"The Invisible Illness: A Guide to Ehlers-Danlos Syndrome"



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Do you feel like your medical issues are often dismissed or misunderstood by doctors and loved ones? Do you struggle with chronic pain, fatigue, and issues with your joints and skin? You may have Ehlers-Danlos Syndrome (EDS), a complex and often misdiagnosed genetic disorder.

In "The Invisible Illness," author Dr. Alvin Philipose bring much-needed awareness and understanding to this often-overlooked condition. Through medical information, he offers guidance and support for those living with EDS, as well as their families and caregivers.

From diagnosis and treatment options to navigating daily life with EDS, this book is a must-read for anyone affected by this condition. With compassion and expertise, "The Invisible Illness" provides the information and resources needed to live a full and fulfilling life with EDS.

Table of Contents

[CHAPTER 1: INTRODUCTION TO EHLERS DANLOS SYNDROME 3](#_Toc124366043)

[SUBTYPES OF EDS AND THEIR SYMPTOMS 4](#_Toc124366044)

[DISCUSSION OF THE PREVALENCE OF EHLER'S-DANLOS SYNDROME AND THE CHALLENGES OF DIAGNOSIS 6](#_Toc124366045)

[CHAPTER 2: THE HISTORY OF EHLER'S DANLOS SYNDROME 7](#_Toc124366046)

[BRIEF HISTORY OF EHLER'S-DANLOS SYNDROME 7](#_Toc124366047)

[DISCUSSION OF THE STIGMA AND MISINFORMATION SURROUNDING EHLER'S-DANLOS SYNDROME IN THE PAST AND PRESENT 8](#_Toc124366048)

[CHAPTER 3: LIVING WITH EHLER'S DANLOS SYNDROME 12](#_Toc124366049)

[DAILY CHALLENGES AND STRUGGLES FACED BY INDIVIDUALS WITH EHLER'S-DANLOS SYNDROME 12](#_Toc124366050)

[THE IMPORTANCE OF SELF-CARE AND FINDING A SUPPORTIVE NETWORK OF HEALTHCARE PROFESSIONALS AND LOVED ONES 13](#_Toc124366051)

[TIPS AND STRATEGIES FOR MANAGING EHLER'S-DANLOS SYNDROME ON A DAILY BASIS 14](#_Toc124366052)

[CHAPTER 4: TREATMENT OPTIONS FOR EHLER'S DANLOS SYNDROME 15](#_Toc124366053)

[TREATMENT OPTIONS AVAILABLE FOR EHLER'S-DANLOS SYNDROME 15](#_Toc124366054)

[THE PROS AND CONS OF EACH TREATMENT OPTION AND THE IMPORTANCE OF FINDING THE RIGHT TREATMENT PLAN FOR EACH INDIVIDUAL 17](#_Toc124366055)

[TIPS FOR NAVIGATING THE HEALTHCARE SYSTEM AND ADVOCATING FOR ONESELF 18](#_Toc124366056)

[CHAPTER 5: COPING WITH THE EMOTIONAL IMPACT OF EHLER'S DANLOS SYNDROME 19](#_Toc124366057)

[EMOTIONAL CHALLENGES OF LIVING WITH A CHRONIC CONDITION 19](#_Toc124366058)

[STRATEGIES FOR COPING WITH THESE EMOTIONS, INCLUDING THERAPY, SUPPORT GROUPS, AND SELF-CARE PRACTICES 19](#_Toc124366059)

[CHAPTER 6: THE FUTURE OF EHLER'S DANLOS SYNDROME 21](#_Toc124366060)

[CURRENT RESEARCH ON EHLER'S-DANLOS SYNDROME AND POTENTIAL DEVELOPMENTS IN TREATMENT AND MANAGEMENT 21](#_Toc124366061)

[THE IMPORTANCE OF PATIENT ADVOCACY AND RAISING AWARENESS ABOUT EHLER'S-DANLOS SYNDROME 22](#_Toc124366062)

[FINAL THOUGHTS ON LIVING WITH EHLER'S-DANLOS SYNDROME AND THE HOPE FOR A BETTER FUTURE FOR THOSE AFFECTED BY THE CONDITION. 23](#_Toc124366063)

[MY CLINICAL EXPERIENCE WITH EULER’S DANLOS SYNDROME 24](#_Toc124366064)

# CHAPTER 1: INTRODUCTION TO EHLERS DANLOS SYNDROME

Ehlers Danlos Syndrome is a rare ailment in which there is an issue with the body's ability to synthesize collagen. This condition is also known as "Cutis hyperelastica." This hereditary issue cannot be remedied with a quick fix or a magic elixir since the severity of the condition can range from being completely harmless to being extremely deadly. The term "cutis hyperelastica" can be understood in a variety of ways, the most fundamental of which relates to an abnormally high degree of hypermobility. This disorder is defined by joints that are able to bend in both directions, which results in the continual dislocation of those joints due to a shortage in muscles and collagen. This condition is characterized by joints that are able to bend in both directions. When the statistics are taken into consideration, one in every ten thousand to fifteen thousand persons have some sort of hyper mobility.

Ehlers-Danlos syndrome can be broken down into a number of different subtypes, each of which is distinguished from the others by its own distinct collection of symptoms and outward manifestations. Ehlers-Danlos syndrome is characterized by a group of symptoms that include hypermobility (extreme flexibility) of the joints, skin that is prone to bruising or that tears easily, and scars that are thick, broad, or elevated. This syndrome affects approximately 1 in 3,000 people in the United States. These signs and symptoms are some of the more common ones. There is also a possibility that you will experience persistent pain, muscle weakness, and a delay in the healing of wounds if you have this condition.

Ehlers-Danlos syndrome is often described to as a genetic ailment, which means that it is caused by abnormalities or mutations in genes that are passed down from parents to offspring. This condition affects around 1 in every 6,000 people in the United States. The genes that have been linked to Ehlers-Danlos syndrome are responsible for the production of the proteins that are required for the correct function and structure of connective tissues. This condition is distinguished by a propensity to the development of brittle connective tissue, which serves as one of its defining characteristics. When these genes are altered, the proteins that they generate might not function appropriately, which is what causes the symptoms of Ehlers-Danlos syndrome. On the other hand, recent hypotheses suggest that a number of autoimmune disorders, such as lupus and lyme disease, together with other ailments that are characterized by a high level of inflammation, might be responsible for the syndrome. These conditions include:

Because there is presently no known cure for Ehlers-Danlos syndrome, the major focus of treatment for patients diagnosed with the disorder is typically directed on the management of their symptoms. The first phase in this process may involve undergoing physical therapy, taking medication to treat pain and possibly other symptoms, and possibly undergoing surgical repair of joint instability or other irregularities. It is absolutely necessary for people who have been given a diagnosis of Ehlers-Danlos syndrome to keep an open line of communication with the members of their healthcare team in order to develop a treatment strategy that may be tailored to fit their specific requirements.

