

How To Have Effective Doctor Appointments

By: Shani Weber, M.S.



Topics

- Building your medical team.
- Preparing for appointments.
- Tips for your in-person and telehealth appointments.
- Emergency Room (ER and A&E) and hospitalizations.
- Patient best practices.



What Is A Medical Team?

- There is not one doctor or medical specialty that can investigate and treat every symptom types of EDS and HSD can cause, as well as comorbid conditions.
- We must build our own medical teams with specialists appropriate for the symptoms we each have.
- The symptoms you have determine which medical specialties you need on your medical team.



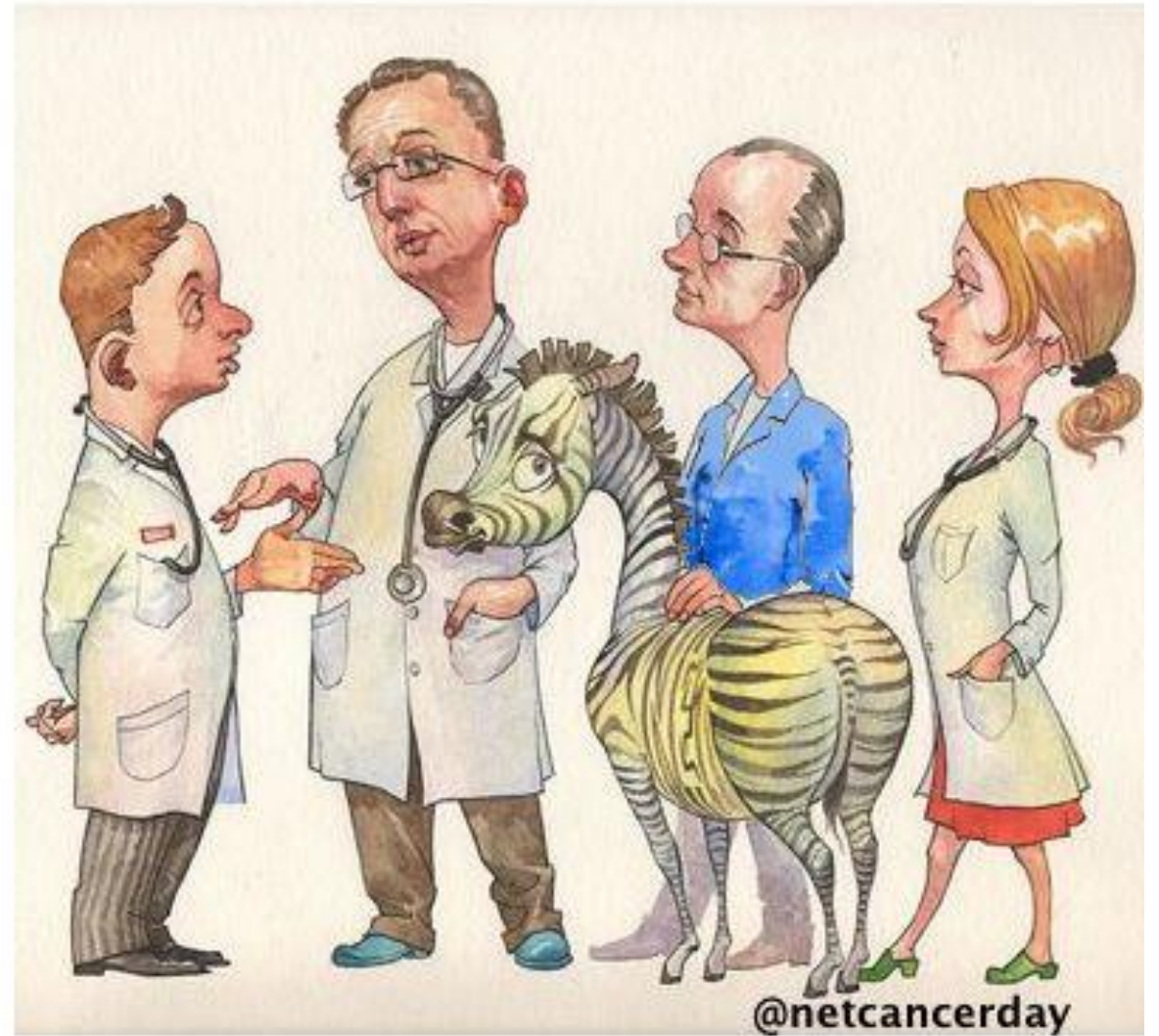
You Are The Medical Team Captain

- You are the most important member of the team because it is your body.
- You need to make sure each doctor on your medical team is kept up to date with your health and treatments other doctors are doing with you.
- It is up to you to lead and manage your medical team.



