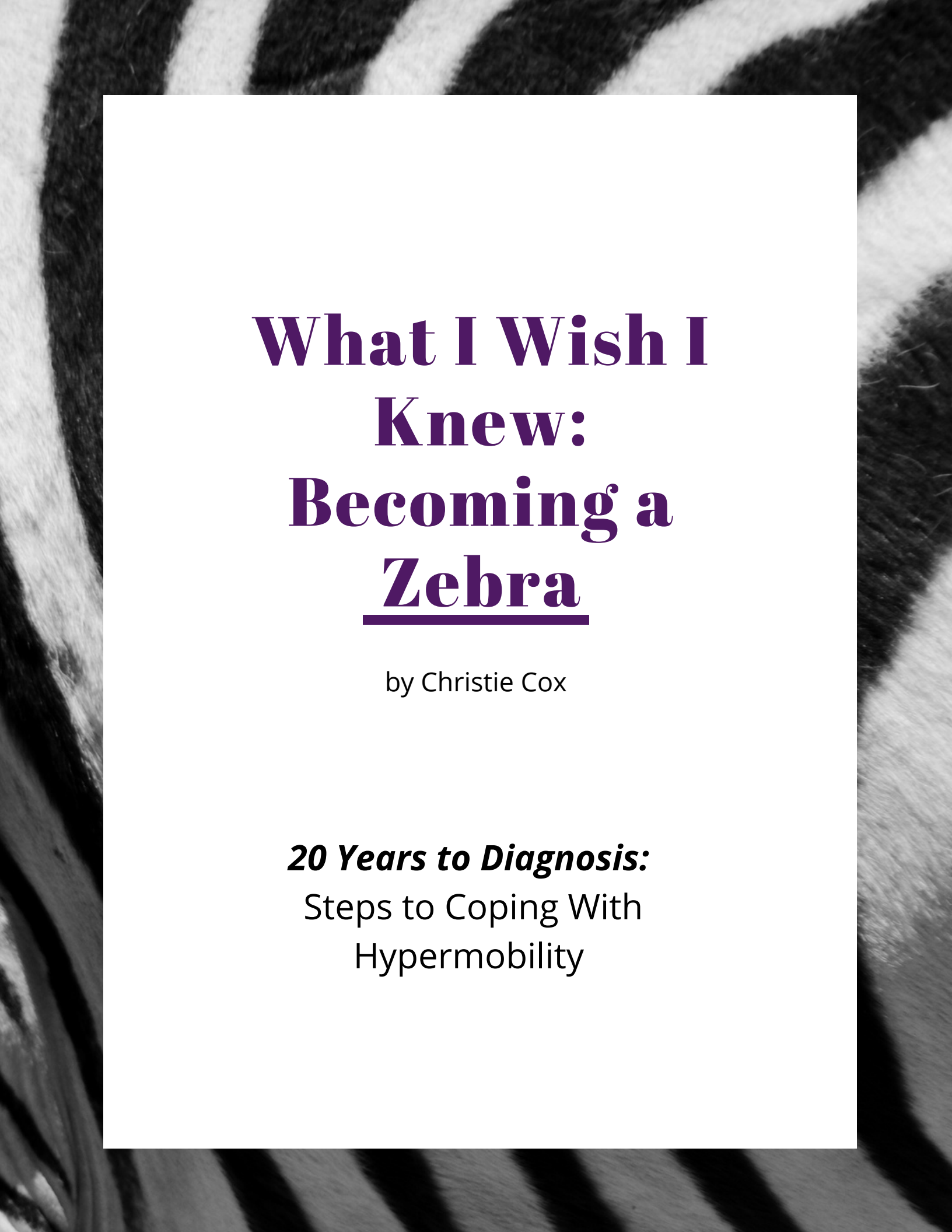


The background of the entire page is a close-up, black and white photograph of a zebra's head and neck, showing the characteristic black and white stripes. The stripes are curved and run diagonally across the frame.

