

<http://tiny.cc/edsguide>

Disclaimer: I'm no expert, I'm just a complex chronic illness patient with a desire to help others. Keep in mind that I'm in the US, this is a work in progress, and this is just what I've found and works for me. YMMV. Always do your own research and consult your healthcare professionals.

Just so you know where I'm coming from I'm an AFAB millennial diagnosed with hEDS, ME, POTS, MCAS, IBS-C, dyshidrotic eczema, cough variant asthma, ASD, ADHD, narcolepsy, and I'm sure others that I'm forgetting. 😊

Note to self on how to link table of contents:

You select the destination text and click insert > bookmark and give it a name. Then you go to the text you want to be able to click on and insert a regular link, but instead of a website address you just start to type the name of your bookmark and select it.

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To add: Blurbs about adenomyosis, hysterectomy, medical debt. Write one about lipedema.

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Seeking diagnosis and/or testing:

Ehlers-Danlos Syndrome

- <https://alanspanosmd.com/wp-content/uploads/2022/03/The-EDS-Predicament-and-How-To-Get-Throu-gh-It.pdf>
- Diagnosis
 - hEDS accounts for 90% of cases
 - hEDS genes unknown at this time
 - hEDS is a clinical diagnosis based on <https://www.ehlers-danlos.com/heds-diagnostic-checklist/>
 - Criterion 1 is flawed
<https://www.medrxiv.org/content/10.1101/2022.04.25.22274226v1.full>
 - Skin hyperextensibility <https://imgur.com/a/GsAyaRF>
 - Any physician CAN technically make this clinical diagnosis, but most WON'T.
 - Rheumatologists should be the specialty for EDS, but gold standard in the US is geneticists
 - <https://clinics.acmg.net/>
 - Not listed: <https://atwalclinic.com>
 - Waitlists of multiple years is normal
 - Many are refusing to see patients for suspected EDS
 - Facebook groups
 - <https://www.ehlers-danlos.com/healthcare-professionals-directory/>
 - Clinical Geneticists are medical doctors (MDs) who have specialized training in Genetics. That means that they did an additional fellowship in Genetics after completing their residency. They also have to pass a board exam given by the ABMGG.
 - Genetic counselors have a Masters degree that focuses on genetics and counseling skills. They have to pass a board exam given by the ABGC. Because they're not doctors, they can't do procedures or physical exams or diagnose diseases.
 - Genetic testing is done in a laboratory on a sample of tissue, often blood, cheek swab, or saliva. But they may also be done on samples of hair, skin, amniotic fluid, or other tissue. Once it arrives at the laboratory, a technician looks for genetic changes.
- Genetic testing only
 - Mainly used to rule out other types of EDS or HCTD
 - 90%+ chance it will come back negative
 - <https://www.ehlers-danlos.com/wp-content/uploads/2017/03/eds-types-chart.jpg>
 - * Inheritance Pattern: AD = autosomal dominant; AR = autosomal recessive
 - https://wikimsk.org/wiki/Ehlers_Danlos_Syndrome
 - Suspected vEDS: <https://www.fightveds.org/genetic-test-form>
 - <https://www.genomemedical.com/> works with Invitae. See also <https://www.invitae.com/us/patients/order/genome-medical>
 - Can be ordered by any physician
 - <https://www.invitae.com/en/providers/test-catalog/test-434340> (doesn't include TNXB for cEDS1)
 - <https://www.invitae.com/en/providers/test-catalog/test-02313> (doesn't include TNXB for cEDS1)
 - <https://www.genedx.com/> (does offer testing for TNXB/cEDS1)

Craniocervical instability

- CXA
- Grabb-Oakes
- Horizontal Harris
- Flexion/extension imaging
 - Commonly used with a high false negative rate

- Digital motion x-ray/vertebral motion x-ray
 - Not usually covered by insurance, seen as kinda hokey.

Atlantoaxial instability

- Atlantic dens interval

Lipedema

- Wtf even are the diagnostic criteria??