What Makes A Good Doctor?

- Ability to connect dots
- Interest in learning new things
- Wanting an equal doctor-patient relationship
- Communicator and collaborator
- A good listener
- A good problem solver



What Makes A Good Patient?



- Takes charge of their health
- Active participant
- Seeks support when needed
- Aware when adjustments need to be made
- Leaves emotions at the door
- Comes prepared and on time
- Willing to try treatment options
- Honest

How To Find Doctors For Your Medical Team

Get recommendations from:

- Family
- Friends
- EDS and HSD Organizations like The Ehlers-Danlos Society
- Local support groups:
<https://www.ehlers-danlos.com/affiliates-support-groups-and-charities/>





Then Decide Who Will Be On Your Medical Team

- Is this doctor familiar with EDS and HSD or willing to learn?
- Is this doctor open to questions?
- Do you feel you and this doctor can work together?
- Do you want to add this doctor to your Medical Team?

How Do You Get The Help You Need

- Have reasonable expectations.
- Collect data.
- Create a goal.
- Prepare an appointment agenda.
- Communicate with your doctors effectively.



Have Reasonable Expectations

Unreasonable

- I want to be pain-free.
- I want all of my doctors to be EDS experts.
- I want a cure today.
- I want immediate access to my doctor.
- I want my doctor to run 100's of tests until the answer is found like Dr. House.
- I want to tell my doctor my life story and every symptom.

Reasonable

- I want my pain low enough for me to function.
- I want my doctor willing to learn about EDS and to be curious.
- I understand there is not a cure for EDS yet.
- I understand the limitations of modern medicine.
- I will focus on one or two symptoms per appointment.



Develop An Appointment Goal

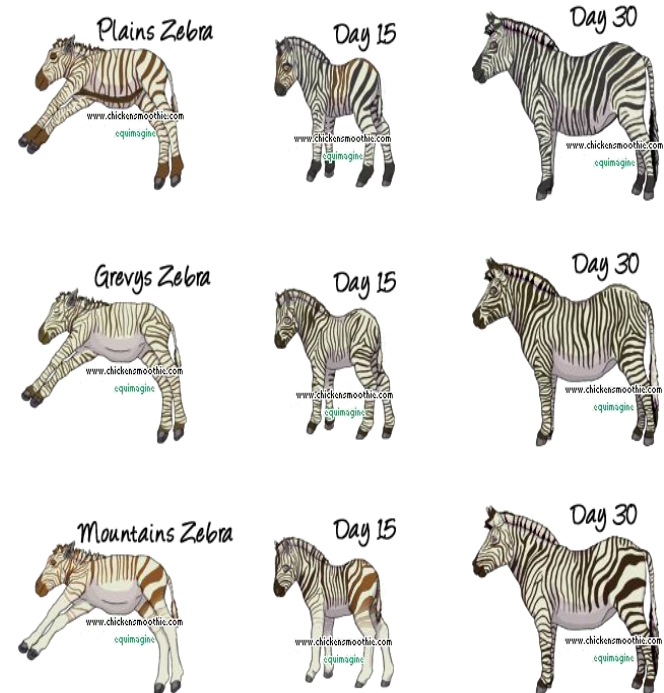
- Your appointment goal is the reason for your visit.
- Your goal is what you will discuss at your appointment.
- Your goal is how you will direct your medical care.

**Your appointment goal is
decided by you.**



Collect Data So You And Your Doctor Know:

- What symptoms you have?
- What triggers your symptoms?
- What makes your symptoms worse?
- What you have tried to treat your symptoms?
- How well (or not) does that treatment work?



