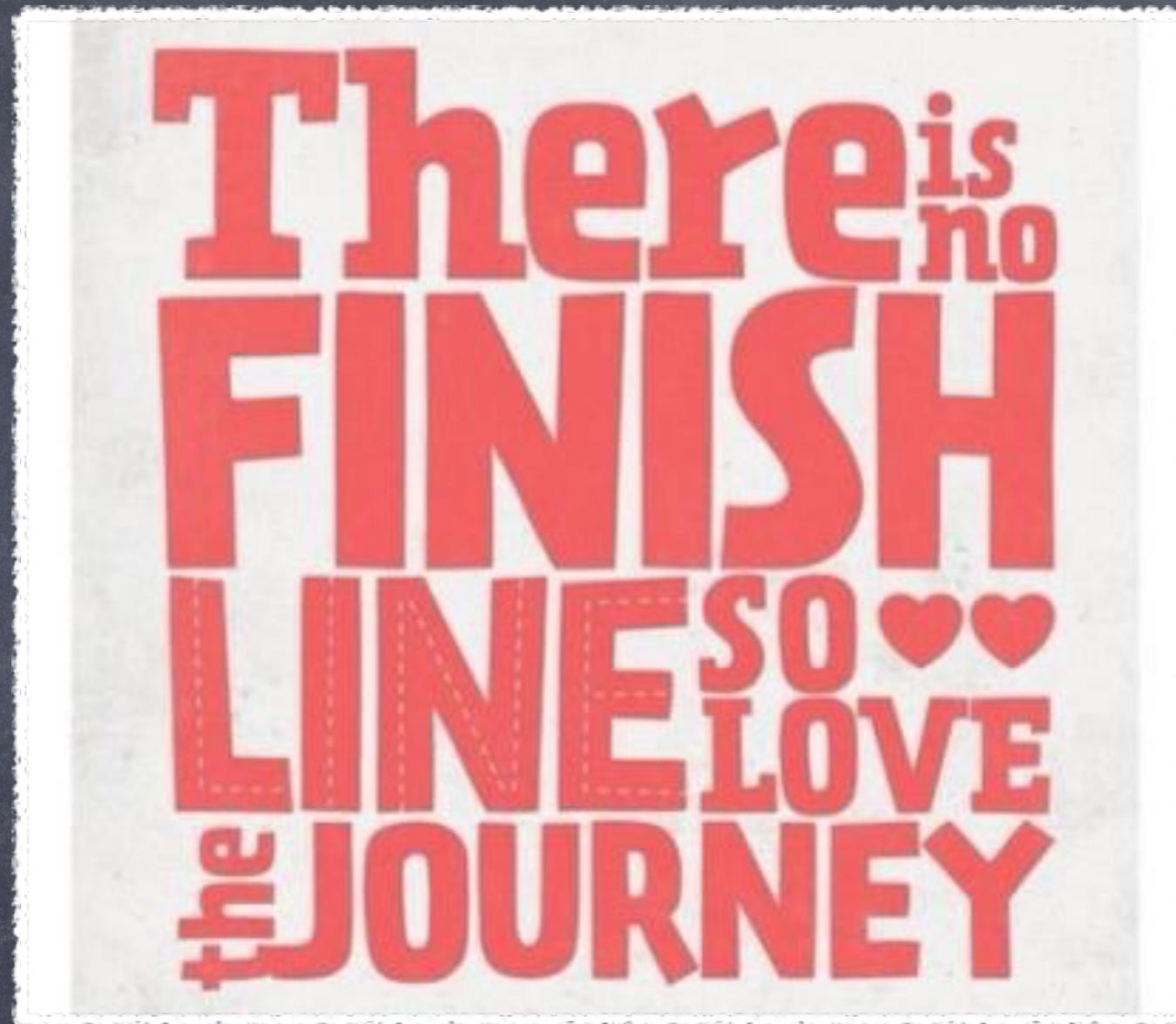




June 18th, 2015

Chris Gnip, PT, DPT, Victor Chang, PT, DPT &  
Kendra Neilsen Myles, Owner - EDS Patient Solutions, LLC



## Moving Naturally with Hypermobility

Christopher Gnip, Victor Chang and Kendra Neilsen Myles are all passionate about helping patients who suffer from chronic pain associated with hypermobility syndromes. Our hope is to help patients learn ways to move naturally with hypermobility, live with less pain, and be empowered to improve their overall health and well-being.