Adenomyosis

- Most doctors will miss it on ultrasound
- Diagnosed via MRI with contrast
- Or hysterectomy pathology

I feel like everyone knows about endometriosis, but have you heard of adenomyosis? I hadn't until I was diagnosed with it, despite it affecting a whopping [20.9% of AFABs](<https://academic.oup.com/humrep/article/27/12/3432/652839>). It's incredibly under diagnosed, and often misdiagnosed as fibroids, but symptoms include:

- Menorrhagia (heavy bleeding)
- Dysmenorrhea (painful periods)
- Dyspareunia (painful intercourse)
- Metrorrhagia (irregular periods)
- Polymenorrhea (prolonged bleeding)
- Enlarged uterus, often globular
- Anemia
- Fatigue
- Weight gain
- Depression
- Infertility
- Chronic pelvic pain
- Chronic back pain
- Chronic leg pain
- Bloating
- Distension
- Frequent urination

Now, wtf is adenomyosis? It's endometrium (uterine lining) within the uterine *muscle*, where it's not supposed to be. The problem with this is that just like the endometrium, these cells thicken, shed, and bleed each month. However, since this tissue isn't supposed to be in the muscle, it doesn't always have a way to drain.

If you're thinking this sounds a lot like endometriosis, you're correct. Adenomyosis is so similar that it used to be called endometriosis interna. The difference is that endometriosis is located outside of the uterus. However, there's a trifecta between adenomyosis, endometriosis, and fibroids. If you have one, you're much more likely to have at least one of the others.

Unfortunately, don't assume that because you've had ultrasounds, biopsies, and/or photos that it will be caught. Radiologists and doctors often fail to notice it on ultrasounds and unless the biopsies/photos were of the myometrium, which can only be done *after* a hysterectomy, it's not possible to see. The gold standard for diagnosis in the US is an MRI.

Myalgic Encephalomyelitis

- Varying criteria, ugh

Narcolepsy

- Will not be caught on a "regular" sleep test
- Requires MSLT or lumbar puncture to diagnose
- <https://www.morethantired.com/>

Autism

- Getting diagnosed didn't get me services or help
- Can't even get any accommodations for it
- Only really helped to learn more about myself
- When used as an explanation, not an excuse, it can help to diffuse misunderstandings and get people to treat me kinder
- Was impossible to find someone who diagnosed adults and took my insurance nearby. I had to travel and estimate costs at \$500 (circa 2017) even though I stayed in network and live in the capital city of the second largest state.
- Probably easier now with telehealth being more common
- Gap exception.
 - <https://www.verywellhealth.com/network-gap-exception-what-it-is-how-it-works-1738418>

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## Clinics:

- Denver/Anschutz
  - [https://gates.cuanschutz.edu/research-focus/ehlers-danlos-syndrome-\(ed\)](https://gates.cuanschutz.edu/research-focus/ehlers-danlos-syndrome-(ed))
- Austin, University of Texas
  - <https://uthealthaustin.org/conditions/hypermobility-syndromes>
- Tulane Hypermobility Clinic
  - <https://hypermobilityclinic.org/>
  - Sketchy, unethical?  
[https://www.reddit.com/r/ehlersdanlos/comments/18rcej6/could\\_a\\_vitamin\\_deficiency\\_cause/](https://www.reddit.com/r/ehlersdanlos/comments/18rcej6/could_a_vitamin_deficiency_cause/)
- Cleveland Clinic
  - Cardiovascular Marfan & Connective Tissue Clinic
  - <https://my.clevelandclinic.org/departments/heart/depts/cardiovascular-marfan-connective-tissue>
- Mayo (fuck you!)
  - <https://www.mayoclinic.org/diseases-conditions/ehlers-danlos-syndrome/care-at-mayo-clinic/mayoclinic-20362179>
  - Phoenix and Scottsdale, Arizona; Jacksonville, Florida; and Rochester, Minnesota
  - "Mayo had SUED patients who qualified for charity care over their medical debt." Charity care is reduced or waived bills.  
<https://www.healthcarefinancenews.com/news/allinas-medical-billing-practices-under-investigation-minnesota-ags-office>
- University of Michigan
  - Motility disorders clinic GI department
  - MCAS clinic
  - Vouched for by u/EngineeringAvalon in r/eds
- DFW - UT Southwestern
  - <https://utswmed.org/conditions-treatments/ehlers-danlos/>
- Casa Colina
  - <https://www.casacolina.org/programs-services/ehlers-danlos-syndromes/>
- Washington/Nevada/Oregon
  - <https://www.theedsclinic.com/>

- Brigham and Women's
  - <https://www.brighamandwomens.org/medicine/genetics/genetics-and-genomic-medicine/hypermobility>
- Kennedy Krieger POTS Clinic
- Center for Complex Neurology in Phoenix, AZ
- Stanford ME/CFS Clinic in Atherton, AZ
  - <https://med.stanford.edu/chronicfatiguesyndrome/patient-care.html>
- Mount Sinai Jeff Wood Paolo Bolognese, NY
  - <https://chiarieds.com/>
- Dr. Klinge
- Good Hope Toronto