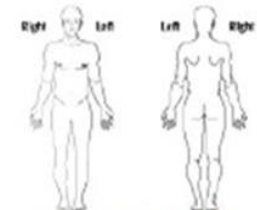
Patient assessment: Pain and symptom diary



SYMPTOM DIARY



This diary can be used to record your symptoms, when they occur and what you did to treat them. It can be taken to your health care appointments to help explain the symptoms you are experiencing. If your symptoms are not relieved by your treatment, call your health care provider.



Use this diagram to show the location of your pain

Date and Time	What is your symptom? <i>Name the symptom and location. Describe the symptom and use the number scale above</i>	What were you doing when the symptom started or got worse?	Did you take medication or try other treatments? <i>If so, what, and how much?</i>	How did they work? <i>Rate the symptom, describe it and use the number scale above</i>	Other comments, issues or side effects?

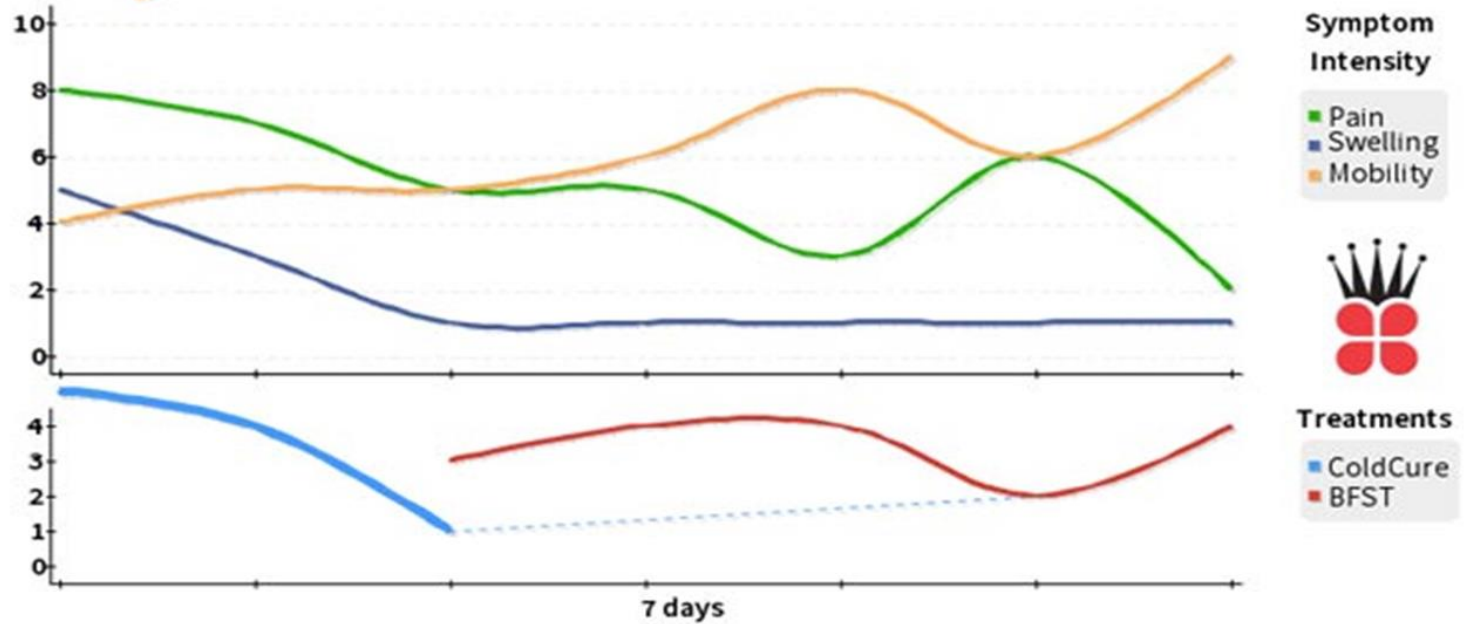
Reviewed April 2009

Adapted from: AGS Panel on Persistent Pain in Older Person. *American Geriatrics Society, J Am Geriatr Soc* 2002; 50: June suppl

Sample Symptom Chart

Graphs of Your Data Can Share Information Quickly.

