EDS EXPLAINED

Learn about EDS
Social Campaign Designed
to Raise Awareness

a guide for newbies



www.care-e-oke.com



why should you care?

Because you likely know someone affected by EDS or hypermobility and may not even realize it.

Get involved in the Care-e-oke Challenge where you can sing along to your favorite song kareoke style to increase global awareness about Ehlers-Danlos syndrome (EDS) and hypermobility. Our goal is to inspire hope, share information, and drive funding of future medical insights for a condition with life-altering effects with no tests, treatments or cure. Don't look back and wish you did more. Learn from other previously neglected disorders that are more commonly understood today as a result of social awareness campaigns such as autism, MS and ALS. Think ice bucket challenge.

EDS patients need to be heard, understood, given compassion and support to navigate this difficult diagnosis journey. You can foster hope by raising awareness in your community or expand it out to the medical community. We hope to increase knowledge and awareness for current and future healthcare workers globally. Plus it's fun to share and care! Sing out loud and proud for those you care about this May!

@edssharenews EDS SHARE

www.care-e-oke.com

get the 411 on EDS





common symptoms

chronic pain and fatigue

frequent joint subluxation, dislocations or injury, easy bruising

joints moving outside normal range or hypermobility

gastrointestinal issues

brain fog

dizziness or clumsiness

elevated heart rate with autonomic overload

can cause anxiety, depression

spinal instability

www.care-e-oke.com

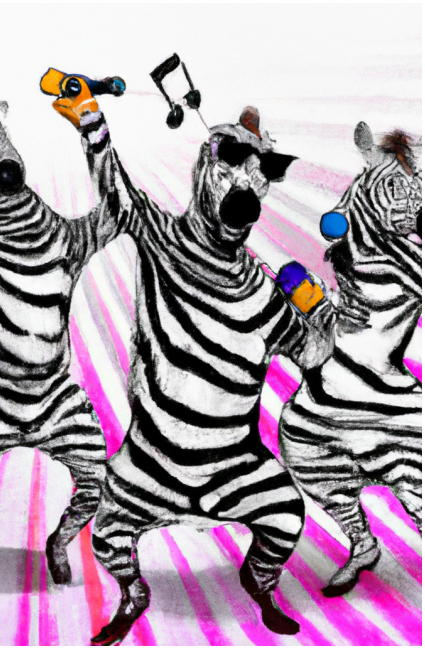
basics to know



Ehlers-Danlos syndrome (EDS) is a complex medical condition that's not easy to explain, but here's a synopsis for those new to this or learning how to help someone they love who is impacted.

There are 13 different types of EDS, hypermobile EDS (hEDS) being the most common with 90% of patients falling in that sub-type according to new research from Tulane University. EDS manifests differently in everyone based on affected organs and symptoms, but the commonality across us all is faulty connective tissue caused by a dysfunction in the body's key protein- collagen.

The impact on the body can vary widely with multi-systemic symptoms in skin fragility, flexibility with joints going out of normal range, tight muscles holding loose ligaments causing pain and chronic fatigue. It can lead to issues in gastrointestinal and/or cardiovascular systems.
Also often presents with neurological or autonomic dysfunction such as dysautonomia or POTS and some allergy-like reactions including mast cell disorders.



Patients often struggle to get diagnosed, averaging 12-14 years of seeing a village of specialized doctors after often being dismissed.

not rare, rarely diagnosed

GETTING DIAGNOSED

To date, the only diagnostic criterion available is the 2017 international classification. It's a doctor checklist to conduct a physical exam with key questions for potentially hypermobile patients. This includes a test called the Beighton Score measuring a few joints for hypermobility. Basically, the higher the score, the more hypermobile the patient presents. Unfortunately for now, it's all we have to test and diagnose hypermobility while scientists search for the genetic markers unknown for this most common type of EDS - hypermobile EDS (hEDS). The remaining types do already have genetic tests available today. For now to learn more about hEDS and Hypermobility syndrome (HSD), check out the nonprofit EDS Society 's hEDS checklist until better resources become available for this misunderstood disorder. No matter the subtype, all EDS patients need to be heard, understood, given compassion and support to navigate the long, arduous diagnosis journey.

EDS is considered a rare disease and the zebra is the symbol for rare diseases so some patients identify with those stripes. We believe it's better to say, "**when you can't connect the issues, think connective tissues**" to expand the aperture of medical trainees. Review resources on what your specialists need to know or tips on getting diagnosed provided by a band of volunteer fellow patients and expert community members.

