **— Dr. Linda Bluestein, MD, Integrative Pain Medicine Physician**

How Your Nervous System Can Affect Sleep

It may help to think of this system like a gas pedal and a brake. One part helps your body stay awake and ready. The other part helps your body slow down and rest. Both parts are important. In the daytime, your body needs energy. At night, it needs calm. If your body has trouble switching gears, you may feel jumpy, restless, or very tired but not sleepy.

Sometimes your body may react too strongly to everyday stresses. Things like pain, not drinking enough, poor sleep, low blood sugar, strong feelings, and bright lights or loud noises can throw your system off. Then your body may swing back the other way. This can make symptoms feel unpredictable and very tiring. If this sounds like you, there is a reason for how you feel.

Why You May Wake Up Tired

Poor sleep quality is common in heritable connective tissue disorders, especially with the overlapping symptoms of dysautonomia and chronic fatigue syndrome. You may fall asleep and stay in bed for many hours, but still wake up feeling worn out. This is called non-restorative sleep. It means you did sleep, but your body did not get enough deep, steady sleep to help you feel better.

Sleep can be broken up in different ways. Sometimes you wake up long enough to notice it. Other times, your body wakes for just a few seconds—so brief that you do not remember. They can happen because of breathing problems, body movements, or no clear reason. In some people with autonomic problems, the nervous system may be causing many of these brief sleep disruptions.

What a Sleep Study May Show

If you have a sleep study, it may show many short sleep breaks and/or not enough deep sleep. It may also show that your heart rate fluctuates a lot during the night rather than staying steady. In simple terms, your body may be working too hard when it should be resting. That can help explain why you feel so tired. For many people, it is a relief to have an answer that fits what they have been feeling.

Sleep and your autonomic nervous system affect each other. When your sleep improves, your body may feel steadier during the day. And when your body is under less stress in the day, sleep may get better at night. That is why care often works best when it looks at the whole picture, not just bedtime.

> *"Poor sleep is often part of a vicious cycle of chronic pain, poor sleep, depression, and fatigue, and each of these must be addressed concurrently in order to break the cycle and improve them all."*
>
> **— Alan Pocinki, MD**

What May Help

There are ways to help your body feel safer and calmer at night. Some do not involve medicine. Slow breathing, relaxation, guided imagery, meditation, or other calm bedtime routines may help your body settle. It also helps to care for the basics. Try to manage pain as well as you can. Drink enough fluids with balanced electrolytes if your clinician says it is right for you. Try not to go too long without eating. Keep your room dark, quiet, and comfortable. If sleep apnea or repeated leg movements are part of the problem, treating those can help too. Small steps can add up, and they do matter.

Sometimes medicine can help too. This may be useful if your body stays too alert at night. Your clinician may talk with you about medicines that help the body calm down or help you get deeper sleep. The right choice depends on your symptoms. It can take time to find what helps most. If the first plan does not work well enough, that is not your fault. It just means your care may need to be adjusted. We often learn step by step what our bodies need.

Conclusion

The bottom line is this: if you wake up tired, feel like your body never fully settles at night, or notice that stress, pain, not drinking enough, fatigue, low mood, or anxiety make sleep worse, your autonomic nervous system may be part of the reason. The good news is that help is available. When care reduces sleep breaks and helps you get deeper sleep, many people feel less tired and better overall. With time, support, and the right plan, sleep can get better. Better rest gives the whole vessel a better chance to recover.

09

Rethinking Pacing

> *Pacing is often described as simply a matter of doing less, but in practice, it is a way of making life more repeatable. It asks you to notice what your body can sustain, what tends to trigger crashes, and how movement, food, hydration, sleep, and stress all affect the cost of a day. Pacing is not punishment, and it is not a cage. It is a practical system for helping you do what matters with fewer setbacks. In that sense, pacing is not about shrinking your life. It is about learning how to sail according to the weather you are actually in.*

This chapter revisits pacing and energy management, acknowledging that common metaphors such as Spoon Theory, Piggy Bank Theory, and Battery Theory do not work for everyone. It reframes pacing as a balance among the core pillars of health—movement, hydration & nutrition, sleep, mental health, and surroundings—and emphasizes that pacing is not just about activity. It is about scaling and balancing all of these pillars together. This chapter is a practical guide to pacing: how to use common metaphors without getting stuck in them, how to identify what actually drains and restores your capacity, and how to build a simple pacing plan that helps reduce crashes and make your energy more predictable.

> *"When working with my patients, I always tell them pacing is often about establishing your hard 'no's.' This isn't really about saying no to things you want to do, or the things others ask you to do. Rather, it is about figuring out what you need to do to keep yourself well despite everything else you need to do. For everyone, this is different. This can be getting sufficient sleep, exercising, eating well, and taking a nap in the afternoon. The challenge is figuring out what you need and making these habits non-negotiable in your life."*
>
> **— Dr. Jessica Pizano, DCN, CNS**

The Problem with Most Pacing Metaphors

If you live with chronic illness, you've probably heard *pacing* explained with an image: Spoon Theory, a piggy bank, a phone battery. These can be useful—but only if they help you make decisions in real time.

All of these metaphors point to the same principle: you have a limited amount of usable capacity each day, and it can change quickly. Your job is to estimate today's capacity, spend it deliberately, and build in recovery before you hit the crash.

Use whichever metaphor makes it easiest to plan. If none of them click, skip the metaphor and track outcomes instead. For one week, write down:

- Your top 3 energy drains (what reliably makes symptoms worse)
- Your top 3 energy restorers (what reliably helps you recover)
- The "warning signs" that show up 30–60 minutes before a crash (pain, nausea, tremor, brain fog, irritability, heaviness, etc.)

Now apply it to a predictable part of your day—your morning routine is a good place to start. If showering, standing, and making breakfast reliably flare symptoms, treat recovery time as a scheduled task, not an afterthought. Example: set a timer for 20–30 minutes of lying down after you get ready (or break the routine into two parts with a rest in between). If your body tends to "reset" with horizontal rest, you'll often buy yourself a steadier afternoon.

A common pacing trap is the "good-hour sprint." You feel a bit better and try to catch up on everything. If that pattern tends to end in a crash, use a rule of thumb: when you feel good, do *half* of what your brain is urging you to do, then reassess. The goal is to protect tomorrow—not just survive today.

Practical definition: pacing is choosing an activity level you can repeat—without triggering a symptom spike that steals days from you. It's not about doing nothing; it's about doing the right amount, with the right recovery built in.

Before you plan your day, do a 60-second check-in. Rate these from 0–10: (1) pain, (2) fatigue, (3) dizziness/instability, (4) brain fog, (5) stress load. If two or more are high for you, plan a "low-capacity day": shorten tasks, add rest breaks, and prioritize only what is most necessary.

> *"I like to recommend the traffic light method, where you create a plan for your best days (green), your hardest days (red), and the days in between. A yellow day may mean a few modified physical therapy exercises and a half day of work or school, for example. This looks different for each person, but the key is building flexibility and expectations into a plan in advance. Over time, this will limit the feeling of constantly running after symptoms, with life spiraling out of control."*
>
> **— Dr. Sarah Cohen Solomon, MD, FAAP, Pediatrician**

Pacing Rests on Five Health Pillars

Many pacing tips sound like a single rule—"don't overdo it." In practice, pacing works better as a system. If you only adjust activity but ignore sleep, hydration, food, stress, and movement quality, you'll keep paying a higher price for the same tasks.

Use the five pillars below as a daily troubleshooting list. When symptoms spike, ask: which pillar is weakest today? Fixing the weakest pillar first often reduces the overall "cost" of everything else.

— 1. Movement

Movement is one of the foundations that makes pacing possible. The goal is not to push your body harder than it can tolerate, but to build steadier support so daily life asks less from your joints, muscles, and nervous system. With hypermobility or connective tissue disorders, both under-movement and over-movement can create problems, so pacing works best when movement is approached as something you can repeat, recover from, and trust over time.

Try rotating movement "types" to spread load: gentle cardio (walk, recumbent bike), strength/resistance, and floor-based mobility/core work. Keep each session short enough that you feel roughly the same—or only slightly tired—two hours later. If you routinely crash after a session, reduce duration or intensity before you add variety.

Use a stop rule: end the session while your form is still good. For many people, strength and stability are protective—especially around joints that don't naturally stay where they should. Consistency beats intensity.

> *"One of the most important lessons I've learned living with hEDS is that it's okay to do the bare minimum during a symptom flare. Many hypermobile people tend toward overachieving and pushing through symptoms, but with hEDS/HSD, there is often an extra layer of complexity affecting nearly every body system. Pushing at 120% almost always backfires, even if you feel fine in the moment. Finding the 'Goldilocks zone' between too much and too little can be difficult and may change over time. It took me a long time to realize that constantly overriding symptoms and forcing myself to keep going was usually what led to bigger crashes later.*
>
> *"One thing I work on with my patients and clients is developing a 3-5-minute routine of 'feel good, safe movements' that they know they can consistently do, even with very low energy or high levels of pain. This looks different for different people, and some may even need to split this up into shorter intervals.*
>
> *"It may feel like it's 'not worth it,' but small amounts of movement can still be incredibly helpful during a flare. A few minutes of gentle movement may reduce stiffness, improve circulation, hydrate the fascia, and help the nervous system feel more regulated without triggering a larger crash later. Sometimes those bare minimum days are exactly what allow someone to keep moving forward instead of ending up in a deeper flare."*
>
> **— Dr. Melissa Koehl, PT**

— 2. Mental Health

Mental and emotional health shape pacing more than people often realize. The goal is not to remove all stress, but to notice how stress, anticipation, overstimulation, and emotional load change what your body can sustain. When mental load is high, the same physical task often costs more, so pacing becomes easier and more effective when you include the care of your mind and nervous system as part of the plan rather than treating it as an afterthought.

Practical tools that help: (1) reduce decision load (simple routines, fewer "maybe" commitments), (2) set boundaries early (shorter visits, shorter calls, clear end times), and (3) use downshifts on purpose (breathing, a short walk, music, lying down with eyes closed). If you notice symptoms rise during stress—even without physical activity—treat that as a real pacing signal, not something to push through.

> *"Pacing is one of the most effective ways to manage chronic pain and energy levels. Pacing may seem fairly straightforward at first; however, most people quickly learn it can be very challenging to maintain. The aspect that trips most people up is staying within your pre-set pacing limit on a good day, when you know you could fit so much more in. The consequence of going beyond your pacing limit — your body's window of tolerance — is that it agitates a very sensitive nervous system, which will respond with pain, fatigue, or both."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

— 3. Nutrition & Hydration

Nutrition and hydration are part of pacing because they affect how steady your body feels from one part of the day to the next. The goal is not perfect eating or drinking, but enough reliable fuel and fluid that you are not adding avoidable stress to a system that is already working hard. When meals are skipped, hydration is inconsistent, or your body is under-fueled, symptoms often become louder, and recovery becomes harder, so pacing works better when these basics are built into the day on purpose.

Quick check: before a demanding block of your day, confirm you've had *something* to eat and that you have a plan for the next meal/snack. Many people do well with a mix of protein + carbohydrate to stay steady (and, if you have medical guidance to do

so, appropriate electrolytes/salt). Keep "default options" on hand, so feeding yourself doesn't require a lot.

Hydration supports energy, focus, and regulation. If dehydration tends to worsen your symptoms, make hydration part of your pacing plan rather than a "nice extra."

Try a routine: drink a glass when you wake up, another mid-morning, one mid-afternoon, and one with dinner (adjust to your needs and any medical guidance). If you're not sure whether hydration affects you, run a two-week experiment: track how your symptoms look on "consistent hydration" days versus "low hydration" days.

> *"The world of nutrition can be complex to navigate, particularly when you are dealing with health issues. Avoid health advice you find online, in social media, or on television. At the end of the day, the foundation of nutrition should be eating the widest range of foods your body tolerates. This will look different for each of us, but any diet that limits you unnecessarily is harmful."*
>
> **— Dr. Jessica Pizano, DCN, CNS**

— 4. Environment

Surroundings and environment are part of pacing because the spaces around you can either increase the effort of daily life or quietly help carry some of that effort for you. The goal is not to make everything perfect, but to shape your environment so it supports comfort, safety, access, and recovery in the body you actually live in. When your space reduces extra reaching, standing, searching, sensory strain, or physical risk, it helps conserve energy and makes steadier pacing more possible.

Supportive surroundings can be very simple. A chair that supports your back well, a shower stool, a bedside table with water and medications within reach, a basket that holds braces, tape, heat packs, or other tools you use often, and phone chargers placed in the rooms where you rest most can all make daily life easier. Soft lighting, a favorite blanket, quieter spaces, or noise-reducing headphones can help calm a nervous system already working hard. An easy snack station in the kitchen, a place to sit while cooking or getting dressed, or a corner set up for rest with pillows, books, music, or something comforting to look at can all become part of your support system. These details may seem small, but when they reduce extra reaching, standing, searching, or sensory strain, they help preserve energy for the parts of life that matter more.

Air quality and temperature can also shape how supportive a space feels. For some people, stale air, smoke, strong scents, dust, or seasonal allergens can add stress to the body, so it may help to open windows when possible, use an air filter or purifier if available, and change HVAC filters on a regular schedule. Keeping fans, vents, or purifiers clean can also make them work better. Temperature matters too: rooms that are too hot, too cold, stuffy, or dry can make resting and functioning harder. If it helps, adjust the thermostat, use layers, blankets, or cooling tools, and note which rooms feel easier on your body than others. The goal is not to control every part of the environment, but to make the air and temperature around you as steady and supportive as you can.

— 5. Sleep

Sleep is one of the pillars that most directly changes what the next day will cost you. The goal is not perfect sleep, but enough rest and recovery so that your pain, focus, mood, and physical capacity do not start each morning from a steeper deficit. When sleep is poor, even ordinary tasks can ask more from you, so pacing becomes more realistic and more compassionate when sleep is treated as a central part of the system rather than a bonus if everything else goes well.

When you need an earlier schedule (appointments, school trips, travel), shift gradually: 10–20 minutes earlier for 2–3 nights. Pair it with one small wind-down cue you can repeat (dim lights, a predictable playlist, a short stretch routine, or screens off for a set window). Keep the goal realistic: you're aiming for a small improvement in stability, not "perfect sleep."

Pacing Is a System

Think of pacing as a system you run—not a set of restrictions you endure. The purpose is to reduce crashes and make your capacity more predictable so you can plan with more confidence.

Use this decision checklist when you're planning an activity (or deciding whether to keep going):

- What does this cost me physically?
- What does it cost me emotionally?
- What does it give me back—connection, meaning, a paycheck, joy, learning, a sense of belonging?
- What supports do I need in place so the cost doesn't become a crash?

Quick practice: pick one "repeatable day" template you can use most weeks. Choose (1) a baseline movement plan you can tolerate, (2) two planned rest breaks, (3) one nutrition default, and (4) one wind-down cue for sleep. Then adjust up or down based on your 60-second check-in.

Travel is a good stress test for pacing because it combines physical load, schedule disruption, and unpredictability. Plan it like a mini project: adjust sleep ahead of time if there's a time change, pack food and fluids so you're not forced into long gaps, and schedule recovery time after travel days instead of stacking full activities immediately.

When a demand is too big, resize it. Break it into steps, add stops, or add an overnight so you can manage pain, movement needs, food, hydration, and rest. This is the practical heart of pacing: match the plan to your body, not the other way around.

Conclusion: Build a Pacing Plan You Can Repeat

If you take only one thing from this chapter, make it this: the best pacing plan is the one you can repeat. Big, heroic days are tempting—but repeatable days are what reduce crashes and slowly expand what you're able to do.

Treat pacing like an experiment. Make one small change, run it for a week, and evaluate the outcome (symptoms, recovery time, and how "expensive" daily tasks feel). When something helps, keep it. When it doesn't, adjust without blaming yourself—your data is the point. Little by little, you learn what kind of pace keeps your boat moving without taking on too much water.

WHAT TO REMEMBER

- Start each morning with a 60-second check-in (pain, fatigue, dizziness/instability, brain fog, stress).
- Pick 1–3 priorities for the day and identify the "must-do" versus "can-wait."
- Support the weakest pillar first (sleep, hydration, nutrition, mental load, or movement quality).
- Use a stop rule before you hit the wall (half the sprint; reassess; add a recovery break).
- Review weekly: what caused crashes, what prevented them, and what you'll change next week.

Daily setup (2–3 minutes): 60-second check-in (0–10): pain, fatigue, dizziness/instability, brain fog, stress. Pick 1–3 priorities; mark what can wait. Support the weakest pillar first: sleep, hydration, nutrition, mental load, movement quality.

During activity (avoid the crash): Use a stop rule: stop while form is good (movement) or before symptoms spike (everything else). If you feel unusually good, do half the "sprint" and reassess. Watch for warning signs 30–60 minutes before a crash (your personal list).

Recovery (make it scheduled): Add planned rest breaks (especially after high-cost tasks like standing, errands, and appointments). Use easy defaults: water routine; a reliable snack/meal option; a wind-down cue for sleep. After a flare, switch to a low-capacity day plan (shorter tasks, more breaks, fewer commitments).

Weekly review (10 minutes): What caused crashes? What prevented them? Which pillar was most often the weak link? Pick one change to run as a one-week experiment.

Travel/event days (plan like a mini project): Adjust sleep 2–3 nights ahead if the schedule shifts. Bring food + fluids; reduce long gaps. Schedule recovery after travel and break big demands into steps (stops, overnights, shorter blocks).

10

Practical Supports for Daily Life

> *Daily life in a body that needs more care is often shaped less by dramatic interventions than by small, repeatable adjustments. The way you stand, sit, carry, reach, rest, wash, drive, prepare food, or support yourself through a transition can change how much effort the day asks from you. This chapter gathers practical strategies that make ordinary life more manageable and more sustainable. None of them needs to be perfect to be useful. Small changes, repeated often, are part of how you keep the boat in good working order.*

You do not need perfect energy, uninterrupted time, or a flawless routine to support a hypermobile body. What helps most is a collection of small practices that reduce strain, improve stability, and make daily life more predictable. This chapter is not about overhauling everything at once. It is about noticing where your body works harder than it needs to and learning how to weave in supports that are realistic enough to keep using.

As you move through your day, the goal is not dramatic improvement. The goal is to make things easier on purpose. When you adapt your routines, your home, your workspace, your car, and your expectations, you stop asking your body to improvise stability all day long. Instead, you create conditions that make steadier movement, better pacing, and less pain more likely.

Instead of asking an already taxed body to tolerate one more big effort, you begin working with how your connective tissue behaves in real life: it changes from day to day, it responds to sleep and stress, and it is deeply influenced by hydration, pacing, posture, and the choices built into your surroundings. Once you start thinking that way, everyday life itself becomes the place where support is practiced.

Start Low and Go Slow

When you live in a body that can flare from the wrong amount of effort, one of the most protective rules you can adopt is simple: start low and go slow. You can apply it to movement, schedule changes, new equipment, hydration strategies, supplements, and food experiments. Small adjustments are easier to observe, easier to tolerate, and easier to learn from. This approach does not mean you are fragile. It means you are paying close enough attention to work with your body rather than against it. If something helps, you can build on it. If something clearly does not, you can back away before it becomes a bigger problem.

Making Movement More Sustainable

You have probably been handed the familiar prescription: a long list of exercises to complete in a single session, several times a week. On paper, that can look reasonable. In your body, it may be the fastest route to a flare, because fatigue changes form, and form is often the difference between building stability and borrowing it from your joints. That is why it helps to think about movement differently. Instead of treating exercise like a single appointment you have to survive, you can treat it like distributed practice. You do one or two movements at a time, repeat them at different points in the day, and let your body learn through frequent, manageable exposure rather than one concentrated effort.

That may mean doing one exercise in the morning after you get dressed, two more later in the day, and a few gentle resets in the evening instead of trying to complete everything in one block. Some days, your version of success may be five minutes at a time. On a flare day, it may be a single stabilizing movement, a breath practice, and stopping there. You are not failing the plan when you adjust it. You are using the plan correctly. It also helps to keep simple notes about what you did, how long it took, what felt supportive, and what pushed you too far. A few quick notes in your calendar or phone can reveal patterns to discuss with your movement clinician and help you build a routine that is actually sustainable.

Isometrics can fit especially well into this kind of routine because they teach you how to recruit the right muscles without creating a lot of joint motion. In practice, that usually means a gentle, deliberate effort rather than a hard clench. You are looking for engagement, not strain: the feeling that a muscle has turned on and is supporting you without triggering breath-holding, shaking, pain, or a sense that you are bracing for impact. A brief abdominal engagement while you breathe, a shoulder-blade setting cue, or a gentle glute activation before standing can all be useful, but the exact version should come from a clinician who understands your body. If an isometric makes you grip harder, lose your breath, or feel less stable rather than more stable, that is a sign to stop and reassess.

Treating Daily Movement as Training

You train in the life you are already living. Loading the dishwasher involves bending, twisting, reaching, gripping, and weight shifting. Carrying laundry requires bracing, balancing, and managing momentum. Walking across a room is not only travel. It is also practice. Brushing your teeth can become an opportunity to notice posture, shift weight with intention, or practice balance safely with a sink or counter nearby. When you begin to think about daily tasks this way, movement stops being something separate that only counts if it happens in exercise clothes or on a schedule. It becomes part of how you support your body throughout the day.

If it helps, imagine a coach quietly observing your form, not to shame you, but to teach you. You slow down just enough to notice whether you are hanging on your ligaments, locking your joints, or leaning into end range because it feels easier in the moment. Then you start changing your environment, so the better choice is also the easier one. In the bathroom, that might mean an electric toothbrush with a wider handle, a shower stool, grab bars, non-slip flooring, or supportive slippers that give your feet more feedback. In the kitchen, it may mean setting up a sitting station so you can prepare food without standing the whole time, storing everyday items where you do not have to reach too high or too low, and using a stool rather than repeatedly bending into low cabinets. These changes are not over-accommodation. They are practical ways to reduce unnecessary strain and save energy for the things that matter more.

Practicing Balance in Daily Life

You do not need a separate balance session to practice balance. You need a routine moment you already have, such as brushing your teeth, washing dishes, or waiting for the microwave. In those ordinary minutes, you can practice steadiness by shifting your weight with intention, noticing whether you are collapsing into one hip, and becoming more aware of how your feet meet the ground. Over time, these tiny practices can make you feel more stable without asking you to carve out a whole new category of exercise.

It can also help to switch sides on purpose from time to time. You might brush with your non-dominant hand, carry something on the other side, or use two hands instead of one when a task is awkward or heavy. If balance is a challenge, keep support nearby and progress conservatively. A counter, sink, wall, or chair can give you a point of contact while you practice. If orthostatic symptoms or dysautonomia are part of your picture, balance work may need to be shorter, gentler, and timed for parts of the day when you are better hydrated and less symptomatic. The goal is not to prove you can do the hardest version. The goal is to build steadiness safely.

Starting the Day Gently

You can begin the day with awareness instead of urgency. Before you sit up, take a quick inventory. Where do you feel stiff? Where do you feel loose? Which joints feel settled, and which ones need a little attention before you ask them to work? You are not judging your body in this moment. You are gathering information. A couple of intentional breaths can help you arrive in your body before you start moving through it. From there, consider small, safe adjustments to help you find a more neutral position before you transition from lying down to sitting, and then from sitting to standing.

Those first transitions of the day matter more than they seem. Rolling, sitting, standing, and taking your first steps to the bathroom all ask something of your joints, your stabilizing muscles, and your autonomic system. If you tend to clench when you are stressed, you will often notice it first in your jaw, shoulders, hands, or toes. A slow inhale and a longer exhale can help you ease some of that guarding before it snowballs. Once you are up, many people do better when hydration starts early and continues in small amounts rather than all at once. If dysautonomia is part of your picture, this may also be the time to use electrolytes or salt in whatever form your care team has recommended. Breakfast does not have to be large to be useful. For

some people, a small, easy-to-digest carbohydrate or a simple snack is a better starting point than forcing a heavy meal too early. After that, a few gentle activation movements can help wake up the stabilizers you will rely on all day.

Some mornings that may look like a few shoulder blade resets, a gentle core cue, an easy reach, or a short check-in with your neck, spine, and hips before the day gets busy. Other mornings, especially after a poor night of sleep or during a flare, the win may simply be getting upright safely, drinking something, and giving yourself a little more time. The point is not to perform a perfect routine. The point is to set the foundation for the day in a way your body can actually tolerate.

Hydration, Nutrition, and Gentle Experimentation

Hydration management is highly individual, but a useful general principle is that many people do better with small, steady intake than with long stretches of nothing followed by a large amount all at once. Dehydration can increase pain, worsen fatigue, slow digestion, and make orthostatic symptoms more noticeable. At the same time, more is not always better. Some people need water alone, while others—especially those with dysautonomia—may need electrolytes or salt in a form and amount that works for their body. If that applies to you, it helps to watch for patterns. Dizziness, headaches, heavy fatigue, cramping, brain fog, or feeling much worse after heat or exertion can all be signs that your hydration strategy needs attention.

> *"Fluid volume is so important because it helps set the foundation for better health in those with chronic illness. This is not just about how much you drink, but about how much fluid your body is able to hold on to and use. In many people, if we do not address it early on, improving symptoms such as fatigue, brain fog, palpitations, lightheadedness, shortness of breath, constipation, and dry, itchy skin can be much more difficult."*
>
> **— Erin Kolb, MSN, FNP-C**

Nutrition often works the same way: what helps most is not a perfect diet but a pattern that is safe, tolerable, and repeatable. If gastrointestinal symptoms are part of your life, you may find that smaller meals, simpler foods, or eating at different times of day work better than forcing a standard three-meal structure. Some people tolerate easy-to-digest foods in the morning and save more complex meals for later.

Many need extra support from a dietitian because of motility problems, nausea, allergies, or MCAS, which can provoke outsized reactions such as flushing, hives, swelling, stomach upset, or other symptoms. You do not have to solve all of this at once. You can experiment gently, keep notes, and look for combinations that leave you feeling more stable than depleted.

> *"The goal is not to find the perfect diet—rather, a balanced, nourishing way of eating that supports your health. Instead of assuming many foods are a problem, look for patterns and work with a knowledgeable provider to understand what may be happening in your own body."*
>
> **— Erin Kolb, MSN, FNP-C**

Clothing, Comfort, and Protecting Your Skin and Joints

Clothing can matter far more than most people realize when you live with an HCTD. If your skin is fragile, sensitive, easily torn, or prone to itching, small details such as seams, labels, fabric content, and garment construction can make a real difference. If you also experience mast cell activation symptoms, something as minor as a scratchy tag or the chemical residue left on new fabric can trigger hives, itching, a rash, or a broader flare. In that context, comfort is not a luxury. It is part of caring for your health. If you have ever gone out in a new piece of clothing and then turned it inside out in a restroom because the seams were irritating your skin, that is not trivial or dramatic. It is a reasonable response to a real physical problem. Protecting your skin and avoiding a flare matters more than how a garment looks from the outside.

It may help to cut out tags before you wear clothes, or better yet, choose tag-free options whenever you can. Washing new clothing before you put it on can also make a meaningful difference, as it removes fragrances, dye residues, and other manufacturing or store chemicals that may irritate your skin or trigger mast cell symptoms. Fragrance-free, dye-free, and allergen-conscious laundry products are often the gentlest choice. Breathable natural fabrics, such as cotton or linen, may feel better against your skin as well.

Fit matters too, and there is no universal answer. Some people with unstable joints do better in more fitted clothing, because gentle compression can provide sensory feedback that helps muscles engage and improve body awareness. Compression garments can support proprioception by giving the nerves in your skin and muscles more information to send to your brain, and research suggests that compression can

be therapeutically useful for certain forms of joint instability and fatigue. For other people, looser clothing feels much better. If your joints are easily irritated or pulled into awkward positions, nonbinding garments may give you the freedom to move without restricting your shoulders, hips, or other joints. Even something as simple as a sleeve that is too tight under the arm or at the cuff can create discomfort that lingers all day.

You may also need to consider how easy it is to put on and take off clothing, especially if pain, inflammation, hand weakness, or early arthritis affects your hands. Learning safer ways to manage buttons, zippers, and other fasteners can help protect your joints, but sometimes the kinder choice is simply to choose pullovers, elastic waistbands, or other pieces that require less strain. If you do wear zippered garments, construction matters there, too. A placket behind the zipper can help protect your skin from the teeth, especially if the garment fits closely. In practice, the best choice may depend on what your day asks of you. If you need more support for exercise, errands, or other active tasks, compression may serve you well. If you are at home in a space already arranged for comfort and safety, looser clothing may be the better fit.

Small practical details matter as well. Clothes should be hemmed properly so that nothing catches under your feet while you walk. If you live with foot deformities, skeletal pain, or gait differences such as clubfoot or in-toeing, anything that drags near the floor can raise your risk of tripping or falling. Sleepwear deserves attention, too. Some people with HCTDs do not fully close their eyes during sleep, and even a small amount of light can interfere with rest. In that case, a soft knit cap that can be pulled down over the eyes, an eye mask, or another comfortable covering that can be pulled over the eyes may help block light and improve sleep quality. Temperature regulation can also be difficult, so keeping lightweight gloves in your bag, purse, jacket pockets, or other everyday places may help you handle sudden chills in air-conditioned spaces during summer or in cold environments during winter.