ME/CFS Clinics:

<https://med.stanford.edu/content/dam/sm/chronicfatiguesyndrome/documents/List%20of%20Clinics%2012152015.docx>

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Sensitive skin:

- National Eczema Association (NEA)
 - Great for sensitive skin even if you don't have eczema
 - Products: <https://nationaleczema.org/eczema-products/>
 - Blue e on packaging
 - Bleach bath: https://nationaleczema.org/wp-content/uploads/2017/06/FactSheet_BleachBath_FINAL.pdf
- Get nitty gritty with ingredients: <https://incidecoder.com/>
- Unscented > fragrance free > with scent/fragrance
- Stuff geared towards infants/babies is often gentler on the skin in general, regardless of NEA approval
- Cleansers > "true" soap (with lye)
- Alcohol is very drying to the skin.
- Use warm water, not hot. Rinse with cold water.
- Hydrocolloid bandages are amazeballs, help me heal faster, better, and the adhesive doesn't bother me. Utilizes moist wound healing. Unfortunately on the expensive side.
- Adhesives can be very damaging to our skin
 - Avoid with
 - liquid bandage
 - Coban (that stuff that sticks to itself like after a blood draw) aka vet wrap
 - Tubular stretch bandage/dressing (solid or net)
 - If adhesive can't be avoided
 - Skin barrier prep! You can get it in wipes or spray.
 - Smith & Nephew
 - Regular
 - Alcohol free version
 - Safe n' Simple
 - Skin Tac
 - Medline
 - Removal
 - Isopropyl myristate (best)

- Goo gone bandage adhesive remover
 - <https://a.co/d/3gHtolQ>
 - Unisolve
 - Alcohol (drying)
 - Acetone (drying)
- Shaving
 - Ditch the expensive piece of shit cartridges for a classic wet shave
 - Double edged (DE) safety razor
 - Cheaper, too!
 - ProSaro sensitive line
 - Pre-shave
 - <https://a.co/d/iqz5Ace>
 - Shave
 - Soap: <https://a.co/d/g3IGVHD>
 - Foam: <https://a.co/d/bgj637a>
 - Cream: <https://a.co/d/hUmHAhR>
 - After shave
 - <https://a.co/d/b7aKzgx>
 - DIY frugal aftershave recipe:
 - 1/2 C witch hazel (Thayer's brand is the only one I know of that's alcohol free)
 - 1 T vegetable glycerin
 - 1 T aloe gel
 - Hot sauce bottle makes a great dispenser
 - <https://maggardrazors.com/>
 - r/wicked_edge
- Zinc supplements
 - Can be harsh on the stomach
 - <https://a.co/d/2jaZG0K>
 - [Link to study between zinc and eczema. Where are you? I can't find you! 🤔]
- MCAS treatments
 - https://www.mastcellaction.org/assets/_/2021/05/26/1c98bdeb-2081-4b5f-94ae-21ed9d3f2394/mcas-treatments-website.png
- Put a layer of petroleum jelly on top of your moisturizer to make it more effective.
 - See "slugging."
- Sunscreen
 - Very important, but we're prone to sensory issues and autism is a common comorbidity.
 - Brush on block, powdered sunscreen: <https://a.co/d/ccunTz1>

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Gear/products:

Please see other sections for specific gear recommendations.

- Joint braces
  - Braces can be invaluable for people with EDS. They are seriously under-used for these patients, mainly because of the bias against braces when over-used for orthopedic injuries. That bias is based on two perceptions. One is that a brace contributes to weakness by reducing the need for muscular support of the braced joint. The other is that undue

immobilization promotes stiffness due to soft tissue contractures. Both these are fatuous when applied to a patient with a joint that is permanently and irredeemably loose because of mechanical inadequacy of its supporting ligaments. The joint can't be used effectively at all, if it repeatedly displaces during movement. But with a brace, it becomes usable again, thereby giving the patient the ability to use the joint, hence to build up strength and prevent stiffness. The strategy is therefore quite different than that of using a brace to restrict movement in one plane, so tissues can heal after a sports injury. By contrast, in hypermobility syndromes the point of the brace is not to restrict active movement, but to permit it.

