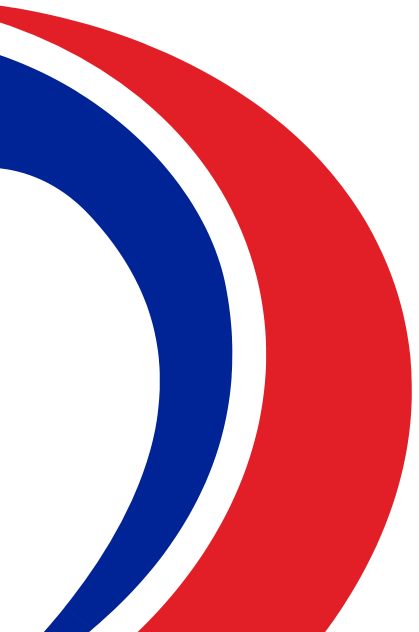


# **Spoon theory: living with chronic illness**



# We don't always look this...

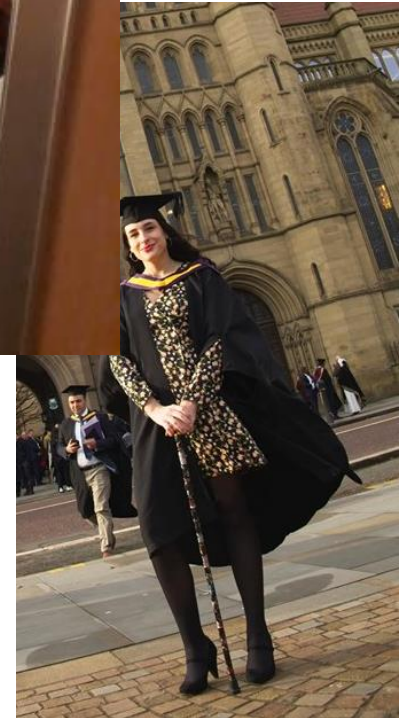
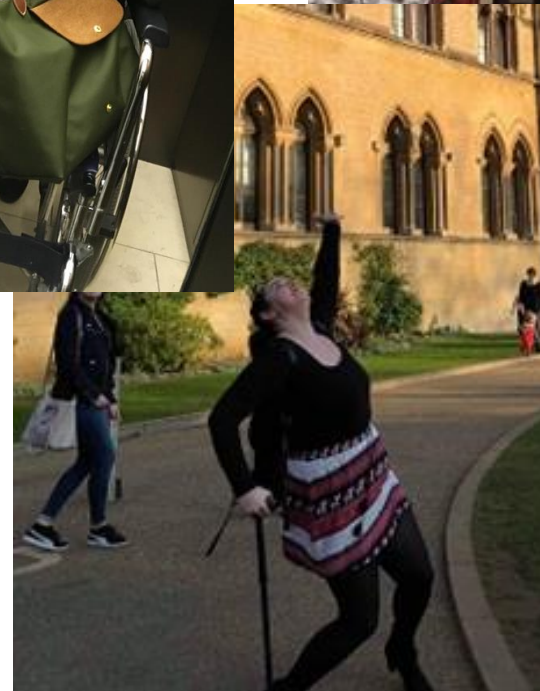
## ...Sometimes we look like this