Shoes are another essential part of your wardrobe. If you live with foot pain, collapsing arches, flat feet, or poor muscle tone, supportive footwear can make a remarkable difference. Many people with HCTDs benefit from good insoles or orthotics, which means choosing shoes that can truly accommodate them. Caring for your feet helps create a stronger, more supportive foundation for the rest of your joints. That foundation can improve alignment, support purposeful movement, and reduce pain and the risk of injury. You may find that you need to change shoes throughout the day, avoid going barefoot, or keep supportive sandals, slippers, or indoor-only shoes in the house. Many people use supportive indoor footwear rather

than traditional slippers, both for joint support and to help keep the home cleaner and lower in allergens.

When you choose shoes, it helps to avoid styles that create pressure points in the forefoot or elsewhere. High heels, for example, can be especially hard on your feet and can also disrupt overall alignment and posture. For hypermobile people, this increases instability and raises the risk of injury. In general, you want support, cushioning, and enough padding, especially if your condition affects fat distribution or leaves your feet with less natural padding than they need. The goal is not simply to cover your feet. It is to support your whole body from the ground up.

Pillows and Cushions as Adaptive Equipment

You can stop thinking about pillows as an indulgence and start thinking about them as equipment. When your joints do not reliably stack on their own, support is not weakness. It is strategy. In bed, that may mean a large pillow between your legs if you sleep on your side, so your knees and ankles are cushioned and your hips stay better aligned. If you sleep on your back, a pillow or wedge under your knees may reduce strain through your lower back and help your body settle more comfortably. Head and neck support matters too. Ideally, the pillow under your head supports the natural curve of your neck without forcing it forward, dropping it too far back, or creating pressure at the base of the skull that may worsen headaches or irritate nearby nerves. Cushions can be just as useful when you are sitting. If your hips, pelvis, SI joints, or tailbone do not tolerate standard seating well, a cushion with the right shape, density, or cutout may improve weight distribution and reduce the pressure that makes sitting painful. For some people, that means support under the pelvis. For others, it means relief around the coccyx or a setup that makes it easier to find a more neutral position without pain radiating down the legs.

You may end up using pillows in bed, on the couch, in the car, or at your desk. That is not excess. That is adaptation. Pillows and cushions can support the arms, elbows, shoulders, neck, or lower back while you recline, watch television, work, or sit with other people, and the right size and firmness are often highly individual. Improvised supports are often the best way to experiment before you spend money. A hand towel rolled tightly and then gradually unrolled can help you discover the diameter that feels best behind your neck or lower back, and it can also help you estimate the width you may want if you later shop for a cervical or lumbar support. Some people need support that spans more of the shoulders, while others do well with a narrower roll. The same process can help you explore whether a simple cylindrical pillow, a

dog-bone shape, or another contour might suit you better. If you are unsure what you should be feeling, an occupational therapist or physical therapist can help guide you. Keeping these supports clean does not have to be complicated or expensive. A regular pillowcase often works as a simple, washable cover, and a rolled towel inside it can create a fully launderable support that is easy to remake as needed. What matters is not whether the support looks elegant. What matters is whether it helps you rest, recover, and move with less pain and less effort.

Using Mirrors to Support Alignment

Mirrors can become one of the simplest coaching tools in your environment. You are not using them to criticize your body. You are using them to learn what your body is doing in real time. When proprioception is unreliable, a quick visual cue can catch tiny misalignments you might otherwise repeat all day. A full-length mirror in a hallway can help you notice whether you are leaning to one side, locking your knees, carrying one shoulder higher than the other, or letting your head drift forward. A smaller mirror at face level near a doorway can serve as a cue for posture, reminding you of what it feels like to arrive in a more even, supported position.

Over time, you begin connecting what you see with what you feel. You may notice that you tilt your head toward your toothbrush instead of keeping it centered and letting your shoulder and arm do the work. You may see your ribs flare, your knees drift backward, your hands clench, or your weight settle more heavily into one hip. These are not failures. They are useful pieces of information. Often, the first correction cue is very small: soften the knees, drop the shoulders, tuck the chin slightly, bring the ribs back to neutral, or spread your weight more evenly between both feet. Once you can see these patterns, you can start making small corrections that reduce effort and make your movements feel safer and steadier.

Making the Bathroom Safer and Easier

The bathroom can be one of the more demanding rooms in the house because it combines standing, turning, reaching, wet surfaces, and tasks that often happen when you are tired or rushing. A few well-chosen supports can make it safer and less physically expensive. A shower stool or shower bench can reduce the effort of bathing, and grab bars or freestanding support frames can make it easier to step in, lower yourself, and get back up with more control. It also helps to think carefully about what is under your feet. If you are prone to tripping, a loose rug is often more of a risk than comfort. If you want cushioning, a non-slip option that stays put and is

easy to clean is usually a better choice. Some people also do better wearing supportive slippers, sandals, or indoor shoes in the bathroom if the extra padding and feedback under the feet improve comfort and stability.

Bathing and personal care products deserve attention, too. If mast cell activation, allergies, or sensitive skin are part of your picture, it may help to look for simpler, fragrance-free products made for sensitive skin, and to ask others with similar sensitivities what they tolerate well. Sometimes the safest and most effective options are also the least complicated ones. Hair washing can also require adaptation. If reaching overhead is fatiguing or painful, it is reasonable to ask for help. For people with cervical instability, leaning the head back over a sink may not be the best option; it may be safer to wash hair while seated and supported instead. The goal is not to force independence in a position that worsens symptoms. The goal is to find a setup that protects your neck, reduces strain, and makes the task manageable.

The bathroom can also become a useful place to practice the same kind of quiet skill-building discussed earlier in this chapter. While you brush your teeth or stand at the sink, you can notice how your weight shifts, whether you collapse into one hip, and whether your shoulders are creeping upward while you concentrate. With a mirror nearby, you may be able to see whether your body is stacked in a more neutral way or whether you are guarding somewhere without realizing it. Some people work on gently shifting weight from one foot to the other during brushing, and others eventually build toward very small balance challenges with support close at hand. A physical therapist can help you decide what kind of progression is appropriate, including which muscles need to stay engaged through the abdomen, hips, lower back, or shoulder girdle so the practice remains supportive rather than destabilizing. The point is not to turn the bathroom into a workout. It is to use an ordinary part of the day to build awareness, improve alignment, and reduce unnecessary strain.

Toileting, Bladder Support, and Pelvic Health

Toileting and bladder issues are common in connective tissue disorders, and they are worth mentioning to your doctor so they can be documented and addressed rather than quietly endured. Constipation, incomplete emptying, hemorrhoids, painful wiping, urgency, leakage, or bladder symptoms can sometimes reflect pelvic floor dysfunction, posture or spinal issues, nerve compression, or the effects of more stretchable connective tissue on the bladder and surrounding support structures. A few practical adjustments may help:

QUICK REFERENCE

- A very short toilet stool can bring the knees above the hips and improve pelvic alignment for bowel movements
- Sensitive skin may do better with softer toilet paper, a bidet attachment, a bidet seat, or fragrance-free sensitive-skin wipes
- Some people find that a small amount of gentle lubricant reduces friction
- Hemorrhoid creams or other soothing products may help if your doctor says they are appropriate

It also helps to think about safety and body position while toileting. Sitting too long on the toilet can aggravate unstable hips, the low back, or circulation, so it is worth learning what timing works best for your body and avoiding long periods of straining or waiting.

- If getting up is difficult, stable support nearby—such as fixed grab bars or a walker frame without wheels used only as a standing aid—may reduce strain.
- Some people also do better with a padded seat or a smaller toilet-seat opening that offers more support to the hips.
- Children and adults who have had painful or frightening toileting experiences may start avoiding the bathroom, which can lead to stool holding, incomplete emptying, discomfort, and sometimes an increased risk of infection.

— Important: Report New Incontinence Promptly

Bladder symptoms matter too. Some people do not notice the need to urinate until urgency is sudden and overwhelming, while others experience leakage or a sense that the bladder stretches too much before signaling. New bowel or bladder incontinence should always be reported promptly, especially if it is sudden, because it can sometimes signal a neurological or spinal problem that needs timely evaluation.

— Pelvic Floor Physical Therapy Can Help

If symptoms persist, ask your doctor about referral to a pelvic floor physical therapist who specializes in the pelvic region. That kind of clinician can help sort out patterns, suggest safer toileting mechanics, and identify whether referral to gastroenterology, neurology, urogynecology, or another specialty might be useful. As with much else in daily life with connective tissue disorders, this often comes down to noticing

patterns, trying one support at a time, and building a bathroom setup that keeps you safer and more comfortable at home.

Making Dental Care Easier on Your Body

Dental care is another daily task that can place more demands on your hands, wrists, jaw, and nervous system than people often realize. Brushing, flossing, and holding small tools can become tiring when your joints are already working hard to stay supported. At the same time, home dental care matters far more than just fresh breath and cavity prevention. It can help lower inflammation, reduce infection risk, and support overall comfort—especially if gum irritation, oral sensitivity, gastrointestinal symptoms, or mast cell activation are part of your picture. If dental care is difficult or uncomfortable, it may help to think of it the same way you would think about any other adaptive task: the goal is to make it easier on purpose, not to force your body through it the hard way. It is also worth asking your dental team to teach you one practical thing at each visit that could make home care easier or more effective for you. If you already know certain ingredients trigger irritation or mast cell symptoms, ask for help identifying toothpaste and oral rinse options that fit your needs.

An electric toothbrush can be a useful way to reduce the force and repetitive motion required for brushing. For many people, a brush with a wider handle or barrel is easier to hold because it requires less gripping and less pressure through the small joints of the hand. A soft, sensitive bristle head is often a good starting point, and brushhead size can also matter if jaw pain makes it hard to open wide. Let the brush do the work for you. Instead of scrubbing with your wrist, many people do better holding the electric toothbrush in place for several seconds on each side of each tooth and letting the vibration or rotation clean more gently. You may need a little extra time around the front teeth or behind the molars, where plaque can be harder to reach. Your dentist or hygienist can help you choose a brush that fits your mouth, hands, and jaw, and show you how to use it effectively without adding unnecessary strain.

Flossing can create similar challenges. Traditional floss may be hard to manage if your fingers do not tolerate pinching and pulling well, and it may irritate gums that are already sensitive or easy to injure. A water flosser can be a helpful alternative because it asks less from the hands while still supporting good oral hygiene. Different tips can serve different purposes, such as rinsing between teeth, cleaning along the gumline, or gently massaging gum tissue. Because sensitivity, gum health, and

dexterity needs vary widely, it is worth asking your dental team which setup makes the most sense for you. Over time, the right tools and a gentler technique can make cleanings less painful, home care less stressful, and your mouth easier to care for. If treatment, pain control, bleeding, or healing concerns overlap with the rest of your care, it can help to make sure your dental team knows the bigger picture.

> *"Any oral hygiene technique that can reduce loading of the joints and stressing of the ligaments would be beneficial. This includes both the jaw and hand joints and any associated ligaments. Brushing and flossing can be strenuous on these joints. Oral hygiene procedures can cause the patient to overopen their mouth or to have prolonged mouth opening during home cleaning.*
>
> *"Using an electric toothbrush, gently holding it in place against each tooth, can reduce strain on the hands. Closing the mouth slightly will help create more space between the teeth and cheeks, allowing the toothbrush to go farther back without having to open wider. If recommended by one's dentist, using a water flosser can help to avoid the need to open the mouth wide. In addition, this technique is easier on the hand joints, avoiding having floss wrapped around the fingers and avoiding using force to get the floss between the teeth."*
>
> **— Denielle C. Medynski, DMD, Diplomate, American Board of Orofacial Pain**

Making Work More Sustainable

Your workstation, whether it is at home or in a formal workplace, should make it easier for you to show up reliably, meet your responsibilities, and produce the work you were hired to do. Sometimes that means changing your setup rather than trying harder inside the same painful one. If you spend much of the day standing, a padded mat and more supportive shoes with adequate arch support may reduce stress on your joints and make upright work more tolerable. If sitting is the better position for your body, you may need a more adjustable chair, a footrest to help keep your hips and knees in a more neutral position, or a different desk setup altogether. Not everyone does best in standard desk seating, and adjustable or standing desks can sometimes make a meaningful difference. Even simple experiments can help you learn what to look for before you invest in equipment. Raising your laptop on a box or shelf, for example, can help you find a screen height that asks less from your neck. Trying a different mouse style, such as an upright ergonomic mouse, or even

switching to your non-dominant hand for part of the day, may reduce strain on the thumb and wrist. If coworkers use setups that seem helpful, asking to briefly try their equipment may give you a clearer sense of what works for you. You may also need more breaks, a private place to recover, or permission to lie down horizontally for a few minutes when being upright for too long becomes too costly. A yoga mat kept under a desk, with a towel to support your neck or knees, can make that kind of reset more possible and may help unload weight-bearing joints and the spine before you return to work. These are not indulgences. They are practical adjustments that can help preserve your health, support your ability to keep contributing, and make a working life more sustainable over time. If you need more guidance, an occupational therapist or another professional who specializes in ergonomic workspace design may be able to help, but it is also reasonable to begin with low-cost experiments and online guidance before deciding what is worth pursuing.

Making Travel and Car Time Easier

The same principle applies in the car. Small supports and a few deliberate habits can make transfers easier, reduce twisting, and lower the physical cost of getting where you need to go. A swivel cushion can help you back into the seat, bring your legs in, and turn to face forward with less strain on your spine and less awkward contorting through your hips and trunk. If the seat or armrest almost works but not quite, a rolled towel inside a pillowcase can be an easy way to experiment with the size and firmness of the support you need before you buy anything. Or you may decide to keep using this kind of improvised support because it is adjustable, affordable, and easy to clean. Some people find that a small lumbar roll, neck support, or cushion under the arm makes the seat much more tolerable, and an improvised support is often portable, washable, and easy to adjust.

Your mirrors can also become posture cues. If you set the seat and headrest so your body is in a more neutral position, with your head supported, your chin slightly tucked, and your spine less collapsed, then adjust the mirrors from that position, a slipping line of sight can remind you to reset your body before discomfort builds. A physical therapist can help you figure out what that neutral posture actually requires in your body, including how much core engagement you need, whether your shoulder blades need more support as you reach toward the steering wheel, and what cues help you maintain that position. The same ideas apply if you are a passenger, even though the visual reference points in the mirrors are slightly different.

It also helps to keep water or other hydration support within easy reach and to use the car's temperature controls early rather than waiting until you are overheated or chilled. If temperature regulation is difficult for you, adjusting airflow and heat or cooling promptly is usually easier and safer than repeatedly adding or removing layers in a moving vehicle. The goal is to make the ride, the posture you hold during it, and the transitions in and out of the car more manageable so that the trip itself does not use up more of your body than it needs to.

Preparing for Flare-Ups and Hard Days

You do not prepare for flare-ups out of pessimism. You prepare because you are practical. When pain spikes, fatigue deepens, dizziness shows up, or one joint stops cooperating, having a plan reduces panic, and panic is expensive in a sensitive nervous system. A little preparation gives you options. It helps you keep a difficult day from turning into a chaotic one.

Part of that preparation is skill-building. It can help to practice simple tasks with your non-dominant hand, learn a second way to do routine activities, and identify which supports you reach for first when a joint is aggravated. It can also help to keep a small go-bag or contingency kit ready. Think of it as the starter version of what you would want for an unexpected hospital visit, an evacuation, a delayed trip, or a day when you cannot get back home easily. Water, shelf-stable snacks or safe foods, chargers, a medication list, a few days of basic toiletries, underwear, tape or braces if you use them, earplugs, an eye mask, and a rolled towel with a pillowcase setup can go a long way. These are not dramatic measures. They are quiet forms of self-respect.

Preparing for Travel, Emergencies, and the Unexpected

One more way to make daily life easier is to keep a go-bag ready. This builds on the same idea behind preparing for flare-ups and unpredictable days: when your body is already working hard, it helps to reduce the number of decisions you have to make in an urgent moment. Think of the bag as the starter version of what you would want if you suddenly had to leave home, stay somewhere unexpectedly, or get through several days with fewer resources than usual. Storms, evacuations, delayed travel, hospital visits, power outages, or simply getting stuck away from home can all become more manageable when the basics are already packed.

In addition to the one-page medical summary mentioned in Chapter 4, it can help to keep a current medication list and, if practical, a couple of days of essentials in the bag. That may include medications or supplements, underwear, basic toiletries, charging cables and adapters, a travel water bottle, and shelf-stable snacks or safe foods you know you can tolerate. If allergies, mast cell triggers, or motility issues are part of your picture, this is especially useful because it provides a small set of foods and products that are less likely to worsen a difficult situation. Some people also include slippers or a comfortable pair of shoes, an eye mask, and earplugs to make rest easier, and a towel with a pillowcase so they have a flexible support they can use as a pillow, neck roll, or joint prop in different positions. If you use splints, braces, or tape for joint stabilization, and you have extras, the go-bag can be a sensible place to keep them so they are available both for everyday needs and for emergencies.

The bag itself matters too. If loose joints, pain, and fatigue are part of daily life, weight distribution and carrying style deserve real consideration. A small roller bag or a roller-backpack combination can be a practical option because it gives you more flexibility in how you manage the weight and makes it easier for someone else to help if needed. Multiple pockets can make the bag easier to use, especially if you add a simple organizer inside for small items such as a first-aid kit, lotion, fidgets or attention supports, a pocket notebook, pens, gloves, or other things you reach for often. Think of the go-bag less as a dramatic emergency kit and more as a quiet form of preparation. It is one more way to support your body, reduce strain, and make the unexpected a little less disruptive.

What This Looks Like in Practice

In real life, this may mean pausing before you get out of bed and noticing what needs support. It may mean drinking early, eating in ways your body actually tolerates, pairing a routine task with one small movement cue, using a mirror as a neutral source of feedback, adjusting your kitchen or bathroom so you can sit instead of stand when that conserves energy, and giving yourself permission to use pillows, braces, stools, footrests, grab bars, or any other support that makes life more manageable. It may mean letting go of the expectation that one perfect routine will save you and instead trusting small, repeatable supports. None of these actions is dramatic on its own. Together, they create a life that asks less from your joints and gives more back to your nervous system.

Conclusion

The common thread through all of these strategies is not perfection. It is support, repetition, and realism. When you make daily tasks easier, reduce unnecessary strain, and build in small forms of feedback and preparation, you give your body more chances to move with steadiness and less cost. The details matter, and so does the repetition of the same few themes: pace what you can, support what needs support, and let ordinary life become the place where stability is practiced. Over time, those small choices can add up to something meaningful—not because any one of them is dramatic, but because together they create a more livable and sustainable way to move through the day. Piece by piece, you are keeping the vessel ready for real life.

11

Accessing Disability Services and Support

> *There are times when formal support becomes necessary—not because you have failed, but because the demands placed on your body and daily life have exceeded what you can continue to carry alone. Disability services, documentation, transportation support, benefits, and other systems can be difficult to navigate, especially when you are already tired and symptomatic. This chapter is about understanding those systems clearly enough to use them with dignity and purpose. Needing the harbor does not mean you have lost your way. It means you are using the structures that help the journey continue.*

Living with a connective tissue variant often means learning, again and again, how to adjust to a body that may not meet the world in predictable ways. You may have spent years pushing through symptoms, explaining yourself, minimizing what hurts, or trying to appear more capable than you feel. Because of that, asking for formal support can stir up grief, resistance, shame, or exhaustion. This chapter is here to remind you that needing help does not diminish your strength. It is simply another form of adaptation, another way of making life more livable, sustainable, and safe.

You may eventually need disability services or practical support in your community, and if that happens, it does not mean you have failed or given up. It means you are learning how to build a life that works with your body instead of against it. Sometimes the support you need is relatively modest, such as a reduced-fare transit pass. In other cases, it may include specialty vans, paratransit, or connecting transportation

services that help you reach municipal transit safely and consistently. Depending on where you live, support may exist at the community, county, state, or federal level. Part of the process is simply learning what is available and allowing that knowledge to widen your sense of what is possible.

If you are working and reach a point where you can no longer continue because of your condition, the process often becomes more complicated, but you are not alone in that experience. Most systems will ask for evidence of both your diagnosis and the way it limits your ability to function reliably at work and in daily life. That may include records of accommodations already attempted, such as changes to your workspace, modified duties, or job restructuring. In the end, the question is usually whether you can consistently meet the demands of work and the basic requirements of everyday life. Seeing the process in those functional terms can make it feel less abstract, even when it remains difficult.

The benefits you may qualify for often depend on your work history, including how much you have worked and how many quarters you have contributed to state or federal systems. Some programs are tied to prior work contributions, while others are means-tested and look closely at your assets and financial resources. In some cases, there are strict rules about how much money you can have in the bank, what kind of vehicle you can own, or what other resources are available to you. These rules can feel harsh, especially when you are already trying to manage a body that asks so much of you. Still, understanding them early can help you avoid painful surprises. If you are applying on behalf of a profoundly disabled child, it is often wise to begin sooner rather than later, since in many systems the range of available services narrows once a person turns 26.

Available services can vary greatly from one state or county to another, and nonprofit or community organizations may offer support that makes a meaningful difference in your daily life. Nutrition assistance, for example, may be federally funded but administered by a state agency, which means the value of benefits, the application process, and the verification requirements can differ depending on where you live. In some places, several support programs are bundled together, so you can visit one office, complete one set of paperwork, and then be guided toward the services you qualify for, such as food, transportation, healthcare, or housing assistance. In other places, each category is handled by a different agency, which may require several separate applications. It can be tiring and discouraging, but learning the landscape one step at a time often makes it feel more manageable.

If you are still employed and have long-term disability insurance through work, it is worth taking time to understand the terms of your plan before a crisis forces quick decisions. Many plans include waiting periods. You may stop working on a certain date, notify the insurer that you intend to apply, and then wait 90, 180, or more days for benefits to begin. Plans may also include time limits, reassessment intervals, and specific standards you must continue to meet. Some pay only if you cannot be retrained for another role within the same company. Others consider whether there is a comparable job that uses your skills and pays a similar income. Across all of these systems, the core question is usually the same: whether you can reliably and safely perform work without putting yourself or others at risk of harm. Knowing those rules ahead of time can help you plan with more confidence and less fear.

That is why it matters so much to answer forms clearly and directly. Whenever you can, describe what you cannot do in functional terms. Explain whether you can shop for groceries, prepare food, bathe independently, drive, get to work or class, manage symptoms without help, or complete everyday tasks consistently. One useful approach is to describe yourself as you are on your worst days and answer from that perspective with honesty and consistency. This can feel unnatural, especially if you have spent years pushing through pain, minimizing what you carry, or trying not to burden other people. But a benefits application is one of the few places where clear honesty about your limits is necessary. These programs are not meant to make you wealthy. They are meant to offer limited support when you genuinely cannot sustain independent functioning or employment in a reliable way.

You also need to be careful with financial arrangements, gifts, or family support, because some forms of assistance can affect your eligibility. Check the rules in your state or country to see whether certain dollar amounts, trust structures, or accounts could disqualify you from benefits. If your parents hope to leave money to you or to another disabled family member, they need to work closely with an attorney to create an appropriate special needs or medical needs trust. The wording matters, and so does the structure. In most cases, a trustee or executor must manage the funds and decide which expenses qualify, rather than leaving full control directly to the beneficiary. This part of the process can feel technical and emotionally loaded, but good legal guidance can protect resources that may matter greatly for your future care.

Good recordkeeping can strengthen the entire process. If you are able, keep copies of your medical records, test results, forms, letters, and communications with your healthcare providers. The advantage of staying organized over time is that when you do need to apply for disability or service support, you already have a paper trail that

stretches back years. You can respond more quickly instead of waiting for the offices to gather documents on your behalf. It also helps to speak with your healthcare providers in ways that clearly connect your symptoms to daily function. When you describe a symptom, explain how it affects your ability to move, work, attend class, prepare meals, care for yourself, or earn a living. That kind of naturally occurring documentation often becomes some of the strongest evidence you can provide.

Personal statements can also strengthen an application. You may be able to include a statement from yourself, a family member, a coworker, a friend, or someone else who has known you for many years. What matters most is that the statement clearly shows how your functioning has changed over time. For example, years ago, you may have been the person who welcomed a new neighbor with homemade food, helped unpack boxes, and moved furniture. Later, you may still have visited and brought something homemade, but no longer be able to help with heavy physical work. Later still, you may have arrived with store-bought food and needed a cane or walker. Eventually, you may have stopped going to their house altogether, while they began coming to yours, helping with groceries, bringing meals, or checking in regularly. A statement like that helps others understand the slow, often painful shift from independence to relying on support.

The same can be true of statements from close friends. A childhood friend might describe how the two of you once met regularly at restaurants or shared activities, then gradually shifted to meeting only at home, and eventually reached a point where they had to bring food, provide transportation, or make all the arrangements because you could no longer manage those tasks yourself. Examples like these help create a fuller picture of how your physical capacity has changed and why you now need assistance. They also remind you that your life has had continuity, even if your abilities have changed. Strong personal statements can support the rest of the evidence and strengthen your application as a whole.

Applying for Benefits and Services

By the time you begin applying for benefits, you may already be carrying fatigue, uncertainty, and the strain of having to explain your life in administrative language. It can help to think of the process in stages rather than as one impossible task. Disability-related support may include income assistance, access to healthcare, in-home services, food assistance, housing assistance, transportation assistance, and local discounts or programs. The exact mix depends on where you live and on whether the program is based on work history, medical need, financial need, or some

combination of these. You do not need to understand everything at once. You only need to begin with the next step.

One of the most important early steps is gathering clear medical evidence. Before filing, collect records that show your diagnosis, treatment history, and the way your condition affects daily living, self-care, education, or work. Consistency matters, whether the application is submitted online, by phone, or in person. If your condition has been progressive, it helps to show how your functioning has changed over time so reviewers can see the pattern rather than a single snapshot.

> *"When applying for disability, a doctor's letter is a vital piece of the puzzle. I always recommend that my clients get medical letters from both their primary care physician and the specialists they see to fully support their case. However, a winning letter doesn't just state what your diagnosis is — it must explicitly detail how that condition restricts your daily ability to function and work. By ensuring your provider speaks the language of 'functional capacity'—quantifying exactly how your symptoms limit tasks like lifting, sitting, standing, or concentrating—you create a bridge between a clinical chart and your reality."*
>
> **— Caroline Kim, BCPA, MSJ**

Medical records are only one part of the picture. Supporting evidence may also come from you, family members, care partners, friends, neighbors, employers, coworkers, educators, classmates, or social service professionals. Together, these perspectives can show what daily life actually looks like when you are unable to work reliably or cannot manage routine tasks such as bathing, preparing meals, shopping, traveling independently, or maintaining a household. In many cases, the combination of clinical records and lived observation creates a stronger application than either one alone.

> *"Strong medical letters are only half the battle. To truly complete your application, this clinical evidence should be paired with personal statements from the people who know you best. While your doctors prove your medical limitations, your friends, family, or former colleagues can testify to the real-world impact on your daily life—creating an undeniable, 360-degree picture of your need for support."*
>
> **— Caroline Kim, BCPA, MSJ**

It is also important to watch the sequence of applications, timelines, and deadlines. Some benefit systems are linked, so approval or denial at one stage may affect what happens next. In the U.S., for example, you may move through paid time off, private disability coverage, state disability, and then Social Security disability, with each stage shaping the next. In the U.K., means-tested and non-means-tested benefits may follow different routes, and an unfavorable initial decision may be followed by reconsideration and then a hearing or tribunal. Missing a deadline, leaving out records, or submitting inconsistent information can slow everything down considerably. If possible, create a simple system for tracking forms, dates, and follow-up steps.

There is also an emotional cost to the application process, and it deserves to be taken seriously. In ordinary life, you may spend a great deal of energy focusing on what you can still do, adapting creatively, and trying to remain hopeful. A benefits application asks for something very different. It asks you to describe your worst days, your deepest limitations, and the most vulnerable parts of your daily life. That mismatch can be psychologically exhausting. If you can, check in with yourself regularly for signs of depression, burnout, or emotional strain, and remember that describing severe limitations on paper is not the same as giving up hope in real life.

Many programs also use some form of means testing. Means testing determines whether you or your family qualify for assistance based on savings, income, assets, and sometimes property or other resources. Depending on the country and the specific program, agencies may consider bank balances, jointly held savings, investments, bonds, lump-sum payments, or other capital. This is why it is so important to understand savings caps, earnings caps, benefit caps, and asset rules before you apply. In some systems, qualifying for one financial support program can make it easier to access related supports such as healthcare, food, caregiving, or housing, but proof of eligibility usually still needs to be submitted to each provider or agency.