## SUBTYPES OF EDS AND THEIR SYMPTOMS

Ehlers-Danlos syndrome, often known as Ehler's-danlos syndrome, refers to a set of hereditary illnesses that impact the body's connective tissues. Connective tissues give the skin, bones, blood vessels, and other organs the support and structure they need to function properly. Collagen is a protein that plays an important role in the formation of connective tissue. Individuals who suffer from Ehlers-Danlos syndrome have anomalies in the production, structure, or function of collagen.

There are thirteen distinct subtypes of Ehlers-Danlos syndrome, each of which is characterized by a unique collection of signs and symptoms.

Ehlers-Danlos syndrome, often known as Ehler's-danlos syndrome, is a set of hereditary illnesses that damage the connective tissues in the body. The following are 13 subtypes of Ehlers-Danlos syndrome. The exact symptoms and traits that are present in each individual are used to classify each person into one of the subtypes. The Ehlers-Danlos syndrome has a total of 13 different subgroups, which are listed below:

1. Classical Ehler's-danlos syndrome (cEhler's-danlos syndrome): This subtype of Ehler's-danlos syndrome is distinguished by hypermobility (excessive joint movement), skin that is delicate and prone to bruising, and scarring that is extensive and thick. This kind of Ehlers-Danlos syndrome is the most prevalent variety, and it is characterized by hypermobility of the joints, skin that is prone to bruising, and scars that are thin and prone to expanding.
2. Hypermobility Ehler's-danlos syndrome (hEhler's-danlos syndrome): This subtype of Ehler's-danlos syndrome is comparable to the classic form of the condition, although its symptoms are milder. People who have hEhler's-danlos syndrome exhibit hypermobility as well as skin that is fragile and readily bruised. However, they do not have the scarring or small head and facial features that are characteristic of people who have cEhler's-danlos syndrome.
3. Vascular Ehler's-danlos syndrome (vEhler's-danlos syndrome): This subtype of Ehler's-danlos syndrome (also known as vEhler's-danlos syndrome) is characterized by highly fragile skin and blood vessels that are prone to rupture. People who have vEhler's-danlos syndrome have skin that is fragile and translucent, and they have a higher risk for life-threatening consequences such artery and organ ruptures.
4. Kyphoscoliosis Ehler's-danlos syndrome (kEhler's-danlos syndrome): This subtype of Ehler's-danlos syndrome is characterized by hypermobility, skin that is soft and readily bruised, and significant curvature of the spine (kyphoscoliosis). People who have Ehlers-Danlos syndrome may have a small head in proportion to the rest of their body, as well as facial features that are more delicate and more likely to dislocate or subluxate.
5. Arthrochalasia Ehlers-Danlos syndrome (aEhlers-Danlos syndrome): This subtype of Ehlers-Danlos syndrome is distinguished by hypermobility, skin that is delicate and prone to bruising, and a hip dislocation that is congenital, or present at birth. People who have Ehlers-Danlos syndrome may have a small head in proportion to the rest of their body, as well as facial features that are more delicate and more likely to dislocate or subluxate.
6. Dermatosparaxis Ehlers-Danlos syndrome (dEhlers-Danlos syndrome): This subtype of Ehlers-Danlos disease is distinguished by skin that is exceedingly delicate and prone to ripping and scarring. People who have dEhler's-danlos syndrome have a characteristic facial look, characterized by large ears that hang loosely and a chin that is thin and pointed.
7. Cardiac-valvular Ehler's-danlos syndrome (cvEhler's-danlos syndrome): This subtype of Ehler's-danlos syndrome is distinguished by abnormalities of the heart valves and other cardiac structures, which can result in a variety of heart-related complications.
8. Spondylodysplastic Ehler's-danlos syndrome (also known as spEhler's-danlos syndrome) is a subtype of Ehler's-danlos syndrome that is distinguished by small stature, aberrant bone growth, and hypermobility. People who have Ehlers-Danlos syndrome may have a tiny head in proportion to the rest of their body, as well as facial features that are more likely to become dislocated or subluxated.
9. Musculocontractural This particular form of Ehlers-Danlos syndrome, also known as mcEhlers-Danlos syndrome, is characterized by hypermobility, skin that is delicate and prone to bruising, and contractures (permanent shortening of muscles or tendons around a joint). People who have McEhler's-Danlos syndrome may have a tiny head in proportion to the rest of their body, as well as facial traits, and they may be more likely to experience dislocations and subluxations.
10. Myopathic Ehler's-danlos syndrome (mEhler's-danlos syndrome): This subtype of Ehler's-danlos syndrome is identified by hypermobility and a lack of muscle strength. People who have MEhler's Danlos syndrome may have a small head in proportion to the rest of their body, as well as facial features, and they may be more prone to dislocations and subluxations.
11. Periodontal Ehler's-danlos syndrome (pEhler's-danlos syndrome): This subtype of Ehler's-danlos syndrome is distinguished by abnormalities of the teeth as well as gum disease.
12. Brittle Cornea Syndrome (BCS): This subtype of keratoconus is distinguished by corneas (the clear outer layer of the eye) that are abnormally thin, fragile, and prone to rupture. In addition to hypermobility, those who have BCS may also have skin that is readily bruised.
13. Ehlers-Danlos syndrome with Progressive Dystonia (Ehlers-Danlos syndrome-DT): This subtype of Ehlers-Danlos disease is distinguished by gradually worsening muscle spasms and poor posture.

It is essential to keep in mind that the characteristics of different subtypes might overlap, and that some people may exhibit characteristics of more than one subtype. It is also essential to keep in mind that Ehler's-danlos syndrome is an uncommon disorder, and it is possible that many people who have Ehler's-danlos syndrome may not have a particular subtype of the condition.

## DISCUSSION OF THE PREVALENCE OF EHLER'S-DANLOS SYNDROME AND THE CHALLENGES OF DIAGNOSIS

Although the exact prevalence of Ehlers-Danlos syndrome is unknown, it is estimated that between 1 in 5,000 and 1 in 20,000 persons around the world are affected by the condition.

