

# What is Ehlers Danlos Syndrome?

*Individuals with EDS have a defect in their connective tissue, the tissue that provides support to many body parts such as the skin, muscles and ligaments. The fragile skin and unstable joints found in EDS are the result of faulty collagen. Collagen is a protein, which acts as a "glue" in the body, adding strength and elasticity to connective tissue*

## Signs & Symptoms

*Symptoms vary widely based on which type of EDS the patient has. In each case, however, the symptoms are ultimately due to faulty or reduced amounts of collagen. EDS typically affects the joints, skin, and blood vessels.*

Pain	Fatigue	Prolapse
Dislocations	Chiari	Preterm labor
Subluxations	Sprains	IBS
Hypermobility	Gastrointestinal issues	Dysautonomia
Osteoarthritis	Atrophic scarring	Flat feet
Osteoporosis	Muscle spasms	Swan neck deformity
Skin Tearing	Poor healing	Degenerative Joint Disease
Stretchy skin	TMJ	Gastritis
Soft skin	POTS	Arthralgia
Mitral Valve Prolapse	Organ rupture	Myalgia
Easy bruising	Aneurysms	Surgical complications

*FB you know you have EDS when*



# Ehlersdanlos Syndrome

**JE Gale**



## **Ehlersdanlos Syndrome:**

### **Ehlers-Danlos Syndrome: A Multidisciplinary Approach** J.W.G. Jacobs,L.J.M. Cornelissens,M.C.

Veenhuizen,2018-08-14 Generalized hypermobility has been known since ancient times and a clinical description of Ehlers Danlos syndrome EDS is said to have first been recorded by Hippocrates in 400 BC Hypermobility syndromes occur frequently but the wide spectrum of possible symptoms coupled with a relative lack of awareness and recognition are the reason that they are frequently not recognized or remain undiagnosed This book is an international multidisciplinary guide to hypermobility syndromes and EDS in particular It aims to create better awareness of hypermobility syndromes among health professionals including medical specialists and to be a guide to the management of such syndromes for patients and practitioners It is intended for use in daily clinical practice rather than as a reference book for research or the latest developments and has been written to be understandable for any healthcare worker or educated patient without compromise to the scientific content The book is organized as follows chapters on classifications and genetics are followed by chapters on individual types organ system manifestations and complications and finally ethics and therapeutic strategies with an appendix on surgery and the precautions which should attend it A special effort has been made to take account of the perspective of the patient two of the editors have EDS The book will be of interest to patients with hypermobility syndromes and their families as well as to all those healthcare practitioners who may encounter such syndromes in the course of their work *Understanding Hypermobile Ehlers-Danlos Syndrome & Hypermobility Spectrum Disorders* Claire Smith,2017

*The Mystery of Ehlers-Danlos Syndrome* Minnie H Lewis,2023-10-26 The Mystery Of Ehlers Danlos Syndrome A Comprehensive Guide for Patients Caregivers and Healthcare Professionals Ehlers Danlos syndrome EDS is a collection of genetic connective tissue illnesses that predominantly affect your skin joints and blood vessel walls People with EDS may experience a wide range of symptoms including joint hypermobility skin fragility chronic pain and fatigue This comprehensive guide provides everything you need to know about EDS from understanding the causes and diagnosis to managing symptoms and improving quality of life The book covers The different types of EDS and their clinical manifestations The latest research on EDS and its treatment Practical strategies for managing EDS on a day to day basis The emotional and psychological impact of living with EDS Resources and support networks for patients families and healthcare professionals Whether you are newly diagnosed with EDS or looking for ways to better manage your condition this book is an essential resource Learn how to navigate the healthcare system advocate for your needs and live a fulfilling life with EDS Who this book is for This book is intended for people living with hEDS and vEDS their caregivers and healthcare professionals It is written in a clear and concise style making it accessible to readers of all backgrounds Benefits of this book If you are living with EDS this book will provide you with the knowledge and tools you need to manage your condition effectively You will learn about the latest research on EDS as well as practical strategies for coping with symptoms and improving your quality of life If you are a

caregiver of someone with EDS this book will help you to better understand the condition and how to support your loved one You will also learn about resources and support networks that are available to help you and your family If you are a healthcare professional this book will provide you with a comprehensive overview of EDS its clinical manifestations and the latest treatment options You will also learn about ways to improve the lives of your patients with EDS Grab your copy today and start living your best life with EDS