# Who am I?

Kendra Neilsen Myles

B.S. Public Health - University of  
Maryland

Owner of EDS Patient Solutions  
& Mediterina Medical Solutions

Co-Owner & Author of Our  
Stories of Strength - Living with  
Ehlers-Danlos Syndrome

Also,

Wife, Mom of 3, 2 pups, EDNF  
Helpline Volunteer & co-admin  
for EDS Athletes FB group





Living with chronic pain is one of the hardest things that many of us have to endure on a daily basis. Living with pain while also coping with the multi-systemic affects of joint hypermobility, commonly diagnosed as Ehlers-Danlos Syndrome (EDS), is even more challenging. Some of the best approaches for managing chronic pain due to Hypermobility Syndrome/EDS are gaining a solid understanding of how hypermobility can effect the entire body, learning how to move and exercise properly, making healthy lifestyle changes, and finding a strong, positive support system.

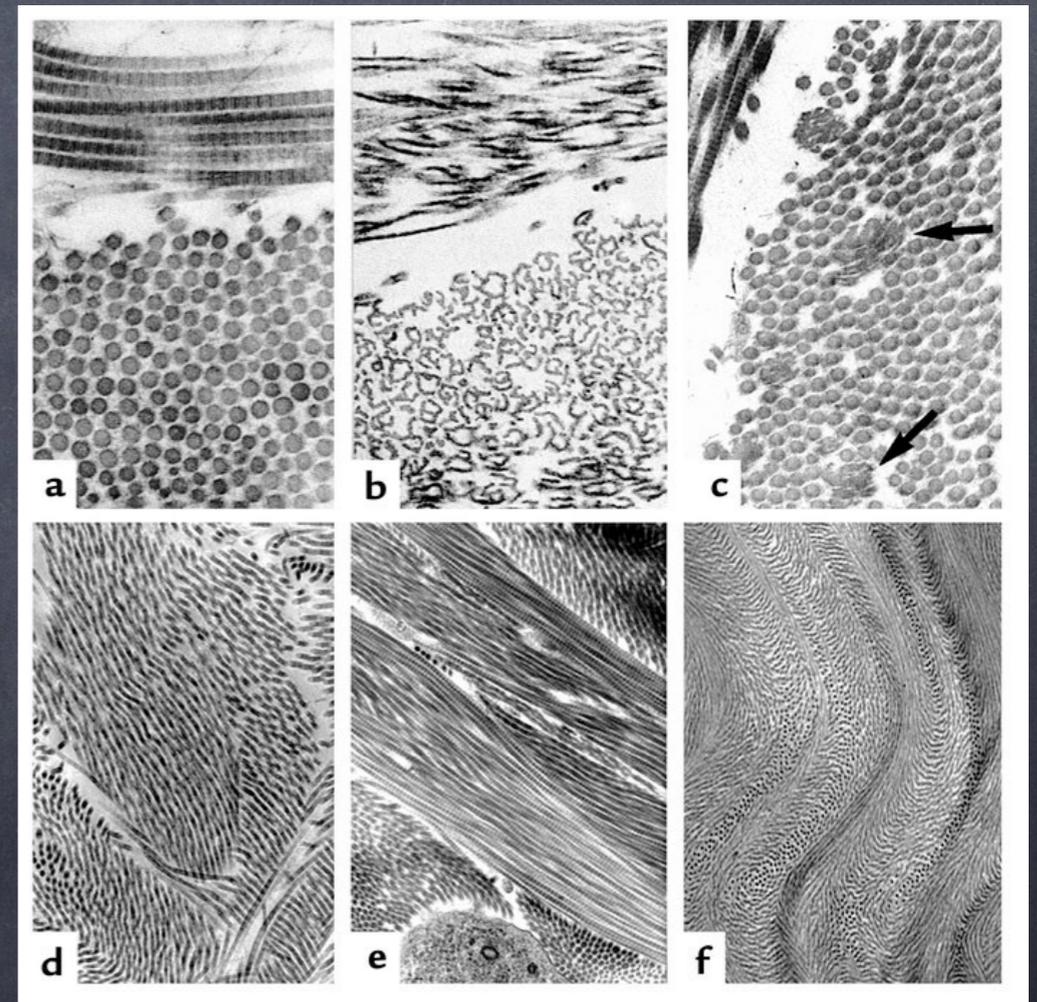
# What is Hypermobility Syndrome?