- See <https://alanspanosmd.com/wp-content/uploads/2022/03/Physical-Therapy-Exercise-Braces-for-People-with-EDS.pdf> now <https://web.archive.org/web/20240122151831/https://alanspanosmd.com/wp-content/uploads/2022/03/Physical-Therapy-Exercise-Braces-for-People-with-EDS.pdf>
- Bauerfeind is a great brand for us
  - <https://www.bauerfeind.com/b2c/Health/Guides/How-Bauerfeind-Can-Help-With-Ehlers-Danlos-Syndrome/c/ehlers-danlos-syndrome>
- Ring splints
  - See if your insurance covers them
  - <https://www.silverringsplint.com/wp-content/uploads/2016/10/Letter-of-Medical-Necessity-of-Multiple-Finger-Orthosis1.pdf>
  - <https://www.silverringsplint.com/consumers/insurance-coverage/>
  - <https://www.zebbrasplints.com/product-page/swan-neck-ring-splint> hurt me. I need a wider and flatter band to disperse pressure.
    - Open ends catch on things, especially hair!
  - Oval 8s
- Aspen Vista multipost therapy cervical collar
- Shoulders and hips are hard to brace
- Three categories
  - Over the counter (OTC) - prefab, no rx needed
  - Off the shelf (OTS) - prefab, rx needed. Usually acquired through an orthotist or DME company
  - Custom
    -
- Hanger Clinic! Renowned orthotists.
- I've tried
  - Bregg fusion knee braces. 🙄
  - Donjoy Armor 👍
  - Donjoy Female Fource 👍👍
- Compression
  - Especially abdominal and upper legs for POTS
  - I like Jobst brand
  - Biofect is a popular brand, but my skin didn't like the "wavy" interior.
  - Reusable "rubber" dishwashing gloves makes pulling on full leg compression a snap
  - Custom compression is a thing
- Toothpaste
  - Livfresh <https://a.co/d/9l61UBm>

- In EDS, the connective tissue that forms gums and enamel can be weak. This causes the enamel to wear out more easily ("soft teeth"), the gums to break down faster, and tissue longer to heal.
- Use a toothbrush with soft bristles and an enamel-protecting dental gel such as LIVFRESH®.
- Traditional toothpastes are abrasive and remove plaque by scrubbing teeth. In contrast, LIVFRESH® breaks up the plaque by repelling bacteria from the tooth surface and prevents bacteria from reattaching to teeth for a longer time. LIVFRESH® is backed by several double-blind clinical studies that document its efficacy as a toothpaste replacement, to dramatically reduce plaque, gum inflammation, and bleeding. A recently published 2019 study also documents its efficacy in reducing pocket depths, a key marker for periodontitis.
- LIVFRESH® is made of all edible products and does not contain any abrasives. It is offered in foaming and non-foaming versions. For people with EDS, we recommend using the color-free, non-foaming version, which does not contain any artificial colors or detergents. Users might feel that they are brushing with mildly flavored water, but the product is efficacious, and users with EDS have reported improved oral health within a month of using the product twice a day.
- -Pradeep Chopra, M.D.
- Buy Livfresh on Amazon (US): <https://a.co/d/cFiJQFO>
- The study he mentioned: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6938303/>
- Another study since then: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8033283/>
- Who is this guy?
- Dr. Pradeep Chopra is the Director of the Pain Management Center of Rhode Island. Dr. Chopra is double Board Certified in Pain Management and Anesthesiology by the American Board of Anesthesiology. Dr. Chopra completed both his Anesthesia residency and his Fellowship in Pain Management at Harvard Medical School.
- Dr. Chopra holds the prestigious appointment of Assistant Professor (Clinical), Department of Medicine, Brown Medical School, Division of Biology and Medicine, and Assistant Professor of Anesthesiology (Adjunct), Boston University School of Medicine.
- Dr. Chopra has a keen interest in both acute and chronic pain management. His approach to treatment of chronic and complex pain states is multi-disciplinary and multi-modality, and is designed to get patients to a point that allows them to do the things they want to do and not let pain take over their lives. He has a special interest in managing complex pain conditions such as Complex Regional Pain Syndrome (CRPS), Reflex Sympathetic Dystrophy (RSD), and connective tissue disorders such as Ehlers-Danlos Syndrome (EDS).
- A list of Dr. Chopra's numerous awards, publications, presentations, and videos can be found at his website at: [painri.com](http://painri.com).
- Stickman Comics
  - Cute, but expensive and maybe not very practical in everyday conversation.
  - <https://stickmancommunications.co.uk/product-category/keyring-cards-product-type/>
- Storage clipboard
  - Great for appointments
  - See handling medical appointments section
  - <https://a.co/d/hH12qDx>
- Medical alert bracelet
  - Silicone ones are cheap and avoid metal allergies
  - Make sure it's a bracelet
  - Nothing fancy like a QR code or USB drive, at least not as your only medical alert
- Shower stool/chair
  - Reduce fatigue
  - POTS