Some find answers in functional medicine or try a geneticist for an initial diagnosis due to the lack of medical knowledge generally. Many GPs, internists and even rheumatologists had very little training saying it was "a paragraph in med school." The results of years of constantly proving yourself can lead patients to feelings of being gaslighted, medical trauma, estrangement from loved ones and disbelief.



PREVALENCE & PRESENTATION

Treatment varies widely because symptoms affect everyone differently despite the same diagnosis while not ‘looking sick’. The most common type, hEDS is thought to be as frequent as *1 in every 500 people.* (Per the scientific research lab at MUSC). Patients typically present predominantly female commonly former athletic abilities and flexibility to excel in dance or gymnastics. They're also prone to injury and sensory heightened or neurological imbalances on a spectrum.

We're often forced to treat 'worst first.'

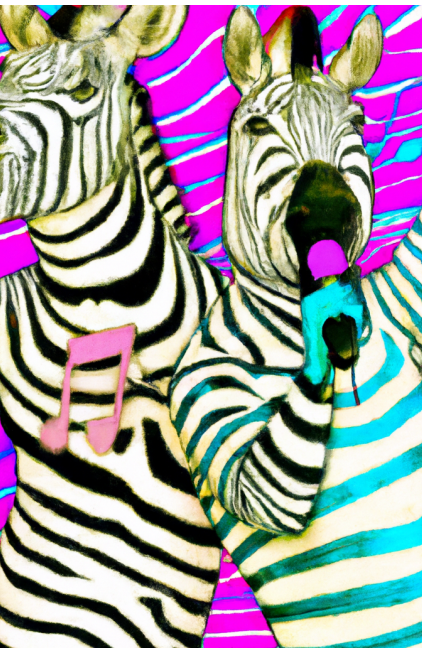
Be aware of the common 'trifecta' of EDS, POTS and MCAS, plus spine issues like CCI and chiari where neurological issues get impacted. Patients often struggle not only with physical issues but emotional and financial burdens in their search for help. Best to be armed with data and these apps can help to track and share info with doctors.

a joint effort

lack of support



Unfortunately it's not just tendons, ligaments and muscles that aren’t well supported. Patients are often dismissed and disbelieved by doctors and loved ones, symptoms thought to be “all in their head.” Simply not true! The medical community must catch up. Governments and academic influencers on budget plans require data-driven research before change can happen.You too can take part in the joint effort to create change for the estimated millions patients and caregivers.



The Care-e-oke Challenge is designed to engage people who know nothing about EDS. **Sing loud, care more, help hypermobility awareness soar!**

help move medicine forward

Patients collaborate on social platforms of every type to share resources, doctors, and connect for support. Here's a list of books on EDS such as the popular *Disjointed* with many experts' input.

Finding expert specialty doctors is hard because **they are rare**!

No good answers on this one. Try starting at this provider list or explore webinars from EDS pioneers. available from several sites and YouTube. The few providers who do treat EDS are usually overwhelmed with long patient wait lists. How can we better resolve this ? How can we as a community connect and move medicine forward?

Here's a start on how to learn more...

- Research credible info - learn how.
- Share free online training for nurses who want to learn more.
- Commit to 1:1 change with programs such as the Rare Compassion program through advocacy nonprofits such as Global Genes.

w w w . c a r e - e - o k e . c o m

what can you do to help?

May is EDS Awareness Month and a great time to join the Care-e-oke Challenge. If you or someone you care about is impacted, learn about the disorder from the collaborative joint effort newsletter.

show & share you care-e-oke



www.care-e-oke.com

INVEST IN HOPE & THE FUTURE OF MEDICINE & SCIENCE

If you're a zebra, find a support group of peers who get it and stay informed with various sites and newsletters of patient curated content at EDS Awareness and The Mighty. Consider crowdsourcing on Patients Like Me and Stuff That Works sharing sites such as Inspire to connect with others.

Join in to spread the word and take action.

Give your time or resources now because someone you know is suffering. Choose to show you care about zebras any way you can. We collected a list of several nonprofits who support EDS patients and doctors through medical research, scientific developments and bands of zebras who leverage technology tools to share resources to find answers faster. Join the collaborative efforts to make it easier to thrive. Stay informed by subscribing to the EDS S.H.A.R.E. (Sending Helpful Articles, Research, and Education) collaborative news to help grow the body of knowledge. Here we band together to share insights, identify patterns in our stripes to find answers faster. Checkout the news archive soon to be searchable. If you have a suggested news article, a blog, a resource or a new medical research publication to share, go here.

