



Create More Effective Doctor Appointments

More than 100 tips you can start using today!

By: Shani Weber, M.S.

How Do You Get the Help You Need?

- ? Build a great medical team
- ? Have reasonable expectations
- ? Collect data
- ? Create a goal
- ? Prepare an appointment agenda
- ? Communicate with your doctors effectively
- ? Teach your doctors about EDS
- ? Understand the roles of hospitals, the ER, your PCP, and specialists



What is an EDS Medical Team?

There is not one type of doctor who can assess and treat all the symptoms EDS can cause. So we need to build our own medical teams with the specialists who can help us feel better and live better with EDS.



EDS Medical Team

Team Captain: You

You are the most important member of the team!



It is up to ***You*** to lead and manage your team!

Other Members of Your Medical Team

- ❑ Primary Care Physician: Manages general health care and makes referrals to specialists
- ❑ Specialists: Varies by how EDS affects you – Your symptoms dictate which specialists you need
- ❑ Other Medical Providers: Physical Therapist, Psychologist, Pharmacist, etc.



What Kind of Specialist Do You Need?

The world of medicine has become evermore specialized. Here is a great website for learning about many of the different types of specialties as well as descriptions of each:

<https://www.bioexplorer.net/types-of-doctors/>



How Often Do You See Your Medical Team?



- ? You may see your PCP every 3, 6, or 12 months to monitor your health and care needs
- ? You will see some specialists, like your Physical Therapist or Pain Specialist regularly but may see other specialists, like your Geneticist or Neurologist, once, twice, or as needed

How Do You Communicate With Your Team?



- ? You may communicate with your team members through patient portals, email, or during appointments
- ? It is up to you to share with your other doctors what each doctor is doing

What Makes a Good Doctor?

- ❑ Ability to connect dots
- ❑ Interest in learning new things
- ❑ Wanting an equal doctor-patient relationship
- ❑ Communicator and collaborator
- ❑ Transparent
- ❑ 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



What Makes a Good Doctor-Patient Relationship?



- ❑ Collaborative
- ❑ Open communication
- ❑ Honest
- ❑ Mutual respect
- ❑ May not always agree but do respect what each brings to the relationship

How to Find Good Doctors for Your Medical Team

Get recommendations from:



Family

Friends

EDS Organizations

Local support groups

Research Potential Doctors

Some information can be found on the doctor's website or by asking front desk staff. Think about what practical aspects you need from this doctor, for example:

- ☐ Do they accept your insurance?
- ☐ What hospitals do they use?
- ☐ Are same-day appointments possible?
- ☐ Are evening or weekend hours available?



Interview Appointment



You are looking for doctors who are:

- ☐ Willing to learn about EDS
- ☐ Communicate well with you
- ☐ Show an interest in helping you feel as well as can be and function as well as you can

Interview Appointment - Questions

You may have specific questions you want to ask the doctor to help you decide if they can be helpful to you. Some examples of questions you may ask are:

- ❑ How many patients with EDS have you treated?
- ❑ Will I see you each appointment or co-workers?
- ❑ Are you or your nurse reachable for questions?
- ❑ What is your health philosophy? Alternative medicine? Western medicine? Other?



Interview Appointment – Doctor’s Role

Figure out what role you want this doctor to fill. Ask the doctor directly if they are willing to fill that role. For example, say, “Are you willing to work with my chronic health condition, Ehlers-Danlos Syndrome, to help me accomplish my goals of sleeping better and having less pain?”

If the doctor is unwilling to fill the role you would like, ask what role they are willing to fill. Then decide if you are ok with that alternate role.



Interview Appointment – Patient's Role

Clearly state what role you are willing to fill as the patient. For example, are you willing to:

- ☐ Try proposed treatment options after careful consideration?
- ☐ Be an active participant in your health care?
- ☐ Understand this doctor will try their best but will not be able to fix everything?



After the Interview - Decide



- ☐ Was this doctor familiar with EDS or willing to learn?
- ☐ Was 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?