The symptoms of Ehlers-Danlos syndrome can vary greatly from person to person, which can make diagnosis difficult. Additionally, there are multiple distinct kinds of Ehlers-Danlos syndrome, which further complicates matters. While some people may have very modest symptoms that aren't noticed by a doctor for a number of years, other people may have severe symptoms that are immediately noticeable. Additionally, many of the symptoms of Ehler's-danlos syndrome might be similar to those of other disorders, which can make it difficult to effectively diagnose Ehler's-danlos syndrome. This is because Ehler's-danlos syndrome is a connective tissue disorder.

At this time, thirteen distinct subtypes of Ehlers-Danlos syndrome have been identified, each of which has its own unique set of diagnostic criteria. It is common practice to base a diagnosis of Ehlers-Danlos syndrome on a combination of the patient's medical history, the results of a physical examination, and genetic testing. In order to acquire an accurate diagnosis and the right therapy for Ehlers-Danlos syndrome, it is essential to consult with a healthcare provider who has experience in diagnosing and managing cases of Ehlers-Danlos syndrome.

The hypermobile variant of Ehlers-Danlos syndrome is characterized by an abnormally broad range of joint movement (also known as hypermobility), which is seen in the majority of Ehlers-Danlos syndrome cases. Infants and children who have hypermobility frequently have low muscle tone, which is referred to as hypotonia. Hypotonia can slow down the development of motor abilities such as sitting, standing, and walking. The lax joints are prone to dislocation, which can result in persistent discomfort and instability. Infants born with the Ehlers-Danlos syndrome subtype known as arthrochalasia exhibit hypermobility and dislocations of both hips at the time of delivery.

Many persons who have Ehlers-Danlos syndromes have skin that is extremely delicate and stretchable (elastic), in addition to having a velvety, soft texture. Those who are affected have a greater propensity to bruise quickly, and certain varieties of the disorder are also associated with aberrant scarring. Wounds that are caused by the traditional type of Ehlers-Danlos syndrome tend to split open with very little blood loss and leave scars that gradually become wider over the course of the affected individual's lifetime.

Issues with bleeding are quite prevalent in those who have the vascular variant of Ehlers-Danlos syndrome. These problems are brought on by the unpredictable ripping (rupture) of organs and blood vessels. These issues can lead to a heightened risk of bruising easily, internal bleeding, a hole in the wall of the intestine (also known as intestinal perforation), as well as a stroke. Women who have vascular Ehlers-Danlos syndrome have an increased risk of having their uterus rupture when they are pregnant. The kyphoscoliotic, classical, and classical-like varieties of Ehlers-Danlos syndrome are further types of the condition that entail rupture of the blood vessels.

Additional indications and symptoms can be associated with the various kinds of Ehlers-Danlos syndrome. The cardiac-valvular type results in serious issues with the valves that regulate the flow of blood through the heart.

# CHAPTER 2: THE HISTORY OF EHLER'S DANLOS SYNDROME

## BRIEF HISTORY OF EHLER'S-DANLOS SYNDROME

In 1892, a Russian dermatologist with the surname Tschernogubow was the first to publish a paper about the condition that would later be known as Ehlers-Danlos syndrome. However, its circulation in the rest of the medical world was limited, most likely as a result of the fact that the paper was published in Russian.

Dr. Lauritz-Edvard Ehlers of Denmark presented his findings at a conference in 1901, nine years after he had initially made them. In the year 1908, a French dermatologist named Henri-Alexandre Danlos identified a disorder that was very similar to this one and referred to it as "hypermobility of joints." The ailment wasn't given its current name, Ehlers-Danlos syndrome, until the 1950s, long after it had already been identified as a separate disorder.

The fundamental concept that was developed by doctors Ehlers and Danlos is still relevant today: those who are affected struggle with hyperflexibility in addition to having skin that is unusually delicate and stretchy. However, thanks to advances in research, medical professionals are now aware that Ehlers-Danlos syndrome can take a wide variety of different forms and subtypes.

In addition, research has demonstrated that joint hypermobility is not the only factor involved; there are other, less evident concerns as well. Among these include issues with the digestive system and persistent pain. As research moves forward, the number of different types and subtypes of the illness, as well as the genetic markers that have been discovered, continue to expand. This is because researchers are still working to untangle the biology and genetic complexity of the syndrome.

Ehlers-Danlos syndrome can be diagnosed using any one of a number of different classification schemes that have been established over the years. Based on the symptoms and physical characteristics of the illness, the original categorization system for Ehler's-danlos syndrome, which was developed in the 1970s, defined six subtypes of Ehler's-danlos syndrome. 1997 saw the development of a revised classification system that acknowledged a total of 13 distinct subgroups of Ehlers-Danlos syndrome.

In 2017, the International Classification of Ehlers-Danlos Syndromes (ICEhler's-danlos syndrome) was published. This classification system recognized 13 subtypes of Ehler's-Danlos syndrome and offered updated diagnostic criteria for each of those subtypes. The ICEhler's-danlos syndrome is now the categorization system for Ehler's-danlos syndrome that is most widely accepted, and it is used by medical professionals all across the world to diagnose and manage the disorder.

In spite of the progress that has been made in comprehending and diagnosing Ehlers-Danlos syndrome, the disorder is still not generally known by the general population and can be challenging to identify. It is common for persons who have Ehlers-Danlos syndrome to either not be diagnosed with the disorder or to be given a diagnosis that is for another ailment instead. This can cause therapy delays and improper management of the condition.

## DISCUSSION OF THE STIGMA AND MISINFORMATION SURROUNDING EHLER'S-DANLOS SYNDROME IN THE PAST AND PRESENT

Both in the past and in the present, Ehlers-Danlos syndrome has been the subject of a considerable amount of negative connotation and inaccurate information. This is most likely attributable to the lack of awareness and understanding of these conditions, as well as the difficulties in appropriately identifying Ehlers-Danlos syndrome.

The misconception that people with Ehlers-Danlos syndrome are trying to draw attention to themselves or are exaggerating the severity of their symptoms is a significant contributor to the stigma and false information that surround this condition. Because many people who have Ehlers-Danlos syndrome do not have any visible physical abnormalities, the symptoms can be easily overlooked or misattributed to other conditions. This belief is often fueled by the fact that many people who have Ehlers-Danlos syndrome do not have any visible physical abnormalities.

In addition, there has been a lack of acknowledgement and comprehension of the impact that Ehlers-Danlos syndrome has on both the day-to-day lives of an individual and their overall health. As a result of a lack of information and comprehension on the part of healthcare providers, many persons who have Ehlers-Danlos syndrome have experienced difficulties in obtaining proper diagnoses and the appropriate treatment for their condition.