### **Issues and Management of Joint Hypermobility**

Brad T. Tinkle,T. Tinkle Brad T. Tinkle,2008 Created as a comprehensive reference for those affected by joint hypermobility and health care providers this guide is written in everyday common sense terms so that joint hypermobility EDS and the medical issues surrounding it become more understandable The author Dr Brad T Tinkle is a leading expert in connective tissue disorders He developed this book as a primer to encourage dialogue between patients and their health care provider s in order to create an individualized treatment plan

### The Ehler Danlos Patient's Sourcebook Paul Kalman,Paul Kalman Ma,Johnson

White,2014-11-01 Ehlers Danlos Syndrome EDS affects the connective tissues the joint and skin problems are due to issues with collagen proteins that stabilize the connective tissue and give it elasticity Prior to 1997 there were 10 recognized types of EDS which were classified by Roman numerals e g EDS I II and III but this has now been simplified to six major types Each type has its own features For example the vascular type of Ehlers Danlos syndrome carries an increased risk of organ rupture including tearing of the aorta and rupture of the uterus womb during pregnancy All types have some effect on the joints Symptoms may first show up during the childhood years although some newborns with certain subtypes are diagnosed with EDS If symptoms are mild the disorder may not be diagnosed until the adult years This informative and concise book guides you through the causes tests and treatment options for EDS

### Symptomatic Clair A. Francomano,Alan J. Hakim,Lansdale

G.S. Henderson,Fraser C. Henderson Sr.,2023-12-05 Symptomatic The Symptom Based Handbook for Ehlers Danlos Syndromes and Hypermobility Spectrum Disorders offers a novel approach structured around the panoply of 75 symptoms with which a person with Ehlers Danlos syndromes EDS and hypermobility spectrum disorders HSD may present to a clinician The content is arranged intuitively from head to feet with each chapter integrating clinical case studies with a concise discussion and two important diagnostic tools a simplified algorithm for diagnosing and treating each symptom and differential diagnoses and alternative explanations for their symptoms This is a handbook that combines the expertise of some 70 leading clinicians representing more than 30 specialties This book is suited for clinicians who need a concise and straight forward presentation of the various and complex symptoms they confront in their clinical practice It brings forth a field of knowledge emerging from interdisciplinary collaboration despite the pressures of specialization that bridges gaps in understanding between the several dozen disciplines implicated in EDS and HSD A comprehensive compendium of the symptoms of EDS and HSD to aid clinicians and patients Symptom based chapters for ease of making a diagnosis A case report differential diagnosis discussion and diagnostic and treatment algorithm for each symptom

### **Our Stories of**

**Strength** Kendra Neilsen Myles, Mysti Reutlinger, 2015-05 An inspirational collection of stories filled with devastation heartbreak triumph and strength as written by those affected by different types of Ehlers Danlos Syndromes These are stories of hope and resilience of strength under adversity of self reliance and new found sources of support They offer one core message to all who suffer from the diverse and difficult manifestations of EDS You are not alone Dr Clair Francomano MD Ehlers Danlos Syndrome is another form of the human body Just as there are tall people short people dark skin colored people and light skin colored people each with their own set of medical issues similarly there are hypermobile people and not so hypermobile people who have different medical issues Our understanding of EDS has improved but we still have a lot of work to do While the medical world works on understanding Ehlers Danlos Syndrome people with EDS have provided us with stories of courage and ingenuity These stories give others and doctors the strength to find solutions PRADEEP CHOPRA MD As a physical therapist who works with many patients suffering from EDS I've seen firsthand how isolating and frustrating EDS can be Along with a more knowledgeable medical field what these patients need most is an understanding that they are not alone and to be given hope Our Stories of Strength provides both community and hope and will be just as effective as any medication or exercise CHRISTOPHER GNIP PT DPT EDS is a group of heritable connective tissue disorders that can cause a wide variety of symptoms throughout different body systems each unique in presentation to the individual The variety of symptoms and presentations proves challenging to the medical community in diagnosing and treating patients many of whom are misdiagnosed and suffer as a result EDS has been commonly viewed as just Benign Joint Hypermobility Syndrome BJHS JHS or Hypermobility Syndrome HMS Based upon recent research the prevalence of EDS exceeds current estimates Kendra Neilsen Myles and Mysti Reutlinger founded Our SOS Media LLC with core values of giving back to non profit organizations creating jobs for people living with invisible and chronic illnesses and providing an outlet to those willing to share their stories through submissions in the Our Stories of Strength anthology series Our SOS Media LLC recognizes that it is through opening doors to needed conversations and sharing stories of strength determination and perseverance that we are able to facilitate positive changes to the way we live and help shape perceptions of those around us as well as in the medical community We are stronger together