Once You Decide This Doctor Is On Your Medical Team, Discuss Long-Term Goals

Do you want your doctor to help you with:

- ☐ Overcoming a challenge you have at home or work?
- ☐ Managing symptoms well enough to return to work?
- ☐ Being able to take fewer medications?
- ☐ Having fewer dislocations?
- ☐ Being able to eat with less pain?

Discuss with your doctor what long-term goal you want to accomplish. Your long-term goals may change over time but are what you and your doctor are working towards.



To Have Helpful Appointments, Prepare!

By doing work before your appointments, you can greatly increase the chances of getting the medical care you need



Have Reasonable Expectations

Unreasonable

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



Reasonable

- ❑ I want my pain low enough for me to function
- ❑ I want my doctor willing to learn about EDS and be curious
- ❑ I understand there is not a cure for EDS yet
- ❑ I arrange with my doctors how best to communicate and when to be seen
- ❑ I understand the limitations of modern medicine



Your appointment goal will dictate what is discussed at the appointment and will be what you and your doctor are trying to accomplish



Your goal is how you will direct your medical care

Your goal is decided by you

Create an Appointment Goal

What do you hope to achieve during this appointment?



- ☐ Interview to see if this doctor is a good fit on your medical team?
- ☐ Images?
- ☐ Tests?
- ☐ Trial new medication?

- ☐ Advice on braces?
- ☐ Mobility aids?
- ☐ Referral to specific specialist?
- ☐ Treatment plan?
- ☐ Paper work filled out?

What do you want to leave the appointment with or knowing?

Your appointment goal dictates what kind of data you need to collect.

Collecting Data

By keeping a symptom diary, chart, graphs, Excel sheet, or using a symptom tracking app, you can:

- ❑ Help you and your doctor see trends or triggers
- ❑ Justify need for testing
- ❑ Support a need for treatment options
- ❑ Provide documentation for disability benefits

Collecting data takes time and is important to do consistently, but the benefits can be enormous in getting the medical care or benefits you need



Why Track Symptoms and Prepare for Appointments?

Because tracking symptoms gets results. A Pew Research Center study found that of those who track symptoms:

- ❑ 46% say that this activity has changed their approach to maintaining their health
- ❑ 40% say it led them to ask a doctor new questions or to get a second opinion
- ❑ 34% of trackers say it's affected a decision about treatment

So if you're not tracking your symptoms, you're missing an easy opportunity to improve your health care.

<http://www.pewinternet.org/2013/01/28/tracking-for-health/>



Collect Data



You and your doctor need to know:

- ☐ What symptoms you have
 - ☐ What triggers your symptoms
 - ☐ What you have tried to treat your symptoms
 - ☐ How that treatment is working
-
- ☐ You can use paper to keep a diary, make charts, or record your data on Excel sheets
 - ☐ You can use apps to track symptoms and treatment

Collect Data - Charts



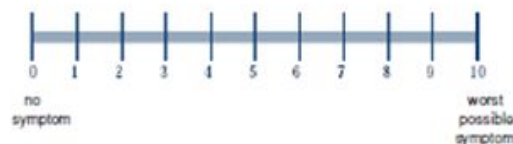
Record:

- ☐ What your symptom is and what your pain level is
- ☐ When it happens and what you were doing beforehand
- ☐ How long it lasts
- ☐ What you have tried to treat it
- ☐ How effective that treatment option has been

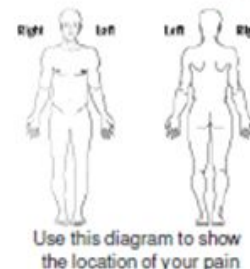
Patient assessment: Pain and symptom diary



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.