What I Wish I Knew: Becoming a Zebra

by Christie Cox

20 Years to Diagnosis:
Steps to Coping With
Hypermobility

What I Wish I Knew: Becoming a Zebra

First, what is hypermobility?

According to the Hypermobility Syndrome Association (HMSA)...

"Hypermobility is where joints bend further than average, and affects around 30% of the population. Many people live with symptoms which can range from mild to disabling, can affect many of the body's systems (not just the joints), and vary over time."

Hindsight is always 20/20. What I wish I knew about decades ago...

All I wished for back then was to be taken seriously, and not be so easily dismissed by doctors. To be heard and to feel validated by my friends and family who couldn't understand the invisible illness inside me and not only the physical, but the psychosocial effects it had on me. Instead, what I have learned is the resilience and courage to keep trying - to be better. In that lesson I became a what's known as medical Zebra.

Why the Zebra?

Doctors are trained to "look for hoofprints" to find commonalities to determine a diagnosis. Sometimes it's a zebra, a rarity. Hypermobile people have adopted the zebra as their mascot and wear their stripes proudly to represent and protect one another in the herd, known as a dazzle.

What Are Hypermobility Syndromes?

A hypermobile joint can bend beyond the typical range of movement. Many people are hypermobile (about 1 in 10) – and hypermobility is more common in women and children. It is commonly found in athletes, especially gymnasts and dancers. Many hypermobile people have no significant symptoms but some do. For this portion of people hypermobility is accompanied by symptoms called symptomatic hypermobility. Symptomatic hypermobility can be due to:

- Specific heritable disorders of connective tissue, like Ehlers-Danlos syndromes, Marfan syndrome, Stickler syndrome, osteogenesis imperfecta and others.
- Joint shape, looser ligaments, or poor muscle tone (without a connective tissue disorder)
- Other conditions (like Down's syndrome, Cerebral Palsy etc)
- Injury or repeated stretching/training (for example in yoga enthusiasts and gymnasts)

Many symptoms are common to people with hypermobility syndromes and may include: Pain (both acute and chronic), fatigue, dislocations or subluxations (where a joint slips partially out of place), frequent injuries (including micro traumas – slight injuries which may not show up on tests or MRIs, but can occur repeatedly in the same area of connective tissue without completely healing), constipation, reflux and other digestive issues, pelvic floor and bladder issues, fragile skin, and easy bruising.

Zebras are our mascot.

Why are zebras so special?

Each individual animal has its own unique striped pattern – this means that no two zebras in the world are ever the same! Did you know that the zebra's pattern also acts as an insect repellent and a natural sunscreen? Because each one's stripes are unique, zoologists theorize that their stripes may also have a social purpose, helping zebras to recognize one another. In the wild, zebras live in sociable groups called dazzles. Their black and white stripes are unique and are as distinctive as human fingerprints.

Common symptoms are not always obvious and difficult to connect the dots. That why it's often called an invisible disease and can, but don't always include:

- Joint instability, displacements or hyper-extension, sprains, strains, subluxations, and/or dislocations leading to widespread muscle pain and chronic fatigue or loss of mobility
- Stomach and digestive problems (like nausea, reflux and slow stomach emptying)
- Bladder and bowel problems including constipation, diarrhea and IBS
- Autonomic dysfunction including rapid heart rate, POTS (e.g. dizziness, fainting, lightheadedness, difficulty regulating temperature)
- Severe allergies, sometimes related to autoimmune or Mastocytosis immunological disorders
- Poor proprioception (sense of self in space) including neurodiversity and hyper-sensitivity
- Easy bruising and slow wound healing
- Cognitive decline, memory loss and brain fog
- Depression, anxiety, ADHD and/or autism features
- Disrupted sleep or need for more rest to recover if not properly pacing
- Eye and vision issues including convergence

Symptoms vary a lot between people, and also vary over time for each individual. It is common for hypermobility to become symptomatic after something changes that tips the hypermobile body from a level of '*can cope*' to '*can't cope*'. This can be triggered by many things, including injury, illness, viral infection (including COVID 19), stress, pregnancy, or changes in activity levels, job, or home life.