It is essential to understand that Ehlers-Danlos syndrome is a severe genetic condition that can have a considerable impact, both physically and mentally, on affected individuals as well as on their families. It is essential to educate people about Ehlers-Danlos syndrome and endeavor to eliminate the stigma and misunderstandings that surround the various conditions that fall under this category.

Many people, including those working in the medical field, are still unaware of the Ehlers-Danlos syndromes (EDS) and the hypermobility spectrum disorders (HSD), as well as the myriad of intricate ways in which these ailments can influence the lives of affected individuals.

Many years may pass before anyone makes the connection between the difficulties found in EDS and HSD. Many people have reported being told that their symptoms are "all in their head," or that they cannot possibly be experiencing the pain or other symptoms that they say they are, or that they are attention-seeking or drug-seeking. Others have reported being told that they cannot possibly be experiencing the pain or other symptoms that they say they are. Imaging and laboratory testing frequently produce normal results. It is not uncommon to receive an incorrect diagnosis, which might delay treatment or lead to unnecessary operations or therapies that are not appropriate.

Myth #1: The Ehlers-Danlos syndromes are ‘just stretchy skin.’

Reality: The Ehlers-Danlos syndromes are a collection of inherited conditions that affect the connective tissue in the body. Connective tissue can be located anywhere in the body, including the skin, the muscles, the tendons and ligaments, the blood vessels, the organs, the gums, the eyes, etc.

They are typically characterized by joint hypermobility (joints that move further than normal range), joint instability (subluxation, a partial separation of the articulating surfaces of a joint; and dislocations, a full separation of the surfaces of a joint), scoliosis and other joint deformities, skin hyperextensibility (skin that can be stretched further than normal) and abnormal scarring, and other structural weaknesses such as hernias and organ prolapse through the There is also a weakness of specific tissues that can lead to major gum and dental disease, eye disease, cardiac valve and aortic root disorders, and life-threatening abdominal organ, uterine, or blood vessel rupture in some of the rarer types of EDS. For example, major gum and dental disease can lead to major eye disease.

People who have EDS are more likely to have co-occurring disorders than the general population. Comorbid conditions, often known as linked symptoms and conditions, are another name for them. These factors add an additional layer of complication to the presentation of their ailment as well as the management of it. Disorders such as functional bowel disorders, autonomic dysfunction, chronic fatigue, neurological concerns such as cord and nerve entrapment and sensory neuropathy, immune hypersensitivity, anxiety disorders, depression, and neurodevelopmental concerns such as autism spectrum disorder and attention deficit hyperactivity disorder are examples of such related disorders.

Myth #2: EDS and HSD is ‘just being a bit bendy.’

Reality: People with EDS and HSD suffer from much more than "just" hypermobility; they also experience joint instability (subluxations and/or dislocations), reduced position sense (proprioception), and an increased risk of injury to the tissues around joints and the surface of joints. This is in addition to the hypermobility that is characteristic of both conditions.

Asymptomatic joint hypermobility is a type of joint hypermobility that does not cause any pain or other symptoms and does not require treatment. The issue arises when joints are not only hypermobile but also unstable at the same time. This leads to sprains of the joints and/or other injuries, which can cause both acute and persistent pain, as well as difficulties with day-to-day activities.

Myth #3: Hypermobile EDS (hEDS) is more severe than hypermobility spectrum disorder (HSD).

Reality: Hypermobility spectrum disorder (HSD), like hypermobility spectrum disorder (hEDS) and other less common kinds of EDS, can have a major impact on a person's health, whether this impact is due to the person's joints or to comorbidities. Concerns about nausea, vomiting, acid reflux, bloating, pain, absorption, and food intolerance are among the most common of these issues. Other common issues include autonomic disturbances of heart rate and blood pressure, bowel and bladder function, and temperature regulation; anxiety, depression, and phobias; and organ / systemic inflammation related to mast cell activation. These connections are not at all fictitious. They have a significant impact on one's quality of life and must be managed properly. When a diagnosis of HSD is made, it is necessary to investigate and treat these additional issues as well.

It is essential that these consequences are managed effectively, and that each person is treated as an individual, regardless of the difficulties that may occur or the diagnosis that may be given. Both HSD and hEDS can be just as severe, but what's more significant is that they require the same kinds of treatment, management, and validation.

Myth #4: Hypermobile EDS (hEDS) is diagnosed by genetic testing.

The reality is that the genetic variant(s) that are responsible for hEDS have not been found as of yet. The inheritance of every other variety of EDS may be traced back to a known genetic cause, which can be verified through genetic testing. The 2017 diagnostic criteria are applied clinically in order to arrive at a diagnosis of hEDS. There is currently no genetic test available to diagnose hEDS.

Before concluding that a person has hEDS, a physician may decide it is necessary to perform a genetic test on the patient in order to eliminate the possibility that the individual has another variety of EDS. This may occur in situations where the doctor believes there are symptoms or a family history that could also match with one of the rarer variants of EDS. As an example, this could be the case if there are signals that could also fit with EDS.

Myth #5: There is no treatment for EDS or HSD.

The reality is that the signs and symptoms of EDS and HSD can be managed and treated in a variety of different ways. In many cases, medical professionals and therapists will employ many of the same therapies that are available for other types of pain disorders, and they will adapt them in some way, such as how physical therapy is done.

The same holds true for treating associated problems, even though there may be unique explanations for the accompanying symptoms that need to be addressed in order to maximize treatment, such as a delayed stomach transit, inflammation of the bladder, sensory neuropathy, and so on.

Vascular diseases in EDS require regular monitoring and therapy to limit the risk of developing high blood pressure. Patients may also be required to take medicine in the form of B blockers or ACE inhibitors, and surgery may be necessary in some cases. These are just some of the many treatments that are available for people with EDS and HSD.

Myth #6: EDS and HSD don’t cause pain.

Reality: Pain and exhaustion are the most prevalent symptoms described by patients with EDS or HSD who visit their primary care physician, accounting for more than ninety percent of all complaints.

It is possible that the individual is experiencing pain in their joints (arthralgia), in their muscles (myalgia), as a result of a problem with their nervous system (neuralgia), or in their abdominal and pelvic organs (visceral pain). In addition, research has revealed that the level of pain that some persons with EDS experience during menstrual bleeding (also known as menorrhagia) is significantly higher than that which is experienced by the general population. A person who suffers from EDS or HSD may experience discomfort for a variety of different reasons.

Myth #8: EDS and HSD can be treated with collagen supplements.

The reality is that there is no evidence to suggest that taking collagen supplements is beneficial for persons who suffer from EDS or HSD. Because the collagen in the supplement is broken down during digestion in the same way that all other proteins are, it does not assist in the repairing or replacing of the defective collagen that the body produces.