Once you are approved, support may extend beyond direct cash benefits. You may gain access to health coverage, prescription support, dental or vision benefits, assistive devices, or durable medical equipment. You may also qualify for in-home support services such as paid care partners, health aides, skilled nursing, physical or occupational therapy, or help with meal preparation and other daily tasks. Additional assistance may include food programs, local food banks, housing subsidies, transportation vouchers, paratransit, utility discounts, and disability-related parking or mobility benefits. Because these services vary widely by country, region, and even county or town, it is worth asking not only what exists in theory but also what is actually available where you live. Sometimes the most helpful support is something no one thinks to mention unless you ask.

Throughout the process, keep careful records and stay clear about which benefits are intended to be covered. Most forms of financial support are designed to help with essentials such as food, clothing, housing, healthcare, and limited personal support, not to create long-term financial security. Some recipients are reviewed or audited later, and overpayments may need to be repaid if an agency determines that asset or income limits were exceeded. Good organization, careful communication, and a realistic understanding of how each benefit works can make the process more manageable. Most of all, remember that asking for support is not a moral failure. For many people living with connective tissue variants, it is a practical act of self-preservation and sometimes the very thing that makes endurance possible.

PART III

Reclaiming a Life Bigger Than Healthcare

Chapters 12-14

- Chapter 12: Living with Joy, Humor, and Purpose
- Chapter 13: Building Supportive Connection
- Chapter 14: Respect, Reciprocity, and Mutual Support

The information in Part III is for educational purposes only and does not constitute medical advice. The contributors are sharing general health education, not providing individualized clinical guidance. Always consult your healthcare provider before acting on any information presented here.

12

Living with Joy, Humor, and Purpose

> *A life shaped by chronic illness can easily become crowded with appointments, symptoms, logistics, and recovery. But healthcare is not meant to be the whole of your life. Joy, humor, meaning, creativity, and companionship are not distractions from survival. They are part of what makes survival worth the effort. This chapter is about making room again for the parts of you that exist beyond diagnosis and treatment. Even a careful voyage needs moments of sunlight on the deck.*

Anxiety in Context

When you live with a heritable connective tissue disorder, giving up on enjoying life is not the goal. Quality of life matters, and joy, humor, and purpose are not extras—they are part of what helps life remain livable. This chapter begins there, with the inner work of making room for a life that is larger than healthcare. Anxiety is often part of that picture. Sometimes it develops as a byproduct of physical symptoms. For example, anxiety can be connected to mast cell activation syndrome, dysautonomia, or both, and it can also be a sign that those conditions need to be investigated further. Beyond the physical side, anxiety makes sense because living with a chronic health condition asks so much of you. You have to put extra effort into communicating, extra effort into maintaining your body, and extra effort into participating in work, school, family life, and everyday situations. When new situations arise, when things do not go as expected, or when other people respond negatively, anxiety can grow. You may even develop a kind of rejection sensitivity, where each dismissal makes you wonder why your ideas, thoughts, contributions, or

efforts are not being received. That can look like family members dismissing you or healthcare professionals disregarding what you say. None of that means something is wrong with you. It means you are responding in a very human way. Anxiety is often your mind and body questioning what is happening mentally, emotionally, and physically, while trying to sort it all out. In many ways, it is your body's way of saying, "Slow down. Something is out of balance. Let's figure this out."

Seen this way, acceptance is not giving up on change; it is making enough room in the present to return to what still nourishes you.

> *"Acceptance is a powerful way to reduce distress and frustration; however, we need to be clear and specific about what to accept. It is only useful to accept things 'for now,' in this present moment. No one really knows what will happen in the future. We can become so consumed with fighting with our chronic issues that we lose connection with all that makes life worth living, the things that give us joy. Accepting things as they are for now can help us use our resources to reconnect with what truly matters to us."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

Making Room for Identity and Interests

Because there is so much emotional complexity involved in living with a heritable connective tissue disorder, seeking mental health support is both reasonable and wise. Everyone needs someone to talk to when life is hard, and with these conditions, there are often peaks and valleys—periods of difficulty alongside periods of stability or joy. You may be trying to understand your own feelings while also figuring out how to explain them to other people. That is a lot to process.

A strong mental health provider can help you work through those emotions and build tools for managing stress, pain, anxiety, and fatigue. Physical therapists, occupational therapists, and other allied health professionals can also help you learn pacing, body awareness, and realistic limits, while providing you with the language to communicate those needs to others. Just because you have this diagnosis does not mean it has to become the only thing you focus on. There is still room for your interests, your creativity, and your identity beyond healthcare. Reading, for example, can support both research and pleasure. While you need to keep up with scientific advances and treatment pathways, sometimes you want to read a novel or a

nonfiction book about something completely different, simply to expand your view of the world. That matters, too. Sports can be another meaningful source of connection and joy. They offer community, history, shared excitement, and accessible ways to participate, whether through broadcasts or, when possible, by attending events in-person at accessible venues. Joy can also come through art, photography, poetry, storytelling, singing, and music.

There are adaptive ways to pursue all of these interests, and many well-known people with connective tissue disorders have built meaningful lives in creative fields. Their work shows that you can adapt your tools, your pace, and your environment while still contributing something important. What you create or support can bring joy to other people as well as to yourself, and that is part of your purpose.

Finding Humor and Adapting Purpose

You do not have to stop appreciating humor just because you live with a connective tissue disorder. In fact, everyday humor may matter even more. Sometimes even the names of the conditions are hard to pronounce, and there can be real levity in comparing the funniest mispronunciations or misunderstandings you have encountered. That does not mean people are doing everything wrong. It simply means you are allowing yourself to notice the lighter moments.

Joy can come from friends, family, pets, time in nature, sunshine, books, movies, music, and whatever forms of comfort or distraction genuinely help you. These are not small things. They fill your soul, strengthen your sense of purpose, and help you keep moving forward in life. They also connect you with other people, so you do not have to face everything alone. If music brings you joy, you might attend a local concert or a free community orchestra performance at a school or church. It is not only about the event itself—it is about sharing an experience with other people. Your life does not have to revolve entirely around appointments, diagnoses, and treatment plans. Those things are important, but they need to fit around a life that also includes joy and purpose.

You may discover that the future you once imagined for yourself no longer fits your body or your needs. Maybe you thought your purpose was to work in banking, only to find that the pace, the sitting, and the scheduling demands were not sustainable. Along the way, though, you may have discovered a love of music. In that case, the skills you learned in banking do not disappear—they become transferable. You might manage finances for a band, do bookkeeping remotely for a music venue, or support a nonprofit that promotes music education. You are still using valuable skills, but now

you are applying them in a setting that feels meaningful and sustainable. That is the kind of adaptation that allows purpose to evolve rather than disappear.

> *"Life is full of difficult challenges. Yet it is not the number or severity of these challenges that determines their impact; it is how we respond to them. Viktor Frankl, a psychiatrist and Holocaust survivor, observed that those who fared best were often the people who found purpose and meaning in their suffering. Determining a purpose increased their ability to cope and thus their chances of survival."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

Mental Health as Daily Practice

— Daily Mental Health Care

Mental health maintenance is an ongoing pursuit, whether or not you live with a chronic illness. Alongside nutrition, hydration, sleep management, and movement, mental health can be considered a fifth pillar of health. Support may begin with a mental health professional, but it does not stop there, just as physical therapy does not stop when the appointment ends. The real work continues in daily life. Every connection you build, every effort you make to calm your mind, every time you create room for complex emotions, and every way you reframe your experience so that it supports your participation instead of interfering with it—these are all part of mental health care. This work supports your ability to find joy, appreciate humor, and stay connected to the world around you. Time in nature, breathing techniques, guided imagery, and calming practices can all help regulate your autonomic nervous system. Those same tools may also reduce pain and help you respond more safely in moments of stress. They can teach you to pause, assess what is happening, and avoid shifting into fight-or-flight mode in ways that could worsen an injury, shut down digestion, or hinder recovery.

Mental health maintenance can also look very ordinary. It might be sharing regular family meals, joining a hiking group or community club, playing an instrument, having tea with a friend, or participating in a neighborhood garden or book club. If those spaces do not already exist, you can create them. You might host a game night every few weeks and invite a few friends to rotate through favorite games. If mobility or energy limitations make leaving home difficult, being the host may actually be the

most supportive option for you, because you can stay in a comfortable environment that already meets your needs. A potluck can work the same way. Whether you host or simply bring a dish you know is safe for you to eat, the deeper purpose is connection, conversation, and the joy of being together.

This is part of how you build a life that does not shrink down to symptoms alone. Joy, humor, creativity, rest, and mental health maintenance are not separate from survival; they are part of what makes survival meaningful. They also prepare you for the next layer of living well: connection. Once you have begun making room for yourself again—your interests, your steadiness, your sense of purpose—you are better able to think about how to build community in ways that feel supportive rather than draining. That is where the next chapter begins. Joy is part of what helps keep the deck bright.

> *"Living with conditions like hEDS/HSD, dysautonomia, or MCAS can make spending time outdoors more challenging, but even small amounts of outside time can have meaningful benefits.*
>
> *"Sunlight helps regulate circadian rhythm, which supports sleep, pain regulation, and energy levels. Fresh air may reduce exposure to indoor irritants that can aggravate mast cell symptoms. Some people are extremely sensitive to temperature changes, but for those who tolerate it reasonably well, being outside briefly on a cool day can sometimes help improve alertness or reduce blood pooling in the extremities. For others, cooler temperatures are absolutely a no-go, so this is very individual.*
>
> *"I often remind my patients (and myself) that getting the benefits of some quality time in nature does not need to mean intense hiking or spending hours outside. If you can tolerate that, then that's fantastic. But if not, even a few minutes outdoors, a short walk, sitting on a rooftop or porch, or simply opening a window can create a noticeable shift in stress levels, muscle tension, and nervous system regulation."*
>
> **— Dr. Melissa Koehl, PT**

13

Building Supportive Connection

Once you have begun protecting joy, identity, and emotional steadiness, the next question is how to build and sustain your most important connections—from your social circle and community to your family and children—without overextending yourself. This chapter explores how to find communities that make room for pacing and accommodation, how to socialize in ways that feel safer and less draining, and how to create shared activities that reduce isolation without requiring overexertion. It also addresses the specific challenges of deciding whether to become a parent and navigating the responsibilities of parenting when managing a complex chronic condition.

"Living with chronic difficulties can quickly lead us to become isolated and disconnected from ourselves and others. As physician and author Gabor Maté has explored, safety is not simply the absence of threat. To truly feel safe, we need connection, particularly with other people such as partners, parents, siblings, children, colleagues, and neighbors. We are inherently social beings and have always existed within relationships. Why does the lonely man leave his home to sit alone on a bench in the town center? To experience a sense of connection and belonging, simply by being around others. One of the most calming influences on the nervous system is simply the presence and proximity of another person."

— Dr. Chad Shepherd, Clinical Psychologist

Choosing Supportive Community

As you build support beyond diagnosis-based groups, it helps to be thoughtful about where and how you participate. Chronic illness spaces can be helpful, but some can also feel overwhelmingly negative, so protecting your mental health means being selective. Look for communities that are clearly defined, have rules for engagement, and include trained moderators or facilitators. These spaces may be online or in person, and they may take the form of virtual gatherings, chat rooms, text threads, or messaging groups. You may also benefit from connecting with people who do not share your exact diagnosis but do share your healthcare network, specialists, or service systems. That can be a practical way to learn which providers other people trust and how to identify clinicians who are compassionate, curious, and collaborative.

> *"We often have limited time with our doctors, but patient communities bridge that gap. They offer real-time support, helping us identify what we need to ask and arrive at appointments better prepared. While medical advice must come from professionals, experienced patient communities are invaluable for navigating complex healthcare systems."*
>
> **— Bridget Porter (Metz), Loeys-Dietz Syndrome Advocate**

There are often early signs that a connection is healthy. You do not feel pressured to explain or defend yourself over and over. Accommodations are treated as ordinary rather than as an inconvenience. Leaving early, resting, changing positions, or pacing yourself is not framed as a problem or a failure. Conversation does not revolve entirely around fear, competition, or medical misinformation. Instead, the exchange feels steadier and more balanced, and reciprocity begins to feel natural rather than draining.

It also helps to remember that not every shared diagnosis creates compatibility. Some spaces reduce isolation, while others quietly increase anxiety, overwhelm, or self-doubt. A supportive connection makes room for pacing, boundaries, and imperfection. It allows people to show up as they are, rather than rewarding performance, intensity, or constant availability. If a group or relationship feels consistently chaotic, overly negative, competitive, or demanding, it is okay to step back. You are not looking for the most intense bond or the most dramatic sense of belonging. You are looking for steadiness: people and spaces where mutual care feels possible, your limits are respected, and connection leaves you feeling more grounded rather than more depleted.

> *"Supportive communities can play an important role in recovery, especially when living with chronic illness. Spaces like The Zebra Club are designed to provide education, movement, shared understanding, and practical strategies in an environment that values pacing, safety, rest, and nervous system regulation."*
>
> **— Jeannie Di Bon, MSc, MA, Movement Educator & Hypermobility Specialist**

Starting Small and Local

Sometimes the best way to begin is very small and very local. Instead of waiting for the perfect group to appear, you might invite one or two people to meet in a setting that is easy to access and easy to leave: a home, a quiet park, a library conference room, a casual restaurant, or a coffee shop. You can also post in an online support group that you would like to meet in person and will be at a specific coffee shop at a specific time for an informal meet-and-greet. If that feels helpful, think of it less as trying to become close to everyone and more as gently sorting for compatibility—meeting different people more than once, changing the location by a few miles in different directions each time, and noticing who shows up. Over time, the roster may shift, widen, and grow. The goal is not to collect as many friends as possible. It is about finding people with whom mutual support feels natural, while also creating opportunities for others to make similar connections.

Low-Energy Ways to Stay Connected

Connection does not always have to mean going somewhere in person. Sometimes the most sustainable forms of contact are shorter, quieter, and easier to repeat: a brief check-in text, a voice message, a shared online watch party, a recurring low-pressure phone call, or sending a photo, article, or meme that says, "I was thinking of you." For some people, a short porch visit or drive-by hello may be far more manageable than a longer outing. These smaller forms of contact still matter. They can help you stay woven into one another's lives without turning connection into another high-cost task. In many cases, shorter, repeatable forms of contact are what make a relationship possible over time.

Shared Activities That Make Connection Easier

Not everyone can afford—financially, physically, or energetically—to travel to a large conference in another city or country to learn from experts or be surrounded by others with the same diagnoses. Many of these events now offer virtual attendance, which can make participation far more accessible. If you find yourself missing the sense of camaraderie that comes with being there in person, consider inviting a few local people to watch together at your home or another convenient, accessible location. For a multi-day event, you might take turns hosting different days. In this way, you can still learn from the conference itself while also creating the informal conversation, networking, and local connections that often happen during breaks.

One helpful way to think about this is to think of it as "socializing with training wheels." That might mean going to a museum with people who understand pacing, mobility limitations, rest breaks, food restrictions, or the need to arrive late or leave early. That shared understanding makes it easier to practice being out in the world without feeling as self-conscious about protecting your health. Over time, that can help you build confidence in wider social settings. Another option is shared activities with accommodations. For example, you and a group might attend a baseball game together in an accessible seating area, with arrangements made in advance for directions, early entry, or other venue support. Purpose-driven social connection can also come through volunteering with a nonprofit related to one of your diagnoses or another cause that matters to you. You might attend a conference, join a monthly video call, help at an information table, or support someone attending for the first time who needs help understanding how everything works. Group meal preparation is another excellent example of social support with purpose. You and a group can work assembly-line style to prepare meals that freeze well in single servings, with tasks divided by ability. One person may shop, another may organize containers, and others may cook, spoon, label, or package. Whether there are two participants or twenty, the idea is the same: you share the labor, reduce the physical burden on each person, and leave with food you know is safe and convenient for you. Some groups do this by cooking one large shared meal, eating together, and then dividing leftovers into single-serving portions to freeze and distribute. The point is not perfection. It is cooperation, accessibility, and meeting a real need together.

Supportive social life is not only about reducing loneliness. It is also about practicing trust, interdependence, and shared effort in ways that feel manageable. Over time, the communities that help carry you may also become communities you help carry in return. The right company can make rough water feel less lonely.

That same spirit of connection—steady, reciprocal, and built for the long haul—shapes one of the most personal questions this community faces: whether and how to become a parent, and how to parent well when your own body needs more care.

Deciding Whether to Become a Parent

Questions about parenthood can make the future feel larger and less predictable, which is one reason they often bring the boat metaphor into sharper focus. This is not the moment to build the biggest boat or gather every possible answer at once. It is a moment to ask what kind of support this next stretch of life would actually require: what your body can sustain, what help would need to be nearby, and what steadiness would make family life more livable. The goal is not to solve the whole horizon. It is to understand what this part of the journey is asking of you.

If you do choose parenthood, the next questions often become practical rather than abstract: how to care for a child well, how to talk about bodies and limits, and how to build family life in a way that supports both safety and independence. The next sections address those questions from two different angles. One focuses on parenting a child who may also have a connective tissue disorder. The other focuses on parenting while living in a body that needs more self-care.

Parenting a Child with an HCTD

If you are parenting a child with a connective tissue disorder, the work is often less about preventing every possible problem and more about helping your child grow into self-knowledge, confidence, and practical body awareness. Of course, you want to keep them safe. But over time, your deeper task is to help them learn how to notice limits, describe symptoms, weigh tradeoffs, and make thoughtful choices about activity, rest, and support. Successful parenting is not measured by how completely you control a child's environment. It is measured by whether that child grows into an adult who understands their body, makes informed decisions, and participates in life as fully and independently as possible.

Part of that process is helping your child learn their diagnosis and learn their body in age-appropriate ways. You can start very simply: the names of body parts, where things are located, and how to describe what it feels like when something hurts, feels tired, feels loose, feels unstable, or just feels "off." Sometimes it helps to make this more visual and less intimidating. An anatomy coloring book or another child-friendly visual can give you something concrete to point to when your child is trying to explain what they feel. If they come to you after an activity and say something hurts, you can invite them to show you where it is and describe it in their own words. Children often use vivid language. They may say something feels "crinkly," "hot," "wobbly," or "like static." You do not need to rush in and correct that. The goal is not

perfect medical language right away. The goal is to help your child feel heard, to get curious together, and to slowly build the kind of body awareness and communication that will serve them later with teachers, coaches, care partners, and clinicians. There is no single right way for a child to describe discomfort. What matters is that they learn their experience is real, worth noticing, and safe to talk about.

Children also need practice making choices about activities, and that learning happens best when they have room to try, room to pause, and room to change their mind without shame. You want your child to feel safe saying, "Yes, I want to try that," and just as safe saying, "No, this does not feel good in my body," or "I need a break." When you respond supportively to both answers, you teach them that listening to their body is a strength, not a failure. Decision-making can start very young. When you ask what feels manageable, what feels exciting, what feels too hard, or what they want help with, you are helping them build a skill they will need for the rest of their life. It is also okay for them to need a break from healthcare itself. Appointments, testing, procedures, and symptom monitoring can become exhausting, especially for a child. Children still need room for joy, play, curiosity, and ordinary life, with you acting as a safety net rather than a constant barrier. Whenever possible, offer choices and expect some negotiation, because that is part of how children learn. If your child wants to try soccer but you already know they enjoy swimming, you might talk together about what each activity asks of their body, what support might help, and whether trying one means adjusting the other for a while. Then revisit the conversation afterward. Ask what felt good, what felt hard, what they loved, what they would change, and whether anything surprised them. These small debriefs build communication, self-awareness, and resilience. And if a beloved activity has to change over time, help your child see that belonging does not disappear just because participation looks different. There are still meaningful roles in the things they love: helper, coach, scorekeeper, photographer, team organizer, or simply someone who stays connected to a community they care about.

Another challenge can arise when parents or care partners do not agree on how to acknowledge or manage symptoms. If you are co-parenting, consistency matters. It helps to work toward an approach that feels steady, fair, and predictable for your child. Try not to fall into a pattern where one parent is always the enforcer and the other is always the rescuer, or where one tells the child what to do while the other only asks what the child wants. That kind of split can unintentionally place the child in the middle and add emotional strain to a body that is already working hard. Just as important, you can model the coping skills you hope your child will develop. If hypermobility, instability, or injury risk are part of the picture, practical skill-building

belongs in everyday life. Encourage adaptability. Let your child practice using both hands for ordinary tasks like eating, grooming, cutting food, writing, or brushing their teeth so that an injury does not automatically feel like a disaster. You can normalize this by doing it yourself from time to time and showing that flexibility in how a task gets done is ordinary, not alarming. The same is true for regulation skills. If you want your child to learn breathing exercises, mindfulness, stretching, pausing before reacting, or checking in with their body, it helps when those things become ordinary family practices rather than special techniques brought out only in crisis. At the end of the day, you might talk together about what went well, what felt hard, what they would change next time, and what brought them joy. You can also model rest, recovery, and routines without shame. When children see you protecting sleep, winding down, stretching, using support when you need it, or treating recovery as something valuable rather than lazy, they learn that caring for the body is part of everyday life. In that way, you are not only helping your child get through the day. You are helping them build habits, language, and beliefs that can support them for years to come.

> *"Pacing often looks different in kids than it does in adults, because it relies on the parents noticing symptoms and putting limits on activities, rather than doing it for oneself. The trouble is, we don't want these kids growing up thinking that they can't participate; we want them to grow up learning how to address their individual needs without sacrificing either community or personal health. It's a tricky task but worth the effort."*
>
> **— Dr. Sarah Cohen Solomon, MD, FAAP, Pediatrician**

One place these parenting decisions often become especially visible is school. Fatigue deserves particular attention when it begins to affect classes, activities, or everyday participation, because a child may look fine from the outside and still be working much harder than other children to sit upright, concentrate, keep joints stable, recover after activity, or simply make it through the day without pain. When that happens, it helps to shift the question from “Why can’t they keep up?” to “What support would help them function more consistently?” Sometimes that means school accommodations such as modified physical expectations, extra time between classes, access to hydration and snacks, a place to rest, flexibility around attendance, or help carrying materials. It may also mean teaching your child that fatigue is information, not laziness or failure. The goal is not to lower expectations for who they can become. It is to give them the support they need to participate in a way their

body can sustain. In the end, what you are building is not a perfect system. It is a relationship grounded in honesty, adaptability, and the kind of steady love that teaches a child their body is something to understand and care for—not fear.

Of course, for many parents, these two realities overlap entirely—parenting a child who shares the same condition while managing it yourself.

> *"As a parent who lives with hypermobility—and who has two hypermobile children—I try to focus on what I can teach my children about their bodies. We talk about positions that are more likely to keep our bodies feeling safe and stable, and we recognize positions of instability together. I try to be mindful to create balance in our days, allowing for periods of energy release and periods of positive rest. We talk about what it means to listen to what our bodies are telling us, and how to create moments of spontaneity with safety. I know there will be challenges along the way, but I am hopeful to teach them how to be advocates for their own care in the future."*
>
> **— Jesse Miller, MS, OTR/L, Occupational Therapist & Craniosacral Therapist**

Parenting When You Live with the Condition

If the previous section is about helping a child understand and live well in their body, this section turns to a different question: how to parent well when your own body needs more care. Parenting from within a heritable connective tissue disorder can stir up complicated feelings. You may wonder whether you are doing enough, or worry that your limitations are somehow letting your children down. Anxiety and guilt can live right alongside the practical demands of everyday life. It helps to remember that there is no single right way to parent well, and one of the most loving things you can do is ask for help in specific, thoughtful ways. When support is built around particular tasks at particular times, you can still remain the primary decision-maker or an equal partner in a co-parenting relationship. In the end, what your child needs most is your love, your presence, and your attention. Years from now, they are unlikely to remember whether the house was always spotless. They are far more likely to remember whether they felt loved, safe, and emotionally secure because those are the things that help children grow in confidence, a sense of belonging, and independence.

> *"Happy, healthy homes do not all look the same, and that's okay—even beneficial. Children learn best by example. So when they are raised by parents with a chronic illness or disability where those needs are accepted and normalized, it can help build empathy, tolerance, compassion, and resilience—all traits that make the world a better place for everyone. Modeling acceptance and self-care is a strength, not a weakness."*
>
> **— Dr. Sarah Cohen Solomon, MD, FAAP, Pediatrician**

For that reason, it can help to get creative with how you spend time together. Try to shape your time with your child around joy, partnership, and a sense of shared purpose. Let them know that their presence is enough. Reassure them that they help simply by loving you and allowing themselves to be loved in return. Small daily routines can become powerful anchors of connection. In the morning, for example, you might sit together at breakfast while they help prepare simple foods. You can arrange the kitchen so they can safely reach cereal, dishes, and utensils, or place the toaster somewhere accessible with a sturdy stool and safety rails if needed. In that kind of setup, they may be able to put a piece of bread or a frozen waffle in the toaster on their own. You may not be able to do every bit of lifting, but children are meant to grow into independence anyway. Many can climb into the car and into their car seat on their own while you help with buckling, which protects your wrists and spares you from lifting that could cause pain or injury.

You can also invite your child to take part in everyday chores in ways that fit their age and abilities. Helping tidy shared spaces can build responsibility while also giving them a sense of ownership in the home. They may feel proud knowing they helped keep things safe, comfortable, and manageable for both of you. Read together, watch shows together, and stay engaged in whatever matters to them. Those years when they still want your company are precious, and that kind of steady connection can support their long-term social and emotional development. At the same time, it is important to protect the balance of the relationship. Your child should not become the person who is solely responsible for chores, meals, or your care. When that kind of help is needed, it is usually healthier to bring in support from outside the immediate parent-child relationship so your family dynamic can remain loving and age-appropriate.

It can also help to be honest with your child about your symptoms, your condition, and your limits in age-appropriate ways. Children are often quite capable of understanding that different adults have different strengths. One adult may be the person they roughhouse with, while another is the person they turn to for a quiet conversation or a story. A grandparent with arthritis may not be able to lift a child, yet that child can still feel deeply loved through attention, laughter, shared reading, and the experience of being taken seriously. You can parent meaningfully in that same way. If your condition means that accommodations, assistive devices, or extra healthcare support need to become part of your home, remember that those changes affect your child's environment too. It may help to include them in simple decisions, such as where a walker should go when it is not in use or how to arrange furniture to create a clear, safe path through the house. Giving your child some agency in their own space can help them feel included, respected, and invested in the way the home works for everyone.

> *"One of the hardest things to tell parents is that sometimes, they need to put their own needs before those of their children. Self-care for a parent with a chronic illness or disability is not optional. There's a reason flight attendants remind us all to put our own mask on before helping others: you can't take care of your child if you don't take care of yourself, too. Does this mean neglect your child? Of course not. It means that finding a balance is a difficult but nonnegotiable task for any parent."*
>
> **— Dr. Sarah Cohen Solomon, MD, FAAP, Pediatrician**

You do not have to do everything. You have to show up—honestly, warmly, and willing to ask for help. The connection you build in the ordinary moments, the quiet mornings, the shared routines, and the small conversations about what hurts and what helps, is not a lesser version of being a parent. It is the whole thing. And somewhere in that, your child learns something important: that a body can need more care and still carry a full life.

14

Respect, Reciprocity, and Mutual Support

> *Over time, the support you receive may also become something you are able to offer. That does not require having everything figured out. It simply means that experience, humility, and lived knowledge can become useful to someone else. This chapter is about respect, reciprocity, and the ways people living with chronic conditions often help build stronger communities for those who come after them. Sometimes paying it forward means becoming, for another person, the harbor you once needed yourself.*

What Reciprocity Really Means

In chronic illness communities, reciprocity often cannot mean equal output, equal energy, or equal help at every moment. It usually has to mean something more flexible: offering what you can when you can, and allowing care to move in different directions at different times. One person may offer rides, another may share information, another may bring humor or emotional steadiness, and another may provide practical help or simply sit beside you and understand. Sometimes your role is to give, and sometimes your role is to receive. Receiving support is part of mutuality, too. Relationships are not at their healthiest when they are treated like ledgers to be balanced line by line, or when anyone feels they must earn care by over-performing. They are healthiest when care can circulate with respect, when people trust that roles may shift over time, and when everyone is allowed to notice and honor both their own limits and others' without shame.

Respecting the Variety of Communities and Organizations

There are so many nonprofits and support groups available that it can feel overwhelming to choose among them. You may hear people say there are too many and that they should all be consolidated, but it can help to step back and consider why so many organizations exist in the first place. People are different. They learn differently, they need different kinds of support, and they reach for different resources at different stages of their journey. Often, an organization exists because at some point someone needed exactly what it had to offer, presented exactly that way. Yes, there is overlap. Yes, there is redundancy. But that is not necessarily a problem. It can serve as a form of checks and balances, helping you confirm whether information is valid, consistent, and trustworthy across different websites and communities. It also gives you more ways to access information in different formats, languages, and countries, which can be especially important if you are living with a rarer or ultra-rare heritable connective tissue disorder.