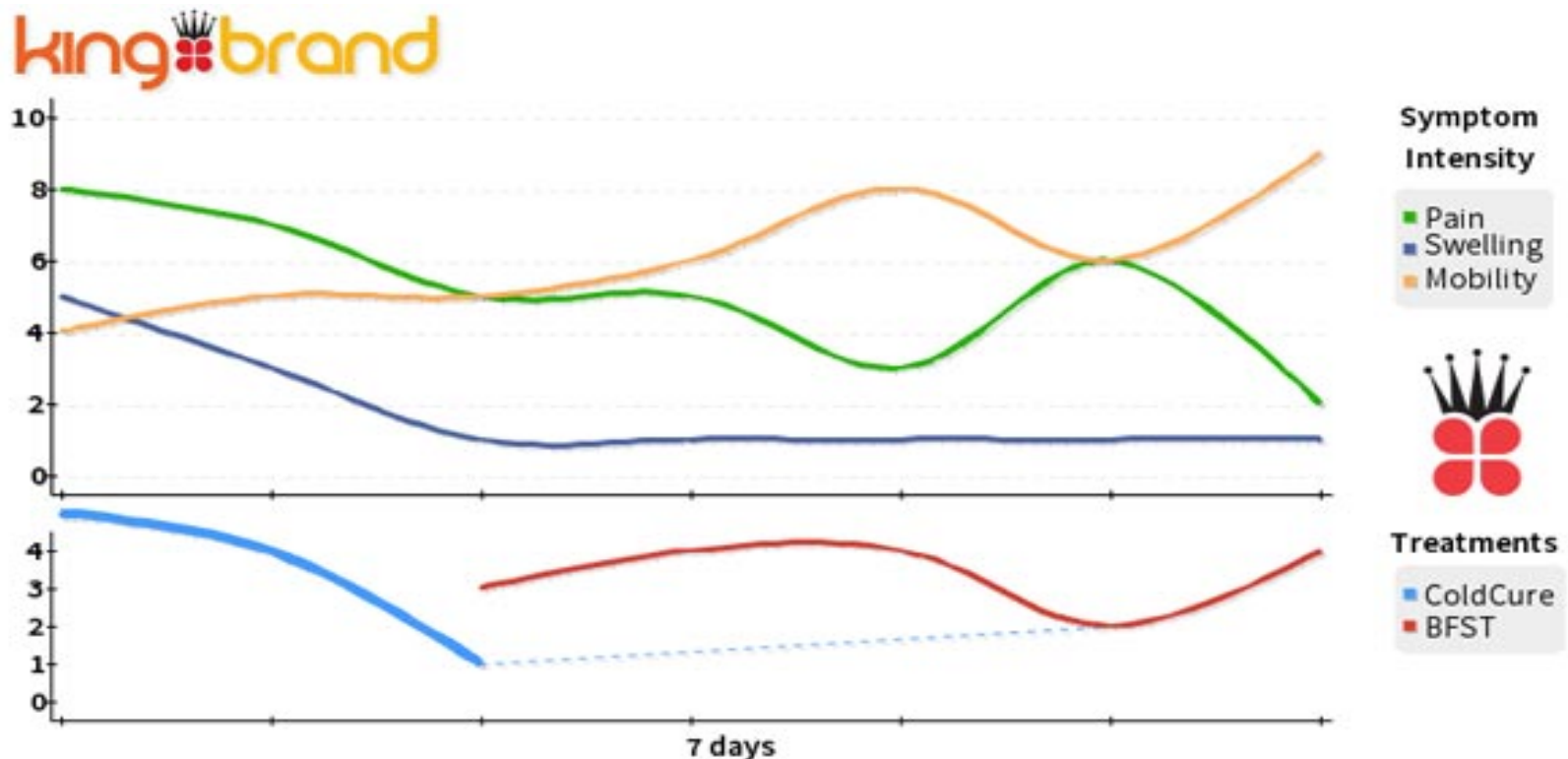
Date and Time	What is your symptom? <i>Name the symptom and location. Describe the symptom and use the number scale above</i>	What were you doing when the symptom started or got worse?	Did you take medication or try other treatments? <i>If so, what, and how much?</i>	How did they work? <i>Rate the symptom, 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 Society 2002; 50: June suppl

Collect Data - Graphs

Graphs can provide your doctor important information quickly.