- <https://a.co/d/eR826oP>
- Detachable flexible shower head
- Under cabinet jar opener
  - Allows you to use both hands on the bottom
  - <https://a.co/d/ctipgml>
- Bar height chair
  - For seated kitchen work
  - <https://a.co/d/d8i0Fq8>
- Pill organizer
  - Might as well make it a fun sensory experience
  - <https://a.co/d/jifni9g>
- Smart watch for tracking heart rate, sleep, etc.
  - Kinda disappointed in my Fitbit Luxe
  - Liking Pixel Watch 2
  - <https://workwellfoundation.org/wp-content/uploads/2023/01/HRM-Factsheet.pdf>
- Home vital minoring
  - Thermometer
  - Blood pressure monitor
    - Wrist ones hurt me less
  - Pulse oximeter
- Tuning fork to rule out a break, not rule in
  - 128Hz
- Right angle glasses/lazy readers
  - Save your neck
  - <https://a.co/d/4N2FAJE>
- Squatty potty
  - Bowel health
  - <https://a.co/d/gaizpgn>
- Kinesiology therapy tape
  - See skin section about adhesives
  - I need to try more brands to find one that doesn't destroy my skin
    - Kinesio, light touch?
    - Rock tape?
- Phone ring holder
  - <https://a.co/d/9jorPSO>
  - Better than popsocket
- Miralax (generic name: polyethylene glycol 3350)
  - For IBS-C
  - I stand by my wife's description of "angelic"
- Neck doohickey (Occipivot)
  - <https://a.co/d/dyyLHio>
  - "Occipital release"
- TENS machine
  - <https://a.co/d/cXorqKM>
- Battery fan
  - <https://a.co/d/dG5bp0f>
- Body braid
  - <https://bodybraid.com/pages/hypermobility-eds>

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Mobility devices:

- Canes
 - ? shape puts your hand right over the length of the cane
 - Chair cane (cane with a seat, great for fatigue and POTS)
 - <https://a.co/d/85gNLQM>
- Crutches
 - Smart Crutches are popular
 - <https://imgur.com/a/W1KB21w>
- Walkers
- Rollators (rolling walkers)
 - Can come with a seat
 - Can come with footrests
- Wheelchairs
 - Transport
 - Can only be pushed
 - Can't self propel
 - Manual
 - Power assist add-ons
 - Electric
 - Great turning radius
 - Fold n Go is a popular brand
 - Power seating options
 - Tilt
 - Recline
 - Leg elevate
 - Lift
 - Hard to transport! Heavy af.
- Mobility Scooters
 - Lighter
 - Cheaper
 - More portable, some break down into pieces
 - Horrible turning radius
- Miracle Mobility 4N1 Multifunctional Electric Walker Wheelchair
 - <https://miraclemobility.com/product/miracle-mobility-4n1-ultra-lite-multifunctional-electric-walker-wheelchair/>
- Health equipment lending programs. Might also be referred to as medical equipment lending closet.
 - <https://findhelp.org>

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## Wheelchair specifics:

- When it's time
  - <https://youtu.be/9EZtjSadqy8>
- YouTube video recommendations for choices and measurements:
  - <https://youtu.be/VdgLeB63Q14>
  - <https://youtu.be/Wjj2BHZKiP4>
  - <https://youtu.be/gz6WzSlxNdE>

- [https://youtu.be/YDOb\\_ni3Q0Q](https://youtu.be/YDOb_ni3Q0Q)
- <https://youtu.be/CTrl-QwgTdw>
- 
- Transporting a wheelchair
  - Public transit
  - Paratransit
  - Hitch mounted wheelchair carriers
    - <https://www.discountramps.com/info/automotive/understanding-limitations-hitch-mounted-carriers/a/b183/>
  - WAV vans
  - <https://medmartonline.com/scootatrailer-mobility-carrier>
  - <https://www.scootatrailer.com/>
  - <https://www.bruno.com/scooter-lifts/chariot>

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Energy Conservation

- Three types of energy
 - Physical
 - Mental (like cramming for a test)
 - Emotional (drama)
- Work smarter not harder
- Being too hot or too cold takes energy
- Digesting food takes energy
- Standing takes more energy. Sit when possible.
- Reaching is energy intensive.
 - Put less used things higher or lower.
 - Use long handled tools when applicable
- Easier to stand up from a higher seated position
- Flushable litter
 - World's Best Cat Litter brand
 - Don't have to bag it up
 - Don't have to take it out of the home
- Emptying dishwasher
 - Gather like things before putting away
 - Remove silverware holder and take to drawer
- Showering
 - Lukewarm water
 - Vent on to remove hot steamy air, which is hard to breathe
 - Shower stool
 - Robe
 - Long handled sponge
- Sit to stand
 - Scoot to edge of seat
 - Tuck feet as far back as possible
 - Lean forward