> *"Living with chronic illness often teaches people the importance of mutual support, shared lived experiences, and compassion. Communities built around respect, pacing, and shared experiences can help people feel less isolated and more understood."*
>
> **— Jeannie Di Bon, MSc, MA, Movement Educator & Hypermobility Specialist**

Staying Humble About Knowledge

Sometimes you need to connect with people whose lived experience is very close to your own to compare notes, resources, and references. That may even include translating information into or out of another language. As you explore these organizations, it helps to stay respectful of the variety that exists and honest about the limits of current knowledge. Science is still evolving. No one knows everything, and the strongest experts are the ones who keep researching, seeing patients, and looking for patterns that advance diagnostics and treatment. They are also the people creating educational content and training clinicians, even if it takes time for that knowledge to reach each individual living with a diagnosis.

Giving Back Sustainably

Giving back does not mean you have to become a mentor, advocate, or educator for everyone who crosses your path. It is healthiest when it is sustainable, and when your experience can help others without becoming your full-time responsibility. Sometimes contribution is small and quiet: answering one question in a support group, sharing a template or resource list, welcoming someone new, participating in a survey, or telling another person what helped you ask a better question at an appointment. These acts still matter. They can pass along steadiness, reduce confusion, and help someone else feel a little less alone without asking you to carry more than your body and life can realistically hold.

As people become more knowledgeable, others often begin turning to them for advice, support, or interpretation. It helps to remember that you are allowed to say, "I don't know." You are allowed to refer people back to clinicians, formal resources, or organizations better equipped to answer their questions. You do not have to carry everyone. In fact, boundaries are part of ethical support. Respect and reciprocity both depend on recognizing that no one person can be everything for everyone, and that helping is healthiest when it remains honest, well-paced, and grounded in what you can realistically offer without harm to yourself or others.

Over time, you may find yourself becoming a guide for others who are earlier in their journey. Mutual support matters in every direction: you learn from people who know more than you, people who know less than you, and people who are learning alongside you. You also support them in return. The most trustworthy people are usually the ones who can say, "I know some things, I do not know everything, and I am still learning." That mindset leaves room for growth and helps you pay support forward.

> *"We can realize how far we have come, not by measuring the distance we have traveled, but by reflecting on all we have learned along the way. Sharing these lessons with others and helping them navigate a difficult path by offering guidance and valuable insights is a wonderful act of compassion; that can ease the suffering of both ourselves and others."*
>
> **— Dr. Chad Shepherd, Clinical Psychologist**

You can also give back by participating in research. That might mean completing surveys from home, allowing limited access to portions of your medical records or imaging, donating blood, saliva, or skin samples to a biobank, or participating in a treatment or intervention study. Some of those experiences may directly benefit you, and all of them contribute to knowledge that may help others. It is always appropriate to ask how your information will be used, how personal identifiers will be separated, and how findings will be shared. Good research welcomes those questions. There will continue to be more to learn, more studies to read, and more updates to diagnostic criteria and treatment pathways as science advances. The pace of change is already much faster than it was decades ago, which gives real hope that knowledge, diagnostics, and care will continue to improve. As you move forward, reliable resources, trusted books, supportive communities, and accessible educational materials can all help you build a life that is informed, connected, and sustainable.

> *"I would like EDS and related conditions to receive the respect and recognition they deserve and need. I also want people to truly understand the multi-systemic nature of these conditions—and for the research to be done to prove what we already know anecdotally."*
>
> **— Lara Bloom, President & CEO, The Ehlers-Danlos Society**

In that way, the movement across these chapters becomes its own kind of practice: making room for joy, building sustainable connection, and then turning outward with respect and reciprocity. You do not have to do all of this at once, and you do not have to do it perfectly. You grow into it over time. And as you do, you help create a world in which the next person has a little more language, a little more support, and a little more hope than you may have had when you began. **Sometimes paying it forward means becoming part of the harbor someone else can trust. That is how the waters get a little less lonely—not all at once, but one steady vessel at a time.**

The information in the following Appendices, Resources, and Further Reading is for educational purposes only and does not constitute medical advice. The contributors are sharing general health education, not providing individualized clinical guidance. Always consult your healthcare provider before acting on any information presented here.

Appendix A

A Patient-Friendly History of the Ehlers-Danlos Syndromes

Introduction

The names used for conditions, the way they are grouped, and the criteria clinicians rely on today did not appear all at once. They were shaped over time through observation, uncertainty, debate, and scientific progress. Understanding that history can make the present feel less confusing, especially when diagnostic language changes or older labels are revised. Medicine, like navigation, depends on charts that are redrawn as knowledge improves.

This overview is written for patients and care partners who want to understand where Ehlers-Danlos syndrome (EDS) came from and why the names and "types" have changed over time. I'll keep the same level of detail as the original text, but in a more conversational, easier-to-scan format.

Quick definition: EDS is a group of heritable connective tissue conditions. Depending on the type, people may have joints that move farther than expected, skin that is unusually soft or fragile, scars that look different than expected, and (in some types) more serious tissue fragility involving organs and blood vessels.

Early Descriptions Before the Name "EDS"

Let's back up. Long before anyone used the term *Ehlers-Danlos syndrome*, doctors noticed a recognizable pattern in some people: very flexible joints, easy bruising/bleeding, unusual scars, and slow or poor wound healing. One of the earliest written references is often attributed to Hippocrates (around 400 BCE), who described Nomads and Scythians with lax joints, prominent, unusual scars, and a tendency toward bruising and bleeding.

Fast-forward to the 17th century: at a medical conference in Holland, a Spanish sailor named George Albes reportedly demonstrated how far the skin on his chest could stretch, pulled out to about an arm's length.

You'll also see references to a 1892 description by Russian dermatologist A. N. Tschernogubov (also spelled Chernogubov). He presented a case study of a teenage boy with recurrent joint dislocations, fragile skin, and poor wound healing. Because his work wasn't widely shared outside Russia for about 50 years, his name is not as well-known internationally today. Inside Russia, the condition is still often called "Tschernogubov's syndrome" (or "Chernogubov's syndrome").

By the late 1800s, these patterns were being documented as recognizable case reports—setting the stage for EDS to be named and described more systematically in the early 1900s.

How EDS Got Its Name

In the early 1900s, two physicians—Edvard Ehlers (Denmark) and Henri-Alexandre Danlos (France)—described similar patients at medical meetings a few years apart (1901 and 1908). Later, as clinicians realized this was a recurring pattern rather than isolated cases, the word "*syndrome*" was added to the name. In 1936, English dermatologist Frederick Parkes-Weber proposed the term **Ehlers-Danlos syndrome** to describe this group of findings.

Genetics Enters the Conversation

Around 1950, Victor McKusick began publishing influential observations about genetics and HCTDs. He edited an early textbook on the topic, *Heritable Disorders of Connective Tissue (1956)*, which brought together case studies and research on conditions such as Marfan syndrome, osteogenesis imperfecta, Stickler syndrome, and EDS. The textbook was updated multiple times; later editions included contributions from researchers such as F. Michael Pope and Peter Beighton (who edited the 5th edition in 1993).

From One Condition to Many Types

As medicine and genetics moved forward—and as more people were recognized as living with EDS—the conversation shifted from "one condition" to "a family of related conditions." Researchers started noticing that certain lab findings and biomarkers (for example, urine tests or skin testing approaches used at the time) tended to appear alongside specific clusters of symptoms. That's where the idea of different EDS "types" comes from.

For a long time, the labels changed frequently. If clinicians noticed a new marker or a more distinctive symptom cluster, a subgroup might get split off and renamed. In the 1960s, naming shifted from Latin descriptors (often hinting at severity) to numbered "types." By the 1970s, some reports described more than twenty types, depending on which system you looked at. In the 1980s, some numbered categories were merged again once it became clear that many people overlapped—for example, "benign generalized joint hypermobility" was grouped with what had been Type 3, which was previously viewed as a more severe joint-hypermobility presentation.

1997: The Villefranche Nosology

A big turning point was the 1997 Villefranche nosology, which tried to simplify the long lists of numbered categories by moving toward a smaller set of named types. In that system, some types stood out because they had very characteristic features, or because there was a test that could support the diagnosis. For example, kyphoscoliotic EDS was linked to severe spinal curvature and could be supported by a urine test for certain proteins (even though the mechanism was not fully understood at the time). Arthrochalasia EDS was separated out largely because it often shows up right away at birth, with findings like clubfoot and congenital hip dislocation. Dermatosparaxis EDS was known for extreme skin fragility and hernias, often along with short stature and profound hypotonia (very "floppy" infants). Vascular EDS has a long record of consistent clinical features and a higher risk of serious complications such as arterial dissection or organ rupture. Hypermobile EDS focused on major joint instability (dislocations and frequent subluxations), while classical EDS was associated with a distinctive soft, "doughy" skin feel and recognizable scarring patterns.

2017 Criteria, hEDS vs. HSD, and the Road Ahead

From 1997 to 2017, things sped up: genetic testing became more available, more patients were diagnosed and followed over time, and case reports became more detailed about symptoms and their progression. That helped sharpen the "phenotypes" (the consistent patterns that define each type) and showed where older labels were getting blurry. By 2017, the international classification expanded to 13 EDS types (up from six in 1997), including several very rare forms that became easier to recognize once genetics entered the picture. Periodontal (dental) EDS is a good example: it was treated as its own category in older numbered systems, then got folded into other categories when dental findings were seen as more general, and

then was pulled back out once genetics showed a consistent inherited pattern that could be tested. Another example is brittle cornea syndrome, which used to be grouped under kyphoscoliotic EDS; later work showed that some people had less dramatic scoliosis but severe, progressive corneal thinning and a predictable chain of eye complications—enough to justify a separate label. Other categories—like musculocontractural EDS (contractures from birth), myopathic EDS (muscle weakness and joint contractures), and spondylodysplastic EDS (often involving short stature)—also became easier to separate as larger datasets made the differences more obvious.

In 2017, the criteria were intentionally narrowed, with the hope that a more specific phenotype (how someone looks clinically and which symptoms they show) would make it easier to find an underlying gene, because historically, that's often how new genetic discoveries have occurred in EDS. In real life, though, many people ended up being told they either "have hEDS" or they fall into a hypermobility spectrum disorder (HSD) category instead. For many patients, that felt like losing access to care or being handed a "lesser" label—even though both are valid diagnoses that deserve time, attention, and effective care.

Why Names Keep Changing

The reason this kind of reclassification keeps happening is pretty straightforward: each revision tries to tighten the definition of a group to make it more consistent and easier to study. That means looking for patterns across symptoms, measurements, imaging, lab results, medical history, and how things change over time—and then asking, "Do the people in this bucket really look alike in a reliable way?" Once a bucket is sufficiently consistent, researchers can study it more effectively and have a better chance of identifying a shared gene or mechanism, which eventually makes confirmatory testing possible.

Some newer categories also highlight how older labels depended on what happened to stand out most during an exam. For example, cardiac valvular EDS was difficult to clinically distinguish for a long time because a person might have been labeled hypermobile, classical, or vascular depending on which joint, skin, or vascular/cardiac findings were most noticeable at the time. "Classical-like" EDS is another example: it can resemble classical EDS but lacks hallmark features such as atrophic (sunken, often widened) scars typical of classical EDS.

How EDS Is Diagnosed Today

Even now, diagnosis usually starts the "old-fashioned" way: a detailed history and a careful physical exam. Clinicians compare what a person is experiencing to the major and minor criteria for different EDS types. A helpful way to picture this is the "poker chip" model: imagine each type has its own color, with major criteria as big chips and minor criteria as smaller ones. Because many features overlap across types (and can even show up in conditions that aren't EDS), someone can end up with chips in multiple colors. Clinically, the biggest pile often points to the best-fit label—and when it's available and makes sense, genetic testing or other biomarkers can help confirm it or sort out close calls.

The intent behind narrowing criteria was to keep a broad hypermobility bucket together and then—as research improves—pull out more clearly defined (and testable) subgroups and give them more precise diagnoses over time. That same approach is behind the current "road to 2026" reclassification effort: using newer science, larger datasets, better biomarkers, broader genetic testing, and more detailed case studies to rethink and tighten the current boundaries. One of the toughest sticking points remains hypermobile EDS (hEDS).

> *"In my work as a patient advocate, I've witnessed the profound shift that happens when someone's health story is finally heard and met with a diagnosis—the relief of being believed, the validation of having their experience named, and the freedom to move forward with clarity instead of confusion."*
>
> **— Maggie Buckley, MBA, BCPA**
>
> Founded by an hEDS patient who waited 15 years for her own diagnosis, EDS Connective was built to change that timeline for all of us still waiting. Our virtual health platform connects patients with independently licensed providers for expert evaluation—online, accessible, and available in all 50 states. Learn more at edsconnective.com.

When to Seek Emergency Care

Most EDS symptoms can be discussed with a regular clinician, but some symptoms should be treated as urgent because they may signal a serious complication. This is especially important to distinguish between general EDS concerns and vascular EDS (vEDS): people with vEDS may need emergency evaluation more quickly for symptoms that could suggest blood vessel or organ injury. In most non-vascular

forms of EDS, the baseline risk of spontaneous arterial rupture or organ rupture is not thought to be the same as it is in vEDS, even though urgent symptoms should still be taken seriously. If something feels suddenly different, severe, or out of proportion to your usual baseline, it is reasonable to seek immediate medical help.

- Sudden, severe chest, back, abdominal, or head pain—especially in vascular EDS, where this may raise concern for arterial dissection, rupture, or another internal emergency
- Trouble breathing, fainting, new confusion, or symptoms that suggest stroke (such as facial droop, trouble speaking, or one-sided weakness)
- Heavy bleeding that does not stop, vomiting blood, black or bloody stools, or coughing up blood—urgent for anyone, but particularly concerning in vascular EDS because internal bleeding or organ rupture can become life-threatening quickly
- A major injury, suspected fracture, or joint dislocation that cannot be safely reduced or controlled
- Sudden vision changes, severe eye pain, or other abrupt neurologic symptoms

If you think you may be having a medical emergency, call emergency services or go to the nearest emergency department right away.

Conclusion

If you're living with EDS (or caring for someone who is), it can be reassuring to know that the shifting labels usually reflect progress—not uncertainty about whether your symptoms are real. Researchers keep refining the categories so each type is easier to recognize, study, and (when possible) confirm with testing. Over time, that work is meant to translate into clearer diagnoses and better, more targeted care. The charts may change, but they are still helping more people find safer passage.

> *"Too many face gaslighting instead of guidance. They're told it's all in their heads. Some are left without answers for years, watching their bodies deteriorate when they could have been building strength, confidence, and autonomy with the right support."*
>
> **— Lara Bloom, President & CEO, The Ehlers-Danlos Society**

Sources for Appendix A appear in Resources and Further Reading.

Appendix B

Marfan Syndrome: An Explainer

Introduction

Marfan syndrome is a genetic condition that affects the body's connective tissue. Connective tissue helps support and hold many parts of the body together, including the heart, blood vessels, eyes, bones, lungs, and skin. Marfan syndrome can affect people in different ways, but the most important health concern is often the aorta, the large blood vessel that carries blood away from the heart.

When the Condition Was First Recognized: Timeline of Naming, Research, and Classification

Marfan syndrome was first recognized for its visible physical features, but over time, doctors came to understand that it was not simply about height, long fingers, or body shape. What at first looked like a skeletal pattern gradually revealed itself as a condition that could affect several body systems at once. The timeline below shows how that understanding developed and how the condition moved from early description into modern diagnosis and research.

Timeline

- 1896: A French doctor named Antoine Marfan described a child with unusually long arms, legs, fingers, and toes. That early report led to the condition being named after him.
- Early 1900s: Doctors began to realize that Marfan syndrome did not only affect height or body shape. It could also affect the eyes and the aorta, which helped explain why some people had serious complications.
- 1929: The name "Marfan syndrome" started being used more widely in medical writing.

- 1950s: Doctors developed a clearer picture of Marfan syndrome and recognized it as a condition that can affect several body systems at once.
- 1986, 1996, and 2010: Experts created and updated official diagnostic guidelines to help doctors tell Marfan syndrome apart from other conditions that can look similar.
- 1991: Researchers found that many people with Marfan syndrome have a change in a gene called FBN1. This discovery helped doctors confirm the diagnosis in some families and improved research into why the condition happens.

As the timeline shows, the story of Marfan syndrome is not only about when it was named. It is also about how the medical picture widened over time. What began as an observation of outward appearance eventually became a deeper understanding of how differences in connective tissue can affect the heart, eyes, skeleton, and other parts of the body. That broader view is what shaped the way diagnosis works today.

Common Features

Marfan syndrome can look very different from one person to another. Some people notice body changes such as being tall and slim with long fingers, while others first learn about it because of an eye problem or a change in the aorta seen on a scan.

- **Heart and blood vessels:** widening of the aorta, leaking heart valves, or, more rarely, a tear in the aorta.
- **Eyes:** a dislocated lens, nearsightedness, retinal problems, cataracts, or glaucoma.
- **Bones and joints:** tall height, long arms and legs, long fingers, curved spine, a sunken or raised chest, flexible joints, or flat feet.
- **Other possible features:** stretch marks, a collapsed lung, back pain, tiredness, or changes in the tissue around the spinal cord.

One reason Marfan syndrome can take time to recognize is that it does not look exactly the same in every person. Some people have many visible features early in life, while others may come to medical attention because of an eye finding, a heart murmur, or a change in the aorta seen on imaging. Looking at the common features together helps explain why diagnosis depends on patterns across body systems rather than on any single trait alone.

How It Is Diagnosed Today

Doctors diagnose Marfan syndrome by reviewing a person's medical history, family history, physical features, eye findings, cardiac imaging, and sometimes genetic test results. The current guideline is called the 2010 Revised Ghent criteria. In simple terms, it gives the most weight to changes in the aorta and to lens dislocation in the eye. In the absence of a family history, those two findings together can be enough to make the diagnosis. If one of them is missing, doctors may also consider a disease-causing change in FBN1 or a high systemic score built from other body features.

- Doctors look closely at the aorta: imaging tests such as echocardiograms help show whether it is enlarged.
- Eye exams matter: a specialist may check whether the lens inside the eye is out of place.
- Body features can add up: things like chest shape, spine curvature, long fingers, flat feet, and certain skin or lung findings may support the diagnosis.
- Genetic testing can help: finding a disease-causing change in FBN1 can support the diagnosis and help with family screening, but not everyone needs a genetic test to be diagnosed.

As doctors gained a clearer understanding of these patterns, diagnosis became more structured and more precise. At the same time, long-term monitoring became especially important because the aorta can be affected in ways that carry serious health risks if they are missed. Modern care is built around that combination: accurately recognizing the pattern, confirming the diagnosis when possible, and then following the parts of the body that need the closest attention over time.

Treatment and Long-Term Monitoring

Treatment and long-term monitoring focus on protecting the aorta, identifying complications early, and reducing strain on the cardiovascular system over time. Most people with Marfan syndrome need regular heart imaging, and some also need eye exams and follow-up for skeletal or lung concerns. Medicines such as beta blockers or angiotensin receptor blockers may be used to reduce stress on the aortic wall, and surgery may be recommended if the aorta reaches a size or growth pattern that increases the risk of tearing. Activity guidance is also part of care, especially when it comes to avoiding heavy straining or high-impact activities that may increase risk.

We know that Marfan syndrome is usually caused by a change in the FBN1 gene and can range from mild to severe. We also know that earlier diagnosis, regular heart scans, medicines that reduce strain on the aorta, and surgery when needed have greatly improved outcomes for many people.

When to Seek Emergency Care

Most symptoms of Marfan syndrome can be monitored over time, but some problems require urgent medical attention. Emergency care is especially important if there are warning signs of aortic dissection, sudden lung collapse, or a serious eye emergency, because quick treatment can prevent permanent harm and may save a life.

- Go for emergency care immediately if there is sudden, severe pain in the chest, upper back, neck, or abdomen, especially if it feels tearing, ripping, or unlike anything felt before.
- Get urgent help for sudden shortness of breath, sharp chest pain, fainting, weakness, numbness, tingling, or a feeling that something is seriously wrong.
- Seek emergency eye care for sudden flashes of light, new floaters, a shadow or curtain over part of the vision, or sudden major vision changes.

If emergency care is needed, call emergency services right away rather than waiting to see if symptoms improve. It also helps to inform the medical team that the person has Marfan syndrome, as this can alert them to the possibility of aortic dissection or other complications that require prompt evaluation.

What We Know, and What We Still Do Not Know

What doctors and researchers still do not fully understand is why two people with the same gene change can have very different symptoms, how to predict exactly which person's aorta will enlarge more quickly, and which treatments work best for each person. Researchers are also still learning more about pain, fatigue, and quality of life in people living with Marfan syndrome.

In short, Marfan syndrome is now far better understood than it was a century ago, but it remains an active area of research. The history of the syndrome shows a steady shift from descriptive observation to formal diagnostic classification, to gene-based and mechanism-based medicine.

Sources for Appendix B appear in Resources and Further Reading.

Appendix C

Loeys-Dietz Syndrome: A Narrative Overview

Introduction

Loeys-Dietz syndrome (LDS) is a clinically and genetically diverse group of inherited connective tissue disorders. It was first recognized in 2005 in people whose condition overlapped with Marfan syndrome but also showed unusual features and a pattern of blood vessel disease that could be especially serious. LDS is now understood to involve pathogenic variants in genes of the transforming growth factor beta (TGFβ) signaling pathway, and these genetic differences help explain why the condition can look very different from one person to another.

The updated 2026 care management primer emphasizes that LDS is not just an aortic condition. In addition to aortic aneurysms and arterial tortuosity, it can involve the face and palate, skeleton, skin, eyes, ears, immune system, digestive tract, lungs, and nervous system. Because expression is so variable, care works best when it is individualized and coordinated across specialties rather than managed by only one clinician.

Timeline of Discovery, Research, and Classification

- 2005: Loeys-Dietz syndrome was first described as a distinct condition associated with aggressive arterial disease and characteristic craniofacial and skeletal features.
- 2006: Follow-up reports expanded the picture, showing that aneurysm syndromes related to TGF-beta receptor mutations could involve a broader spectrum of vascular risk than first recognized.
- Late 2000s to 2010s: Genetic testing broadened the diagnosis beyond the earliest reported features and showed that multiple genes in the transforming growth factor beta signaling pathway could lead to related Loeys-Dietz presentations.
- 2010s to early 2020s: Imaging and surveillance recommendations became more systematic, with greater emphasis on monitoring the entire arterial tree rather than only the aortic root.

- 2020s: Research has increasingly focused on genotype-phenotype differences, long-term outcomes, and how best to tailor monitoring and timing of intervention for different genetic forms of LDS.

When the Condition Was First Recognized

LDS was first described as its own condition in 2005 by Dr. Bart Loeys and Dr. Harry Dietz. Before that, many people with LDS may have been thought to have other connective tissue disorders, such as Marfan syndrome. What made LDS stand out was that some patients had a dangerous pattern of artery problems at a younger age and sometimes with smaller aneurysms than doctors expected. Early reports also described certain physical features, such as wide-set eyes and a split or broad uvula, but over time, it became clear that not everyone with LDS has these classic signs.

At first, the earliest descriptions of LDS emphasized the features that were easiest to recognize: aggressive vascular disease, younger age of presentation, and certain craniofacial findings. Over time, however, clinicians began to see that this early picture was incomplete. Not everyone with LDS looked the same, and some people who did not have the most "classic" appearance still carried important vascular risks.

How Understanding and Diagnosis Evolved

Our understanding of LDS has changed a great deal since it was first recognized. At first, doctors mainly identified it by looking for a group of visible features and artery problems. Over time, genetic testing has shown that LDS can be caused by changes in several genes and that people can be affected very differently. Because of this, doctors now rely less on appearance alone and more on a combination of family history, heart and blood vessel imaging, and genetic testing. This has made it easier to find people who may not have obvious outward signs but still need careful monitoring. It has also improved care for family members, because relatives can be tested and followed early if needed.

That shift in understanding is one reason the list of common features now spans several body systems. LDS is not defined by any one outward sign alone. Instead, it is recognized through patterns involving blood vessels, skeletal features, facial structure, skin, and sometimes other organ systems as well. Looking at these features together helps explain why the condition can be easy to miss if attention stays focused on only one part of the body.

Common Features

Loeys-Dietz syndrome can affect multiple parts of the body, and the pattern can look quite different from one person to another. Some people have very noticeable physical features, while others are first identified because of artery findings on imaging or a strong family history.

- **Arteries and the heart:** enlargement of the aorta, aneurysms, arterial tortuosity, or a risk of arterial tear or dissection.
- **Craniofacial features:** widely spaced eyes, a bifid or broad uvula, cleft palate, or other facial and palate differences.
- **Bones and joints:** scoliosis, chest wall differences, long fingers, flexible joints, joint instability, or foot differences.
- **Other possible features:** skin findings, easy bruising, digestive symptoms, allergic or immune-related issues, and symptoms that overlap with other connective tissue disorders.

Quick Takeaways

- Loeys-Dietz syndrome (LDS) can affect many parts of the body, but the biggest concern is often the heart and blood vessels.
- Regular scans and checkups are important because blood vessel changes may happen over time, even if someone feels well.
- Genetic testing can help confirm the diagnosis and show whether other family members may also need screening.
- Care often works best with a team that may include heart doctors, genetic specialists, surgeons, and other providers, depending on symptoms.
- With the right monitoring and care plan, many people with LDS can reduce risk and get support for everyday health concerns.

How It Is Diagnosed Today

Today, LDS is diagnosed by combining medical history, family history, physical findings, vascular imaging, and genetic testing. Current diagnosis generally requires a pathogenic or likely pathogenic variant in one of the genes currently recognized for LDS, and testing is especially important in people with unexplained aortic root enlargement, arterial aneurysm or tortuosity at a young age, suggestive craniofacial or skeletal findings, or a family history of aneurysm, dissection, or a known

LDS-related variant. Because some people have only subtle outward features, a normal early heart scan does not completely rule out future risk, and relatives may also need targeted testing and follow-up.

Treatment and Long-Term Monitoring

Treatment for LDS focuses on reducing the risk of life-threatening vascular events while also managing the many other body systems the condition can affect. Long-term care often includes regular echocardiograms, imaging of the head through the pelvis to look for aneurysms and arterial tortuosity, medicines such as beta blockers or angiotensin receptor blockers, activity guidance, and preventive surgery when blood vessel size, growth rate, family history, or genetic subtype suggests higher risk. The updated 2026 primer also highlights the importance of coordinated care for related concerns such as craniofacial differences, scoliosis and bone fragility, hearing and vision issues, allergy or gastrointestinal disease, pregnancy planning, pain, fatigue, and mental health. In practice, this means that many people benefit from a multidisciplinary team and, when possible, input from centers with specific experience in LDS.

The goal of the updated primer is to improve clinical awareness and patient outcomes by giving healthcare teams a more practical, individualized framework for care. It reflects expert consensus and a broad literature review, but it also makes clear that some questions remain, especially for the rarer genetic subtypes, for long-term risk prediction, and for how best to tailor surveillance and intervention across age groups, sex, pregnancy, and family history.

When to Seek Urgent Care

- Get help right away for sudden, severe chest, back, neck, or belly pain.
- Go to the ER for sudden trouble breathing, fainting, weakness, trouble speaking, or a very bad headache.
- Get urgent eye care for sudden vision loss, flashes, or many new floaters.
- If something feels seriously wrong, get checked and tell the care team you have Loeys-Dietz syndrome.

What We Know, and What We Still Do Not Know

Even though doctors know much more about LDS now than they did when it was first described, there are still important unanswered questions. People with the same genetic change can have very different symptoms and very different levels of risk, and doctors do not always know why. Researchers are still learning about the long-term outlook for people with some of the rarer genetic forms of LDS, the best timing for certain surgeries, and the safest ways to manage pregnancy and childhood growth in people with the condition. There is also ongoing research into whether future treatments might target the disease more directly instead of mainly lowering stress on the arteries. In other words, LDS is much better understood than it once was, but it is still an active area of research, and care continues to improve.

Sources for Appendix C appear in Resources and Further Reading.

Appendix D

Understanding Mast Cells and Mast Cell Activation Syndrome

Key Questions Answered

Mast Cell Activation Syndrome (MCAS) is a disorder in which mast cells release chemical mediators—such as histamine, tryptase, leukotrienes, and prostaglandins—inappropriately or excessively, causing recurrent symptoms that can affect multiple organ systems. These episodes often resemble allergic reactions or anaphylaxis and may involve the skin, gastrointestinal tract, airways, cardiovascular system, and nervous system. MCAS is distinct from mastocytosis: in MCAS, mast cells are usually not increased in number, but they are abnormally activated.

When Was MCAS First Identified?

The concept of MCAS emerged in the late 2000s and was formally proposed around 2010, with the first widely cited international consensus framework published in 2012. In practical terms, this means MCAS is a relatively new diagnosis compared with mastocytosis, which has been recognized for much longer. Since then, expert groups have refined the definition and classification as more evidence has accumulated.

Has the Identification, Evaluation, and Diagnostic Pathway Evolved Since Then?