**Our Stories of Strength** Kendra Neilsen Myles, 2016-10-20 3rd edition 6x9 black and white paperback version

**The Ehlers-Danlos Syndrome** Peter Beighton, 1970 Ehlers Danlos Syndrome

**Joint Hypermobility Handbook** Brad T. Tinkle, 2010 As a followup to his previous best selling book Issues and Management of Joint Hypermobility A Guide for the Ehlers Danlos Syndrome Hypermobility Type and the Hypermobility Syndrome Dr Tinkle has created this handbook with several contributors to expand insights into the understanding and management of Ehlers Danlos Syndrome Hypermobility Type and the Hypermobility Syndrome Dr Tinkle has received many accolades for his ability to take a complex condition and make it understandable in everyday language provides a wealth of information about the natural history and physical and medical management It should be of great value to patients The American Journal of Medical

Genetics Reader comments a useful tool in helping me obtain the type of care I need to manage my disorder This book is simple but not oversimplified It is an excellent basic resource giving a clear concise and useful overview for those like myself who live with hypermobility Super book for EDS Finally a book that everyone can understand thoroughly explores the problems associated with EDS HM It is a relief to realize that it is not just me a tremendous service for the health care community and the families and friends of those diagnosed or not yet formally diagnosed folks with EDS HM joy and clarity in reading the very easy to read text chapters detailing out the impact of EDS HM In addition to the wealth of positive reviews Dr Tinkle s previous book on the same subject was a best seller in several categories Genetics Medical Genetics Orthopedics Family and General Practice Brad T Tinkle M D Ph D is a clinical and clinical molecular geneticist at Cincinnati Children s Hospital Medical Center CCHMC He specializes in caring for individuals with heritable connective tissue disorders such as Ehlers Danlos syndromes Marfan syndrome osteogenesis imperfecta and achondroplasia among the many *Molecular Genetics and Pathogenesis of Ehlers-Danlos Syndrome and Related Connective Tissue Disorders* Marina Colombi ,Marco Ritelli,2020-12-14 Ehlers Danlos syndromes EDS are a group of heritable connective tissue disorders HCTDs characterized by a variable degree of skin hyperextensibility joint hypermobility and tissue fragility The current EDS classification distinguishes 13 subtypes and 19 different causal genes mainly involved in collagen and extracellular matrix synthesis and maintenance EDS need to be differentiated from other HCTDs with a variable clinical overlap including Marfan syndrome and related disorders some types of skeletal dysplasia and cutis laxa The clinical recognition of EDS is not always straightforward and for a definite diagnosis molecular testing can be of great assistance especially in patients with an uncertain phenotype Currently the major challenging task in EDS is to unravel the molecular basis of the hypermobile EDS that is the most frequent form and for which the diagnosis is only clinical in the absence of any definite laboratory test This EDS subtype as well as other EDS reminiscent phenotypes are currently investigated worldwide to unravel the primary genetic defect and related pathomechanisms The research articles case report and reviews published in the Special Issue entitled Molecular Genetics and Pathogenesis of Ehlers Danlos Syndrome and Related Connective Tissue Disorders focus on different clinical genetic and molecular aspects of several EDS subtypes and some related disorders offering novel findings and future research and nosological perspectives **Joint Hypermobility Syndrome (Ehlers-Danlos)** Christopher J. Maloney,Dr Christopher J Maloney Nd,2015-05-27 For patients with chronic pain and those who love them an exploration of the causes and treatments available for those with hypermobility Originally published as Dr Maloney s medical notes for patients the book has been entirely rewritten with a focus on an easy read Dr Maloney has also added more research including a possible treatment that could resolve the chronic pain of joint hypermobility If you have been told that your pain is simply due to genetics find out why this cannot be the case **Disjointed** Diana Jovin,2020-03-31 Disjointed is for patients with hEDS HSD and the physicians who treat them hEDS HSD is an underrecognized complex multisystemic

