# One Woman's Struggle With Ehlers Danlos Syndrome

Ehlers Danlos Syndrome (EDS) is a rare genetic disorder affecting the connective tissues in the body. This chronic condition can lead to a wide range of symptoms, including joint hypermobility, chronic pain, skin fragility, and even organ rupture. While EDS can affect anyone, it primarily affects women.

## The Story of Rachel

In our society, stories of triumph are often celebrated, while struggles and challenges are usually overlooked. However, it is important to shed light on the daily struggles faced by individuals living with Ehlers Danlos Syndrome, such as the story of Rachel Thompson (name changed for privacy).

**Being Built Wrong: One Woman’s Struggle with Ehlers-Danlos Syndrome** by Josh Armstrong(Kindle Edition)

★★★★☆ 4.4 out of 5

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Rachel was diagnosed with Ehlers Danlos Syndrome at the age of 16, after experiencing years of unexplained pain and injuries. She recalls being told by doctors that her symptoms were merely a result of growing pains or exaggeration. However, her persistence paid off when she finally found a doctor who recognized her condition.

Rachel's journey with EDS has been anything but easy. The constant pain and fatigue have made it difficult for her to engage in everyday activities that many of us take for granted. Simple tasks like walking or even holding a cup of tea can be excruciatingly painful for her. Despite facing numerous challenges, Rachel has remained determined to not let her condition define her life.

## Challenges and Triumphs

Living with Ehlers Danlos Syndrome requires constant adaptation and resilience. Rachel has faced numerous challenges, both physically and emotionally, as she navigates through life with this rare condition. From frequent hospital visits to multiple surgeries, every day brings a set of unique obstacles that she must overcome.

One of the biggest hurdles Rachel has faced is the lack of understanding from those around her. Many people assume that because she looks fine on the outside, she must not be in significant pain. This lack of empathy and understanding can be emotionally draining for someone already going through so much physically.

> ***“"I often feel isolated and misunderstood. It's frustrating when people expect me to push through the pain and just carry on. It's not that simple for me," says Rachel.”***

Despite these challenges, Rachel has found solace in the support of online communities and support groups. Connecting with others who share similar experiences has provided her with a sense of belonging and understanding that is difficult to find in the outside world.

### Raising Awareness

Ehlers Danlos Syndrome is a relatively unknown condition, often misdiagnosed or overlooked by medical professionals. Rachel has made it her mission to raise awareness about EDS and advocate for better understanding and treatment options.

Through her blog and social media platforms, Rachel shares her journey with EDS, providing insights into the daily challenges she faces. She educates others about the condition, its symptoms, and the impact it has on her life. By sharing her story, Rachel hopes to inspire empathy, understanding, and support for individuals with EDS.

### A Message of Hope

While living with Ehlers Danlos Syndrome is undoubtedly challenging, Rachel's story is one of resilience and hope. She encourages others living with EDS to never give up and emphasizes the importance of self-care and seeking proper medical support.

Rachel's journey isn't just about her struggles with EDS; it's also about her resilience, accomplishments, and the progress she has made despite the odds stacked against her. She is an inspiration to others, reminding them that they are not alone in their battles.

The story of Rachel Thompson sheds light on the daily struggles and triumphs of individuals living with Ehlers Danlos Syndrome. It is crucial to recognize the challenges faced by those with invisible illnesses and provide them with the support and understanding they deserve.

By sharing her story and advocating for awareness, Rachel has become an advocate for individuals with EDS and an inspiration to many. Her journey reminds us to value the strength and resilience it takes to face unseen battles and encourages empathy towards those who may be silently struggling.

# 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
Dislocations
Subluxations
Hypermobility
Osteoarthritis
Osteoporosis
Skin Tearing
Stretchy skin
Soft skin
Mitral Valve Prolapse
Easy bruising

Fatigue
Chiari
Sprains
Gastrointestinal issues
Atrophic scarring
Muscle spasms
Poor healing
TMJ
POTS
Organ rupture
Aneurysms

Prolapse
Preterm labor
IBS
Dysautonomia
Flat feet
Swan neck deformity
Degenerative Joint Disease
Gastritis
Arthralgia
Myalgia
Surgical complications

*FB you know you have EDS when*

Together, we can make a difference and create a world where individuals with Ehlers Danlos Syndrome and other invisible illnesses are seen, heard, and supported.

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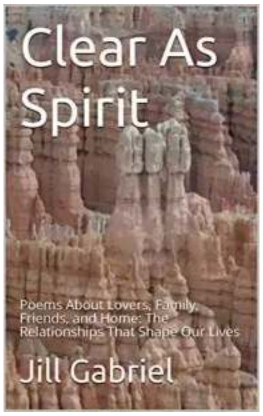
The following story was written in 2010 by my daughter Alexa who passed away on October 11 2011 from complications due to Ehlers-Danlos Syndrome (EDS). Most people do not even know that EDS exists and, for that matter, most doctors unfortunately do not understand it and often diagnose it as a psychiatric issue versus a disease/illness. I hope this story increases awareness of EDS and related disorders – perhaps it will inspire people to understand that many diseases are not observable and that they need to be more compassionate towards others.



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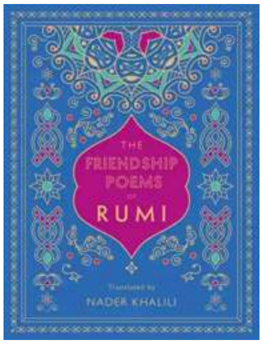

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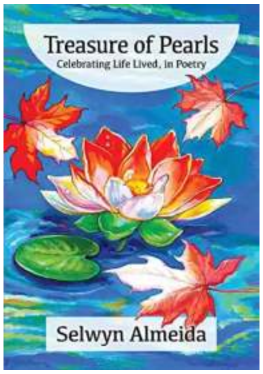

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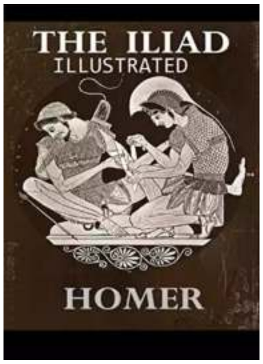

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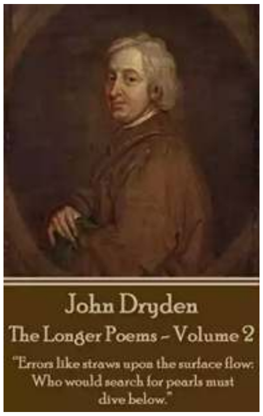

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