- Use momentum of leaning forward to move forward
- Straighten
- Don't hurt your wrists helping yourself up
- Standing
 - Don't lock your knees
- Posture/ergonomics
- Curbside pickup
- Look up a map of where you're going or what aisle to find things on to reduce aimless wandering

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#### Accommodations for work

- <https://askjan.org/info-by-role.cfm#for-individuals> Employee section, about 2/3 of the way down
- <https://askjan.org/disabilities/Ehlers-Danlos-Syndrome.cfm>
- Learn your rights under the ADA
- ALWAYS file with the EEOC (expect them to do nothing, though)
- keep meticulous records
  - get things in writing
  - Covertly audio record if in one party consent state
- Learn about FMLA and anything your state might have.
- <https://askjan.org/> in general
- Don't expect your employer to have your back, or to know shit about the law.
- HR is there for your employer, not you
- Look into your state's voc rehab and disability rights orgs, too.

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Handling medical appointments:

- Blood draw/IV
 - If prone to vasovagal reactions:
 - Lie down
 - Ice pack on face/neck
 - Battery fan
 - <https://a.co/d/dG5bp0f>
 - Emesis bag
 - Keep pressure dressing on for 30 minutes instead of 10-15
 - Make sure pressure dressing is relatively tight
 - Smallest possible gauge. Butterfly or pediatric needle isn't always possible, it can cut the blood cells or medication
 - No fishing! Make them repeat this to you before they commence.
 - No students/in training
 - Someone should stretch the surrounding tissue to make it taught so the veins don't roll and be less painful
 - Elbow veins are less likely to roll than back of the hand veins
 - Be uber super duper hydrated
 - Use heat or slap the skin to help the veins be more prominent
 - Use a red light to see the veins more prominently
- If you're in a one party consent state, you can record the conversation.

- I'd recommend doing this covertly and audio only.
- Ignore any signage that says you can't record if your state laws say you can. It's just a sign.
- If brain foggy, I go in with a list of things I want to touch on.
- Some questions I found that I think are great to ask in many situations are:
 - What are the chances this will help me?
 - What are the chances this will harm me?
 - What are the alternatives?
 - What happens if we do nothing?
- Use numbers where possible like time, pain (scale 0-10), effort, sleepiness, fatigue, etc.
 - Mankoski Pain Scale
 - <https://www.painscale.com/article/mankoski-pain-scale>
 - Epworth sleepiness scale
 - <https://www.mercy.net/content/dam/mercy/en/pdf/fatigue-severity-scale-epworth-sleepiness-scale-questionnaire.pdf>
 - Fatigue Severity Scale
 - <https://www.mercy.net/content/dam/mercy/en/pdf/fatigue-severity-scale-epworth-sleepiness-scale-questionnaire.pdf>
 - Rate of perceived effort (RPE)
 - ME/fibro functioning scale
 - http://cfselfhelp.org/files/rating_scale.pdf
 - https://me-pedia.org/wiki/Questionnaires_and_tools_to_assess_ME/CFS_symptoms_or_severity
 - http://www.cfselfhelp.org/library/type/log_forms_worksheets
- Answer or tell about things when they're at their worst.
- Creating good medical records:
 - <https://howtogeton.wordpress.com/2019/08/01/how-to-have-great-visits-that-create-great-records/>
- Storage clipboard
 - I take it to appointments
 - It's got a clipboard for writing/filling out paperwork
 - It's got storage for documents
- Documents I tend to bring
 - Printed out up to date med list
 - Providers get a list of everything I've gotten through insurance for the past 8 years which has 30+ no longer applicable meds
 - Copy of my EDS/POTS/MCAS/IBS-C diagnoses
 - A "resume" of important health info
 - Mostly for my brain fog
 - Name
 - Date of birth
 - Address
 - Insurance info
 - **Major diagnoses and their corresponding ICD-10 codes**
 - Code for hEDS is Q79.62
 - I use Q79.60, which is unspecified Ehler Danlos because I have a FBN2 mutation
 - New code for POTS as of Oct 1, 2022: G90.A
 - New code for myalgic encephalomyelitis as of Oct 1, 2022: G93.32
 - Surgeries/procedures
 - Treating providers and their info
 - Practice paperwork (filled out ahead of time and on the computer, if possible)