The vast majority of EDS types result in abnormal collagen rather than a lack of collagen. No dietary supplement can alter the "directions" given by genetics to continue manufacturing faulty collagen.

Myth #9: You can be ‘too old’ or ‘too young’ to have EDS or HSD.

The reality is that EDS and HSD can affect individuals of any age. These conditions are present at birth in a person and continue to manifest themselves throughout their lives.

Myth #10: ‘You don’t look like someone who has EDS or HSD.’

The reality is that anyone of any ethnicity, gender, age, or physical shape can be affected by either EDS or HSD. Some of the more uncommon forms of EDS are associated with distinct facial characteristics, however this is not always the case. The remark that "you don't look like someone with EDS or HSD" is unhelpful because there is no established 'look' associated with either EDS or HSD.

# CHAPTER 3: LIVING WITH EHLER'S DANLOS SYNDROME

## DAILY CHALLENGES AND STRUGGLES FACED BY INDIVIDUALS WITH EHLER'S-DANLOS SYNDROME

Due to the consequences of this genetic illness on the connective tissue of the body, individuals who have Ehlers-Danlos syndrome (EDS) frequently encounter a range of different obstacles and struggles on a daily basis. Individuals who have EDS have connective tissue that is exceptionally flexible and fragile, and this tissue gives the skin, the muscles, and the organs the support and structure they need to function properly. This can result in a variety of symptoms, including the following:

1. Pain: People with EDS often experience chronic pain due to the fragility of their connective tissue and the frequent injuries they may sustain as a result. Joints may be prone to dislocations and subluxations, and soft tissue injuries may take longer to heal.
2. Fatigue: EDS can also cause chronic fatigue due to the physical strain of managing pain and mobility issues, as well as the added energy expenditure required to perform basic daily tasks.
3. Mobility issues: The fragility of connective tissue in individuals with EDS can also lead to mobility issues. Joint hypermobility (excessive movement in the joints) can cause instability and difficulty with activities such as walking, standing, and climbing stairs. Some individuals with EDS may also experience scoliosis (curvature of the spine) or kyphosis (abnormal rounding of the upper back).

Individuals who have EDS may also experience difficulties with daily activities such as dressing, bathing, and grooming as a result of joint hypermobility or pain. Additionally, these individuals may experience social isolation as a consequence of the disorder's unpredictable nature and the physical limitations it causes. Because of the persistent pain and the various difficulties they experience, some people with EDS develop anxiety, depression, and other mental health conditions as a result of their condition. This can have a substantial influence on their mental health.

## THE IMPORTANCE OF SELF-CARE AND FINDING A SUPPORTIVE NETWORK OF HEALTHCARE PROFESSIONALS AND LOVED ONES

The practice of tending to one's own needs in order to preserve one's mental, emotional, and physiological wellbeing is referred to as self-care. It entails participating in activities that enhance physical and mental well-being, such as exercising, eating a nutritious diet, getting adequate sleep, and handling stress in a positive manner.

An essential component of good self-care is putting together a support system that includes loved ones as well as medical professionals. It is essential to surround yourself with individuals who can provide you with support, encouragement, and direction when you are in a difficult situation. This could make you feel more connected to others and less isolated, and it might also give you a sense of community and belonging.

When it comes to managing chronic health diseases or mental health issues, having a supportive network of healthcare experts is very vital. [Cited in Medical News Today] These trained specialists are able to offer specialized care and assistance, in addition to assisting you in the development of management strategies for your condition. They are also able to provide advice on how to maintain your health in a manner that is both effective and practical over the course of your lifetime.

It is crucial to have a network of loved ones who are able to provide emotional support and encouragement, in addition to receiving support from healthcare specialists. Having people in your life who care about you and are willing to listen to you talk about how you're feeling can be a great source of strength and comfort, especially when things are going poorly in your life.

In a nutshell, it is essential to practice good self-care in order to keep one's physical, mental, and emotional health in good standing. Finding a supportive network of healthcare professionals and loved ones is an important part of this, as it can provide the support, guidance, and encouragement required to manage chronic health conditions or mental health issues and maintain overall well-being. This is why it is important to find a supportive network.

## TIPS AND STRATEGIES FOR MANAGING EHLER'S-DANLOS SYNDROME ON A DAILY BASIS

Here are some tips and strategies for managing Ehler's-Danlos syndrome (EDS) on a daily basis:

1. Follow a treatment plan: If you have been diagnosed with EDS, it is important to follow the treatment plan recommended by your healthcare provider. This may include taking medications, attending physical therapy, and following a healthy lifestyle.
2. Practice good posture: EDS can affect the stability of your joints, so it is important to practice good posture to help reduce the risk of injury. This may involve standing up straight, avoiding slouching, and taking regular breaks to stretch and move around.
3. Use assistive devices: Assistive devices, such as canes, walkers, or braces, can help support your joints and reduce strain on your muscles. Talk to your healthcare provider about what assistive devices may be right for you.
4. Get enough rest: It is important to get enough rest to help manage the symptoms of EDS. This may involve setting a regular sleep schedule and finding ways to relax before bedtime, such as reading or listening to calming music.
5. Eat a healthy diet: A healthy diet can help manage the symptoms of EDS and support overall health. This may include eating a variety of fruits, vegetables, and whole grains, as well as limiting processed and sugary foods.
6. Stay active: Regular physical activity can help improve joint stability, flexibility, and strength. However, it is important to avoid activities that put too much strain on your joints or cause pain. Talk to your healthcare provider about what types of physical activity are safe and appropriate for you.
7. Find support: Managing EDS can be challenging, so it is important to have a support system in place. This may include friends, family, or a support group of others who are living with EDS.

# CHAPTER 4: TREATMENT OPTIONS FOR EHLER'S DANLOS SYNDROME

## TREATMENT OPTIONS AVAILABLE FOR EHLER'S-DANLOS SYNDROME

There is no cure for EDS, but various treatment options can help manage the symptoms and improve quality of life. The most appropriate treatment plan will depend on the specific type of EDS, the severity of the symptoms, and the individual needs of the patient.

Medications:

* Nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen can help reduce pain and inflammation in the joints.
* Muscle relaxants and painkillers such as tramadol may be prescribed for muscle spasms and chronic pain.
* Autonomic nervous system stabilizers such as midodrine may be used to treat problems with blood pressure and other autonomic dysfunction.
* In some cases, medications such as propranolol or fludrocortisone may be used to treat specific symptoms such as postural orthostatic tachycardia syndrome (POTS) or hypotension (low blood pressure).