kingbrand



You Can Track Your Symptoms With An App

iOS

- Symple
- CatchMyPain
- Flaredown
- My Pain Diary
- PainScale
- Chronic Pain Tracker
- FibroMapp
- WebMD Mobile Pain Coach
- Ibeatpain for teens



Android

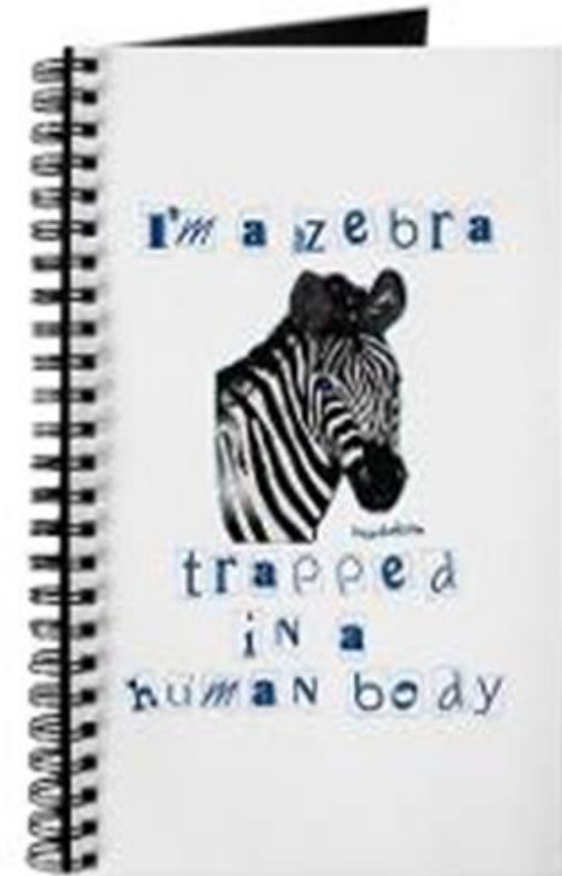
- CatchMyPain
- My Pain Diary
- Flaredown
- Manage My Pain
- Chronic Pain Tracker
- FibroMapp
- WebMD Mobile Pain Coach
- Symple
- PainScale

Create Your Appointment Agenda

An Appointment Agenda helps you communicate with your doctor quickly about your appointment goal and supporting data. Create a new Appointment Agenda for each appointment.

List:

- Appointment goal
- Medications and relevant history
- Timeline of symptoms and new symptoms
- What you tried for treating and how that worked
- Samples, pictures, or short video of symptoms



Sample Appointment Agenda

Date: 3-28-20 Doctor Seen: Dr. Smith Weight: BP: HR:

Goal: Determine cause and review treatment options for increasing dizziness.

Diagnoses: Hypermobile Ehlers-Danlos Syndrome, Osteoarthritis

Current Medications: Tramadol ER 300mg/day, Vit. D3 2000IU/day

Health issues new since last visit: Becoming dizzy as many as 7 times per day, especially when standing for more than 10 minutes. Reported symptoms to pain management specialist Dr. Jones on 1-16-20.

Treatment tried and results: Consuming 80oz of fluids per day, salting my food, and compression hose with no improvement in dizziness.

Notes:

Questions: 1. Should I buy a blood pressure monitor? 2. Can you recommend one? 3. When should I seek emergency medical care with this symptom?

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At Your Appointment

- Provide a copy of your Appointment Agenda to your doctor and have a copy for yourself to write notes on.
- State your appointment goal, i.e., the reason for your visit.
- Share your collected data, either a chart or from an app.



At Your Appointment

- Bring a family member or friend as an advocate and extra pair of eyes and ears if possible.
- Take notes during the appointment or ask to record the appointment. It is too hard to remember everything.
- Ask written questions ~ but limit to a few for more effective appointments.



Be Specific



- Nature of symptoms
- Frequency
- Functional impact

Example: Instead of saying, “I have headaches”, say “In the last month, I have had seven headaches all at the base of my skull with stabbing pain above my eyes which disrupted my sleep and ability to drive”.

At Your Appointment, Remember...

- Your doctors are experts of the human body and you are the expert of you.
- You are not looking for validation, but are looking for problem solving.
- Your focus needs to be on information sharing, identifying priorities, and deciding upon solutions.
- You need to be a good time manager to meet your appointment goal.