- Usually means joints are hypermobile or double-jointed
- Previously referred to as Benign Joint Hypermobility Syndrome (BJHS), Hypermobility Syndrome (HMS), Ehlers-Danlos Syndrome Type III or "really, really flexible."
- Ehlers-Danlos Syndrome Type III is now Ehlers-Danlos Hypermobility Type
- BJHS, HMS, EDS Type III/HEDS & "really, really flexible" are all now recognized as Ehlers-Danlos Syndrome Hypermobility Type (or another type of EDS)



# Types of EDS

- Hypermobility EDS (Type III)
- Classical EDS (Type I & II)
- Vascular EDS (Type IV)
- Kyphoscoliosis Type
- Arthrochalasia Type
- Dermatosparaxis Type



# Other types of EDS

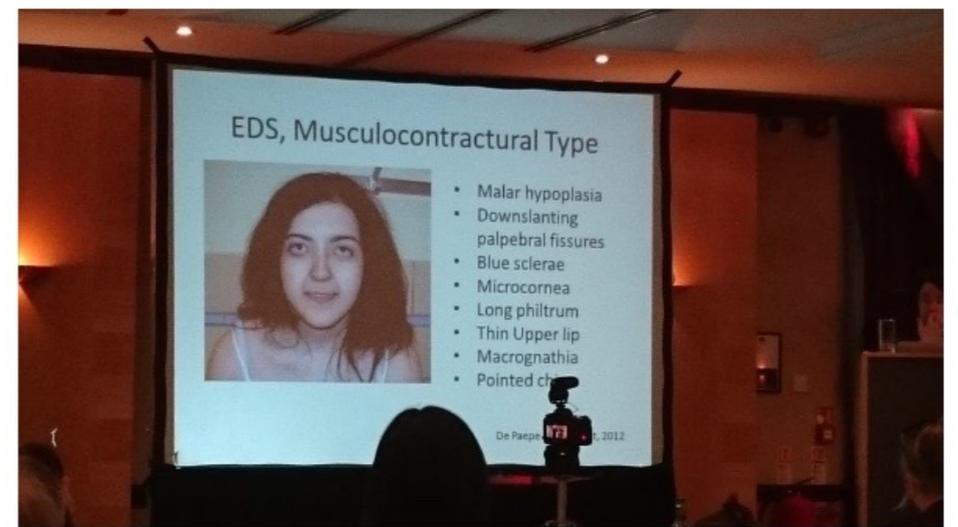
- Musculo-contractional type
- Multiplex congenital
- Periodontitis Type
- Progeroid
- B3GALT6 Deficiency
- Cardiac valvular
- FKBP14-related
- Spondylocheirodysplastic
- Tenascin-X Deficient
- Periventricular heterotopia, ED variant



EDS UK

@ehlersdanlosuk

One of the recently defined type of #EDS is the Musculocontractional Type which is caused by mutations in CHST14 gene.