Yes. Early thinking focused heavily on tryptase elevation and on distinguishing MCAS from mastocytosis and ordinary allergy. Over time, clinicians recognized that some patients have convincing mast cell–mediated symptoms but do not show a dramatic or persistent tryptase elevation outside acute episodes. As a result, evaluation has become more structured and nuanced: clinicians now focus on three pillars—(1) recurrent, severe, episodic symptoms in at least two organ systems, (2) objective evidence of mast cell mediator release during a flare compared with baseline, and (3) meaningful improvement with mast cell–directed treatment. The modern pathway also emphasizes ruling out mimics and related conditions such as systemic

mastocytosis, hereditary alpha-tryptasemia, IgE-mediated allergy, medication reactions, chronic urticaria, and other inflammatory or autonomic disorders.

How do Consensus 1 and Consensus 2 Differ?

Feature	Consensus 1	Consensus 2	Clinical Significance
Original publication/ timing	Formally published in 2012, based on a 2011 consensus proposal and later reaffirmed in updates and reviews.	Originally published in 2011 as a broader mast cell activation disease approach and later explicitly labeled "consensus-2" in a global review published in 2020.	This helps readers understand that the two frameworks were developed in parallel rather than one simply replacing the other.
Named authors/groups	Most closely associated with Peter Valent, Cem Akin, Michel Arock, Mariana Castells, Dean Metcalfe, and collaborators from international mast cell and allergy/immunology groups.	Most closely associated with Lawrence Afrin, Gerhard Molderings, and a large international group of clinicians who later coauthored the 2020 "global consensus-2" review.	Naming the groups clarifies that the disagreement reflects different expert traditions and clinical priorities, not just a wording difference.
Core philosophy	Prioritizes specificity and diagnostic validation. The goal is to identify patients with strong objective evidence of mast cell mediator release and avoid overdiagnosis.	Prioritizes sensitivity and clinical recognition. The goal is to identify patients whose symptom patterns strongly suggest mast cell disease, even when current biomarkers are incomplete or difficult to capture.	This is the core practical divide: one framework aims to reduce false positives, while the other aims to reduce missed cases.
Clinical pattern required	Typically requires recurrent severe episodic symptoms affecting at least two organ systems at the same time.	Places more weight on chronic multisystem symptom patterns and recurring mast cell-type flares, even when episodes are harder to document in a narrowly defined way.	This affects which patients are considered for diagnosis, especially those with chronic but less sharply documented symptom patterns.
Biomarker emphasis	Strong emphasis on objective mediator elevation, especially the tryptase rule of 20% above baseline plus 2 ng/mL, with other	Accepts that mediator evidence may be supportive but not always definitive, and argues that current biomarkers may miss	This shapes how much weight clinicians place on negative or incomplete laboratory results when symptoms

	validated mediators used when available.	many clinically real cases.	strongly suggest mast cell activation.
Treatment response	Requires meaningful response to mast cell–targeted treatment as one of the diagnostic pillars.	Also values repeated improvement with mast cell–directed therapy, but gives broader diagnostic weight to this in the overall clinical picture.	This matters when diagnosis depends partly on a therapeutic trial, especially if laboratory confirmation is difficult to obtain.
Main strength	Higher specificity; more reproducible for research and mainstream specialty practice.	Greater clinical inclusiveness; may capture patients who otherwise remain undiagnosed because biomarker testing is insensitive or mistimed.	This helps explain why Consensus 1 is often favored in formal research while Consensus 2 appeals to clinicians seeing more diagnostically complex patients.
Main limitation	May underdiagnose some patients whose symptoms are convincing but whose laboratory criteria are not captured.	May overdiagnose some patients because the threshold for objective confirmation is broader and more clinically permissive.	These tradeoffs are central to patient care because they influence both missed diagnoses and the risk of labeling unrelated symptoms as MCAS.
How it is used today	More commonly treated as the standard reference framework in allergy/immunology literature and formal reviews.	More commonly used by clinicians and authors who believe current strict criteria miss a substantial number of true mast cell disease cases.	This helps readers understand why different specialists may evaluate the same patient differently depending on which framework they follow.

Takeaway: Consensus 1 is generally the stricter, biomarker-centered framework used to improve diagnostic certainty, while Consensus 2 is the broader, more clinically permissive framework used to reduce the chance of missing patients whose symptoms strongly suggest mast cell disease.

"MCAS can look like a lot of other conditions, and many other conditions can share symptoms with MCAS, so careful evaluation really matters. That is why I like to step back and look at the whole picture: medical history, symptom patterns, labwork, response to treatment, fluid volume, nutrition, and the many small pieces that may be adding up. We do not want to get tunnel vision and assume every symptom is coming from mast cells. We also need to think carefully about how each treatment affects the whole body, so we are not helping one problem while making another worse."

— Erin Kolb, MSN, FNP-C

How Is MCAS Diagnosed?

MCAS is usually diagnosed by combining history, laboratory testing, and treatment response. A typical workup looks for: recurrent severe episodes involving at least two organ systems at the same time (for example, flushing plus diarrhea, or hives plus wheezing and lightheadedness); a documented rise in mast cell mediators during or soon after a flare compared with baseline; and improvement with therapies that block mast cell mediators or reduce mast cell activation.

Key tests may include acute and baseline serum tryptase, urinary histamine metabolites, urinary leukotriene E4, and urinary prostaglandin D2 metabolites. Additional evaluation may include testing for KIT mutations, hereditary alpha-tryptasemia, allergy triggers, and—when indicated—bone marrow or tissue studies to rule out clonal mast cell disease such as systemic mastocytosis. A normal baseline tryptase does not rule out MCAS, and diagnosis can be challenging because mediator levels must often be captured close to the time of symptoms.

How Is MCAS Treated and Managed?

Treatment is individualized and usually combines trigger management, symptom control, and emergency planning. Common first-line medications include H1 antihistamines and H2 blockers. Depending on symptoms, clinicians may add leukotriene blockers, mast cell stabilizers such as cromolyn or ketotifen, aspirin in selected prostaglandin-driven cases, or biologic therapy such as omalizumab for recurrent severe reactions. Patients with anaphylaxis risk typically need an epinephrine auto-injector and a clear emergency action plan.

Long-term management also includes identifying and reducing triggers when possible, treating associated conditions (such as allergy, mastocytosis, hereditary alpha-tryptasemia, asthma, GI disease, or chronic urticaria), and coordinating care across specialties when symptoms are multisystem. For refractory or clonal disease, specialists may consider more advanced therapies. Because the field is still evolving, management is often stepwise and may require reassessment over time as new evidence emerges.

Sources for Appendix D appear in Resources and Further Reading.

Appendix E

Understanding Dysautonomia and Orthostatic Intolerance

Key Questions Answered

Dysautonomia is a general term for health problems that affect the autonomic nervous system. This is the body system that controls automatic functions such as heart rate, blood pressure, sweating, temperature control, digestion, and bladder function. When this system is not working well, people may feel dizzy or lightheaded when they stand, have a racing heart, feel very tired, have trouble thinking clearly, feel sick to their stomach, or even faint. Dysautonomia can occur on its own or alongside other conditions, such as diabetes, autoimmune disease, connective tissue disorders, neurologic disease, vitamin deficiencies, or illness after an infection. One of the best-known forms is postural orthostatic tachycardia syndrome, or POTS. POTS can affect many parts of the body, not just heart rate, which is one reason it is often misunderstood or diagnosed late.

When Was Dysautonomia First Recognized?

Problems related to the autonomic nervous system have long been described, but doctors did not always use the same names for them. Over many years, patients with dizziness, pounding heartbeats, weakness, and poor tolerance for standing or exercise were described in different ways. The term POTS was introduced in 1993 by a Mayo Clinic team led by neurologist Philip Low. That helped give a clearer name to a group of patients who had long-lasting symptoms when upright and a large increase in heart rate on standing. Since then, the broader term dysautonomia has become more widely used to describe disorders of the autonomic nervous system as a whole.

Mini-Chronology

- **Mid- to late 1800s:** Doctors begin describing patients who feel dizzy, weak, or short of breath when standing, even though these symptoms are not yet grouped under one diagnosis.
- **Early 20th century:** Similar symptoms are described using older names such as neurocirculatory asthenia. At the time, doctors had fewer tools to measure what was happening in the body.
- **Mid-20th century:** As doctors learn more about the autonomic nervous system, they begin separating fainting, blood pressure problems, and other autonomic disorders into more specific categories.
- **1970s to 1980s:** The terms orthostatic intolerance and orthostatic tachycardia appear more often. This reflects growing awareness that some people become very symptomatic when standing, even if their blood pressure does not drop in the usual way.
- **1993:** A Mayo Clinic team led by Philip Low introduced the term postural orthostatic tachycardia syndrome (POTS), giving a clearer name to this pattern of symptoms and heart rate changes.
- **2000s:** Researchers describe POTS as a condition with more than one possible cause or pattern, including nerve-related, low-blood-volume, and higher-adrenaline forms.
- **2010s:** Expert groups publish clearer guidance on how to diagnose and manage POTS and related disorders
- **2020s:** POTS and dysautonomia receive much more attention, especially after COVID-19, which helps more people and clinicians recognize these conditions earlier.

Has the Identification, Evaluation, and Diagnostic Pathway Evolved Since Then?

Yes. In the past, doctors often focused on people who fainted or had clear blood pressure problems. Over time, they learned that some people mainly have a large rise in heart rate when they stand rather than a drop in blood pressure. Today, the evaluation is more structured. For POTS, doctors usually look for symptoms that have lasted at least 3 months, worsen with standing and improve with lying down, along with a heart rate increase of at least 30 beats per minute in adults or 40 beats per minute in teens within 10 minutes of standing or tilt testing. The diagnosis also

requires that the person does not have orthostatic hypotension. Doctors now also know that one normal test does not always rule POTS out, and they try to separate it from other conditions that can look similar, including anxiety, panic symptoms, chronic fatigue, or deconditioning.

How Do Common Dysautonomia Syndromes Differ?

Feature	POTS	Orthostatic Hypotension	Neurocardiogenic /Vasovagal Syncope	Clinical Significance
Core hemodynamic pattern	Heart rate increases markedly within 10 minutes of standing, but blood pressure does not fall as seen with orthostatic hypotension.	Blood pressure drops after standing, which may or may not be followed by a change in heart rate.	A reflex causes blood pressure and sometimes heart rate to drop, which can lead to fainting.	Telling these patterns apart helps doctors choose the right tests and treatment.
Typical symptom profile	Fast heartbeat, dizziness, feeling faint, tiredness, brain fog, headache, nausea, poor exercise tolerance, sleep problems, and other symptoms that can affect daily life.	Dizziness, blurred vision, weakness, falls, fainting, and symptoms that may worsen with dehydration or prolonged standing.	Feeling warm, sweaty, nauseated, pale, or visually dim before fainting, often after pain, stress, heat, or standing too long.	Symptoms can overlap, so it helps for doctors to ask detailed questions even when basic testing seems clear.
Common clinical context	Often starts after a viral illness, growth spurt, hormonal change, injury, concussion, surgery, or pregnancy, and may overlap with hypermobility, migraine, chronic fatigue, autoimmune disease, or mast cell symptoms.	Can happen due to nerve problems, dehydration, medication side effects, hormonal problems, or certain brain and nervous system disorders.	Can occur in otherwise healthy people, but may also occur alongside other forms of orthostatic intolerance.	This context can help show whether the problem is a primary autonomic disorder or part of another health condition.
Initial evaluation	Standing or tilt testing, review of triggers and symptom pattern, medication review, and checking for other causes such as anemia, dehydration, thyroid disease, or severe deconditioning.	Checking blood pressure and heart rate while lying down and standing, reviewing medications, and looking for signs of dehydration, anemia, nerve problems, or other medical causes.	Reviewing triggers and warning signs, checking vital signs, and performing tilt testing if the diagnosis remains unclear.	Even simple bedside testing can be very helpful when symptoms occur during testing and measurements are taken carefully.

Management emphasis	Education, fluids, extra salt when appropriate, compression garments, pacing, gentle reconditioning, and medicines chosen to fit the person's symptom pattern.	Treating the cause when possible, improving fluid intake, using compression when helpful, and sometimes using medicine to support blood pressure.	Learning triggers, staying hydrated, using physical counter-maneuvers, and following a plan to help prevent fainting episodes.	Treatment works best when it matches the person's symptom pattern instead of using the same approach for everyone.

Takeaway: Dysautonomia is not one single disorder. It is a group of conditions that can look similar but may need different tests and different treatments.

How Is Dysautonomia Diagnosed?

Doctors diagnose dysautonomia by carefully listening to the person's symptoms, checking vital signs, and determining whether further testing is needed. They often ask when symptoms started, what makes them worse, whether standing is a trigger, and whether there are other problems such as headache, nausea, bloating, bowel changes, bladder symptoms, fatigue, sleep problems, or trouble thinking clearly. A simple standing test done in the office can be very helpful. In suspected POTS, doctors look for symptoms when upright and a clear rise in heart rate without the blood pressure drop seen in orthostatic hypotension. An electrocardiogram (ECG) is often part of the first evaluation, and some patients may also need blood work, heart rhythm monitoring, heart ultrasound, or formal autonomic testing.

Part of the diagnosis is determining which type of autonomic problem is present and whether it occurs on its own or as part of another condition. Doctors also need to rule out other reasons for a fast heart rate, such as anemia, dehydration, infection, thyroid disease, medication side effects, or prolonged bed rest. Some people with POTS also have related conditions such as migraine, joint hypermobility, chronic fatigue symptoms, fibromyalgia, autoimmune disease, or mast cell-related symptoms. Because symptoms can come and go, diagnosis sometimes takes repeated visits, repeated testing, and coordination among different specialists.

How Is Dysautonomia Treated and Managed?

Treatment depends on the person's symptoms, daily challenges, and the underlying cause. For many people with POTS and related disorders, treatment starts with lifestyle modifications. These often include learning what triggers symptoms, avoiding prolonged standing, staying out of excessive heat when possible, drinking more fluids, increasing salt intake if the clinician recommends it, using compression garments, and starting a slow, gentle exercise program that may begin in seated or lying-down positions. The goal is usually not an instant cure. Instead, the goal is to reduce symptoms, help the person function better, and improve quality of life over time.

Some people also need medication. Depending on the symptom pattern, doctors may choose medicines to help slow the heart rate, raise blood pressure, improve blood volume, or help blood vessels tighten when standing. Treatment often needs to be adjusted over time. Exercise can also help, but it works best when individualized and carefully paced so it does not trigger a major flare. Long-term care may involve a primary care clinician, autonomic specialists, nurses, physical therapists, rehabilitation specialists, mental health support, and other clinicians, depending on the person's needs.

What Is the Relationship Between Long-COVID and POTS?

Long-COVID has made more people aware of POTS and related forms of dysautonomia. Some people develop ongoing symptoms after COVID-19 that look very similar to POTS, including a racing heart, dizziness, fatigue, exercise intolerance, brain fog, sleep problems, stomach symptoms, and trouble with temperature regulation. Not every person with Long-COVID has POTS, but the overlap matters because untreated orthostatic intolerance can make recovery much harder. This is one reason early recognition, careful standing tests, and thoughtful rehabilitation are so important.

Future Research, Care Needs, and Avenues of Exploration

Researchers are still working to better understand why dysautonomia and POTS happen and why symptoms can look so different from one person to another. Future studies will likely examine the body systems involved, including the nervous system, blood volume, blood vessel control, inflammation, immune system changes, and small blood vessels. Better tests and biomarkers may help doctors diagnose these conditions earlier and choose treatments more precisely.

Research is also needed to learn which treatments work best for which patients. Many current treatments are used off-label, which means they were not originally approved specifically for POTS. Future studies may compare medicines more directly, test newer therapies, and design better exercise and rehabilitation programs for people who are very sensitive to exertion.

Another major need is better access to care. Many people wait years for a diagnosis and struggle to find clinicians who are familiar with autonomic disorders. Future progress will depend not only on new science but also on better care pathways, more education for healthcare professionals, more clinics that bring different specialists together, and services designed with patient and caregiver needs in mind.

When Should Someone Seek Medical Care?

Someone should seek medical care if they have repeated fainting, worsening dizziness, frequent falls, a new or severe racing heart, trouble staying hydrated, symptoms that interfere with school, work, or daily activities, or symptoms that started after a major illness or infection. Urgent evaluation may also be needed for chest pain, trouble breathing, severe weakness, new confusion, or injuries related to fainting. Even when symptoms are not an emergency, it is reasonable to seek evaluation if upright symptoms are persistent, unexplained, or worsening over time.

Questions to Ask Your Clinician

- *Could my symptoms fit POTS, orthostatic hypotension, vasovagal syncope, or another form of dysautonomia?*
- *What tests do I need, and can a standing test be done in the office?*
- *Are any of my medicines making my symptoms worse?*
- *Should I change my fluid, salt, compression, or activity plan?*
- *What symptoms should prompt urgent medical attention?*
- *Do I need a referral to cardiology, neurology, autonomic medicine, physical therapy, or another specialist?*

Glossary of Medical Terms

Autonomic nervous system: The part of the nervous system that controls automatic body functions such as heart rate, blood pressure, sweating, digestion, and bladder function.

Dysautonomia: A general term for disorders that affect the autonomic nervous system.

Orthostatic intolerance: Symptoms that get worse when standing and improve when lying down.

POTS: Short for postural orthostatic tachycardia syndrome, a form of dysautonomia in which heart rate rises too much on standing and symptoms worsen when upright.

Orthostatic hypotension: A drop in blood pressure after standing that can cause dizziness, weakness, or fainting.

Vasovagal syncope: A common type of fainting caused by a sudden change in heart rate and blood pressure.

Palpitations: Feeling like the heart is racing, pounding, fluttering, or skipping beats.

Presyncope: Feeling as if you might faint, even if you do not actually lose consciousness.

Brain fog: A common term for trouble concentrating, thinking clearly, remembering, or processing information.

Deconditioning: Loss of strength and fitness that can happen after illness or a long period of inactivity.

Tilt table test: A test in which a person is strapped to a table that tilts upright while heart rate and blood pressure are monitored.

Sources for Appendix E appear in Resources and Further Reading.

Resources and Further Reading

> *Good resources do not remove uncertainty, but they can make a complex journey easier to understand and less isolating. They give you language, context, and a place to return when you want to go deeper into a topic or check a source for yourself. This section gathers research, clinical guidance, and further reading so you have something trustworthy to navigate by. Even experienced travelers need charts they can return to.*

General References Used Across This Book

The sources below informed the development of this book. They are included here as broader background and supporting references.

Aalberts JJ, van den Berg MP, Bergman JE, du Marchie Sarvaas GJ, Post JG, van Unen H, Pals G, Boonstra PW, van Tintelen JP. The many faces of aggressive aortic pathology: Loeys-Dietz syndrome. *Netherlands Heart Journal*. 2008;16(9):299–304. doi: 10.1007/BF03086168.

Adham S, Zinzindohoué F, Jeunemaitre X, Frank M. Natural history and surgical management of colonic perforations in vascular Ehlers-Danlos syndrome: a retrospective review. *Diseases of the Colon & Rectum*. 2019;62(7):859–866. doi: 10.1097/DCR.0000000000001383.

Adham S, Trystram D, Albuisson J, Domigo V, Legrand A, Jeunemaitre X, Frank M. Pathophysiology of carotid-cavernous fistulas in vascular Ehlers-Danlos syndrome: a retrospective cohort and comprehensive review. *Orphanet Journal of Rare Diseases*. 2018;13(1):100. doi: 10.1186/s13023-018-0842-2.

Adib N, Davies K, Grahame R, Woo P, Murray KJ. Joint hypermobility syndrome in childhood: a not-so-benign multisystem disorder? *Rheumatology*. 2005;44(6):744–750. doi: 10.1093/rheumatology/keh557.

Afrin LB. Some cases of hypermobile Ehlers-Danlos syndrome may be rooted in mast cell activation syndrome. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2021;187(4):466–472. doi: 10.1002/ajmg.c.31944.

Alagiakrishnan K, Schoenberger SL, Chasan A, Jill R, Berman EL. Ehlers-Danlos syndrome type IV with Charcot-Marie-Tooth disease: an unusual combination of diseases. *Journal of Clinical Rheumatology*. 1999;5(4):215–218. doi: 10.1097/00124743-199908000-00007.

Alazami AM, Al-Qattan SM, Faqeih E, Alhashem A, Alshammari M, Alzahrani F, Al-Dosari MS, Patel N, Alsagheir A, Binabbas B, Alzaidan H, Alsiddiky A, Alharbi N, Alfadhel M, Kentab A, Daza RM, Kircher M, Shendure J, Hashem M,

Alshahrani S, Rahbeeni Z, Khalifa O, Shaheen R, Alkuraya FS. Expanding the clinical and genetic heterogeneity of hereditary disorders of connective tissue. *Human Genetics*. 2016;135(5):525–540. doi: 10.1007/s00439-016-1660-z.

Amemiya M, Nakamura R, Yoshimura M, Takagi T. Proximal tibiofibular joint dislocation due to Ehlers-Danlos syndrome: posterolateral open-wedge high tibial osteotomy combined with medial closed-wedge distal femoral osteotomy can correct severe valgus deformity. *BMJ Case Reports*. 2022;15(11). doi: 10.1136/bcr-2022-250308.

Angwin C, Zschocke J, Kammin T, Björck E, Bowen J, Brady AF, Burns H, Cummings C, Gardner R, Ghali N, Gröbner R, Harris J, Higgins M, Johnson D, Lepperdinger U, Milnes D, Pope FM, Sehra R, Kapferer-Seebacher I, Sobey G, Van Dijk FS. Non-oral manifestations in adults with a clinical and molecularly confirmed diagnosis of periodontal Ehlers-Danlos syndrome. *Frontiers in Genetics*. 2023;14:1136339. doi: 10.3389/fgene.2023.1136339.

Aoyama T, Francke U, Gasner C, Furthmayr H. Fibrillin abnormalities and prognosis in Marfan syndrome and related disorders. *American Journal of Medical Genetics*. 1995;58(2):169–176. doi: 10.1002/ajmg.1320580216.

Arendt-Nielsen L, Kaalund S, Bjerring P, Høgsaa B. Insufficient effect of local analgesics in Ehlers-Danlos type III patients (connective tissue disorder). *Acta Anaesthesiologica Scandinavica*. 1990;34(5):358–361. doi: 10.1111/j.1399-6576.1990.tb03103.x.

Arneson MA, Hammerschmidt DE, Furcht LT, King RA. A new form of Ehlers-Danlos syndrome: fibronectin corrects defective platelet function. *JAMA*. 1980;244(2):144–147.

Artoni A, Bassotti A, Abbattista M, Marinelli B, Lecchi A, Gianniello F, Clerici M, Bucciarelli P, La Marca S, Peyvandi F, Martinelli I. Hemostatic abnormalities in patients with Ehlers-Danlos syndrome. *Journal of Thrombosis and Haemostasis*. 2018;16(12):2425–2431. doi: 10.1111/jth.14310.

Asafu Adjaye Frimpong G, Aboagye E, Tannor EK, Chigbu NCC, Daboner VT. Coarctation of the aorta with arterial tortuosity syndrome: a case report with cinematic rendering. *International Medical Case Reports Journal*. 2022;15:349–354. doi: 10.2147/IMCRJ.S362434.

Ayres JG, Pope FM, Reidy JF, Clark TJ. Abnormalities of the lungs and thoracic cage in the Ehlers-Danlos syndrome. *Thorax*. 1985;40(4):300–305. doi: 10.1136/thx.40.4.300.

Badauy CM, Gomes SS, Sant'Ana Filho M, Chies JA. Ehlers-Danlos syndrome (EDS) type IV: review of the literature. *Clinical Oral Investigations*. 2007;11(3):183–187. doi: 10.1007/s00784-006-0092-x.

Baeza-Velasco C, Rodriguez N, Parra L, Gutiérrez-Rosado T. Adjustment to disease and quality of life in people with vascular Ehlers-Danlos and Loeys-Dietz syndromes: a mixed-method study. *Frontiers in Psychology*. 2023;14:1019863. doi: 10.3389/fpsyg.2023.1019863.

Baeza-Velasco C, Van den Bossche T, Grossin D, Hamonet C. Difficulty eating and significant weight loss in joint hypermobility syndrome/Ehlers-Danlos syndrome, hypermobility type. *Eating and Weight Disorders*. 2016;21(2):175–183. doi: 10.1007/s40519-015-0232-x.

Barajas BD, Sun A, Rimoin DL, Reinstein E. Recurrent compartment syndrome in a patient with clinical features of a connective tissue disorder. *American Journal of Medical Genetics Part A*. 2013;161A(6):1442–1446. doi: 10.1002/ajmg.a.35894.

Baumann M, Giunta C, Krabichler B, Rüschendorf F, Zoppi N, Colombi M, Bittner RE, Quijano-Roy S, Muntoni F, Cirak S, Schreiber G, Zou Y, Hu Y, Romero NB, Carlier RY, Amberger A, Deutschmann A, Straub V, Rohrbach M, Steinmann B, Rostásy K, Karall D, Bönnemann CG, Zschocke J, Fauth C. Mutations in FKBP14 cause a variant of Ehlers-Danlos syndrome with progressive kyphoscoliosis, myopathy, and hearing loss. *American Journal of Human Genetics*. 2012;90(2):201–216. doi: 10.1016/j.ajhg.2011.12.004.

Beijk I, Knoef R, van Vugt A, Verra W, Nellensteijn J. Sacroiliac joint fusion in patients with Ehlers-Danlos syndrome: a case series. *North American Spine Society Journal*. 2021;8:100082. doi: 10.1016/j.xnsj.2021.100082.

Benistan K, Foy M, Gillas F, Genet F, Kane M, Barbot F, Vaugier I, Bonnyaud C, Gader N. Effects of compression garments on balance in hypermobile Ehlers-Danlos syndrome: a randomized controlled trial. *Disability and Rehabilitation*. 2024;46(9):1841–1850. doi: 10.1080/09638288.2023.2209742.

Bennett SE, Walsh N, Moss T, Palmer S. Understanding the psychosocial impact of joint hypermobility syndrome and Ehlers-Danlos syndrome hypermobility type: a qualitative interview study. *Disability and Rehabilitation*. 2021;43(6):795–804. doi: 10.1080/09638288.2019.1641848.

Berglund B, Mattiasson AC, Nordström G. Acceptance of disability and sense of coherence in individuals with Ehlers-Danlos syndrome. *Journal of Clinical Nursing*. 2003;12(5):770–777. doi: 10.1046/j.1365-2702.2003.00776.x.

Biesecker LG, Erickson RP, Glover TW, Bonadio J. Molecular and cytologic studies of Ehlers-Danlos syndrome type VIII. *American Journal of Medical Genetics*. 1991;41(3):284–288. doi: 10.1002/ajmg.1320410305.

Bisson JI, Ariti C, Cullen K, Kitchiner N, Lewis C, Roberts NP, Simon N, Smallman K, Addison K, Bell V, Brookes-Howell L, Cosgrove S, Ehlers A, Fitzsimmons D, Foscarini-Craggs P, Harris SRS, Kelson M, Lovell K, McKenna M, McNamara R, Nollett C, Pickles T, Williams-Thomas R. Guided, internet-based cognitive behavioural therapy for post-traumatic stress disorder: pragmatic, multicentre, randomised controlled non-inferiority trial (RAPID). *BMJ*. 2022;377:e069405. doi: 10.1136/bmj-2021-069405.

Blackburn PR, Xu Z, Tumelty KE, Zhao RW, Monis WJ, Harris KG, Gass JM, Cousin MA, Boczek NJ, Mitkov MV, Cappel MA, Francomano CA, Parisi JE, Klee EW, Faqeih E, Alkuraya FS, Layne MD, McDonnell NB, Atwal PS. Bi-allelic alterations in AEBP1 lead to defective collagen assembly and connective tissue structure, resulting in a variant of Ehlers-Danlos syndrome. *American Journal of Human Genetics*. 2018;102(4):696–705. doi: 10.1016/j.ajhg.2018.02.018.

Böckler D, Meisenbacher K, Peters AS, Grond-Ginsbach C, Bischoff MS. Endovascular treatment of genetically linked aortic diseases. *Gefässchirurgie*. 2017;22(Suppl 1):1–7. doi: 10.1007/s00772-016-0221-z.

Bonamichi-Santos R, Yoshimi-Kanamori K, Giavina-Bianchi P, Aun MV. Association of postural tachycardia syndrome and Ehlers-Danlos syndrome with mast cell activation disorders. *Immunology and Allergy Clinics of North America*. 2018;38(3):497–504. doi: 10.1016/j.iac.2018.04.004.

Borisova NV, Safronova EE, Krasnopol'skaya KD, Blinnikova OE, Polyudov SA. Enzyme-linked immunoassay and electrophoretic separation of collagens secreted by cultured skin fibroblasts of patients with Ehlers-Danlos and Marfan syndromes. *Biomedical Science*. 1991;2(5):523–529.