At The Appointment, This Is Key

- Be open to trying different treatment options.
- If you say no to everything proposed, then the doctor's toolbox of treatment options is empty.



Telemedicine Appointments

Prepare for telemedicine appointments the same way you prepare for in-person appointments.



Advice From Doctors For Telemedicine Appointments

- Understand that the appointment is best for documenting what is going on.
- When possible, take your own vitals before the appointment, such as blood pressure, temperature, pulse-oxygen readings, glucose levels, etc.
- Keep the appointment focused on your appointment goal. These appointments are not the time to take your doctor on a tour of your remodeled kitchen or newly finished basement.



Emergency Room (ER)/A&E



The role of the Emergency Room (ER) and A&E are to *stabilize* patients:

So patients can be referred back to their local doctors.

or

So patients can be admitted into the hospital.

Go To The ER Or A&E When You Have These Or Other Emergent Symptoms:

- Chest pain with vomiting or shortness of breath.
- Sudden and sharp abdominal, chest or pelvic pain.
- Unexplained or unceasing bleeding.
- Difficulties with breathing or circulation.
- Difficulties speaking or partial paralysis.
- Loss of vision.
- Sharp flank pain.
- Broken bones.





Do Not Go To The ER Or A&E, But Schedule An Appointment With Your Doctor If...

- Your symptoms can wait for you to see your doctor.
- You know the problem but want the ER to give you pain medication.
- Your doctor has not figured out what the problem is yet so you are hoping Dr. House is in the ER who will do all the testing to figure it out.
- You are well enough to ask on Facebook or other social media, “Should I go to the ER/A&E?”

If Admitted Into The Hospital, Bring:

- Your list of doctors, medications, surgeries.
- An advocate ~ family member or friend (when permitted).
- A bag with a book or things to do to pass time.
- Comfortable clothing.
- A favorite pillow.
- Insurance information.
- Emergency contacts.
- Your phone and charger.



Remember Your Regular Checkups



- Annual physicals
- Dental
- Eye appointments
- Vaccinations
- Bone density
- Gynecological/mammograms/colorectal
- Cholesterol and blood pressure screenings
- Investigate with your doctor any new symptoms

Do not assume every new symptom is due to EDS.

Beware Of Red Flags

- Communication issues
- Condescending attitude
- Unable to answer questions
- Unwillingness to discuss concerns
- Unwillingness to explore treatment options
- Disrespectful
- Not respectful of time

Not all Doctor-Patient relationships are productive ~ Consider parting ways if yours is not working.

***Note: These behaviors can be exhibited by both doctors and patients**



Patient Tips – Do These



- When scheduling, request the 30-minute or longer appointment slot.
- The earlier in the day the appointment is scheduled, the less behind schedule the doctor will be (thus the less time you spend waiting to see the doctor).
- Know where the office is and plan to arrive early to fill out paperwork.
- Keep prescriptions through one pharmacy.

Patient Tips – Do These As Well

- Understand the limits of the medical world: tests, images, prescriptions, and surgeries.
- Know your rights as a patient.
- Thank your doctors, nurses, and staff when they provide good service and care.





Patient Tips – Don't Do These

- Don't bad-mouth other doctors to your doctor. The one exception is if you are reporting about a doctor this one refers patients to...but report in a clinical way and not a “victimized” way.
- Don't lie about how you are taking medications or using treatment options.
- Don't take it personally if your doctor is discussing weight or lifestyle choices. The doctor is sharing information on known risks to health.



Patient Tips – Some More Don't Do These

- Don't assume a prescription or surgery is the solution for all problems. Sometimes PT, OT, or alternative options will provide better outcomes.
- Don't assume that your doctor can solve all problems in one appointment. Identify the most pressing problem early in the appointment.
- Don't expect doctors to read EDS and HSD articles during the appointment. Only bring articles from scientific, peer-reviewed journals or international or national patient organizations and not from Wikipedia, Blogs, or Social Media posts.

Thank You

To learn more about having the effective appointments, you can watch my webinar on the Ehlers-Danlos Society's YouTube channel.



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I hope you get the care you need.