# How is EDS Diagnosed?

- Usually by a geneticist
- Beighton Score
- Brighton Criteria
- Assessment of joint hypermobility, personal medical history, current symptoms & family medical history.
- Combination of major & minor criteria as determined by the 1997 EDS Nosology (To be redone in 2016 at the EDS International Symposium)

**THE BEIGHTON SCORE**  
( 4 / 9 = HYPERMOBILITY )

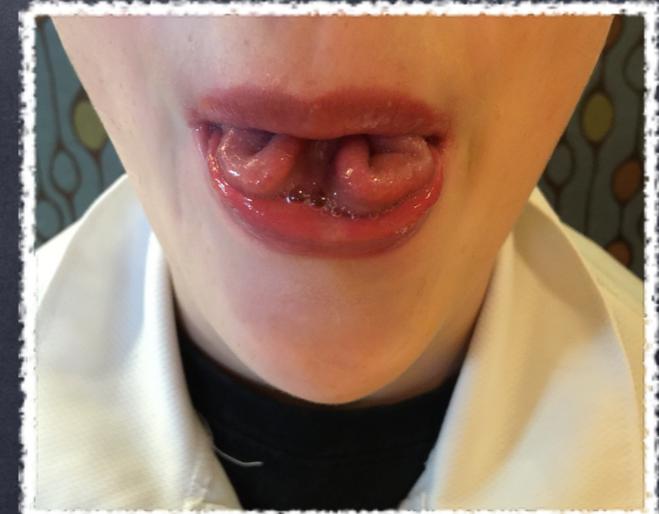
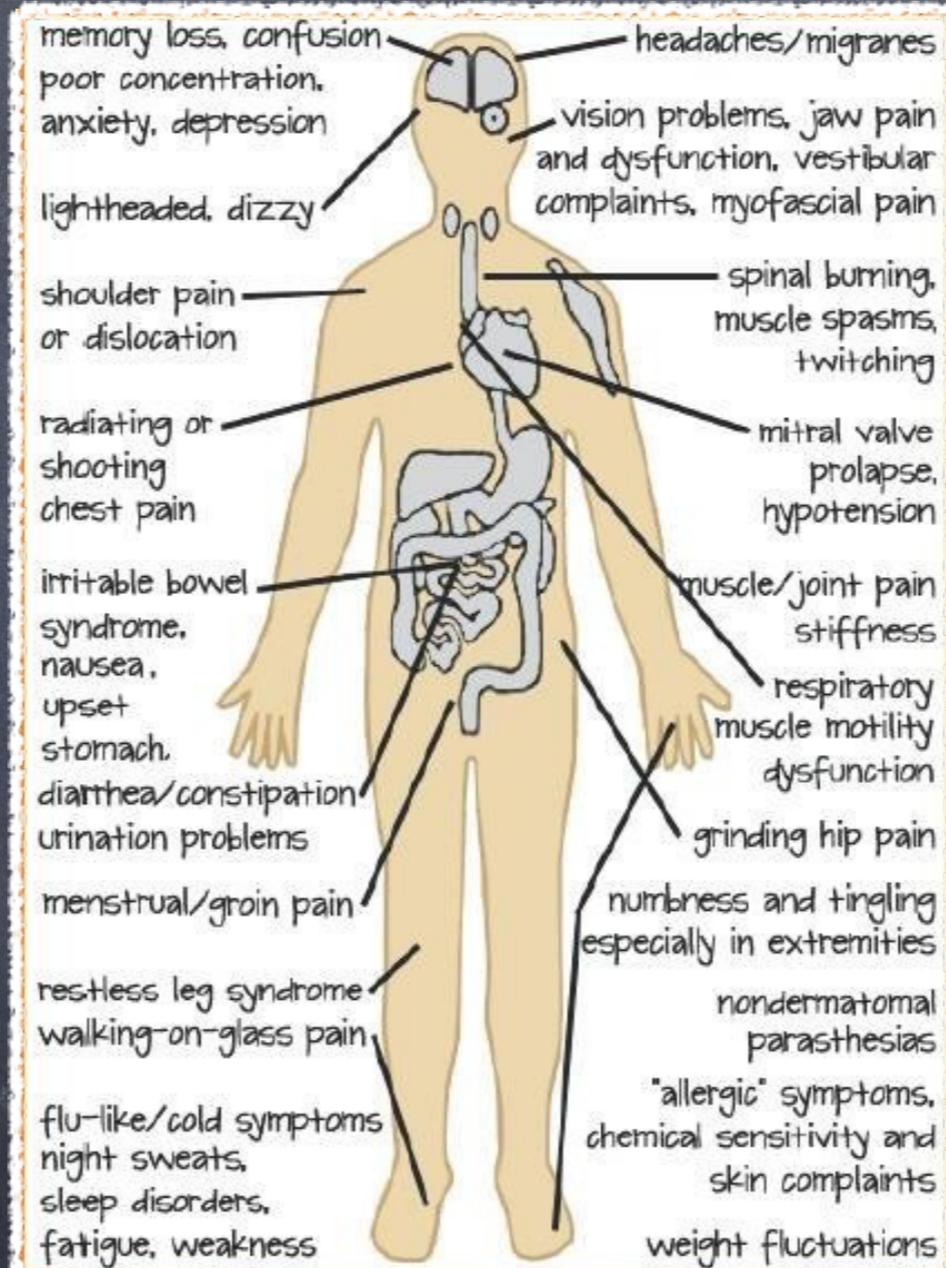
The diagram illustrates the Beighton Score with four illustrations: 1. A hand being pulled back towards the shoulder, labeled '1 point for each hand'. 2. A hand being pulled towards the thumb, labeled '1 point for each little finger'. 3. An arm being pulled towards the shoulder, labeled '1 point for each elbow'. 4. A person performing a deep forward bend, labeled '1 point, with straight legs'.