Bowen JM, Sobey GJ, Burrows NP, Colombi M, Lavallee ME, Malfait F, Francomano CA. Ehlers-Danlos syndrome, classical type. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):27–39. doi: 10.1002/ajmg.c.31548.

Brandt T, Hausser I, Orberk E, Grau A, Hartschuh W, Anton-Lamprecht I, Hacke W. Ultrastructural connective tissue abnormalities in patients with spontaneous cervicocerebral artery dissections. *Annals of Neurology*. 1998;44(2):281–285. doi: 10.1002/ana.410440224.

Brandt T, Morcher M, Hausser I. Association of cervical artery dissection with connective tissue abnormalities in skin and arteries. In: *Frontiers of Neurology and Neuroscience*. 2005;20:16–29. doi: 10.1159/000088131.

Thompson, CE. Raising A Handicapped Child: A Helpful Guide for Parents of the Physically Disabled. Oxford University Press. 2000

Warnink-Kavelaars J, van Oers HA, Haverman L, Buizer AI, Alsem MW, Engelbert RHH, Menke LA. Parenting a child with Marfan syndrome: Distress and everyday problems. Am J Med Genet A. 2021;185(1):50-59. doi: 10.1002/ajmg.a.61906.

Chapter References

The sources below are organized by chapter so you can easily find the research, clinical guidance, and further reading that support specific parts of the book. Short source notes appear only in chapters that draw more directly on diagnostic criteria, medical frameworks, or research-heavy material.

Chapter 1: Calm Is the First Step Forward

Chapter 1 uses a short source note in the body rather than a full chapter bibliography.

Almada AL, Casquinha P, Cotovio V, Heitor Dos Santos MJ, Caixeiro A. The potential role of psychosocial rehabilitation in palliative care. J R Coll Physicians Edinb. 2018 Dec;48(4):311-317. doi: 10.4997/JRCPE.2018.405. PMID: 30488884.

Darnall, B. Psychological Treatment for Patients With Chronic Pain (Clinical Health Psychology Series). American Psychological Association. 2018.

Darnall BD, Burns JW, Hong J, Roy A, Slater K, Poupore-King H, Ziadni MS, You DS, Jung C, Cook KF, Lorig K, Tian L, Mackey SC. Empowered Relief, cognitive behavioral therapy, and health education for people with chronic pain: a comparison of outcomes at 6-month Follow-up for a randomized controlled trial. Pain Rep. 2024 Jan 25;9(1):e1116. doi: 10.1097/PR9.0000000000001116. Erratum in: Pain Rep. 2024 Jul 24;9(4):e1177. doi: 10.1097/PR9.0000000000001177. PMID: 38288134; PMCID: PMC10824382.

Di Bon J. The Integral Movement Method for Hypermobility Management. Illustrated ed. Singing Dragon; 2025.

Kabat-Zinn J. Mindfulness for Beginners: Reclaiming the Present Moment and Your Life. St. Martin's Essentials / Sounds True. 2016.

Kabat-Zinn J. Wherever You Go, There You Are: Mindfulness Meditation in Everyday Life. Hyperion. 1994.

Kim S, Jang Y, Choi J, Song K, Song JK, Choi M. Path analysis of illness uncertainty and psychosocial adaptation of patients with Marfan syndrome. Eur J Cardiovasc Nurs. 2024;23(2):197-205. doi: 10.1093/eurjcn/zvad063.

Tinkle B, Castori M, Berglund B, Cohen H, Grahame R, Kazkaz H, Levy H. Hypermobile Ehlers-Danlos syndrome (a.k.a. Ehlers-Danlos syndrome type III and Ehlers-Danlos syndrome hypermobility type): clinical description and natural history. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):48–69. doi: 10.1002/ajmg.c.31538.

van Dessel N, den Boeft M, van der Wouden JC, Kleinstäuber M, Leone SS, Terluin B, Numans ME, van der Horst HE, van Marwijk H. Non-pharmacological interventions for somatoform disorders and medically unexplained physical symptoms (MUPS) in adults. Cochrane Database Syst Rev. 2014 Nov 1;2014(11):CD011142. doi: 10.1002/14651858.CD011142.pub2. PMID: 25362239; PMCID: PMC10984143.

Vanwesemael M, Danckaerts M, Schevenels S, Schevenels W, Martens F. Depressieve en angstklachten bij erfelijke bindweefselaandoeningen: casus en systematisch literatuuroverzicht [Depressive and anxiety symptoms in hereditary connective tissue disorders : case description and systematic literature review]. Tijdschr Psychiatr. 2023;65(9):572-579. Dutch. PMID: 37947469.

Warnink-Kavelaars J, de Koning LE, Rombaut L, Menke LA, Alsem MW, van Oers HA, Buizer AI, Engelbert RHH, Oosterlaan J; Pediatric Heritable Connective Tissue Disorder Study Group. Heritable connective tissue disorders in childhood: Decreased health-related quality of life and mental health. Am J Med Genet A. 2022 Jul;188(7):2096-2109. doi: 10.1002/ajmg.a.62750. Epub 2022 Apr 8. PMID: 35393672; PMCID: PMC9321696.

Chapter 2: What This Diagnosis Means for You

Abdo H, Calvo-Enrique L, Lopez JM, Song J, Zhang MD, Usoskin D, El Manira A, Adameyko I, Hjerling-Leffler J, Ernfors P. Specialized cutaneous schwann cells initiate pain sensation. *Science*. 2019;365(6454):695–699. doi: 10.1126/science.aax6452.

Alomari M, Hitawala A, Chadalavada P, Covut F, Momani LA, Khazaaleh S, Gosai F, Ashi SA, Abushahin A, Schneider A. Prevalence and predictors of gastrointestinal dysmotility in patients with hypermobile Ehlers-Danlos syndrome: a tertiary care center experience. *Cureus*. 2020;12(4):e7881. doi: 10.7759/cureus.7881.

Arnaud P, Milleron O, Hanna N, Ropers J, Ould Ouali N, Affoune A, Langeois M, Eliahou L, Arnoult F, Renard P, Michelon-Jouneaux M, Cotillon M, Gouya L, Boileau C, Jondeau G. Clinical relevance of genotype–phenotype correlations beyond vascular events in a cohort study of 1500 Marfan syndrome patients with FBN1 pathogenic variants. *Genetics in Medicine*. 2021;23(7):1296–1304. doi: 10.1038/s41436-021-01132-x.

Asahara H, Inui M, Lotz MK. Tendons and ligaments: connecting developmental biology to musculoskeletal disease pathogenesis. *Journal of Bone and Mineral Research*. 2017;32(9):1773–1782. doi: 10.1002/jbmr.3199.

Autonomic Disorders Consortium. Rare Diseases Clinical Research Network, National Institutes of Health.

Barallobre-Barreiro J, Loeys B, Mayr M, Rienks M, Verstraeten A, Kovacic JC. Extracellular matrix in vascular disease, part 2/4: JACC focus seminar. *Journal of the American College of Cardiology*. 2020;75(17):2189–2203. doi: 10.1016/j.jacc.2020.03.018.

Barnum R. Problems with diagnosing conversion disorder in response to variable and unusual symptoms. *Adolescent Health, Medicine and Therapeutics*. 2014;5:67–71. doi: 10.2147/AHMT.S57486.

Beckers AB, Keszthelyi D, Fikree A, Vork L, Masclee A, Farmer AD, Aziz Q. Gastrointestinal disorders in joint hypermobility syndrome/Ehlers-Danlos syndrome hypermobility type: a review for the gastroenterologist. *Neurogastroenterology and Motility*. 2017;29(8):e13013. doi: 10.1111/nmo.13013.

Bennett SE, Walsh N, Moss T, Palmer S. Understanding the psychosocial impact of joint hypermobility syndrome and Ehlers-Danlos syndrome hypermobility type: a qualitative interview study. *Disability and Rehabilitation*. 2021;43(6):795–804. doi: 10.1080/09638288.2019.1641848.

Blagowidow N. Obstetrics and gynecology in Ehlers-Danlos syndrome: a brief review and update. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2021;187(4):593–598. doi: 10.1002/ajmg.c.31945.

Blitshteyn S. Dysautonomia: a common comorbidity of systemic disease. *Immunol Res.* 2025;73(1):105. doi:10.1007/s12026-025-09661-2. PMID: 40624434; PMCID: PMC12234583.

Bloom L, Schubart J, Bascom R, Hakim A, Francomano CA. The power of patient-led global collaboration. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2021;187(4):425–428. doi: 10.1002/ajmg.c.31942.

Bowen JM, Sobey GJ, Burrows NP, Colombi M, Lavallee ME, Malfait F, Francomano CA. Ehlers-Danlos syndrome, classical type. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):27–39. doi: 10.1002/ajmg.c.31548.

Brock I, Prendergast W, Maitland A. Mast cell activation disease and immunoglobulin deficiency in patients with hypermobile Ehlers-Danlos syndrome/hypermobility spectrum disorder. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2021;187(4):473–481. doi: 10.1002/ajmg.c.31940.

Bulbena A, Baeza-Velasco C, Bulbena-Cabré A, Pailhez G, Critchley H, Chopra P, Mallorquí-Bagué N, Frank C, Porges S. Psychiatric and psychological aspects in the Ehlers-Danlos syndromes. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):237–245. doi: 10.1002/ajmg.c.31544.

Byers PH. Vascular Ehlers-Danlos syndrome. In: Adam MP, Ardinger HH, Pagon RA, Wallace SE, Bean LJH, Gripp KW, Mirzaa GM, Amemiya A, editors. *GeneReviews® [Internet]*. University of Washington; 2019.

Byers PH, Duvic M, Atkinson M, Robinow M, Smith LT, Krane SM, Greally MT, Ludman M, Matalon R, Pauker S, Quanbeck D, Schwarze U. Ehlers-Danlos syndrome type VIIA and VIIB result from splice-junction mutations or genomic deletions that involve exon 6 in the COL1A1 and COL1A2 genes of type I collagen. *American Journal of Medical Genetics*. 1997;72(1):94–105. doi: 10.1002/(SICI)1096-8628(19971003)72:1<94::AID-AJMG20>3.0.CO;2-O.

Castells M, Giannetti MP, Hamilton MJ, Novak P, Pozdnyakova O, Nicoloro-SantaBarbara J, Jennings SV, Francomano C, Kim B, Glover SC, Galli SJ, Maitland A, White A, Abonia JP, Slee V, Valent P, Butterfield JH, Carter M, Metcalfe DD, Akin C, Lyons JJ, Togias A, Wheatley L, Milner JD. Mast cell activation syndrome: Current understanding and research needs. *Journal of Allergy and Clinical Immunology*. 2024;154(2):255–263. doi: 10.1016/j.jaci.2024.05.025.

Castori M. Ehlers-Danlos syndrome(s) mimicking child abuse: is there an impact on clinical practice? *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2015;169(4):289–292. doi: 10.1002/ajmg.c.31460.

Dawidowicz J, Szotek S, Matysiak N, Mielańczyk Ł, Maksymowicz K. Electron microscopy of human fascia lata: focus on telocytes. *Journal of Cellular and Molecular Medicine*. 2015;19(10):2500–2506. doi: 10.1111/jcmm.12665.

Debette S, Germain DP. Neurologic manifestations of inherited disorders of connective tissue. In: *Handbook of Clinical Neurology*. 2014;119:565–576. doi: 10.1016/B978-0-7020-4086-3.00037-0.

Di Bon J. *The Integral Movement Method for Hypermobility Management*. Illustrated ed. Singing Dragon; 2025.

EURORDIS. *The Voice of 12,000 Patients*. 2009.

Fikree A, Chelimsky G, Collins H, Kovacic K, Aziz Q. Gastrointestinal involvement in the Ehlers-Danlos syndromes. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):181–187. doi: 10.1002/ajmg.c.31546.

Fogoros RN. Dysautonomia: a family of misunderstood disorders. About.com Guide. Updated November 13, 2011.

Follis RH Jr. Osteogenesis imperfecta congenita: a connective tissue diathesis. *Journal of Pediatrics*. 1952;41(6):713–721. doi: 10.1016/S0022-3476(52)80292-6.

Follis RH Jr. Histochemical studies on cartilage and bone. III. Osteogenesis imperfecta. *Bulletin of the Johns Hopkins Hospital*. 1953;93(6):386–399.

Follis RH Jr. Maldevelopment of the corium in the osteogenesis imperfecta syndrome. *Bulletin of the Johns Hopkins Hospital*. 1953;93(4):225–233.

Gillies AR, Lieber RL. Structure and function of the skeletal muscle extracellular matrix. *Muscle & Nerve*. 2011;44(3):318–331. doi: 10.1002/mus.22094.

Goldstein DS, Robertson D, Esler M, Straus SE, Eisenhofer G. Dysautonomias: clinical disorders of the autonomic nervous system. *Ann Intern Med.* 2002;137(9):753-763. doi:10.7326/0003-4819-137-9-200211050-00011. PMID: 12416949.

Grubb BP, Karas B. Clinical disorders of the autonomic nervous system associated with orthostatic intolerance: an overview of classification, clinical evaluation, and management. *Pacing Clin Electrophysiol.* 1999;22(5):798-810. doi:10.1111/j.1540-8159.1999.tb00546.x. PMID: 10353141.

Hakim A, De Wandele I, O'Callaghan C, Pocinki A, Rowe P. Chronic fatigue in Ehlers-Danlos syndrome-hypermobile type. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):175–180. doi: 10.1002/ajmg.c.31542.

Halverson CME, Clayton EW, Garcia Sierra A, Francomano C. Patients with Ehlers–Danlos syndrome on the diagnostic odyssey: rethinking complexity and difficulty as a hero's journey. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2021;187(4):416–424. doi: 10.1002/ajmg.c.31935.

Kakavas S, Karayiannis D, Mastora Z. The complex interplay between immunonutrition, mast cells, and histamine signaling in COVID-19. *Nutrients*. 2021;13(10):3458. doi: 10.3390/nu13103458. PMID: 34684460; PMCID: PMC8537261.

Kratunova E, Zhang IL, da Fonseca MA. Dental considerations in patients with Loeys-Dietz syndrome: a review of the literature and case report. *Journal of Clinical Pediatric Dentistry*. 2021;45(3):193–198. doi: 10.17796/1053-4625-45.3.8.

Lepperdinger U, Zschocke J, Kapferer-Seebacher I. Oral manifestations of Ehlers-Danlos syndromes. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2021;187(4):520–526. doi: 10.1002/ajmg.c.31941.

Meester JAN, Verstraeten A, Schepers D, Alaerts M, Van Laer L, Loeys BL. Differences in manifestations of Marfan syndrome, Ehlers-Danlos syndrome, and Loeys-Dietz syndrome. Ann Cardiothorac Surg. 2017 Nov;6(6):582-594. doi: 10.21037/acs.2017.11.03. PMID: 29270370; PMCID: PMC5721110.

Mittal N, Mina DS, McGillis L, Weinrib A, Slepian PM, Rachinsky M, Buryk-Iggers S, Laflamme C, Lopez-Hernandez L, Hussey L, Katz J, McLean L, Rozenberg D, Liu L, Tse Y, Parker C, Adler A, Charames G, Bleakney R, Veillette C, Nielson CJ, Tavares S, Varriano S, Guzman J, Faghfoury H, Clarke H. The GoodHope Ehlers-Danlos Syndrome Clinic: development and implementation of the first interdisciplinary program for multi-system issues in connective tissue disorders at Toronto General Hospital. *Orphanet Journal of Rare Diseases*. 2021;16(1):357. doi: 10.1186/s13023-021-01962-7.

National Academies of Sciences, Engineering, and Medicine. Overview of hereditary disorders of connective tissue. In: *Selected Heritable Disorders of Connective Tissue and Disability*. National Academies Press; 2022.

National Institute of Neurological Disorders and Stroke. Dysautonomia information page.

Pena C, Moustafa A, Mohamed AR, Grubb B. Autoimmunity in syndromes of orthostatic intolerance: an updated review. *J Pers Med.* 2024;14(4):435. doi:10.3390/jpm14040435. PMID: 38673062; PMCID: PMC11051445.

Richards S, Aziz N, Bale S, Bick D, Das S, Gastier-Foster J, Grody WW, Hegde M, Lyon E, Spector E, Voelkerding K, Rehm HL. Standards and guidelines for the interpretation of sequence variants: a joint consensus recommendation of the American College of Medical Genetics and Genomics and the Association for Molecular Pathology. *Genetics in Medicine*. 2015;17(5):405–423. doi: 10.1038/gim.2015.30.

Roma M, Marden CL, De Wandele I, Francomano CA, Rowe PC. Postural tachycardia syndrome and other forms of orthostatic intolerance in Ehlers-Danlos syndrome. *Autonomic Neuroscience*. 2018;215:89–96. doi: 10.1016/j.autneu.2018.02.006.

Schubart JR, Bascom R, Francomano CA, Bloom L, Hakim AJ. Initial description and evaluation of EDS ECHO: an international effort to improve care for people with the Ehlers-Danlos syndromes and hypermobility spectrum disorders. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2021;187(4):609–615. doi: 10.1002/ajmg.c.31960.

Speed TJ, Mathur VA, Hand M, Christensen B, Sponseller PD, Williams KA, Campbell CM. Characterization of pain, disability, and psychological burden in Marfan syndrome. *American Journal of Medical Genetics Part A*. 2017;173(2):315–323. doi: 10.1002/ajmg.a.38051.

Steinmann B, Royce PM, Superti-Furga A. The Ehlers-Danlos syndrome. In: Steinmann B, Royce PM, editors. *Connective Tissue and Its Heritable Disorders: Molecular, Genetic, and Medical Aspects*. 2nd ed. New York: Wiley-Liss; 2002:431–524. doi: 10.1002/0471221929.ch9.

Syx D, De Wandele I, Rombaut L, Malfait F. Hypermobility, the Ehlers-Danlos syndromes and chronic pain. *Clinical and Experimental Rheumatology*. 2017;35(Suppl 107):116–122.

Tinkle B, Castori M, Berglund B, Cohen H, Grahame R, Kazkaz H, Levy H. Hypermobile Ehlers-Danlos syndrome (a.k.a. Ehlers-Danlos syndrome type III and Ehlers-Danlos syndrome hypermobility type): clinical description and natural history. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):48–69. doi: 10.1002/ajmg.c.31538.

Wang XJ, Babameto M, Babovic-Vuksanovic D, Bowen JM, Camilleri M. Audit of gastrointestinal manifestations in patients with Loeys-Dietz syndrome and vascular Ehlers-Danlos syndrome. *Digestive Diseases and Sciences*. 2021;66(4):1142–1152. doi: 10.1007/s10620-020-06265-8.

Wong S, Hasan S, Parducci C, Riley BA. The gastrointestinal effects amongst Ehlers-Danlos syndrome, mast cell activation syndrome and postural orthostatic tachycardia syndrome. *AIMS Allergy and Immunology*. 2022;6(2):19–24. doi: 10.3934/Allergy.2022004.

Connizzo BK, Yannascoli SM, Soslowsky LJ. Structure-function relationships of postnatal tendon development: a parallel to healing. *Matrix Biology*. 2013;32(2):106–116. doi: 10.1016/j.matbio.2013.01.007.

Fernandez A, Jaquet M, Aubry-Rozier B, Suter M, Aybek S, Berna C. Functional neurological signs in hypermobile Ehlers-Danlos syndrome and hypermobile spectrum disorders with suspected neuropathic pain. *Brain and Behavior*. 2024;14(2):e3441. doi: 10.1002/brb3.3441.

Fiengo E, Sbarbati A. Lipedema and hypermobility spectrum disorders sharing pathophysiology: a cross-sectional observational study. *Journal of Clinical Medicine*. 2025;14(20):7195. doi: 10.3390/jcm14207195.

Galletti C, Camps-Font O, Teixidó-Turà G, Llobet-Poal I, Gay-Escoda C. Association between Marfan syndrome and oral health status: a systematic review and meta-analysis. *Medicina Oral, Patología Oral y Cirugía Bucal*. 2019;24(4):e473–e482. doi: 10.4317/medoral.23037.

Kratunova E, Zhang IL, da Fonseca MA. Dental considerations in patients with Loeys-Dietz syndrome: a review of the literature and case report. *Journal of Clinical Pediatric Dentistry*. 2021;45(3):193–198. doi: 10.17796/1053-4625-45.3.8.

Loeys BL, Dietz HC. Loeys-Dietz syndrome. In: Adam MP, Ardinger HH, Pagon RA, Wallace SE, Bean LJH, Gripp KW, Mirzaa GM, Amemiya A, editors. *GeneReviews® [Internet]*. University of Washington; 2018.

Nesargikar PN, Spiller B, Chavez R. The complement system: history, pathways, cascade and inhibitors. *European Journal of Microbiology and Immunology*. 2012;2(2):103–111. doi: 10.1556/EuJMI.2.2012.2.2.

Poshattiwar RS, Acharya S, Shukla S, Kumar S. Neurological manifestations of connective tissue disorders. *Cureus*. 2023;15(10):e47108. doi: 10.7759/cureus.47108.

Torre YS, Wadeea R, Rosas V, Herbst KL. Lipedema: friend and foe. *Hormone Molecular Biology and Clinical Investigation*. 2018;33(1). doi: 10.1515/hmbci-2017-0076.

Chapter 6: What Integrative Care Looks Like in Real Life

Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. Health Aff (Millwood). 2008 May-Jun;27(3):759-69. doi: 10.1377/hlthaff.27.3.759. PMID: 18474969.

Boon H, Verhoef M, O'Hara D, Findlay B, Majid N. Integrative healthcare: arriving at a working definition. Altern Ther Health Med. 2004 Sep-Oct;10(5):48-56. PMID: 15478786.

Bluestein L. Educational writing and commentary on connective tissue disorders, hypermobility, and integrative care. See also public-facing resources and clinical education materials by Linda Bluestein.

Cassidy S, Solvang ØS, Granja C, Solvoll T. Flipping healthcare by including the patient perspective in integrated care pathway design: A scoping review. Int J Med Inform. 2024 Dec;192:105623. doi: 10.1016/j.ijmedinf.2024.105623. Epub 2024 Sep 19. PMID: 39317033.

Cypko MA, Wilhelm D. Ladies and Gentlemen! This is no humbug. Why Model-Guided Medicine will become a main pillar for the future healthcare system. Int J Comput Assist Radiol Surg. 2024 Oct;19(10):1919-1927. doi: 10.1007/s11548-024-03269-x. Epub 2024 Sep 23. PMID: 39312002.

Dovey-Pearce G, Flannery H. Integrating psychology into paediatric healthcare: A UK perspective. Clin Child Psychol Psychiatry. 2021 Apr;26(2):313-322. doi: 10.1177/13591045211000786. Epub 2021 Mar 24. PMID: 33761794.

England BR, Smith BJ, Baker NA, Barton JL, Oatis CA, Guyatt G, Anandarajah A, Carandang K, Chan KK, Constien D, Davidson E, Dodge CV, Bemis-Dougherty A, Everett S, Fisher N, Fraenkel L, Goodman SM, Lewis J, Menzies V, Moreland LW, Navarro-Millan I, Patterson S, Phillips LR, Shah N, Singh N, White D, AlHeresh R, Barbour KE, Bye T, Guglielmo D, Haberman R, Johnson T, Kleiner A, Lane CY, Li LC, Master H, Pinto D, Poole JL, Steinbarger K, Sztubinski D, Thoma L, Tsaltskan V, Turgunbaev M, Wells C, Turner AS, Treadwell JR. 2022 American College of Rheumatology Guideline for Exercise, Rehabilitation, Diet, and Additional Integrative Interventions for Rheumatoid Arthritis. Arthritis Care Res (Hoboken). 2023 Aug;75(8):1603-1615. doi: 10.1002/acr.25117. Epub 2023 May 25. PMID: 37227116.

Knutson L, Johnson PJ, Sidebottom A, Fyfe-Johnson A. Development of a hospital-based integrative healthcare program. J Nurs Adm. 2013 Feb;43(2):101-7. doi: 10.1097/NNA.0b013e31827f2229. PMID: 23343726.

Chapter 7: Listening to Pain, Building Support

Bluestein LS. Pain management in patients with hypermobility disorders: frequently missed causes of chronic pain. *Top Pain Manag*. 2017;32(12):1-10. [doi:10.1097/01.TPM.0000521090.64732.c6](https://doi.org/10.1097/01.TPM.0000521090.64732.c6)

Albayrak I, Yilmaz H, Akkurt HE, Salli A, Karaca G. Is pain the only symptom in patients with benign joint hypermobility syndrome? *Clin Rheumatol*. 2015;34(9):1613-1619. [doi:10.1007/s10067-014-2610-6](https://dx.doi.org/10.1007/s10067-014-2610-6)

Alsiri N, Al-Obaidi S, Asbeutah A, Almandeel M, Palmer S. The impact of hypermobility spectrum disorders on musculoskeletal tissue stiffness: an exploration using strain elastography. *Clin Rheumatol*. 2019;38(1):85-95. [doi:10.1007/s10067-018-4193-0](https://dx.doi.org/10.1007/s10067-018-4193-0)

Arendt-Nielsen L, Kaalund S, Bjerring P, Høgsaa B. Insufficient effect of local analgesics in Ehlers-Danlos type III patients (connective tissue disorder). *Acta Anaesthesiol Scand*. 1990;34(5):358-361. [doi:10.1111/j.1399-6576.1990.tb03103.x](https://dx.doi.org/10.1111/j.1399-6576.1990.tb03103.x)

Arendt-Nielsen L, Kaalund S, Hogsaa B, Bjerring P, Grevy C. The response to local anaesthetics (EMLA-cream) as a clinical test to diagnose between hypermobility and Ehlers-Danlos type III syndrome. *Scand J Rheumatol*. 1991;20(3):190-195.

Armon K. Musculoskeletal pain and hypermobility in children and young people: is it benign joint hypermobility syndrome? *Arch Dis Child*. 2015;100(1):2-3. [doi:10.1136/archdischild-2014-306556](https://dx.doi.org/10.1136/archdischild-2014-306556)

Arthur K, Caldwell K, Forehand S, Davis K. Pain control methods in use and perceived effectiveness by patients with Ehlers-Danlos syndrome: a descriptive study. *Disabil Rehabil*. 2016;38(11):1063-1074. [doi:10.3109/09638288.2015.1092175](https://dx.doi.org/10.3109/09638288.2015.1092175)

Atici A, Aktas I, Akpinar P, Ozkan FU. The relationship between joint hypermobility and subacromial impingement syndrome and adhesive capsulitis of the shoulder. *North Clin Istanb*. 2018;5(3):232–237. doi: 10.14744/nci.2017.35119.

Baeza-Velasco C, Bourdon C, Montalescot L, de Cazotte C, Pailhez G, Bulbena A, Hamonet C. Low- and high-anxious hypermobile Ehlers-Danlos syndrome patients: comparison of psychosocial and health variables. *Rheumatology International*. 2018;38(5):871–878. doi: 10.1007/s00296-018-4003-7.

Basem JI, Lin T, Mehta ND. A comprehensive review: chronic pain sequelae in the presence of Ehlers-Danlos syndrome. *Current Pain and Headache Reports*. 2022;26(12):871–876. doi: 10.1007/s11916-022-01093-z.

Bathen T, Hangmann AB, Hoff M, Andersen LO, Rand-Hendriksen S. Multidisciplinary treatment of disability in Ehlers-Danlos syndrome hypermobility type/hypermobility syndrome: a pilot study using a combination of physical and cognitive-behavioral therapy on 12 women. *American Journal of Medical Genetics Part A*. 2013;161A(12):3005–3011. doi: 10.1002/ajmg.a.36060.

Benistan K, Foy M, Gillas F, Genet F, Kane M, Barbot F, Vaugier I, Bonnyaud C, Gader N. Effects of compression garments on balance in hypermobile Ehlers-Danlos syndrome: a randomized controlled trial. *Disability and Rehabilitation*. 2024;46(9):1841–1850. doi: 10.1080/09638288.2023.2209742.

Bennett SE, Walsh N, Moss T, Palmer S. Developing a self-management intervention to manage hypermobility spectrum disorders (HSD) and hypermobile Ehlers-Danlos syndrome (hEDS): an analysis informed by behaviour change theory. *Disability and Rehabilitation*. 2022;44(18):5231–5240. doi: 10.1080/09638288.2021.1933618.

Besson L, Kalisch L, Baeza-Velasco C. Multidimensional assessment of pain in women with hypermobile Ehlers-Danlos syndrome: a comparative study with rheumatoid arthritis. *Kinésithérapie*. 2020;20(224–225):3–8. doi: 10.1016/j.kine.2020.05.004.

Bitterman A, Clancy D. The management of pain and hypermobility in Ehlers-Danlos syndrome. Comment on "Pain in Ehlers-Danlos syndrome" by Benistan et al. *Joint Bone Spine*. 2021;88(1):105089. doi: 10.1016/j.jbspin.2020.105089.