Collect Data - Apps

- ? Symple
- ? CatchMyPain
- ? Nanulume
- ? My Pain Diary
- ? MyRA
- ? Chronic Pain Tracker
- ? FibroMapp
- ? WebMD Mobile Pain Coach
- ? TrackMyStack



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iOS

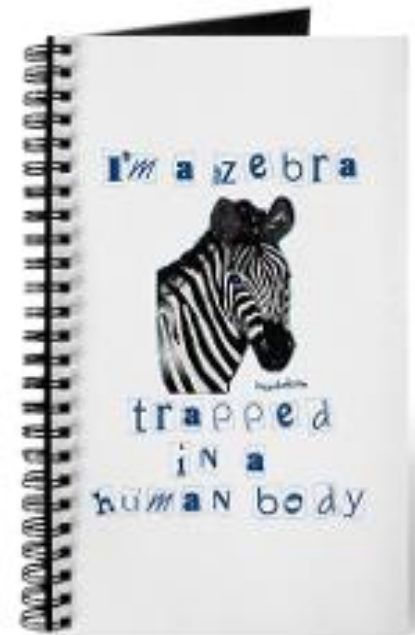
Android

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:

- ☐ Goal
- ☐ Medications and relevant history
- ☐ Timeline of symptoms
- ☐ What you tried and how that worked
- ☐ Samples, pictures, or short video of symptoms



Sample Appointment Agenda

Date: 4-12-17 **Doctor Seen:** Dr. James **Weight:BP:**

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

Pre-existing Conditions: Ehlers-Danlos Syndrome, Hypermobility type, POTS, 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. Smith on 2-16-17 who said to consult you.

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?

Sample Appointment Agenda

Date: 4-12-17 **Doctor Seen:** Dr. James **Weight:** 121 lbs **BP:** 94/76

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

Pre-existing Conditions: Ehlers-Danlos Syndrome, Hypermobility type, POTS, 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. Smith on 2-16-17 who said to consult you.

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

Notes: Dr. said to increase sodium to 4000mg/day and to buy Thermatabs. Agreed to chart when dizzy, what I had been doing, how much fluids/salt I consume, and how that is working.

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? 4. Where can I buy Thermatabs? 5. Does the sodium include what I eat?

Stay Organized

You need to keep and have easy access to your:

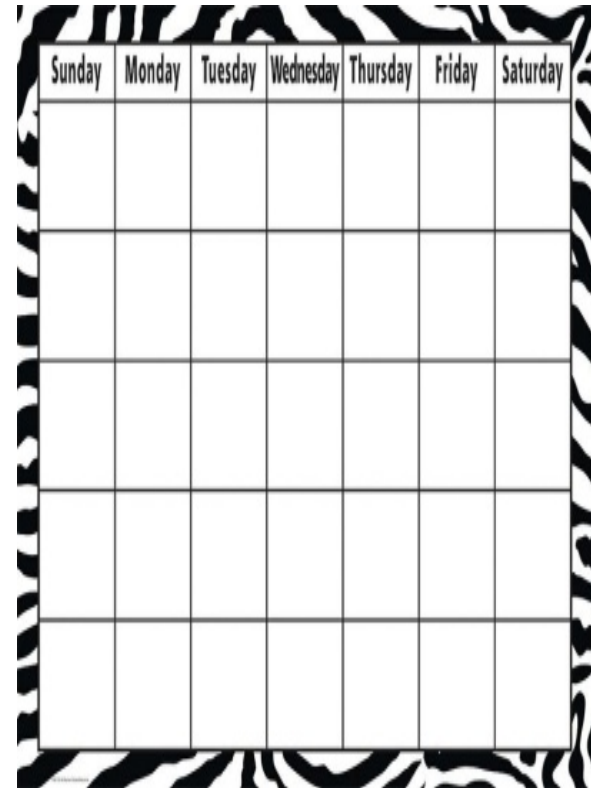
- ❑ Collected data
- ❑ Appointment agendas
- ❑ Medical records
- ❑ EDS articles and brochures to share
- ❑ Medical journal articles

By having these well organized, you can share them when needed at any appointment



Tools to Stay Organized

- ❑ MyMedical – App for keeping personal health records
- ❑ Google Calendar – Use to record when doctor appointments are, sharing that information with others, alarms to remind you when to do or take things
- ❑ Loansome Doc – NIH department allows you to order the full article to abstracts you have seen in PubMed
- ❑ Dragon Speak – Voice to text software



Accordion File for Records and Notes



Can purchase at many stores for less than \$10.00. Organize medical records, PT exercises, appointment notes, practitioner contact information, medication history, surgery history, brochures and articles about EDS, and future appointments.