**Adeline Rosenberg**

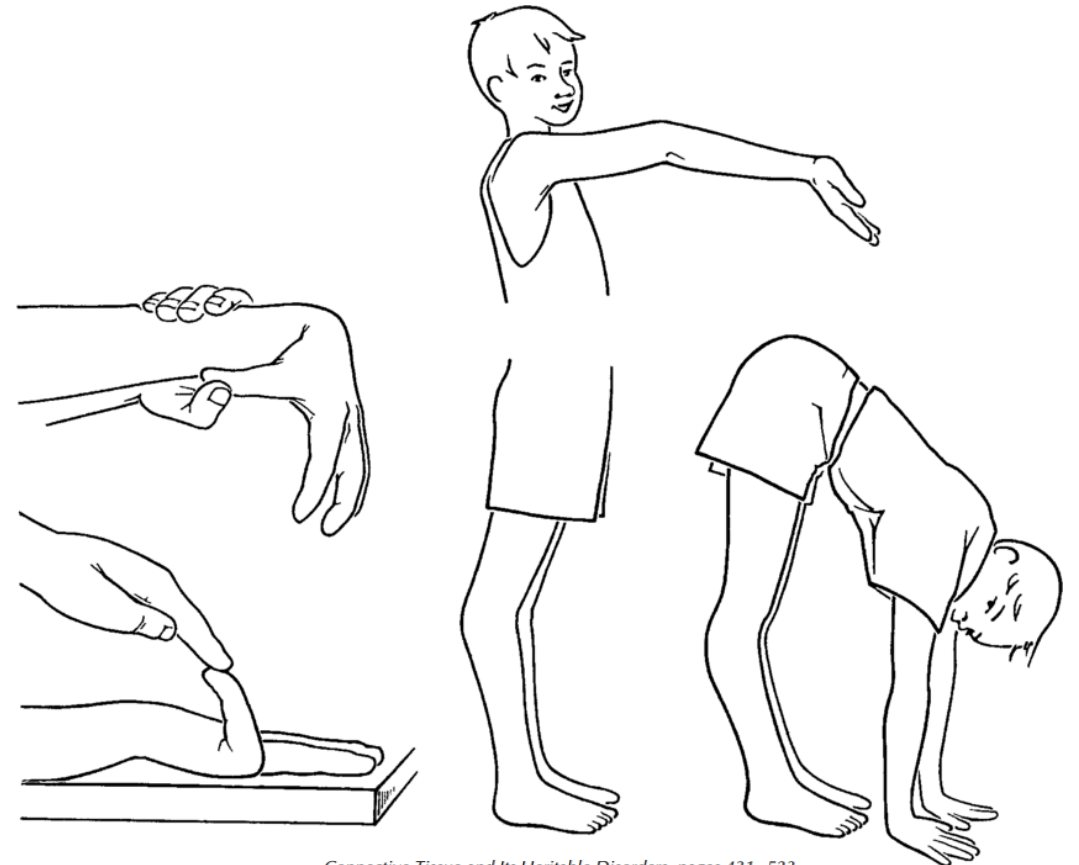


**Francesca Ounsworth**



# Ehlers-Danlos Syndrome (EDS): the science

- EDS is a group of rare genetic connective tissue disorders affecting 1:5,000 – 1:40,000 people globally
- EDS results from collagen deficiencies and abnormalities
- EDS can cause
  - Joint hypermobility, instability and dislocation
  - Skin hyper-extensibility and fragility
  - Gastrointestinal and cardiovascular dysfunction
  - And issues anywhere there is connective tissue (which is everywhere!)



*Connective Tissue and Its Heritable Disorders*, pages 431–523  
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# Ehlers-Danlos Syndrome (EDS): the reality

- Chronic pain
- Chronic fatigue
- Brain fog
- Second-guessing yourself
- Missing out
- **Planning life around illness**



trash baby  
@real\_jellyfish

My doctor confirmed another shoulder subluxation and sent me away with no pain relief I'm - 🙄



Jameela Jamil 🌈  
@jameelajamil

Ehlers Danlos Syndrome means always having people doubt your illness and injuries because you look okay. #edsawareness  
#itisntinyourhead  
#imsorrypeoplearedicks



ru {she/her}  
@chr0nicallycute

about to have an appt with the pain nurse about reducing my meds but let's see if she totally dismisses my csf leak as a migraine....

# What is spoon theory?

- Coined by Christine Miserandino in 2003

**my friend asked me,  
out of the blue,  
what it felt like to have lupus  
and be sick.**

- A widely used metaphor in the disabled and chronic illness community for energy budgeting and planning life around chronic pain and fatigue

**when you're healthy, you  
have a never-ending supply  
of spoons. when you're sick,  
you need to know exactly  
how many spoons you have.**

**i explained that she needed  
to choose the rest of her day  
wisely. when your spoons  
are gone, they are gone.**

**you can't do it all.**

# Resources

- [What are the Ehlers-Danlos Syndromes?, The Ehlers-Danlos Society](#)
- [Ehlers-Danlos syndrome, U.S. National Library of Medicine](#)
- ['The spoon theory' could help you understand Selena Gomez's lupus diagnosis, MTV News](#)