Blau IN. Joint hypermobility and headache. *Cephalalgia*. 1999;19(9):765–766. doi: 10.1046/j.1468-2982.1999.19097653.x.

Cholerzyńska H, Zasada W, Tselios K, Grygiel-Górniak B. Sleep disorders in connective tissue diseases-coexisting diseases or disease components? *Journal of Clinical Medicine*. 2024;13(13):3656. doi: 10.3390/jcm13133656.

Bogart KR, Dermody SS. Relationship of rare disorder latent clusters to anxiety and depression symptoms. *Health Psychology*. 2020;39(4):307–315. doi: 10.1037/hea0000840.

Booshanam DS, Cherian B, Joseph CP, Mathew J, Thomas R. Evaluation of posture and pain in persons with benign joint hypermobility syndrome. *Rheumatology International*. 2011;31(12):1561–1565. doi: 10.1007/s00296-010-1514-2.

Bulbena A, Sperry L, Pailhez G, Gago J. Anxiety, temporomandibular disorders, and joint hypermobility syndrome. Response to "Psychological assessment of patients with temporomandibular disorders: confirmatory analysis of the dimensional structure of the Brief Symptoms Inventory 18." *Journal of Psychosomatic Research*. 2006;61(6):851. doi: 10.1016/j.jpsychores.2006.10.005.

Camerota F, Mariani R, Cordiano G, Di Trani M, Lodato V, Ferraris A, Pasquini M, Celletti C. The language of pain in the hypermobile Ehlers-Danlos syndrome: metaphors as a key to understanding the experience of pain and as a rehabilitation tool. *Brain Sciences*. 2023;13(7):1042. doi: 10.3390/brainsci13071042.

Carvalho HC, Machado NCSS, Yanez-Silva A, Rocabado M, Junior ARDP, Alves LP, Ribeiro W, Lazo-Osorio RA. Autonomic nerve regulation in joint hypermobility patients with myofascial trigger points by musculoskeletal interfiber counterirritant stimulation (MICS). *Medical Engineering & Physics*. 2022;109:103903. doi: 10.1016/j.medengphy.2022.103903.

Castori M, Celletti C, Camerota F. Ehlers-Danlos syndrome hypermobility type: a possible unifying concept for various functional somatic syndromes. *Rheumatology International*. 2013;33(3):819–821. doi: 10.1007/s00296-011-2275-2.

Castori M, Celletti C, Camerota F, Grammatico P. Chronic fatigue syndrome is commonly diagnosed in patients with Ehlers-Danlos syndrome hypermobility type/joint hypermobility syndrome. *Clinical and Experimental Rheumatology*. 2011;29(3):597–598.

Celletti C, Castori M, Morico G, Camerota F. Joint hypermobility syndrome/Ehlers-Danlos syndrome hypermobility type: constructing a rehabilitative approach. *International Journal of Clinical Rheumatology*. 2014;9(2):103–106. doi: 10.2217/ijr.13.74.

Celletti C, Paolucci T, Maggi L, Volpi G, Billi M, Mollica R, Camerota F. Pain management through neurocognitive therapeutic exercises in hypermobile Ehlers-Danlos syndrome patients with chronic low back pain. *BioMed Research International*. 2021;2021:6664864. doi: 10.1155/2021/6664864.

Chaleat-Valayer E, Denis A, Zelmar A, Pujol A, Bernadou A, Bard-Pondarre R, Touzet S. VETCOSED study: efficacy of compressive garments for patients with hypermobile Ehlers-Danlos syndrome on shoulder stability and muscle strength. *Disability and Rehabilitation*. 2022;44(13):3165–3172. doi: 10.1080/09638288.2020.1860142.

Clark NL, Kainth GS, Johnson M, Rangan A, Kottam L, Swainston K. Psychological interventions to improve pain, fatigue, anxiety, depression, and quality of life in children and adults with hypermobility spectrum disorders and Ehlers-Danlos syndrome: a systematic review. *Rheumatology International*. 2024;44(1):41–55. doi: 10.1007/s00296-023-05503-2.

Daman M, Shiravani F, Hemmati L, Taghizadeh S. The effect of combined exercise therapy on knee proprioception, pain intensity and quality of life in patients with hypermobility syndrome: a randomized clinical trial. *Journal of Bodywork and Movement Therapies*. 2019;23(1):202–205. doi: 10.1016/j.jbmt.2017.12.012.

De Wandele I, Colman M, Hermans L, Van Oosterwijck J, Meeus M, Rombaut L, Brusselmans G, Syx D, Calders P, Malfait F. Exploring pain mechanisms in hypermobile Ehlers-Danlos syndrome: a case-control study. *European Journal of Pain*. 2022;26(6):1355–1367. doi: 10.1002/ejp.1956.

De Wandele I, Rombaut L, Leybaert L, Van de Borne P, De Backer T, Malfait F, De Paepe A, Calders P. Dysautonomia and its underlying mechanisms in the hypermobility type of Ehlers-Danlos syndrome. *Seminars in Arthritis and Rheumatism*. 2014;44(1):93–100. doi: 10.1016/j.semarthrit.2013.12.006.

Dolso M, Juul-Kristensen B, Skou ST, Sogaard K, Sondergaard J, Juhl CB, Liaghat B. Psychological factors and symptom duration are associated with exercise-based treatment effect in people with hypermobile shoulders: a secondary analysis of a randomised controlled trial. *Musculoskeletal Science and Practice*. 2023;66:102798. doi: 10.1016/j.msksp.2023.102798.

Dupin AC, Wain E, Labidi Y, Delvenne P. A rare cause of epigastric pain: splenic artery dissection and pseudoaneurysm of celiac trunk in the Ehlers-Danlos syndrome type IV. *Digestive Diseases and Sciences*. 2022;67(8):4258–4260. doi: 10.1007/s10620-021-07291-w.

Ercolani M, Galvani M, Franchini C, Baracchini F, Chattat R. Benign joint hypermobility syndrome: psychological features and psychopathological symptoms in a sample pain-free at evaluation. *Perceptual and Motor Skills*. 2008;107(1):246–256. doi: 10.2466/PMS.107.1.246-256.

Fernandez A, Aubry-Rozier B, Vautey M, Berna C, Suter MR. Small fiber neuropathy in hypermobile Ehlers-Danlos syndrome/hypermobility spectrum disorder. *Journal of Internal Medicine*. 2022;292(6):957–960. doi: 10.1111/joim.13539.

Ferrell WR, Tennant N, Sturrock RD, Ashton L, Creed G, Brydson G, Rafferty D. Amelioration of symptoms by enhancement of proprioception in patients with joint hypermobility syndrome. *Arthritis & Rheumatism*. 2004;50(10):3323–3328.

Ghafouri N, Backryd E, Dragioti E, Rivano Fischer M, Ringqvist A, Gerdle B. Effects of interdisciplinary pain rehabilitation programs on neuropathic and non-neuropathic chronic pain conditions: a registry-based cohort study from the Swedish Quality Registry for Pain Rehabilitation (SQRP). *BMC Musculoskeletal Disorders*. 2023;24(1):357. doi: 10.1186/s12891-023-06462-2.

Gullapalli PA, Javed S. Multidisciplinary chronic pain management strategies in patients with Ehlers-Danlos syndromes. *Pain Management*. 2022;13(1):5–14. doi: 10.2217/pmt-2022-0050.

Gurley-Green S. Living with the hypermobility syndrome. *Rheumatology*. 2001;40(5):487–489. doi: 10.1093/rheumatology/40.5.487.

Hakim AJ, Grahame R, Norris P, Hopper C. Local anaesthetic failure and mobility. *Journal of the Royal Society of Medicine*. 2005;98(2):84–85. doi: 10.1258/jrsm.98.2.84.

Hakimi A, Bergoin C, De Jesus A, Hoorelbeke A, Ramon P, Florea O, Fabre C, Mucci P. Multiple sustainable benefits of a rehabilitation program in therapeutic management of hypermobile Ehlers-Danlos syndrome: a prospective and controlled study at short- and medium-term. *Archives of Physical Medicine and Rehabilitation*. 2023;104(12):2059–2066. doi: 10.1016/j.apmr.2023.06.012.

Halverson CME, Kroenke K, Penwell HL, Francomano CA. Evolving attitudes toward numeric pain assessment among patients with hypermobile Ehlers-Danlos syndrome: a qualitative interview study. *Pain Medicine*. 2023;24(6):713–715. doi: 10.1093/pm/pnac167.

Iatridou K, Mandalidis D, Chronopoulos E, Vagenas G, Athanasopoulos S. Static and dynamic body balance following provocation of the visual and vestibular systems in females with and without joint hypermobility syndrome. *Journal of Bodywork and Movement Therapies*. 2014;18(2):159–164. doi: 10.1016/j.jbmt.2013.10.003.

Janmey I, Hudson PL, Lee J, Forschner C, James K, Von Bargen E. Characterization of pelvic floor disorders among women with Ehlers-Danlos syndrome in comparison to women without connective tissue disorders. *Female Pelvic Medicine & Reconstructive Surgery*. 2020;26(10 Suppl 1):S146. doi: 10.1097/SPV.0000000000000936.

Jonik S, Rothka AJ, Cherin N. Systemic pain relief after omalizumab injection in a patient with hypermobile Ehlers-Danlos syndrome: a case report. *Clinical Case Reports*. 2024;12(1):e8431. doi: 10.1002/ccr3.8431.

Kalisch L, Boniwell I, Osin E, Baeza-Velasco C. Feeling good despite EDS: the effects of a 5-week online positive psychology programme for Ehlers-Danlos syndromes patients. *Journal of Happiness Studies*. 2022;23:79–87. doi: 10.1007/s10879-021-09521-8.

Kalisch L, Hamonet C, Bourdon C, Montalescot L, de Cazotte C, Baeza-Velasco C. Predictors of pain and mobility disability in the hypermobile Ehlers-Danlos syndrome. *Disability and Rehabilitation*. 2020;42(25):3679–3686. doi: 10.1080/09638288.2019.1608595.

Kulesa-Mrowiecka M, Piech J, Gazdzik TS. The effectiveness of physical therapy in patients with generalized joint hypermobility and concurrent temporomandibular disorders: a cross-sectional study. *Journal of Clinical Medicine*. 2021;10(17):3808. doi: 10.3390/jcm10173808.

Lattimore P, Harrison F. Pilot study of an online-delivered mindfulness meditation in Ehlers-Danlos syndrome (hEDS): effect on quality of life and participant lived experience. *Disability and Rehabilitation*. 2023;45(23):3833–3840. doi: 10.1080/09638288.2022.2140843.

Leone CM, Celletti C, Gaudiano G, Puglisi PA, Fasolino A, Cruccu G, Camerota F, Truini A. Pain due to Ehlers-Danlos syndrome is associated with deficit of the endogenous pain inhibitory control. *Pain Medicine*. 2020;21(9):1929–1935. doi: 10.1093/pm/pnaa038.

Levine D, Work B, McDonald S, Harty N, Mabe C, Powell A, Sanford G. Occupational therapy interventions for clients with Ehlers-Danlos syndrome (EDS) in the presence of postural orthostatic tachycardia syndrome (POTS). *Occupational Therapy in Health Care*. 2022;36(3):253–270. doi: 10.1080/07380577.2021.1975200.

Liaghat B, Skou ST, Sondergaard J, Boyle E, Sogaard K, Juul-Kristensen B. Short-term effectiveness of high-load compared with low-load strengthening exercise on self-reported function in patients with hypermobile shoulders: a randomised controlled trial. *British Journal of Sports Medicine*. 2022;56(22):1269–1276. doi: 10.1136/bjsports-2021-105223.

Luder G, Aeberli D, Mebes CM, Haupt-Bertschy B, Baeyens JP, Verra ML. Effect of resistance training on muscle properties and function in women with generalized joint hypermobility: a single-blind pragmatic randomized controlled trial. *BMC Sports Science, Medicine and Rehabilitation*. 2021;13(1):10. doi: 10.1186/s13102-021-00238-8.

Marti F, Lindner G, Ravioli S. Resistance to local anaesthetics: a literature review. *British Journal of Anaesthesia*. 2022;129(2):e43–e45. doi: 10.1016/j.bja.2022.05.006.

Mitakides JE. The effect of Ehlers-Danlos syndromes on TMJ function and craniofacial pain. *CRANIO*. 2018;36(2):71–72. doi: 10.1080/08869634.2018.1435092.

Neice AE, Stubblefield EE, Woodworth GE, Aziz MF. Peripheral nerve block in patients with Ehlers-Danlos syndrome, hypermobility type: a case series. *Journal of Clinical Anesthesia*. 2016;33:26–30. doi: 10.1016/j.jclinane.2016.01.005.

Niermeyer M, Ball D, Green M, Jensen B, Pace L, Shingleton R, Fawver B, Trapp SK. Interoceptive attention regulation in Ehlers-Danlos syndromes: associations between pain and psychiatric symptom severity. *Translational Behavioral Medicine*. 2021;11(10):1923–1930. doi: 10.1093/tbm/ibab049.

Palmer S, Bailey S, Barker L, Barney L, Elliott A. The effectiveness of therapeutic exercise for joint hypermobility syndrome: a systematic review. *Physiotherapy*. 2014;100(3):220–227. doi: 10.1016/j.physio.2013.09.002.

Palmer S, Cramp F, Clark E, Lewis R, Brookes S, Hollingworth W, Welton N, Thom H, Terry R, Rimes KA, Horwood J. The feasibility of a randomised controlled trial of physiotherapy for adults with joint hypermobility syndrome. *Health Technology Assessment*. 2016;20(47):1–290. doi: 10.3310/hta20470.

Rahman A, Daniel C, Grahame R. Efficacy of an out-patient pain management programme for people with joint hypermobility syndrome. *Clinical Rheumatology*. 2014;33(11):1665–1669. doi: 10.1007/s10067-014-2539-9.

Reina-Bueno M, Vazquez-Bautista C, Palomo-Toucedo IC, Dominguez-Maldonado G, Castillo-Lopez JM, Munuera-Martinez PV. Custom-made foot orthoses reduce pain and fatigue in patients with Ehlers-Danlos syndrome: a pilot study. *International Journal of Environmental Research and Public Health*. 2020;17(4):1359. doi: 10.3390/ijerph17041359.

Reychler G, De Backer MM, Piraux E, Poncin W, Caty G. Physical therapy treatment of hypermobile Ehlers-Danlos syndrome: a systematic review. *American Journal of Medical Genetics Part A*. 2021;185(10):2986–2994. doi: 10.1002/ajmg.a.62393.

Rombaut L, Malfait F, De Wandele I, Taes Y, Thijs Y, De Paepe A, Calders P. Muscle mass, muscle strength, functional performance, and physical impairment in women with the hypermobility type of Ehlers-Danlos syndrome. *Arthritis Care & Research*. 2012;64(10):1584–1592. doi: 10.1002/acr.21726.

Rombaut L, Malfait F, De Wandele I, Thijs Y, Palmans T, De Paepe A, Calders P. Balance, gait, falls, and fear of falling in women with the hypermobility type of Ehlers-Danlos syndrome. *Arthritis Care & Research*. 2011;63(10):1432–1439. doi: 10.1002/acr.20557.

Rosinsky PJ, Annin S, Maldonado DR, Kyin C, Meghpara MB, Shapira J, Lall AC, Domb BG. Arthroscopic ligamentum teres reconstruction: minimum 2-year patient-reported outcomes with subanalysis of patients with Ehlers-Danlos syndrome. *Arthroscopy*. 2020;36(8):2170–2182. doi: 10.1016/j.arthro.2020.04.028.

Sahin N, Baskent A, Cakmak A, Salli A, Ugurlu H, Berker E. Evaluation of knee proprioception and effects of proprioception exercise in patients with benign joint hypermobility syndrome. *Rheumatology International*. 2008;28(10):995–1000. doi: 10.1007/s00296-008-0566-z.

Schubert-Hjalmarsson E, Fasth A, Ickmans K, Mardbrink EL, Söderpalm AC, Lundberg M. Central sensitization in adolescents with hypermobility spectrum disorder or hypermobile Ehlers-Danlos syndrome: a feasibility study. *Pilot and Feasibility Studies*. 2023;9(1):97. doi: 10.1186/s40814-023-01320-3.

Simmonds JV, Herbland A, Hakim A, Ninis N, Lever W, Aziz Q, Cairns M. Exercise beliefs and behaviours of individuals with joint hypermobility syndrome/Ehlers-Danlos syndrome—hypermobility type. *Disability and Rehabilitation*. 2019;41(4):445–455. doi: 10.1080/09638288.2017.1398278.

Song B, Yeh P, Nguyen D, Ikpeama U, Epstein M, Harrell J. Ehlers-Danlos syndrome: an analysis of the current treatment options. *Pain Physician*. 2020;23(4):429–438.

Spanhove V, De Wandele I, Malfait F, Calders P, Cools A. Home-based exercise therapy for treating shoulder instability in patients with hypermobile Ehlers-Danlos syndrome/hypermobility spectrum disorders: a randomized trial. *Disability and Rehabilitation*. 2023;45(11):1811–1821. doi: 10.1080/09638288.2022.2076932.

Thompson B, Stocks R, Themelis K, Amato M, Pound A, Cipinova ZC, Shah-Goodwin L, Timeyin J, Barritt A, Harrison NA, Critchley HD, Davies KA, Eccles JA. Symptomatic joint hypermobility: relevance to inflammation and autonomic-induced pain and fatigue in fibromyalgia and ME/CFS. *Psychosomatic Medicine*. 2020;82(6):A64. doi: 10.1097/PSY.0000000000000835.

Tinkle BT. Joint hypermobility and headache. *Headache*. 2014;54(8):1412–1413. doi: 10.1111/head.12416.

Toprak Celenay S, Ozer Kaya D. Effects of spinal stabilization exercises in women with benign joint hypermobility syndrome: a randomized controlled trial. *Rheumatology International*. 2017;37(9):1461–1468. doi: 10.1007/s00296-017-3713-6.

Traub K, Stage KH. The Ehlers-Danlos syndrome presenting with flank pain. *Journal of Urology*. 2001;165(5 Pt 1):1614. doi: 10.1016/S0022-5347(05)66360-4.

Tudini F, Levine D, Healy M, Jordon M, Chui K. Evaluating the effects of two different kinesiology taping techniques on shoulder pain and function in patients with hypermobile Ehlers-Danlos syndrome. *Frontiers in Pain Research*. 2023;4:1089748. doi: 10.3389/fpain.2023.1089748.

Voermans NC, Knoop H. Both pain and fatigue are important possible determinants of disability in patients with the Ehlers-Danlos syndrome hypermobility type. *Disability and Rehabilitation*. 2011;33(8):706–707. doi: 10.3109/09638288.2010.531373.

Vuong V, Mosabbir A, Paneduro D, Picard L, Faghfoury H, Evans M, Gordon A, Bartel L. Effects of rhythmic sensory stimulation on Ehlers-Danlos syndrome: a pilot study. *Pain Research and Management*. 2020;2020:3586767. doi: 10.1155/2020/3586767.

Zhou Z, Rewari A, Shanthanna H. Management of chronic pain in Ehlers-Danlos syndrome. *Medicine (Baltimore)*. 2018;97(45):e13115. doi: 10.1097/MD.0000000000013115.

Chapter 8: When Rest Does Not Restore You

Cholerzyńska H, Zasada W, Tselios K, Grygiel-Górniak B. Sleep disorders in connective tissue diseases—coexisting diseases or disease components? Journal of Clinical Medicine. 2024;13(13):3656. doi: 10.3390/jcm13133656.

Clark NL, Kainth GS, Johnson M, Rangan A, Kottam L, Swainston K. Psychological interventions to improve pain, fatigue, anxiety, depression, and quality of life in children and adults with hypermobility spectrum disorders and Ehlers-Danlos syndrome: a systematic review. *Rheumatology International*. 2024;44(1):41–55. doi: 10.1007/s00296-023-05503-2.

Hakim A, De Wandele I, O'Callaghan C, Pocinki A, Rowe P. Chronic fatigue in Ehlers-Danlos syndrome-hypermobile type. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):175–180. doi: 10.1002/ajmg.c.31542.

Pocinki A. Autonomic Dysfunction in EDS [Video Lecture]. The Dysautonomia Project Annual Dyscourse; 2026. Available at: https://www.youtube.com/watch?v=Z_9KilQf30o&t=201s

Pocinki A. The Role and Treatment of Autonomic Dysfunction in EDS-Associated Sleep Disorders [Lecture]. Ehlers-Danlos Society Global Learning Conference; August 2022. *(Note: This lecture may no longer be publicly accessible.)*

Appendix A: A Patient-Friendly History of the Ehlers-Danlos Syndromes

Beighton P, McKusick VA. *Heritable Disorders of Connective Tissue*. 5th ed. Mosby; 1993.

Beighton P, de Paepe A, Danks D, et al. International nosology of heritable disorders of connective tissue, Berlin, 1986. *American Journal of Medical Genetics*. 1988;29:581–594.

Beighton P, De Paepe A, Steinmann B, Tsipouras P, Wenstrup RJ. Ehlers–Danlos syndromes: revised nosology, Villefranche, 1997. *American Journal of Medical Genetics*. 1998;77(1):31–37.

Beighton P, Price A, Lord J, Dickson E. The variants of the Ehlers–Danlos syndrome. *Annals of the Rheumatic Diseases*. 1969;28:228.

Denko CW. Chernogubov's syndrome: a translation of the first modern case report of the Ehlers–Danlos syndrome. *Journal of Rheumatology*. 1978;5(3):347–352.

McKusick VA. *Heritable Disorders of Connective Tissue*. 4th ed. Mosby; 1972.

Malfait F, Francomano C, Byers P, et al. The 2017 international classification of the Ehlers–Danlos syndromes. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2017;175(1):8–26.

Parapia LA, Jackson C. Ehlers–Danlos syndrome: a historical review. *British Journal of Haematology*. 2008;141(1):32–35.

Patel P, Prabhu AV, Oddis CV. The rise of Henri-Alexandre Danlos and his contributions to dermatologic therapeutics and radiation research. *JAMA Dermatology*. 2016;152(10):1113.

Appendix B: Marfan Syndrome

The Marfan Trust. Marfan Trust website and patient resources.

The Marfan Foundation. Patient information, diagnostic tools, and research updates.

Marfan Europe Network. European patient network information and educational resources.

Loeys BL, Dietz HC, Braverman AC, Callewaert BL, De Backer J, Devereux RB, Hilhorst-Hofstee Y, Jondeau G, Faivre L, Milewicz DM, Pyeritz RE, Sponseller PD, Wordsworth P, De Paepe AM. The revised Ghent nosology for the Marfan syndrome. Journal of Medical Genetics. 2010;47(7):476–485. doi: 10.1136/jmg.2009.072785.

Pyeritz RE. The Marfan syndrome. Annual Review of Medicine. 2000;51:481–510. doi: 10.1146/annurev.med.51.1.481.

Tinkle BT, Lacro RV, Burke LW, Holm TM, Maurer SH, Mathur S, Roach ES, Sable C. Health supervision for children and adolescents with Marfan syndrome. Pediatrics. 2023;151(4):e2023061450. doi: 10.1542/peds.2023-061450.

Mahmood SUB, Velasquez CA, Zafar MA, Ziganshin BA, Elefteriades JA. Medical management of aortic disease in Marfan syndrome. Annals of Cardiothoracic Surgery. 2017;6(6):654–661. doi: 10.21037/acs.2017.11.03.

Treasure T, Takkenberg JJM, Pepper J. Surgical management of aortic root disease in Marfan syndrome and other congenital disorders associated with aortic root aneurysms. Postgraduate Medical Journal. 2016;92(1084):112–117. doi: 10.1136/postgradmedj-2015-133651.

Appendix C: Loeys-Dietz Syndrome

Loeys BL, Dietz HC. Loeys-Dietz Syndrome. In: GeneReviews® [Internet]. University of Washington, Seattle; updated September 12, 2024.

Loeys BL, Chen J, Neptune ER, Judge DP, Podowski M, Holm T, Meyers J, Leitch CC, Katsanis N, Sharifi N, Xu FL, Myers LA, Spevak PJ, Cameron DE, De Backer J, Hellemans J, Chen Y, Davis EC, Webb CL, Kress W, Coucke P, Rifkin DB, De Paepe AM, Dietz HC. A syndrome of altered cardiovascular, craniofacial, neurocognitive and skeletal development caused by mutations in TGFBR1 or TGFBR2. Nature Genetics. 2005;37(3):275–281. doi: 10.1038/ng1511.

Loeys BL, Schwarze U, Holm T, Callewaert BL, Thomas GH, Pannu H, De Backer JF, Oswald GL, Symoens S, Manouvrier S, Roberts AE, Faravelli F, Greco MA, Pyeritz RE, Milewicz DM, Coucke PJ, Cameron DE, Braverman AC, Byers PH, De Paepe AM, Dietz HC. Aneurysm syndromes caused by mutations in the TGF-beta receptor. New England Journal of Medicine. 2006;355(8):788–798. doi: 10.1056/NEJMoa044888.

Isselbacher EM, Preventza O, Black JH 3rd, et al. 2022 ACC/AHA Guideline for the Diagnosis and Management of Aortic Disease. Journal of the American College of Cardiology. 2022;80(24):e223–e393. doi: 10.1016/j.jacc.2022.08.004.

Khodabakhshian N, Howell AJ, Perez Lopez P, Hui W, Mertens LL, Guerra VC. Impact of genotype-phenotype interactions on cardiovascular function in paediatric Loeys-Dietz syndrome. CJC Pediatric and Congenital Heart Disease. 2024;3(2):47–54. doi: 10.1016/j.cjcpc.2023.12.003.

MacCarrick G, Afifi RO, Allen R, Almpani K, Black JH 3rd, Boyce AM, Braverman AC, Cameron DE, Caplan J, Cervi E, Cha MJ, Christensen J, van de Laar IMBH, Demo E, Dewals W, Doyle AJ, Doyle JJ, Fischbein MP, Fleischer J, Fleischman F, Frischmeyer-Guerrerio PA, Guerrerio AL, Hugeunard AL, Jani PH, Jordan CP, Kim HJ, Krebsová A, Kockova R, Lee JS, Lobner K, Narula N, Niknahad A, Neptune E, Pedroza AJ, Perry M, Richer J, Rios-Sanchez J, Roman MJ, Russo M, Schweber J, Shalhub S, Sorber R, Speed T, Sponseller PD, Vincent TL, Whelan A, Zeiler SR, Loeys B, Dietz HC 3rd. Loeys-Dietz Syndrome: 2026 updated care management primer. Genetics in Medicine. 2026 Apr 14:102577. doi: 10.1016/j.gim.2026.102577.

Appendix D: Mast Cell Activation Syndrome (MCAS)

Castells M, Giannetti MP, Hamilton MJ, et al. Mast cell activation syndrome: Current understanding and research needs. Journal of Allergy and Clinical Immunology. 2024;154(2):255–263. doi: 10.1016/j.jaci.2024.05.025.

Gulen T, Akin C. Current concepts in mast cell activation syndromes. Annals of Allergy, Asthma & Immunology. 2024;132(1):8–17. doi: 10.1016/j.anai.2023.08.009.

Lyons JJ, Chovanec J, O'Connell MP, et al. Hereditary alpha tryptasemia: genotyping and associated clinical features. Immunology and Allergy Clinics of North America. 2018;38(3):483–495. doi: 10.1016/j.iac.2018.04.001.

Molderings GJ, Afrin LB, Castells M, et al. Mast cell activation disease: an underappreciated cause of neurologic and psychiatric symptoms and diseases. Brain, Behavior, and Immunity - Health. 2021;15:100273. doi: 10.1016/j.bbih.2021.100273.

Monaco A, Choi D, Uzun S, Maitland A, Riley B. Association of mast-cell-related conditions with hypermobile syndromes: a review of the literature. Immunologic Research. 2022;70(4):419–431. doi: 10.1007/s12026-022-09280-1.

Nesargikar PN, Spiller B, Chavez R. The complement system: history, pathways, cascade, and inhibitors. European Journal of Microbiology and Immunology. 2012;2(2):103–111. doi: 10.1556/EuJMI.2.2012.2.2.

Valent P, Akin C, Arock M, et al. Definitions, criteria, and global classification of mast cell disorders with special reference to mast cell activation syndromes: a consensus proposal. International Archives of Allergy and Immunology. 2012;157(3):215–225. doi: 10.1159/000328760.

Valent P, Bonadonna P, Hartmann K, Brockow K. Why the 20% + 2 tryptase formula is a diagnostic gold standard for severe systemic mast cell activation and mast cell activation syndrome. International Archives of Allergy and Immunology. 2019;180(1):44–51. doi: 10.1159/000501229.

Appendix E: Understanding Dysautonomia and Orthostatic Intolerance

Autonomic Disorders Consortium. Rare Diseases Clinical Research Network, National Institutes of Health.

Benarroch EE. Postural tachycardia syndrome: a heterogeneous and multifactorial disorder. *Mayo Clin Proc.* 2012;87(12):1214-1225. doi:10.1016/j.mayocp.2012.08.013.