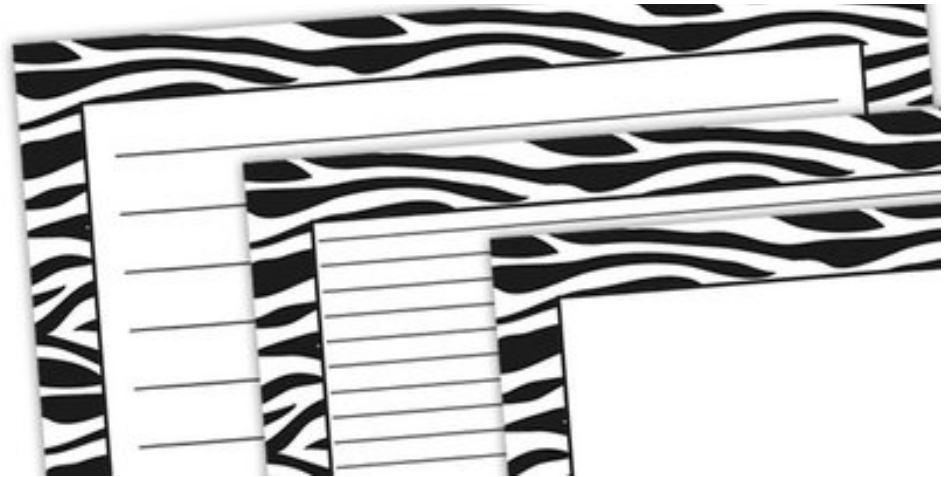
At the Appointment – Bring Your Data and Agenda

- ❑ Provide a copy of your agenda to your doctor and keep a copy for yourself
- ❑ Share pictures of the symptom or samples of body fluids that may help solve what is going on
- ❑ Share data you collected for symptoms, what you are trying for treatment, and how it is working
- ❑ Share graphs or other collections of your data from apps