disorder with the silos of healthcare specialties often working against effective and efficient treatment With 21 specialist 6 resource chapters Disjointed brings together physician patient and parent perspectives to support the goal of earlier and more complete intervention Ehlers-Danlos Syndrome: New Insights for the Healthcare Professional: 2013 Edition ,2013-07-22 Ehlers Danlos Syndrome New Insights for the Healthcare Professional 2013 Edition is a ScholarlyPaper that delivers timely authoritative and intensively focused information about Additional Research in a compact format The editors have built Ehlers Danlos Syndrome New Insights for the Healthcare Professional 2013 Edition on the vast information databases of ScholarlyNews You can expect the information about Additional Research in this book to be deeper than what you can access anywhere else as well as consistently reliable authoritative informed and relevant The content of Ehlers Danlos Syndrome New Insights for the Healthcare Professional 2013 Edition has been produced by the world s leading scientists engineers analysts research institutions and companies All of the content is from peer reviewed sources and all of it is written assembled and edited by the editors at ScholarlyEditions and available exclusively from us You now have a source you can cite with authority confidence and credibility More information is available at <http://www.ScholarlyEditions.com>

*Molecular Genetics and Pathogenesis of Ehlers-Danlos Syndrome and Related Connective Tissue Disorders* Marina Colombi,Marco Ritelli,2020 Ehlers Danlos syndromes EDS are a group of heritable connective tissue disorders HCTDs characterized by a variable degree of skin hyperextensibility joint hypermobility and tissue fragility The current EDS classification distinguishes 13 subtypes and 19 different causal genes mainly involved in collagen and extracellular matrix synthesis and maintenance EDS need to be differentiated from other HCTDs with a variable clinical overlap including Marfan syndrome and related disorders some types of skeletal dysplasia and cutis laxa The clinical recognition of EDS is not always straightforward and for a definite diagnosis molecular testing can be of great assistance especially in patients with an uncertain phenotype Currently the major challenging task in EDS is to unravel the molecular basis of the hypermobile EDS that is the most frequent form and for which the diagnosis is only clinical in the absence of any definite laboratory test This EDS subtype as well as other EDS reminiscent phenotypes are currently investigated worldwide to unravel the primary genetic defect and related pathomechanisms The research articles case report and reviews published in the Special Issue entitled Molecular Genetics and Pathogenesis of Ehlers Danlos Syndrome and Related Connective Tissue Disorders focus on different clinical genetic and molecular aspects of several EDS subtypes and some related disorders offering novel findings and future research and nosological perspectives Ehlers-Danlos Syndrome: New Insights for the Healthcare Professional: 2011 Edition ,2012-01-09 Ehlers Danlos Syndrome New Insights for the Healthcare Professional 2011 Edition is a ScholarlyPaper that delivers timely authoritative and intensively focused information about Ehlers Danlos Syndrome in a compact format The editors have built Ehlers Danlos Syndrome New Insights for the Healthcare Professional 2011 Edition on the vast information databases of ScholarlyNews You can expect the information about Ehlers Danlos Syndrome in this eBook

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[Ehlers-Danlos/Hypermobility Syndromes and Other Connective Tissue Disorders](#) Nicholas L. DePace,Stephen Soloway,Michael Yayac,Joe Colombo,2025-09-26 This book covers Ehlers Danlos and hypermobility syndromes with an emphasis on treatment of the parasympathetic and sympathetic P S nervous system dysfunctions Unfortunately most EDS HSD patients have been misdiagnosed and misunderstood by providers EDS HSD is a multisystem multifaceted disorder that is poorly understood The P S manifestations and treatments are also poorly understood throughout the healthcare community To this end the authors wish to teach providers and patients alike to reduce the life long suffering from both the disorder and the marginalization There are two aspects of teaching that are required and provided by this book improved understanding of EDS HSD and improved understanding of P S autonomic dysfunction and treatment For example with the autonomic nervous system more treatment or therapy is never better Relief of P S dysfunction must be low and slow to prevent causing more symptoms from higher doses of medication or polypharmacy To this end stress often sets patients back and both providers and patients alike must have proper expectations set for successfully improving patient outcomes quality of life and productivity The book starts with an introduction to and history of the disorder Chapter II provides a review of the genetics of collagen the source of the disorders Chapters III through IX detail the various forms of EDS HSD and goes into more detail on the more common and more well known variants of EDS HSD Chapter X discusses structural cardiovascular and pulmonary dysfunction associated with EDS HSD Chapter XI discusses structural gastrointestinal and urogenital dysfunction



associated with EDS HSD The book ends with Chapter XII which details the involvement of the P S nervous systems and how to treat which also has general application to other chronic disorders This is an ideal guide for rheumatologists and primary care physicians treating patients with Ehlers Danlos and hypermobility syndromes and patients and their loved ones in understanding their disease and disorders and the associated treatments and therapies

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