- Referral/records/results like bloodwork or imaging
- State medical records release form
 - Texas:
 - <https://www.texasattorneygeneral.gov/sites/default/files/files/divisions/consumer-protection/hb300-Authorization-Disclose-Health-Info.pdf>
- Flowchart on what pharmacy to send meds to
 - I'm a dork
 - You don't need to do this
- Forms I need signed
- If you need forms filled out and signed, fill it out yourself as much as possible!
 - Makes sure it gets done right
 - Less work on them
 - Might save you bullshit paperwork fees
 - Bring a blank copy just in case
- If you need a letter, you can write it yourself!
 - Makes sure it's done right
 - Less work for them
 - Leave room for a letterhead
 - Leave room for a signature
- If you get pushback, ask *why*. Oftentimes I've found that they either have a perfectly good reason, or they're a POS you don't want to be seeing them anyway.
 - "Help me understand..."
- Again, if you're in a one party consent state, you can covertly record the conversation.
- If you're not very assertive, it might be helpful to invent an overbearing friend or family member that REALLY wants you to look into this and just won't shut tf up until you get checked out for it.
- If you are quite assertive and they turn you down, tell them to document that they turned you away. Apparently this has a high success rate of making them behave.
- I also find it helps to be like "this is on my radar and I want to find out if I have or don't have this" and state that your end goal is really to get answers, feel better, improve your quality of life, or whatever.
- Make it clear that this is just a stepping stone and you're not invested in a particular answer or diagnosis, but the *right* answer or diagnosis.
- "I'm experiencing [whatever,] and I'd like to figure out the cause and relieve it. Also, you should know that I have hypermobile Ehlers-Danlos syndrome, which is a connective tissue disorder, and it often causes [whatever] in this specialty, so we'd like to make sure we consider that in addition to whatever else you think is important."
- "We've been advised to do [whatever] test as a rule-out, which will help us diagnostically even if it's negative." We found physicians seemed to be more relaxed about the workup if they knew a negative result on a test would still be an important input to another specialist.
- What patients should do to prepare for different types of specialist appointments when traveling, in order to make the most of the time there:
 - http://shayahealth.com/resources/TCAPP_EDSWorksheet%20.pdf
- Fax
 - more secure than email
 - also more universal as opposed a separate patient portal for each provider
 - Don't usually get set up with a patient portal until after your first appointment
 - Record of it being sent
 - Faxzero.com
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## Health Insurance Tricks

- Rundown on US healthcare terms and important questions to ask when choosing insurance:  
<https://vaden.stanford.edu/insurance-referral-office/health-insurance-overview/how-us-health-insurance-works>
- Another rundown and types of plans:  
<https://www.uclahealth.org/patient-resources/billing-insurance/how-health-insurance-works>
- <https://www.verywellhealth.com/reimbursement-2615205>
- Asking a doctors office if they “accept” your insurance is not the correct wording. They can accept it on an out of network basis. Offices won’t be up front unless you ask specifically, because they want you to book an appointment.
- Whatever answer you get, verify with your insurance. Dont just look online, or go by ZocDoc, for example. Both of those places are often out of date or straight up put there under false pretenses.
- Get a prescription for anything/everything to count towards your out of pocket maximum
  - <https://www.verywellhealth.com/how-to-save-after-out-of-pocket-maximum-1738986>
  - OTC meds
  - OTC braces
  - OTC compression
- Gap exceptions
  - <https://www.verywellhealth.com/network-gap-exception-what-it-is-how-it-works-1738418>
- Medications often cheaper than places that take your insurance:
  - <https://costplusdrugs.com/>
  - Probably won't count towards your out of pocket maximum
- CPT codes
  - Ask providers for them
  - Look them up
  - Reference them when contacting insurance
  - Useful for paperwork
- I had a chat bot write me an appeal letter, and it was fantastic
  - <https://poe.com/ChatGPT>
  - You can tell it, "write me a health insurance appeal letter. I have x insurance. They denied me x. I believe it should be covered and will save them money in the long run because x, y, and z."
- <https://forms.dollarfor.org/?aid=social&sid1=dollarfor>
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Long Term Care Insurance

- Get it, ASAP.
- <https://lifelifehappens.org/long-term-care-insurance-101/>

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## Recommended reading:

<https://www.standinguptopot.org/iv-saline>

<https://alanspanosmd.com/articles/>

<https://howtogeton.wordpress.com/>

Muldowny PT Book

<https://www.pdfdrive.com/living-life-to-the-fullest-with-ehlers-danlos-syndrome-guide-to-living-a-better-quality-of-life-while-having-eds-e176209559.html>