Physical therapy:

* Physical therapy can help strengthen muscles and improve mobility and function. Exercises may focus on improving core stability, balance, and coordination.
* Occupational therapy can help individuals with EDS learn techniques to manage daily activities and reduce the risk of injury.
* Surgery:
* In some cases, surgery may be recommended to stabilize joints or repair damaged tissues. However, people with EDS may be at higher risk for complications from surgery due to the fragility of their connective tissues.
* Orthopedic surgery may be used to treat joint instability or dislocations.
* Plastic surgery may be used to repair scars or other tissue damage.

It is critical for people who have EDS to collaborate intently with their healthcare providers in order to formulate an effective treatment strategy. In certain cases, this may need a mix of drugs, physical therapy, and surgery, in addition to changes in lifestyle, such as avoiding particular activities or making use of assistive devices. Prolotherapy, often referred to as regenerative injection therapy, is a form of treatment that involves injecting a solution into injured or weakened tissue in order to boost the body's natural healing process. This sort of treatment is commonly used to treat soft tissue injuries. It is believed that it works by inducing a mild inflammatory reaction in the area that has been injected. This response causes the body to produce new collagen, which in turn helps the tissue become stronger.

There is some evidence to suggest that prolotherapy may be beneficial in the treatment of Ehler's Danlos syndrome (EDS), which refers to a set of hereditary illnesses that affect the connective tissues in the body. EDS can be identified by a number of symptoms, including but not limited to hypermobility of the joints, skin that is prone to bruising and scarring, and irregularities in the blood vessels.

Prolotherapy has been utilized in the treatment of a variety of musculoskeletal diseases, including as back pain, osteoarthritis, and tendinitis. Additionally, there have been some studies that have suggested that it may be beneficial in lowering pain and improving function in EDS patients. However, in order to have a complete understanding of the benefits and hazards of prolotherapy in this population, additional research is required.

It is essential to keep in mind that prolotherapy is not a treatment that can reverse the effects of EDS, nor should it be utilized as the only method of care. It is possible that it will be most helpful when used in conjunction with other treatments, such as occupational therapy, physical therapy, and pharmaceuticals, in order to control the symptoms of EDS and enhance the patient's quality of life overall. Because of its capacity to maintain connective tissue, and the fact that it is natural and hence creates very few adverse effects, it continues to be one of the most effective therapeutic alternatives.

A form of treatment known as prolozone involves injecting ozone into injured connective tissue in order to promote the body's natural process of healing and restoration. Ozone is a highly reactive gas that has been demonstrated to increase the creation of collagen. Collagen is a protein that contributes to the consolidation and upkeep of connective tissue. Ozone is known to have this effect. When injected into damaged tissue, ozone has the potential to boost the natural healing process of the body and assist in the restoration of damaged tissue. Prolozone, according to the claims of certain medical professionals, can also assist to reduce inflammation and enhance circulation, both of which may contribute further to the healing of damaged tissue.

Dry needling is a technique that includes stimulating trigger points in the muscles and connective tissue by using solid needles that are very thin. It can help to relax muscle spasms and promote circulation, both of which can aid in the healing process, therefore it is regarded to be useful in treating injury to connective tissue. This is why it is thought to be effective. Dry needling may also assist to reduce inflammation and improve range of motion, both of which can be beneficial in treating the pain and suffering associated with connective tissue damage. Dry needling is a form of treatment that uses needles. It is essential to emphasize that dry needling is a procedure that must be carried out alone by a qualified and authorized healthcare practitioner.

## THE PROS AND CONS OF EACH TREATMENT OPTION AND THE IMPORTANCE OF FINDING THE RIGHT TREATMENT PLAN FOR EACH INDIVIDUAL

The precise form of Ehlers-Danlos syndrome (EDS), the degree to which the symptoms are manifested, and the specific requirements of the patient will all play a role in determining the EDS treatment plan that will be the most effective. It is critical for people who have EDS to collaborate closely with their healthcare providers in order to devise a treatment strategy that takes into account their unique requirements and objectives.

Medications:

Pros:

* Nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen can help reduce pain and inflammation in the joints.
* Muscle relaxants and painkillers such as tramadol may be effective in relieving muscle spasms and chronic pain.
* Autonomic nervous system stabilizers such as midodrine can help improve blood pressure and other autonomic dysfunction.
* Cons:
* Some medications may have side effects, such as stomach upset or dizziness.
* Long-term use of certain medications, such as NSAIDs, may have negative effects on the gastrointestinal tract.

Physical therapy:

Pros:

* Physical therapy can help strengthen muscles and improve mobility and function.
* Occupational therapy can help individuals with EDS learn techniques to manage daily activities and reduce the risk of injury.

Cons:

* Physical therapy may be time-consuming and may require regular visits to a therapist.
* Some people with EDS may have difficulty with certain exercises or may be at higher risk for injury during therapy.

Surgery:

Pros:

* Surgery may be necessary to stabilize joints or repair damaged tissues.
* Orthopedic surgery can help treat joint instability or dislocations.
* Plastic surgery can be used to repair scars or other tissue damage.

Cons:

* Surgery may be expensive and may not be covered by insurance.
* People with EDS are at higher risk for complications from surgery due to the fragility of their connective tissues.

It is essential to thoroughly analyze the benefits and drawbacks of each therapy option in order to arrive at the treatment strategy that is most appropriate for the person who has EDS. In certain cases, this may need a mix of drugs, physical therapy, and surgery, in addition to changes in lifestyle, such as avoiding particular activities or making use of assistive devices.

## TIPS FOR NAVIGATING THE HEALTHCARE SYSTEM AND ADVOCATING FOR ONESELF

Here are some tips for navigating the healthcare system and advocating for yourself:

1. Know your healthcare rights: It's important to understand your rights as a patient, including the right to access your medical records, the right to second opinions, and the right to refuse treatment. Understanding your rights can help you advocate for yourself and make informed decisions about your care.
2. Find a healthcare provider you trust: It's important to have a healthcare provider that you trust and feel comfortable with. This can make it easier to communicate your concerns and ask questions about your care.
3. Keep track of your health: Keep a record of your health history, including any diagnoses, treatments, and medications. This information can be useful when discussing your care with healthcare providers.
4. Be an active participant in your care: Don't be afraid to ask questions and express any concerns you have about your care. It's important to be an active participant in your healthcare, and this includes being involved in decision-making about your treatment.
5. Know how to access healthcare resources: It's important to know how to access healthcare resources, such as medical records, prescription refills, and appointment scheduling. This can help you stay on top of your care and ensure that you get the treatment you need.
6. Use your healthcare benefits: Make sure to use your healthcare benefits, such as insurance coverage, to access the care you need. If you have trouble understanding your benefits or accessing care, don't be afraid to ask for help.
7. Seek support: If you feel overwhelmed or need additional support, consider seeking help from a healthcare advocate or social worker. These professionals can help you navigate the healthcare system and advocate for yourself.