Bhatia R, Kizilbash SJ, Ahrens SP, Killian JM, Kimmes SA, Knoebel EE, et al. Outcomes of adolescent onset postural orthostatic tachycardia syndrome. *J Pediatr.* 2016;173:149-153. doi:10.1016/j.jpeds.2016.02.035.

Blitshteyn S. Dysautonomia: a common comorbidity of systemic disease. *Immunol Res.* 2025;73(1):105. doi:10.1007/s12026-025-09661-2.

Blitshteyn S, Fedorowski A. The risks of POTS after COVID-19 vaccination and SARS-CoV-2 infection: more studies are needed. *Nat Cardiovasc Res.* 2022;1:1119-1120.

Carew S, Connor MO, Cooke J, Conway R, Sheehy C, Costelloe A, Lyons D. A review of postural orthostatic tachycardia syndrome. *Europace*. 2009;11(1):18-25. doi:10.1093/europace/eun324.

Conner R, Sheikh M, Grubb B. Postural orthostatic tachycardia syndrome (POTS): evaluation and management. *Br J Med Pract.* 2012;5(4):540.

Fedorowski A. Postural orthostatic tachycardia syndrome: clinical presentation, aetiology and management. J *Intern Med.* 2019;285(4):352-366. doi:10.1111/joim.12852.

Fogoros RN. Dysautonomia: a family of misunderstood disorders. About.com Guide. Updated November 13, 2011.

Garland EM, Celedonio JE, Raj SR. Postural tachycardia syndrome: beyond orthostatic intolerance. *Curr Neurol Neurosci Rep.* 2015;15(9):60. doi:10.1007/s11910-015-0583-8.

Goldstein DS, Robertson D, Esler M, Straus SE, Eisenhofer G. Dysautonomias: clinical disorders of the autonomic nervous system. *Ann Intern Med.* 2002;137(9):753-763. doi:10.7326/0003-4819-137-9-200211050-00011.

Grubb BP. Postural tachycardia syndrome. *Circulation*. 2008;117(21):2814-2817. doi:10.1161/CIRCULATIONAHA.107.761643.

Grubb BP, Karas B. Clinical disorders of the autonomic nervous system associated with orthostatic intolerance: an overview of classification, clinical evaluation, and management. *Pacing Clin Electrophysiol*. 1999;22(5):798-810. doi:10.1111/j.1540-8159.1999.tb00546.x.

Khurana RK. Experimental induction of panic-like symptoms in patients with postural tachycardia syndrome. *Clin Auton Res*. 2006;16(6):371-377. doi:10.1007/s10286-006-0365-0.

Lau DH, Fedorowski A, Raj SR, Schild C, Pace LA, Blitshteyn S, Raj V, Boris JR, Kavi L, Seeley MC, Gallagher C, et al. Postural orthostatic tachycardia syndrome: a state-of-the-art review. *Heart Lung Circ*. 2026;35(2):171-185. doi:10.1016/j.hlc.2025.09.004.

Low PA, Sandroni P, Joyner M, Shen WK. Postural tachycardia syndrome (POTS). *J Cardiovasc Electrophysiol*. 2009;20(3):352-358. doi:10.1111/j.1540-8167.2008.01407.x.

National Institute of Neurological Disorders and Stroke. Dysautonomia information page.

Oldham WM, Lewis GD, Opotowsky AR, Waxman AB, Systrom DM. Unexplained exertional dyspnea caused by low ventricular filling pressures: results from clinical invasive cardiopulmonary exercise testing. *Pulm Circ*. 2016;6(1):55-62. doi:10.1086/685054.

Pederson CL, Brook JB. Health-related quality of life and suicide risk in postural tachycardia syndrome. *Clin Auton Res*. 2017;27(2):75-81. doi:10.1007/s10286-017-0399-5.

Pena C, Moustafa A, Mohamed AR, Grubb B. Autoimmunity in syndromes of orthostatic intolerance: an updated review. *J Pers Med*. 2024;14(4):435. doi:10.3390/jpm14040435.

Pocinki A. Autonomic Dysfunction in EDS [Video lecture]. The Dysautonomia Project Annual Dyscourse; 2026. Available at: https://www.youtube.com/watch?v=Z_9KilQf30o&t=201s

Raj S, Sheldon R. Management of postural tachycardia syndrome, inappropriate sinus tachycardia and vasovagal syncope. *Arrhythm Electrophysiol Rev*. 2016;5(2):122-129. doi:10.15420/AER.2016.7.2.

Raj SR. The postural tachycardia syndrome (POTS): pathophysiology, diagnosis & management. *Indian Pacing Electrophysiol J*. 2006;6(2):84-99.

Raj SR, Guzman JC, Harvey P, et al. Canadian Cardiovascular Society position statement on postural orthostatic tachycardia syndrome (POTS) and related disorders of chronic orthostatic intolerance. *Can J Cardiol*. 2020;36:357-372. doi:10.1016/j.cjca.2019.12.024.

Safavi-Naeini P, Razavi M. Postural orthostatic tachycardia syndrome. *Tex Heart Inst J*. 2020;47(1):5-11. PMCID: PMC7046364. PMID: 32148459.

Schondorf R, Low PA. Idiopathic postural orthostatic tachycardia syndrome: an attenuated form of acute pandysautonomia? *Neurology*. 1993;43(1):132-137. doi:10.1212/WNL.43.1_Part_1.132.

Seeley MC, Gallagher C, Ong E, Langdon A, Chieng J, Bailey D, et al. Poor health-related quality of life in postural orthostatic tachycardia syndrome in comparison with a sex- and age-matched normative population. *Clin Auton Res*. 2023;33:469-477.

Seeley MC, Lau DH, Gallagher C. Postural orthostatic tachycardia syndrome: diagnosis and management guide for nurses. *Nurs Res Rev*. 2023;13:41-49.

Seeley MC, Wilson G, Ong E, Langdon A, Chieng J, Bailey D, et al. Biological sex-dependent differences in postural orthostatic tachycardia syndrome. *Eur J Cardiovasc Nurs*. 2025;24:762-771.

Shaw BH, Stiles LE, Bourne K, Green EA, Shibao CA, Okamoto LE, et al. The face of postural tachycardia syndrome: insights from a large cross-sectional online community-based survey. *J Intern Med*. 2019;286:438-448.

Sheldon RS, Grubb BP 2nd, Olshansky B, Shen WK, Calkins H, Brignole M, et al. 2015 Heart Rhythm Society expert consensus statement on the diagnosis and treatment of postural tachycardia syndrome, inappropriate sinus tachycardia, and vasovagal syncope. *Heart Rhythm*. 2015;12(6):e41-e63. doi:10.1016/j.hrthm.2015.03.029.

Uppal J, Baker JR, Hira R, Karalasingham K, Ranada S, Deol P, et al. Physiological and clinical comparison of active stand and head-up tilt tests in postural orthostatic tachycardia syndrome (POTS). *Auton Neurosci*. 2025;260:103281. doi:10.1016/j.autneu.2025.103281.

Vernino S, Bourne KM, Stiles LE, Grubb BP, Fedorowski A, Stewart JM, et al. Postural orthostatic tachycardia syndrome (POTS): state of the science and clinical care from a 2019 National Institutes of Health Expert Consensus Meeting—Part 1. *Auton Neurosci*. 2021;235:102828.

Building Your Library

Building a personal library can be a comforting way to gather knowledge, encouragement, and practical support in one place. This expanded list is organized into reader-friendly categories to help you explore books on everyday living, medical understanding, movement and rehabilitation, dysautonomia, and lived experience, so you can return to the resources that meet you where you are and grow with you over time. Take what feels helpful now, and leave the rest for later.

— Practical Guides for Everyday Life

Finding Joy with an Invisible Chronic Illness: Proven Strategies for Discovering Happiness, Meaning, and Fulfillment **by Christopher Martin**
A thoughtful guide for living with invisible chronic illness, centered on resilience, self-compassion, stress reduction, and meaning-making. It may be especially encouraging for readers looking for gentle, practical ways to cope, communicate more clearly, and build a life that feels more sustainable and fulfilling.

Holding It All Together When You're Hypermobile: Achieve a Better Life Experience with EDS, POTS, and Joint Instability **by Christie Cox**
A compassionate, patient-centered guide to living with hypermobile EDS, POTS, and joint instability, blending lived experience with practical self-advocacy. It may be especially helpful for readers who want reassurance, useful coping tools, and support in navigating diagnosis, daily life, and conversations with clinicians and loved ones.

Joint Hypermobility Handbook: A Guide for the Issues & Management of Ehlers-Danlos Syndrome Hypermobility Type and the Hypermobility Syndrome **by Brad T. Tinkle**
A clear, patient-friendly introduction to joint hypermobility and related Ehlers-Danlos presentations, covering symptoms, diagnosis, and day-to-day management. It can be a reassuring starting point for readers who want practical guidance and enough medical context to feel more confident in conversations with clinicians.

— In-Depth Medical and Reference Books

Disjointed: Navigating the Diagnosis and Management of Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders **edited by Diana Jovin**
An in-depth, multidisciplinary overview of hypermobile EDS and HSD, bringing together perspectives from clinicians, patients, and caregivers. It may be especially valuable for

readers who want a fuller understanding of diagnosis, symptom patterns, and management across specialties.

Living with Vascular Ehlers-Danlos Syndrome: The Complete Global Guide for Patients, Families, and Physicians **by Marcel Lewandowski**
A comprehensive guide to vascular Ehlers-Danlos syndrome covering medical facts, daily safety, emergency planning, coping, and care coordination. It may be especially supportive for patients, families, and clinicians who want a practical resource for feeling more prepared and informed while navigating VEDS.

Symptomatic: The Symptom-Based Handbook for Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders **edited by Clair A. Francomano, Alan J. Hakim, Lansdale G.S. Henderson, and Fraser C. Henderson Sr.**
A symptom-based handbook that organizes EDS and HSD by how they present in real life, supported by case examples and diagnostic pathways. It may be especially useful for readers who want help making sense of symptoms and exploring possible explanations and management options.

Transforming Ehlers-Danlos Syndrome: A Global Vision of the Disease **by Stéphane Daens and Isabelle Dubois Brock**
A wide-ranging exploration of Ehlers-Danlos syndrome that examines history, classification, emergencies, long-term progression, and emerging theories. It may be especially meaningful for readers who want a broader, big-picture perspective on the condition and its many complexities.

— Books on Dysautonomia and Related Conditions

The Dysautonomia Project **by Kelly Freeman, David S. Goldstein, and Charles R. Thompson**
A clear, accessible guide to autonomic nervous system disorders, including symptoms, diagnosis, treatment options, and patient experience. It may be especially helpful for readers living with POTS, dysautonomia, or related conditions who want a clearer understanding of what they are facing.

— Pain Science and Trauma-Informed Understanding

Explain Pain **by David Butler and G. Lorimer Moseley**
A clear, accessible introduction to modern pain science that explains how pain is shaped by the nervous system, context, stress, and perceived threat—not just tissue damage alone. It may be especially helpful for readers who want language and concepts that reduce fear, make persistent pain feel less mysterious, and support more confident, compassionate rehabilitation.

***The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma* by Bessel van der Kolk**
A widely read exploration of how trauma can affect the brain, body, memory, and sense of safety, along with an overview of therapeutic approaches that may support healing. It may be especially meaningful for readers who are trying to understand the overlap between chronic stress, nervous system dysregulation, trauma history, and physical symptoms in a broader mind-body context.

— Books on Movement, Exercise, and Physical Therapy

***The Integral Movement Method for Hypermobility Management* by Jeannie Di Bon**
A practical movement guide for hypermobility that emphasizes gentle progression, body awareness, stability, breathing, and pain-informed exercise. It may be especially supportive for readers who want a calm, structured approach to building strength and confidence without overdoing it.

***Hypermobility Without Tears: Moving Pain-Free with Hypermobility and EDS* by Jeannie Di Bon**
A step-by-step movement guide for people with hypermobility and EDS, focused on reducing pain and improving body awareness. It may be especially encouraging for readers seeking gentle, practical exercises focused on breath, relaxation, stability, balance, and posture.

***Living Life to the Fullest with Ehlers-Danlos Syndrome* by Kevin Muldowney and Kathleen Muldowney**
A widely used physical therapy resource centered on the Muldowney exercise protocol for joint stabilization and safer exercise progression. It may be especially helpful for readers looking for a hands-on rehabilitation approach that feels structured, careful, and supportive.

— Personal Stories and Rare Condition Memoirs

***Life Hanging by a Thread: Marfan Syndrome* by Zachary T. Pothier and S. J. Theriault**
A personal introduction to Marfan syndrome that combines basic medical explanation with firsthand narrative. It may resonate with readers who want an accessible overview while also feeling seen in the emotional and family dimensions of the condition.

***Mo: A Loeys-Dietz Syndrome Memoir* by Kate H. Jurgens, RN, with forewords by Gretchen Oswald, MS, CGC, and Hal Dietz, MD**
A memoir of one family's journey to a Loeys-Dietz syndrome diagnosis, told through personal reflection and journal-style entries. It may be especially meaningful for readers looking for connection, understanding, and a lived picture of rare disease, complex care, and family resilience.

Additional Reading on Chronic Illness and Disability

This companion list gathers memoir, disability justice, body-based writing, and experimental or collective work that may offer language, perspective, and solidarity. Browse by category and return to the titles that feel most useful to you over time.

— Memoir, Essays, and Personal Reflection

These books foreground lived experience through memoir, essay, and reflective nonfiction. Together, they offer intimate, thoughtful writing on disability, illness, identity, and the texture of everyday life.

Being Seen **by Elsa Sjunneson**
A sharp, accessible memoir-in-essays about blindness, representation, and claiming visibility on one's own terms. It may be especially meaningful for readers looking for personal reflection that is clear-eyed, politically aware, and grounded in lived experience.

Body Friend **by Katherine Brabon**
A novel about chronic pain, friendship, and the intimate negotiations involved in living with an altered body. It may resonate with readers who want fiction that captures the emotional and relational textures of illness without losing subtlety or tenderness.

How to Tell When We Will Die **by Johanna Hedva**
An essay collection that moves between criticism and memoir to examine illness, art, interdependence, and survival. It may be especially compelling for readers who appreciate intellectually rich writing that still feels personal, urgent, and emotionally alive.

Ill Feelings **by Alice Hattrick**
A formally inventive meditation on illness, care, and maternal inheritance that blends memoir with critical reflection. It may be especially rewarding for readers interested in books that experiment with form while staying intimate and emotionally precise.

Some of Us Just Fall **by Polly Atkin**
A lyrical memoir that reflects on chronic illness, landscape, and the fragility of daily life. It may be especially comforting for readers drawn to quiet, reflective prose that honors vulnerability, place, and endurance.

— Disability Justice, Politics, and Social Critique

These books focus on disability justice, structural inequality, and the political dimensions of embodiment. Together, they offer frameworks for thinking about access, power, race, care, and collective resistance.

***Black Disability Politics* by Sami Schalk**
A rigorous study of Black disability politics that traces how race, disability, and activism intersect in U.S. social movements. It may be especially valuable for readers seeking a deeper framework for understanding disability through history, organizing, and structural analysis.

***Care Work: Dreaming Disability Justice* by Leah Lakshmi Piepzna-Samarasinha**
A foundational collection of essays on disability justice, collective care, and building liberatory access practices. It may be especially supportive for readers who want language for interdependence, community accountability, and imagining more livable futures.

***Crip Authorship: Disability as Method* edited by Mara Mills and Rebecca Sanchez**
An edited collection that explores disability not just as a topic but as a way of reading, writing, and producing knowledge. It may be especially useful for readers interested in scholarship, criticism, and experimental approaches to disability studies.

***Unlearning Ableism* by Jamie Shields and Celia Chartres-Aris**
An introductory guide that invites readers to identify ableist assumptions and imagine more accessible social worlds. It may be especially helpful for readers who want an approachable entry point into disability politics and cultural critique.

***White Supremacy Is All Around: Notes from a Black Disabled Woman in a White World* by Akilah Cadet**
A personal and political examination of racism, ableism, and institutional power from the perspective of a Black disabled woman. It may be especially meaningful for readers seeking writing that connects lived experience with systemic critique in direct, accessible language.

— Body, Illness, and Grief

These books center the body as a site of pain, change, grief, and meaning-making. They explore how illness and bodily experience shape perception, relationships, and language.

***A Bloody Scandal* by Evelyn Scott**
A forthcoming title that appears to engage menstruation, stigma, and the cultural politics of the body. It may be especially relevant for readers interested in how bodily experience becomes charged with shame, silence, and social meaning.

***The Body Is a Doorway* by Sophie Strand**
A hybrid work that approaches the body as porous and relational, linking illness, ecology, and spiritual imagination. It may be especially compelling for readers drawn to boundary-crossing writing that connects embodiment to the natural and more-than-human world.

***The Shape of the Pain* by Chris Thorpe and Rachel Bagshaw**
A collaborative work that investigates chronic pain through theatre, testimony, and experimental nonfiction. It may be especially interesting for readers who want language for pain that moves beyond conventional medical description.

***This Is Body Grief* by Jayne Mattingly**
A practical and reflective book that names the grief of bodily change and offers language for living through it. It may be especially supportive for readers who are adjusting to loss, altered capacity, or a changing relationship with their body.

— Experimental, Collective, and Anthology Work

These titles move beyond conventional forms through collaboration, experimentation, and hybrid writing. They may be especially meaningful for readers interested in collective voice, formal innovation, and disability writing as method.

***Disability Visibility: First-Person Stories from the Twenty-First Century* edited by Alice Wong**
A landmark anthology that brings together a wide range of disabled voices through essays, manifestos, testimonies, and personal narratives. It may be especially valuable for readers who want an expansive, multi-voiced introduction to contemporary disability culture and experience.

***The Future Is Disabled: Prophecies, Love Notes and Mourning Songs* by Leah Lakshmi Piepzna-Samarasinha**
A hybrid, movement-rooted collection that blends essay, manifesto, and intimate reflection to imagine disabled futures through collective care and political survival. It may be especially resonant for readers who appreciate writing that is visionary, intimate, and grounded in community struggle.

— Fiction

These titles offer imaginative, story-driven ways into disability, illness, and embodiment. They may be especially appealing for readers who want fiction that brings chronic illness and physical difference into fantasy, adventure, and emotionally rich narrative worlds.

***Get a Life, Chloe Brown* by Talia Hibbert**
A witty contemporary romance featuring a protagonist with chronic pain who sets out to rebuild her life on her own terms. It may be especially appealing to readers looking for warmth, humor, and disability representation woven into a character-driven love story.

***The Fourth Wing Series* by Rebecca Yarros**
A fast-paced fantasy series that follows Violet Sorrengail through a brutal dragon-rider war college while incorporating chronic pain, physical vulnerability, and adaptation into the story. It may be especially engaging for readers who want immersive speculative fiction with a disabled main character whose body is part of the narrative rather than written around it.

***One for All* by Lillie Lainoff**
A swashbuckling reimagining of The Three Musketeers featuring a heroine with POTS who navigates danger, ambition, and belonging. It may be especially meaningful for readers looking for adventurous fiction that pairs disability representation with momentum, courage, and found-family energy.

— Also Worth Exploring

Sick Magazine
A literary magazine featuring writing on illness, care, disability, and the complexities of embodied life. It may be especially appealing to readers who want shorter-form work alongside books.

Ache
A magazine devoted to feminist writing on illness, health, bodies, and pain. It may be especially meaningful for readers interested in contemporary essays and cultural commentary on embodiment.

Books for Children and Families

We hope this shareable book list offers a helpful starting point for children and families as they explore topics like hypermobility, disability, medical visits, body awareness, and how the human body works. To make it easier to browse, the books below are grouped by theme so you can quickly find the titles that best match a child's age, interests, and current needs.

Families may want to choose one or two books from each category depending on their child's age, interests, and current needs. Together, these titles can support understanding, reassurance, and positive conversations at home, in school, or during medical care.

— Condition-Specific Books

Bendy Wendy and the (Almost) Invisible Genetic Syndrome **by Brad T. Tinkle**
Especially helpful for older children or tweens who may be navigating an Ehlers-Danlos syndrome or joint hypermobility diagnosis. Recommended age: Tweens.

Dazzling Stripes: A Story About Ehlers-Danlos Syndrome **by Emma Yao Baker**
A simple, child-friendly story that helps explain Ehlers-Danlos syndrome in an accessible way.

HSD and Me: A Child's Story of Hypermobility Spectrum Disorder **by Sarah O'Driscoll and Jack O'Driscoll**
A gentle rhyming introduction for young children learning about a new diagnosis. Suitable for early conversations about HSD and what daily life can feel like. Recommended age: 3–7.

My Hypermobility **by Leah Pinnington**
A reassuring story about resilience, adaptation, and confidence for children living with hypermobility. Recommended age: 5–12.

— Disability, Difference, and Inclusion

Caramba **by Marie-Louise Gay**
A warm, whimsical picture book about feeling different, building self-acceptance, and discovering unique strengths in unexpected ways. Recommended age: 4–8.

Isis Learns that Being Different is Okay by LaQuisha Beckum and Arwa Salameh
A supportive story about self-acceptance, difference, and finding confidence. Recommended age: 0–6.

Rare Is Everywhere **by Deborah Katz**
A vibrant picture book that uses rare animals to help children celebrate differences, diversity, and self-acceptance in a positive, accessible way. Recommended age: 0–10.

Sprinkles and Superheroes **by Paige Kalik and Emily Amerson**
A family-centered story that may be especially meaningful for siblings learning alongside a child with medical or developmental needs. Recommended age: 8–10.

This Is Me **— Kids With Special Needs and Disabilities Series**
A simple book that can help open conversations about identity, disability, and feeling seen.

Why Me, Mama? **by Katherine Lockwood and Evgeniya Erokhina**
A warm, thoughtful picture book that encourages empathy, kindness, and understanding of disability differences.

— Doctor Visits, Hospitals, and Surgery Preparation

***Doctor Ninja* by Mary Nhin**
A playful introduction to doctor visits that can help reduce fear and build familiarity. Recommended age: 1–5.

***Magic Air: Ten Kid-Sized Steps to Surgery* by Alana Smith and Roksana Barwinska**
A clear, kid-friendly picture book that walks children through what to expect on surgery day, including anesthesia. Recommended age: 4–8.

***Ready Set Prep* — Series recommendation**
A series of toddler and child preparation books covering topics such as doctor visits, hospitals, and surgery in simple language.

— Body Awareness and Feelings

***Listening to My Body* by Gabi Garcia and Ying Hui Tan**
An excellent resource for helping children notice body sensations, connect them to feelings, and learn how to express what they need. Recommended age: 3–8.

***Surfing the Worry Imp's Wave* by Sharon Selby and Carl Lobos**
An engaging, child-friendly book that helps children understand anxiety and learn practical tools for managing worries using cognitive behavioral therapy and mindfulness concepts. Recommended age: 6–12.

— Human Body Learning Books and Activity Books

***Human Body Preschool Activity Book* by Kristie Wagner**
Great for preschoolers who learn best through mazes, coloring, and hands-on activities. Recommended age: 3–5.

***Human Body Activity Book for Kids* by Katie Stokes**
A strong choice for early-elementary learners seeking a playful introduction to how the body works. Recommended age: 5–7.

***Human Anatomy Activity Book for Kids* by Shannan Muskopf**
Best for older elementary children who are ready for more detailed anatomy activities and science-based learning. Recommended age: 8–12.

***Inside Your Outside! All About the Human Body* by Tish Rabe and Aristides Ruiz**
A classic, engaging overview of the human body for younger children. Recommended age: 4–8.

Voices to Follow

This list highlights people and organizations that share education, advocacy, support, and practical resources related to hypermobility, connective tissue disorders, and associated conditions. It is intended as a starting point for finding informed voices, helpful communities, and reputable sources of information.

— People

Lara Bloom (@lara.bloom)
Patient advocate, speaker, and educator focused on Ehlers-Danlos syndromes and related conditions.

Linda Bluestein, MD (@hypermobilitymd)
Clinician, coach, and podcast host focused on hypermobility and related conditions.

Jeannie Di Bon (@jeannie_di)
Movement therapist and educator focused on hypermobility, EDS, and chronic pain.

Dr. Irman Forghani (@dr_irman_genetics)
Clinical genetics, hereditary connective tissue disorders, vascular malformations

Clair Francomano, MD (@dr.clairfrancomano)
Clinician and researcher focused on EDS and connective tissue disorders.

Cortney Gensemer, PhD (@cortdoesscience)
Research scientist and science communicator focused on hEDS, HSD, and related conditions.

Betsy Grunch, MD (@ladyspinedoc)
Neurosurgeon and educator focused on the brain, spine, and body.

Jenna Justice, DPT (@thehypermobiledpt)
Physical therapist and educator focused on hypermobility care and coaching.

Samuel Kelokates, PT, DPT (@the.headache.pt)
Physical therapist focused on headache, neck pain, and related symptoms.

Melissa Koehl, DPT (@dr.melissakoehl.pt)
Physical therapist and Pilates instructor focused on hypermobility care and movement education.

Jesse Miller, MS, OTR/L (@conscious.connections.ot)
Occupational therapist focused on the mind-body connection and supportive care.

Liam J. Nelson (@liamjnelson)
Comedian and advocate living with Marfan syndrome.

Emily Rich, OT (@emilyrichot)
Occupational therapist, researcher, and educator focused on POTS, EDS, and related chronic conditions.

Sarah Cohen Solomon, MD (@thebendypediatrician)
Physician and educator focused on pediatric hypermobility and related conditions.

Sabrina Vaz (@therealsabrinavaz)
Coach, movement specialist, and certified somatic practitioner focused on Pilates, wellness, and supporting people with Ehlers-Danlos syndrome and related challenges.

Zachary Spiritos, MD, MPH (@drzacspiritos)
Physician focused on evidence-based gastrointestinal health and whole-person well-being.

Nicole Woodruff, OTD, OTR/L (@nicolepelvicot)
Occupational therapist focused on hypermobility, nervous system regulation, and pelvic health.

— Organizations

Annabelle's Challenge (@annabelleschallenge)
Organization focused on raising awareness of and support for vascular Ehlers-Danlos syndrome.

Chronic Illness Hotline (@chronicillnesshotline)
Support resource offering 24/7 text support for people living with chronic illness, pain, injury, and disability.

Collagen Advocacy Network (@collagenadvocacynetwork)
Advocacy and community resources focused on connective tissue disorders.

Connective Wellness Co (@connectivewellnessco)
Clinic offering in-person and virtual care for hypermobility and related conditions.

CTD Network Australia (@ctdnetworkaust)
Community resource focused on connective tissue disorders in Australia.

EDS Connective (@edsconnective)
Virtual health platform facilitating access to online hEDS and HSD diagnostic evaluation by independently licensed providers in all 50 states, no referral needed.

The Ehlers-Danlos Society (@ehlers.danlos)
Global organization providing education, advocacy, and resources for Ehlers-Danlos syndromes and hypermobility spectrum disorders.

Ehlers-Danlos UK (@ehlersdanlosuk)
Charity providing information, support, and advocacy for people with Ehlers-Danlos syndromes and hypermobility spectrum disorders.

Hypermobility Syndromes Association (@hmsacharity)
UK charity providing information, support, education, and advocacy for people with symptomatic hypermobility and related disorders.

Loeys-Dietz (@loeysdietz)
Advocacy and education resource focused on Loeys-Dietz syndrome.

Loeys-Dietz Canada (@loeysdietzcanada)
Advocacy and support resource focused on Loeys-Dietz syndrome in Canada.

The Marfan Foundation (@themarfanfoundation)
Nonprofit organization providing education, support, and advocacy for people with Marfan syndrome and related conditions.

Marfan Trust (@marfantrust)
Charity providing support and information for people affected by Marfan syndrome and related conditions.

Pain UK (@pain_uk)
Alliance of charities providing a voice for people in pain and signposting support across a wide range of painful conditions.

U.S. Pain Foundation (@us_pain_foundation)
Nonprofit organization providing education, advocacy, support, and practical resources for people living with chronic pain.

When Your Body Needs More Care

A Practical Guide to Hypermobility, Connective Tissue Disorders, and Creating a Life That Works

A diagnosis of hypermobility or a connective tissue disorder marks the beginning of a new way of navigating the world. Maggie Buckley offers a roadmap grounded in five core pillars of health—from managing chronic pain to building a coordinated care team—along with practical skills to steady the boat and reclaim a life defined by more than just healthcare.

"This is the Serenity Prayer in book form."

– **Dacre Knight, MD, MS, FACP**
Foreword & Medical Reviewer
Medical Director, EDS & Hypermobility Disorders Center, University of Virginia
Chief Medical Officer, The Ehlers-Danlos Society

AUTHOR

Maggie Buckley, MBA, BCPA
Board Certified Patient Advocate

PUBLISHED BY EDS CONNECTIVE

EDS Connective is a virtual health platform facilitating access to online hEDS and HSD diagnostic evaluation by independent physicians in all 50 states, no referral needed. Learn more at edsconnective.com.