There is no cure for being hypermobile, but there are many things that can help manage symptoms. With the right management, many hypermobile people will find that their lives improve - sometimes beyond what they thought was possible.



Just as every human has a unique set of fingerprints, every zebra has a unique stripe pattern. We are still not entirely sure how the zebra got its stripes, but there are many theories. One is that they may provide a dazzling form of camouflage against predators such as lions. When zebras are moving in a herd, their stripe patterns could make it hard to attackers to pick out individual animals.

Common Patterns in Zebra Stripes Observed

- Many people (not actual zebras in the wild grasslands of Africa) who are correctly diagnosed with hypermobility or Ehlers Danlos Syndrome (hEDS) are predominantly female. **Some studies say as high as 85% of all hEDS patients are women and young girls.**
- Many people have a history of being thin, even lanky, with long arms and legs and often flat feet. **Many are clumsy, young athletes who were prone to injury.** Some are extremely flexible. I always just thought I was good at yoga!
- Initial symptoms are often masked and diagnosed as symptoms. **Uncorrelated symptoms are often very difficult to diagnose and test for.** Many common occurrences include: thyroid dysfunction, blood sugar imbalances, gastrointestinal issues, pelvic floor and prolapse concerns and too often misdiagnosed anxiety and/or depression. In the early days, doctors often have not identified the root cause of hypermobility and a diagnosis can be very hard to get, usually requiring a geneticist or Beighton Scale testing by a knowledgeable medical provider. It took me 17 years following several incorrect root cause diagnoses including autoimmune disease.
- Wellness can become more paramount often **following a life-event change that worsens symptoms such as pregnancy/birth, accumulated chronic stress, injury or even a viral infection, including Covid-19 and Epstein-Barr virus.**

How do zebras protect each other?

Zoologists believe stripes offer zebras protection from predators in a couple of different ways. The first is as simple pattern-camouflage, much like the type the military uses in its fatigue design. The wavy lines of a zebra blend in with the wavy lines of the tall grass around it. Zebras live in open, grassy areas and have several adaptations, or special characteristics that help them survive in their habitat.

Scientists think their stripes serve as sunscreen and bug repellent, act as camouflage, and help them recognize each other.

Galloping Forward Without Falling



Suggestions for Stepping Into Zebra Shoes

- **LEARN AS MUCH AS YOU CAN:** Don't take "I don't know" or "I can't help you" for an answer from your medical providers. Your most important asset is your health. Research solutions, therapies and make necessary appointments with long waiting lists for specialists. It's worth the wait to see someone who gets it. It takes a village to diagnose and treat our multi-systemic issues and packing your patience is vital to the process.
- **DON'T BE DISSED:** Don't give up despite disappointment, disrespect, and oftentimes dismissal from doctors or loved ones. It's called 'practicing medicine' for a reason.
- **GET ENGAGED:** Use the power of the information age to virtually attend webinars, join support groups, and attend educational conferences to engage with peers when you can't travel.
- **JOIN THE HERD:** Locate and participate in support groups. Many online communities can provide immense value and compassionate understanding for the struggles you might face, but don't let it get you down.

What we can learn from certain animals who have adapted to living under pressure.

In the book *Why Zebras Don't Get Ulcers*, a highly acclaimed guide to stress (for humans), Dr. Robert Sapolsky speaks about the latest discoveries in the field of stress physiology. From this wise and witty offering, scientists and nonscientists alike can learn the ways in which chronic stress – the twenty first century's black plague – has become one of the leading proximal causes of death, leading to strokes and heart attacks along with a variety of other sub-optimal outcomes, from decreased immunity to insomnia, anxiety, depression, addiction, obesity, heart disease, and serious memory loss.