# CHAPTER 5: COPING WITH THE EMOTIONAL IMPACT OF EHLER'S DANLOS SYNDROME

## EMOTIONAL CHALLENGES OF LIVING WITH A CHRONIC CONDITION

Living with a chronic condition can be emotionally challenging, as it can involve ongoing medical treatment, lifestyle changes, and the possibility of physical limitations. This can lead to a range of emotions, including:

* Isolation: Chronic conditions can sometimes limit your ability to participate in activities you enjoy, which can lead to feelings of isolation and loneliness.
* Frustration: Coping with a chronic condition can be frustrating, as it may require ongoing medical treatment and lifestyle changes. It can be difficult to adjust to these changes, and you may feel frustrated with your body and the limitations it imposes.
* Anxiety: Living with a chronic condition can be unpredictable, and you may worry about the impact of your condition on your daily life and future. This can lead to feelings of anxiety.

It's important to recognize that these emotions are normal and to find ways to cope with them. Some strategies for managing these emotions include:

* Connecting with others: It can be helpful to connect with others who are living with similar conditions, as this can provide a sense of support and community. You may also find it helpful to connect with friends and family members who can provide emotional support.
* Seeking professional support: If you're struggling with your emotions, it may be helpful to seek support from a mental health professional, such as a therapist or counselor.

## STRATEGIES FOR COPING WITH THESE EMOTIONS, INCLUDING THERAPY, SUPPORT GROUPS, AND SELF-CARE PRACTICES

People who have to deal with a chronic illness on a daily basis may have a greater risk of developing depression. Mental health disorders can be treated, just like chronic physical illnesses. There are many different approaches that can assist improve your health so that you can have a better quality of life despite the disease you have. You can improve your ability to deal with the effects of a chronic illness by taking better care of both your physical and emotional health.

Below are some tips that may help you work towards emotional well-being:

1. Educate yourself about your illness and make sure you fully comprehend it. Empowerment is an essential component of successful disease management, and having the knowledge and information necessary to make informed decisions and choices can help you feel more in control of your life.
2. Find the correct provider for you: It is essential that you are able to ask questions and explain yourself in a manner that you are comfortable with. If you need help finding a provider, you might consider contacting either your insurance company or a reputable teaching hospital in your area. You can also talk to other people who have the same ailment as you for recommendations, such as through a support group, and you can consult with a physician whose opinion you trust. Both of these options are available to you.
3. Discuss the state of your mental health with your primary care provider: Your care provider needs to be aware of both your physical and mental state in order to properly care for you. Dealing with a chronic illness can make dealing with the stress of regular life more difficult and can also have an effect on how well you feel overall. It may be more challenging to manage and treat your health if you also struggle with depression and anxiety. Your physician will be able to guide you through the process of determining the most appropriate strategy to treat your feelings, which may involve receiving recommendations for counseling, medication, or talk therapy. Social workers, psychologists, and other professionals who provide mental health care are able to offer essential support to patients who are attempting to manage the effects of chronic illness.
4. As a result of living with a chronic disease, your responsibilities may evolve. Living with a chronic illness may alter your priorities and have an effect on your sense of who you are and how you see yourself. Your duties in areas such as job, school, relationships, family planning, and caregiving may shift, or you may find that you require assistance in one of these areas. It's possible that you'll go through a range of emotions as a result of these shifts; if you do, you might want to consider having a conversation with someone you
5. Define your circle of support: Be aware of the people on whom you may rely: You could find that you require assistance with certain duties or emotional support as a result of changes that occur in your life. At different points in life or for various causes, you may require assistance from members of your family, friends, and neighbors, as well as from support organizations, religious or spiritual communities, and healthcare providers. Consider and precisely describe what it is that you require.
6. As a result of living with a chronic disease, your responsibilities may evolve. Living with a chronic illness may alter your priorities and have an effect on your sense of who you are and how you see yourself. Your duties in areas such as job, school, relationships, family planning, and caregiving may shift, or you may find that you require assistance in one of these areas. It's possible that you'll go through a range of emotions as a result of these shifts; if you do, you might want to consider having a conversation with someone you
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# CHAPTER 6: THE FUTURE OF EHLER'S DANLOS SYNDROME

## CURRENT RESEARCH ON EHLER'S-DANLOS SYNDROME AND POTENTIAL DEVELOPMENTS IN TREATMENT AND MANAGEMENT

The treatment for EDS focuses on symptom management and the prevention of consequences because there is no cure for the condition. The treatment may consist of drugs to manage the pain, physical therapy to enhance joint stability and function, and skin care to prevent scars and sores.

In prolotherapy, a sort of treatment, a solution is injected into an injured or weaker joint or muscle in order to boost the body's natural healing processes. This type of treatment is also known as "prolo" Prolotherapy has been found to be helpful for certain EDS patients in improving joint stability and reducing discomfort. Prolotherapy is a treatment option for EDS; however, its efficacy is not well established, and additional study is required to determine both its safety and its effectiveness.

Ongoing research is being conducted on EDS, which includes studies on the genetics of EDS, the mechanisms underlying the many manifestations of the condition, as well as the development of new treatments. For instance, researchers are looking into the possibility of using stem cells to repair damaged connective tissue in people who have EDS. They are also looking into the possibility of using gene therapy to correct the underlying genetic mutations that cause EDS. Both of these areas of research are currently under investigation.

In general, the treatment of EDS calls for a multidisciplinary approach that encompasses a wide variety of approaches to care, including physical therapy, pain management, and skin care. People who have EDS should have a close working relationship with their healthcare team in order to build an individualized treatment plan that is tailored to their very particular requirements.

## THE IMPORTANCE OF PATIENT ADVOCACY AND RAISING AWARENESS ABOUT EHLER'S-DANLOS SYNDROME

Ehlers-Danlos syndrome (EDS) awareness and patient advocacy are crucial for a variety of reasons.

To begin, EDS is a rare disorder; as a result, many people who have EDS may have trouble acquiring an accurate diagnosis or the right treatment for their condition. Advocacy on the part of patients can assist raise awareness about a problem among medical professionals, which in turn can improve the likelihood of receiving a fast and accurate diagnosis.

Second, increasing understanding of the difficulties experienced by persons who have EDS and reducing the stigma associated with having the condition can both be accomplished through increasing knowledge of EDS. In addition to this, it can assist in drawing attention to the necessity of further study being conducted on the illness as well as the creation of novel remedies.