**Brighton Criteria**

- Major Criteria
  - Beighton score of  $\geq 4$  (Figure 4)
  - Arthralgia for longer than 3 months
- Minor Criteria
  - Beighton score of 1, 2, or 3 (Figure 4)
  - Arthralgia ( $>3$ -month duration) or back pain ( $>3$ -month duration) spondylosis/spondylolisthesis
  - Dislocation or subluxation in more than one joint on more than one occasion
  - Three or more soft tissue lesions (tenosynovitis, bursitis)
  - Marfanoid habitus (tall, slim, spinal height  $>1.03$  ratio), upper segment  $<0.89$  ratio), arachnodactyly
  - Skin striae, hyperextensibility, thin scarring
  - Ocular signs: drooping eyelids, myopia, ectopia lentis
  - Varicose veins, hernia, or uterine prolapse
  - Mitral valve prolapse
- Requirement for Diagnosis
  - Any one of the following:
    - two major criteria
    - one major plus two minor criteria
    - four minor criteria
    - two minor criteria and unequivocal degree relative in family history

**BEIGHTON SCORE + BRIGHTON CRITERIA = EHLERS - DANLOS SYNDROME**

# Other signs & symptoms of hypermobility



# Types of Hypermobility Syndromes

- Ehlers-Danlos Hypermobility Type (previously JHS, BJHS & EDS Type III)
- Other Ehlers-Danlos Syndromes (Classical EDS, VEDS, etc.)
- Marfan Syndrome
- Loeys-Dietz Syndrome
- Osteogenesis Imperfecta (OI)
- Down Syndrome
- Lots of overlaps of signs & Symptoms!



# I have EDS now what?

- Remain as active as possible
- Focus on what you can control vs. what you can't.
- Overall health & wellness is much more than what you eat & exercise – you must also find ways to get adequate sleep, rest & pace yourself (I'm terrible at this)
- The past is the past – don't dwell on it. Focus on the present & the future.
- Be mindful of online behaviors & how they affect you psychologically, emotionally & physically

Don't bring up  
the past of a  
person who is  
trying to improve  
their future.

[WWW.LIVELIFEHAPPY.COM](http://WWW.LIVELIFEHAPPY.COM)

# I have EDS, now what? (cont)

- Watch-out of hearsay and hysteria. Focus on the facts as we know them up to this point.
- Don't look to collect labels and other diagnosis. (I.e. Deal with issues as they come vs. look to see if you have "it" too.)
- Find ways to help yourself vs. depending too much on healthcare providers for pain management & other symptoms (I.e. always have to go to massage therapist for muscle pain. Try foam roller and learning self-massage at home)
- Give healthcare a break - don't waste energy of what they "should know" and "should be doing." Focus on what YOU can do. You are your own best advocate & partner with your docs in your healthcare.
- Consider medical crisis counseling or a health-coach if really struggling



**When "I" is replaced by 'we' even 'illness' turns into 'wellness'**

# Some additional thoughts

"...the best way to manage EDS and joint hypermobility is through a consistent and dedicated exercise regime. Be it closed chain exercises to improve balance and proprioception. Or exercises designed to get stronger. Or core work, posture and muscle control. In whatever form you exercise, the important thing was to improve the way you move, and to move and use your body as much as you can."