<https://www.kobo.com/us/en/ebook/disjointed-1>

<https://edswellness.org/anesthesia-surgery-alerts-for-ehlers-danlos-syndromes-eds-and-related-disorders-linda-bluestein-md/>

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Useful links:

https://www.reddit.com/r/Damnthatinteresting/comments/um7ys8/electron_microscopy_picture_of_normal_colagen/

<https://edsdiagnoses.glideapp.io/dl/a400f7>

<https://web.archive.org/web/20220930021932/https://www.ehlersdanlos.ca/pharmacological-considerations-in-ehlers-danlos-syndrome/>

<https://www.stuffthatworks.health/ehlers-danlos-syndrome>

<https://bearable.app/free-chronic-illness-resume/>

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Other Random Shit

- <https://docdro.id/LC1ssJS> PT4ME pdf
- TSA
  - <https://www.tsa.gov/contact-center/form/cares>
- Funeral industry is a scam, see: <https://funerals.org/>
- How to address kids (or even adults, you don't owe them your medical history) asking about mobility aids:
  - "I'm okay 😊 Everybody's body is different and some people need a little bit of help sometimes. Some people wear glasses to help them see better, some people use hearing aids to help them hear better, and some people use wheelchairs, walkers, crutches, and canes to help them move around from place to place. I am one of those people and you might have other people in your life who use these special tools too! Do you have friends or family who use any of these things? These tools can help us spend time with the people we care about and do the things that we love, my [mobility aid] helps me be here with all of you!"
- USPS Mail door delivery
  - <https://faq.usps.com/s/article/If-I-have-Hardship-or-Medical-Problems-how-do-I-request-Door-Delivery>
  - <https://about.usps.com/forms/ps1528.pdf>
- Inclined bed therapy

- Service Dogs
  - Make sure the place is Assistance Dogs International (ADI) certified!
    - <https://assistancedogsinternational.org/main/looking-for-an-assistance-dog/>
    - Will rarely cost money in my experience
- Contraindicated treatments
  - Steroids break down connective tissue
  - Prolotherapy is contraindicated for us because of our fucked up healing processes (for example: atrophic scars). We also tend to be on NSAIDs and/or narcotics because of the pain, which are further contraindicated. See <https://orthopedicreviews.openmedicalpublishing.org/article/33921-a-comprehensive-update-of-prolotherapy-in-the-management-of-osteoarthritis-of-the-knee>
  - Platelet rich plasma (PRP) injections: 78%-90% of us have at least one platelet function abnormality (<https://www.sciencedirect.com/science/article/pii/S1538783622029543>). Add in issues with hypovolemia and POTS/dysautonomia in the creation of PRP with increased risk of bleeding at injection sites.
  - Avoid drugs that increase your risk of bleeding—such as anticoagulants and antiplatelet agents—because those affected with EDS are at higher risk for bruising and injury. The Food and Drug Administration (FDA) also recommends avoiding fluoroquinolone antibiotics if you have EDS because of an association of this class of medication with the occurrence of aneurysm.
  - These drugs increase the risk of prolonged bleeding
    - NSAIDS
    - NAPROSYN
    - HEPARIN
    - TORADOL
    - IBUPROFEN
    - ANAPROX
    - SEPTRA -DS
    - CORTICOSTEROIDS
    - ASPIRIN
    - BACTRIM- DS
    - FIORINAL
    - PERCODAN
    - MOTRIN
    - PREDNISON
    - See <https://web.archive.org/web/20220930021932/https://www.ehlersdanlos.ca/pharmacological-considerations-in-ehlers-danlos-syndrome/>
  - Ice, see: <https://www.drmirkin.com/fitness/why-ice-delays-recovery.html>
- [www.dysautonomiasupport.org%2Fwp-content%2Fuploads%2F2023%2F03%2FA-Beginners-Guide-to-Evaluating-Research-2023\\_compressed.pdf](http://www.dysautonomiasupport.org%2Fwp-content%2Fuploads%2F2023%2F03%2FA-Beginners-Guide-to-Evaluating-Research-2023_compressed.pdf)
- PEACE and LOVE: [https://www.physio-pedia.com/Peace\\_and\\_Love\\_Principle](https://www.physio-pedia.com/Peace_and_Love_Principle)
- Clinical trials: <https://www.mayo.edu/research/clinical-trials/diseases-conditions/ehlers-danlos-syndrome/>
- All Comorbidities
  - <https://edsdiagnoses.glideapp.io/dl/da19fa>