People who have EDS may benefit from improved access to services and support if they have patient advocates working on their behalf. Access to specialist medical treatment, assistive gadgets and equipment, and support groups could all be included in this category.

Individuals and groups can advocate for persons with EDS in a variety of different ways, as well as increase awareness of the condition in a number of different methods. Examples of this could be:

1. Participating in awareness campaigns and events, such as EDS Awareness Month in May.
2. Sharing information about EDS on social media and other platforms.
3. Joining or supporting advocacy groups and organizations that focus on EDS.
4. Contacting local and national representatives to advocate for the needs of people with EDS.
5. Educating healthcare providers about EDS, including the diagnostic process and treatment options.

Overall, patient advocacy and raising awareness about EDS can help to improve the lives of people with the condition by increasing understanding and access to resources and support.

**DIGITAL MOTION X-RAY, ULTRASOUND AND PROLOTHERAPY FOR THE DIAGNOSIS AND TREATMENT OF EHHLER’S-DANLOS SYNDROME**

Digital motion X-rays are a type of diagnostic imaging test that captures images of the moving human body using X-rays. This imaging technique is sometimes referred to as dynamic radiography. Connective tissue injuries, such as those affecting the ligaments or tendons, as well as disorders affecting the joints, such as dislocations or instability, are frequently evaluated with this method.

During a digital motion X-ray exam, the patient is instructed to carry out a certain movement or set of movements while the radiologist captures X-ray images of the area being examined. After collecting these images, a radiologist or another type of medical specialist looks at them to determine how the joints and connective tissue are moving and how well they are functioning.

The use of digital motion X-rays can be helpful in the diagnosis of a wide range of musculoskeletal conditions and injuries, such as sprains, strains, and other types of soft tissue injuries. They are also able to assist in determining the root cause of recurrent joint discomfort and difficulties with mobility.

Ultrasound is a medical imaging technique that uses high frequency sound waves to create images of the inside of the body. It is a non-invasive and painless procedure that is often used to diagnose and monitor conditions involving the musculoskeletal system, including connective tissue damage.

To use ultrasound to diagnose connective tissue damage, a healthcare provider will apply a special gel to the skin over the area of interest and then move a handheld device called a transducer over the skin. The transducer sends out high frequency sound waves that pass through the skin and other tissues and are reflected back to the transducer. The reflected sound waves are then converted into images that can be viewed on a computer screen.

Ultrasound is particularly useful for diagnosing connective tissue damage because it allows healthcare providers to see real-time images of the tissue, which can help them identify any abnormalities or signs of damage. It is also useful for monitoring the healing process after connective tissue damage has been identified.

## FINAL THOUGHTS ON LIVING WITH EHLER'S-DANLOS SYNDROME AND THE HOPE FOR A BETTER FUTURE FOR THOSE AFFECTED BY THE CONDITION.

Having Ehlers-Danlos syndrome (EDS) can make day-to-day life a struggle and test one's resolve on multiple fronts. EDS refers to a set of genetic conditions that damage the connective tissue in the body. Connective tissue is what gives the skin, blood vessels, bones, and other organs and tissues the support they need to function properly. Those affected by EDS may experience a variety of symptoms, including joint hypermobility, skin that is prone to bruising or scarring, and fragile tissues that are readily damaged.

The treatment for EDS typically consists of symptom management and the prevention of additional accidents or consequences because there is no cure for the condition. Physical therapy, the use of assistive devices, and medication are all potential components of this treatment plan for managing pain and other symptoms. It is essential for individuals who have EDS to maintain close communication with the members of their healthcare team in order to formulate a treatment strategy that is adapted to their specific requirements and objectives.

In spite of the difficulties associated with having EDS, there is still optimism for a brighter future. Ongoing research is being conducted into EDS and other connective tissue disorders. Scientists are attempting to better understand the causes of these conditions and are seeking to discover new treatments. In addition, developments in medical technology and treatment have made it feasible for persons with EDS to enjoy longer lives that are also healthier. This has resulted in an increase in their overall life expectancy.

Staying knowledgeable about your illness, working closely with your healthcare team, and being an advocate for your needs and rights are ultimately the most important things you can do to live a healthy life with EDS. People who have EDS have the potential to lead lives that are rich in satisfaction and purpose when they receive the appropriate care and support.

# MY CLINICAL EXPERIENCE WITH EULER’S DANLOS SYNDROME

 Many of my patients come to me with similar symptoms and issues reflecting Ehler’s Danlos Syndrome, including pain in joints such as the neck, lower back, wrists, rib cage, ankles, and shoulders. Cervical and joint instability is very common. These symptoms often resemble autoimmune conditions like lupus, Lyme disease, and fibromyalgia. Many patients have tried various treatments such as physical therapy, medications, epidural injections, and alternative therapies like chiropractic and acupuncture, but find that these treatments are not effective or do not provide long-lasting relief. These patients may also experience symptoms such as vertigo, migraines, and stomach pain and gastrointestinal issues due to vagus nerve inflammation. Blood work often reveals inflammation in the body, including high levels of C-reactive protein and low levels of vitamin D. Even when patients take vitamin D supplements, the body may not be able to properly absorb the nutrients due to chronic inflammation.

This condition is more common in women than men and tends to develop after puberty. As patients age, the condition may progress and be exacerbated by hormonal changes, poor posture, and poor diet.

To diagnose this condition, I perform a comprehensive examination and blood work to assess the current state of the patient's body. I may also recommend a Digital Motion X-ray Study, MRI, and/or a digital ultrasound to check the integrity of the connective tissue. These tests may show that the symptoms are severe, even if the MRI appears normal.

Treatment may include a combination of dry needling, prolozone therapy, neural therapy (targeting specific trigger points to calm nerves), decompression therapy, and infusions to promote collagen growth and reduce inflammation. I may also recommend MTHFR genetic screenings and methylated B-12 and vitamin D injections.

Contrary to what some in the medical community may believe, this is not simply a psychological condition. Early treatment is key to managing symptoms and maintaining overall wellness. Patients may need to work harder to manage their symptoms, but making healthy lifestyle choices such as following an anti-inflammatory diet, stretching, exercising, and practicing stress management can be helpful. Once symptoms are stabilized, additional therapies such as dry needling, cupping, fascial release massage, and low force chiropractic may be beneficial.

If you or someone you know may be experiencing chronic pain due to Ehler's Danlos syndrome, please contact Venturis at 405-848-7246 or email venturisclinic@gmail.com.