# Additional thoughts (cont)

So, how do we stay active, when so many of us feel that we need to avoid activity because it causes us more pain, or because we have gotten hurt previously? And, what about the post-exercise fatigue so many feel?

"There was a recognition that in order to become active, people with hypermobility need to challenge the fear-avoidance cycle that arises from having injury and pain."

My goal - Focus on doing something for "just 5 minutes" a day.

## Maladaptive behaviours in EDS

- Pain catastrophizing
- Fear of Pain
- **Kinesophobia:** some evidence that it does not correlate with actual intensity of pain or quality of life scores (Biomed Res Int. 2013; Jul 2014) and it has been proposed that it is a major prognostic determinant in EDS (Curr Pain Headache Rep 2009, 13:593-600)

@SFHEDS @EdsPatientSol  
#Just5Minutes has taken off in my house! all my kids do 5mins of Physio every day and if they feel great carry on



# Latest info & research



EDS UK

@ehlersdanlosuk

"If the effects of exercise could be patented by a pharmaceutical company, it would be widely prescribed"

[#EDSUKconference](#)

[#EhlersDanlos](#)

5/9/15, 4:12 AM



EDS UK

@ehlersdanlosuk

"The biggest gap is our knowledge in the genetics of [#ehlersdanlos](#) is within the hypermobility type"

[#EDSUKconference](#)



EDS UK

@ehlersdanlosuk

1. We see a very wide difference in the manifestations of men & women EDS patients. Dr. Francomano thinks this may be due to hormones & men



EDS UK

@ehlersdanlosuk

"Look after your neck in [#EDS](#). No smoking, avoidance of trauma, good posture, see a good physiotherapist to strengthen."

[#EDSUKconference](#)

6/13/15, 6:46 AM



EDS UK

@ehlersdanlosuk

"[#ehlersdanlos](#) is the most complicated condition in medicine, so many overlaps"

[#EDSUKconference](#)



EDS UK

@ehlersdanlosuk

For every element of connective tissue there are genes that encode those elements. For each of those genes there is an associated disorder.

# Resources

- Ehlers-Danlos National Foundation ([www.ednf.org](http://www.ednf.org))
- Ehlers-Danlos Support UK ([www.ehlers-danlos.org](http://www.ehlers-danlos.org))
- Hypermobility Syndromes Association UK ([www.hypermobility.org](http://www.hypermobility.org))
- EDS Awareness' free webinars ([www.chronicpainpartners.com](http://www.chronicpainpartners.com))
- Ehlers-Danlos Today ([www.edstoday.com](http://www.edstoday.com))



Don't give up  
the beginning is always the hardest.

commencearevolution.tumblr.com

A few links from my website:

- "I have EDS, now what?" - <http://strengthflexibilityhealtheds.com/2015/06/04/i-have-eds-now-what-eds-info-links-resources/>
- EDS Exercise & PT resources - <http://strengthflexibilityhealtheds.com/2015/04/07/answers-to-questions-about-exercise-and-eds->

# How to find me

Website & blog: [www.sfheds.com](http://www.sfheds.com)

Twitter - @EDSPatientSol & @SFHEDS

Facebook - <https://www.facebook.com/EdsSolutionsLLC> & <https://www.facebook.com/strengthflexibilityhealtheds>