But there's good news too. We can also discover the ways in which certain animals like Zebras have adapted to living marvelously well under pressure. According to Sapolsky, these lucky animals tend to have the following in common:

An outlet for frustration
A sense of predictability
A feeling of control
An optimistic outlook
Social support

Source: <https://www.gottman.com/blog/5-things-zebras-can-teach-us-about-fighting-stress/>

What I Wish I Knew: Becoming a Zebra

Becoming a Zebra - How To's

- **SEEK EXPERTS:** There are not very many clinical trials ongoing for hypermobility and hEDS. If they are, they're hard to get into. Work toward identifying research hospitals (like MUSC), the Cleveland clinic and other speciality difficult to diagnose treatment hospitals. Some specialists have EDS-focused clinics like Alan Spanos MD, Clair Francomano MD, Alan Pocinki MD and newcomer Alissa Zingman MD. The system is currently overwhelmed by patients and many do not take new patients.
- **SHARE:** It is paramount to share what works and what doesn't, good/bad, opinions, and any helpful resources with others. Remember, you're not alone! Scientists believe today that hEDS could be found in 1 of every 500 people. That's millions of us, despite the fact that animal zebras are becoming extinct (as of 2021, there are only an estimated 2,400 zebras in the wild).
- **PAUSE:** Sometimes you have to take health hiatus and pause the circumstances of life to get well. This can mean no longer working (but work as long as you are able and learn about disability options), being a primary caregiver, and so much more. But if you cannot care for yourself, you will not be able to care for others.
- **SUPPORT:** Do what you can to advocate, fundraise or bring awareness to the plight of hypermobility, EDS and its common comorbidities like dysautonomia and mastocytosis.
- **FOCUS:** Remember, it is best to stay resilient in problem solving mode. When you don't have the answers, keep looking. Do not give up!
- **REACH OUT:** When in doubt, work through it with a fellow patient (learn more about why zebras hug on the next page). Support is critical and skill building in calming yourself, and leaning on others will restore your sanity.
- **WHEN ALL ELSE FAILS:** Focus on eating when you're hungry and sleeping when you're tired. That's it, for now, until the flare passes. It's usually a flare and it too will pass. Try to maintain a positive outlook and take one breath at a time.

The Future of Healthcare

Following the global COVID-19 pandemic, there is a more robust focus on wellness, investment in treatments, an increase in patient advocacy and support of enhanced patient rights. There is U.S. legislation funding similar chronic illness many people have been diagnosed with like long Covid and viruses that cause inflammation leading to disease. Remain hopeful! Crowdsource your care with others using sites like PatientsLikeMe and StuffThatWorks.

The Zebra Lifestyle: Commonalities with Animals in the Wild

Like other hoofed animals, such as horses and giraffes, zebras have locking joints (unlike our hypermobile human ones). This means they can subconsciously lock their knees into position and doze without worrying about falling over. This adaptation has many benefits: it ensures the zebras are alert to predators and can escape quickly if threatened. However, to achieve deep sleep, zebras do need to lie down.

Zebras are herd animals, sort of social butterflies by nature. These dazzling animals bond by scratching and grooming each other with their teeth. They communicate with each other through facial expressions and loud braying, snorting, and barking sounds. The “zebra hug” (shown in the photo below from Bryan Moore) ensures that no predator can sneak up on them since, as each is looking in the opposite direction, together they have a full 360 degree view of the plain around them. This behavior is less about camaraderie than it is about survival. They get tiring standing out there on the plains all day, especially during the hottest part of the day. It would be great to sit or lie down but that is very dangerous with lions, cheetahs, leopards, and hyenas on the prowl. So, zebras will stand astride resting their head on their neighbors back or neck. This takes the strain off their neck while still maintaining their diligence in looking for predators while they both look out for each other, much like medical zebras do.



The social support we medical zebras give each other can be a true source of vitality – making an impact far beyond our in-the-moment emotional or physical state. Rather than bottling up our frustration until we feel hopeless, helpless, and totally haywire we can reach out to each other to gain access to coping skills, empathy, and validation that can increase our feelings of control and to endure a positive outlook. It is only when we feel truly seen, heard, and understood that we are soothed, lowering each other’s levels of stress hormones and cortisol, working together to weather the storm. In this way, we can live better, enjoying not only radically improved sense of self, but longer, healthier, and happier lives.