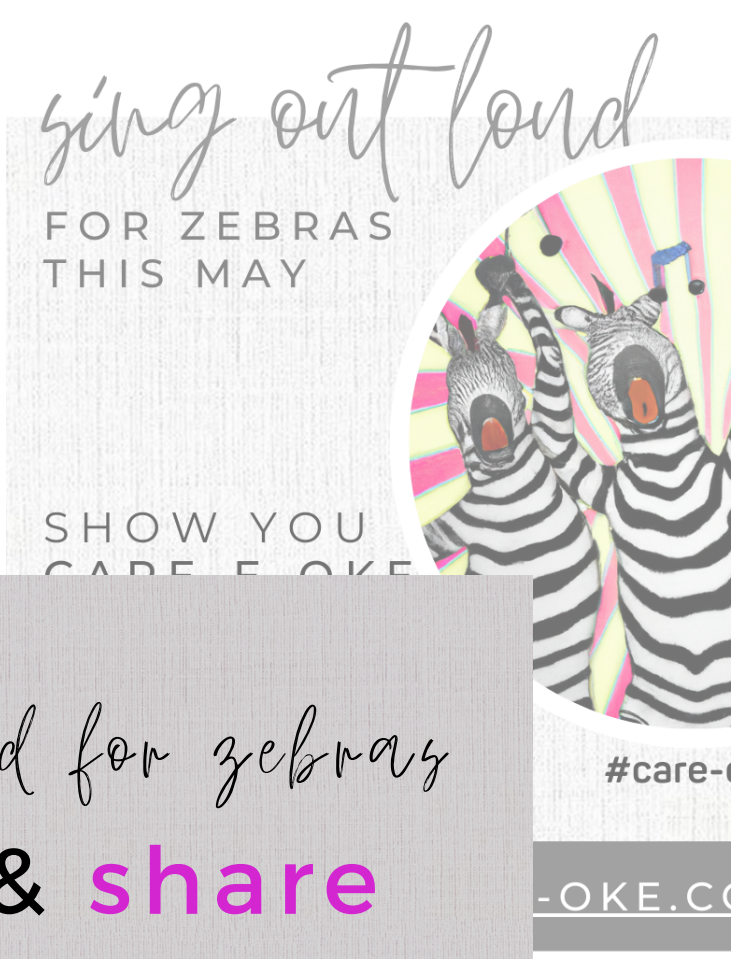
no excuses not to

one-click to donate



- Donate to expert medical research at Bobby Jones CSF
- Support science searching for answers and diagnostic tests at MUSC's Norris Lab
- Complete the survey on the financial burden of EDS on families paid for by EDSRF.org
- Invest in learning about **other EDS-related nonprofits** around the world to help advocates do more to support the EDS community



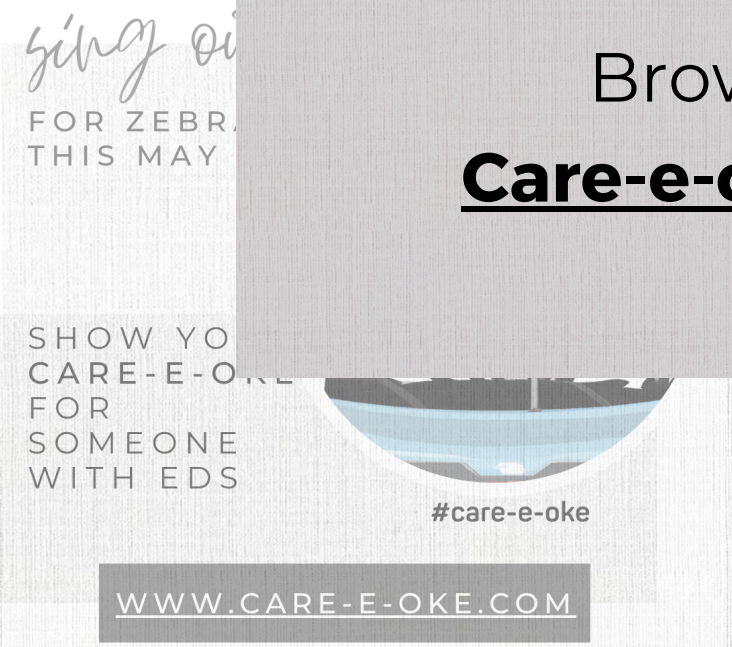


sing out loud for zebras

show & share you care-e-oke

Browse the

Care-e-oke Toolkit



Care-e-oke was produced by a band of zebras to support raising EDS and hypermobility awareness. Together in a joint effort, they share resources on EDS at www.edsshare.com where you can collaborate and contribute to the collection to connect us.

w w w . c a r e - e - o k e . c o m