Instagram - @edspatientsolutions & @strengthflexibilityhealtheds

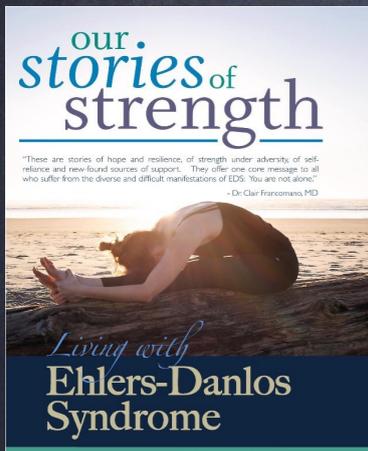
Tumblr - [Activfaith3/StrengthFlexibilityHealthEDS](http://Activfaith3/StrengthFlexibilityHealthEDS)

Pinterest - @StrFLxHLthEDS

Join the Our Stories of Strength movement: Twitter @strengthstories

Facebook: <https://www.facebook.com/OurStoriesOfStrength> [www.ourstoriesofstrength.com](http://www.ourstoriesofstrength.com)

Stay updated on upcoming seminars, find helpful resources, and articles on physical therapy, exercise & other related health information.  
[www.movingnaturallywithhypermobility.com](http://www.movingnaturallywithhypermobility.com)



FIBROMYALGIA

Skin Hyperextensibility

ANEURYSMS

Chronic Fatigue

Anxiety & Depression

Migraines

Chronic Pelvic Pain

Arthritis

Chronic GI Issues

Allergies

RAYNAUD'S SYNDROME

Body Aches

POTS

Dislocations

Scoliosis

LUPUS

SEVERE GROWING PAINS

Living with chronic pain is one of the hardest things that many of us have to endure on a daily basis. Living with pain while also coping with the multi-systemic affects of joint hypermobility, commonly diagnosed as Ehlers-Danlos Syndrome (EDS), is even more challenging. Some of the best approaches for managing chronic pain due to Hypermobility Syndrome/EDS are gaining a solid understanding of how hypermobility can effect the entire body, learning how to move and exercise properly, making healthy lifestyle changes, and finding a strong, positive support system.

Please see resources below for living well with hypermobility.



Hernias

Smooth, Velvety and Translucent Skin

CHRONIC JOINT & LIMB PAIN

Bruises Easily

Widened

Atrophic

Scars

THYROID

Joint Hypermobility

Stay updated on upcoming seminars, find helpful resources, and articles on physical therapy, exercise & other related health information. [www.movingnaturallywithhypermobility.com](http://www.movingnaturallywithhypermobility.com)

[strength/flexibility/health/EDS](http://strength/flexibility/health/EDS)

Health Educator & Life Coach. Speaker & Writer. Info, resources & wellness coaching for individuals, families, and the practitioners who treat them. Website & blog: [www.sfheds.com](http://www.sfheds.com)  
Twitter - @EDSPatientSol & @SFHEDS  
Facebook - <https://www.facebook.com/EdsSolutionsLlc> & <https://www.facebook.com/strengthflexibilityhealtheds>  
Instagram - @edspatientsolutions & @strengthflexibilityhealtheds  
Tumblr - [Activfaith3/StrengthFlexibilityHealthEDS](http://Activfaith3/StrengthFlexibilityHealthEDS)  
Pinterest - @StrFlxHlthEDS



our stories of strength

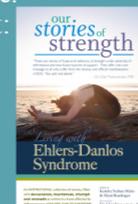
*Our Stories of Strength - Living with Ehlers-Danlos Syndrome* - Debut anthology by Our SOS Media, LLC. Over 50 stories from people living with Ehlers-Danlos Syndrome. Included in the anthology are stories of adversity, misdiagnosis, heartbreak, and devastation turned to strength, determination, and perseverance.

Join the *Our Stories of Strength* movement:

Twitter @strengthstories

Facebook: <https://www.facebook.com/OurStoriesOfStrength>

[www.ourstoriesofstrength.com](http://www.ourstoriesofstrength.com)



Cervical Instability

SLOW WOUND HEALING

Muscle Hypotonia

Dental Problems

Bladder Issues

VERY FLEXIBLE

VERY FLEXIBLE

SLEEP ISSUES

MITRAL VALVE PROLAPSE