Long live the zebras!

Suggested Apps for Pattern Tracking

It's vital to have documented evidence of symptoms when you see doctors. Here are a few apps that help you manage that process easily.

-  **Medisafe** (<https://www.medisafeapp.com/>) – a simple medication management tool with reminder for seamless management of tracking what you take, when
-  **Flaredown** (<http://flaredown.com/>) - is a trigger tracking app where you check-in daily to give a brief update on your conditions, symptoms, treatments, the health factors that have affected you and to give a final summary of that day so you can pick up on trends
-  **Pip Stress Tracker** (<https://thepip.com/>)– personal stress management tracking device
-  **MyFitnessPal** (<https://www.myfitnesspal.com/>) – simple app journal for weight tracking, food, exercise and daily water daily consumption
-  **My ID** (<https://shop.getmyid.com/>)- great basic medical app that allows you to store all your relevant medical information, including your conditions, medications, insurance information can be shared with first responders
-  **Endive** (<https://endive.app/>) is an app that allows you to document and track each meal you eat and any gut health-related symptoms for IBS and more. It helps monitor triggers you pick up on, then is compiled into a weekly report for you to look back over to review and analyze patterns
-  **Day One** (<https://dayoneapp.com/>) - is a journaling app that gives you a clear and easy way to document anything you'd like to keep tabs on including voice notes, photos or even videos along with the text
-  **MyLinks** (<https://www.mylinks.com/>) – is a free application to help you gather, manage, and share all of your personal health records from one secure location, fully under your control
-  **Manage My Pain (MMP)** (<https://managemypainapp.com/>) is a great app if you suffer from any form of chronic pain and can be used to document the severity of your pain

Get insights from fellow patients, doctors and
community leader advocates!

The Ultimate Guide to Dealing with Hypermobile EDS

You might be a zebra but you're not rare or alone anymore. In her book, ***Holding It All Together When You're Hypermobile***, Christie Cox offers an in-depth exploration of the invisible chronic illness of hypermobile Ehlers Danlos Syndrome (hEDS). After facing and learning to manage the many life-altering changes that accompany hypermobility and its comorbidities, Christie discovered that despite our different symptoms that the diagnosis can carry the same burdens - emotional, physical, financial. Join the dazzle by subscribing for updates on the 2022 publication and gain access to hundreds of hEDS resources at www.holdingitaltogether.com.

A community of support is growing, and hypermobile EDS is becoming more recognized. Many community members joined Christie in the development of her book including fellow patients, medical experts and advocates as a crowdsourced effort including patient inspired cover art. For zebras suffering with hEDS, this book shares a proven path to help you overcome, to foster wellness and find peace with the diagnosis. Her book explores the basics of hypermobile EDS, it's common comorbidities, tips on getting diagnosed, coping strategies, lifestyle changes, and tons of other resources on how to get help. It also delves into the future of scientific medical research, in search of tools for earlier diagnosis and treatment, and how to foster a positive mindset in the face of despair. Ms. Cox provides the tools needed to get back to work or school, build confidence with medical insights from specialists, and empower yourself with knowledge that will change your life for the better.



Christie

Christie Cox was always bendy and sometimes witty. It wasn't until she was properly diagnosed with Ehlers Danlos Syndrome at 48 years old that she understood her quirkiness. Following decades of unrecognizable and untreatable health issues, since learning of her condition she has gone from being disbelieved to determined. Ms. Cox now devotes her focus, energy, and passion to supporting others facing a similar fate. She lives outside Washington DC with her husband, John, and their dog, Rodeo. When she isn't busy researching solutions to chronic health concerns for herself and her clients, she loves being in nature and enjoys the outdoors. To learn more about Christie, or to access her free patient resources and to engage with her inspiring patient health advocacy, visit her business website at www.journey2joyous.com.