At the Appointment – Plan How to Get Needed Information

- ❑ 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





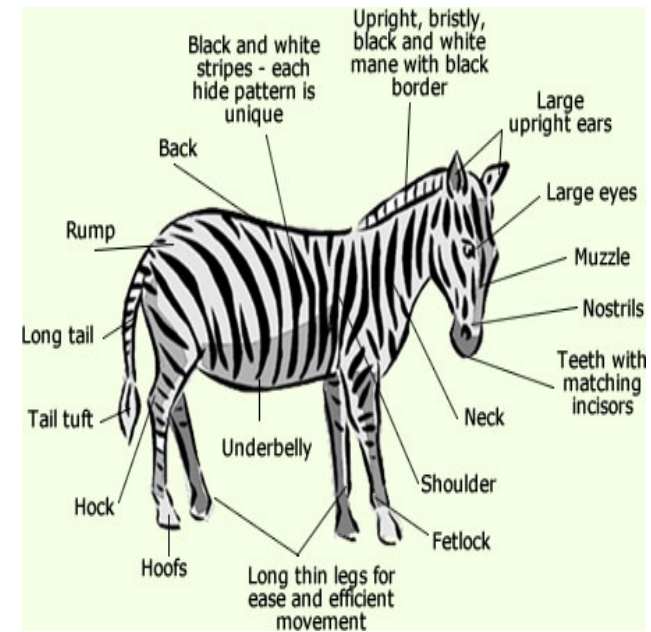
Be Specific

- Nature of symptoms
 - Frequency
- Functional impact

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

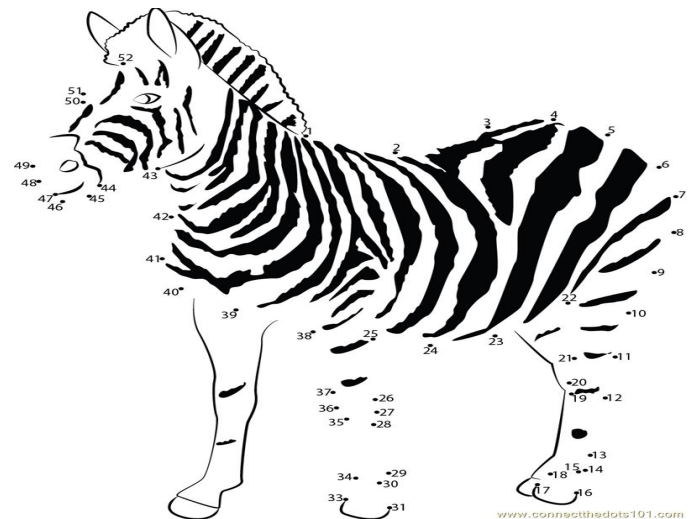
At the Appointment – Share EDS Information

- ❓ Educate your doctor about EDS
- ❓ Say you have “Ehlers-Danlos Syndrome” and your type – do not just say “EDS” until you’re sure your doctor knows what it is
- ❓ Refer to Ehlers-Danlos Society Medical Resource Guides and peer-reviewed journal articles:
<http://ehlers-danlos.com/medical-professionals/>
- ❓ Bring EDS articles, but try to bring what is relevant to the goal of your appointment or symptoms you are having
- ❓ Understand your doctor cannot read lengthy EDS articles during the appointment. A good doctor will read the literature at another time.



Teach Your Doctors About EDS

- ❑ Share Brochures <https://ehlers-danlos.com/brochures/>
- ❑ Share Medical Journal articles
<http://onlinelibrary.wiley.com/doi/10.1002/ajmg.c.v175.1/issuetoc>
- ❑ Increase your doctors' awareness of EDS as a *Heritable Connective Tissue Disorder that can affect any body system*



At the 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



Patient Tips – Do...



- ❑ 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 – More Do's...

- ❓ Be honest about everything...it is the only way the doctor will have the information they need to develop a plan that may help. Shading the truth or leaving out important details helps no one!



- ❓ Contact your insurance company prior to treatments to be sure they are covered—same with specialists and clinics to see if they are in-network or how to get them labeled as such. This will save you lots of stress.

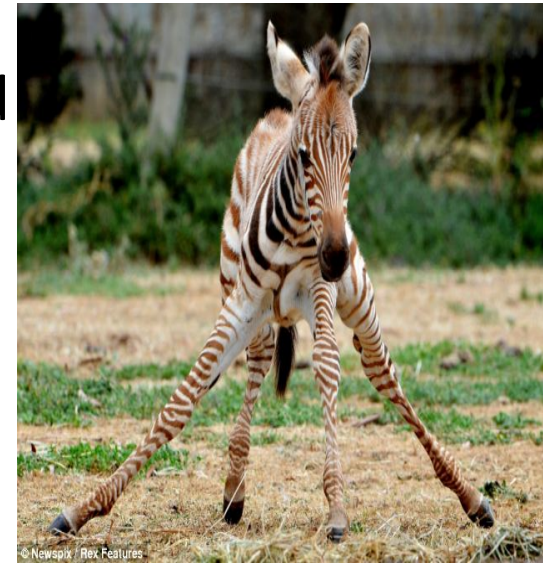
Patient Tips – And More Do's...



- ❑ Understand the limits of the medical world: tests, images, prescriptions, and surgeries
- ❑ Make addendums to medical records to correct mistakes
- ❑ Know your HIPPA rights as a patient
- ❑ Thank your doctors, nurses, and staff when they provide good service and care

Patient Tips – Don't...

- ❓ 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 – A Few More Don'ts...

- ❓ 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 articles during the appointment ~ Only bring articles from scientific, peer-reviewed journals or national patient organizations and not from Wikipedia, Blogs, or Social Media posts



At the Appointment –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**

The Emergency Room – Should You Go?

The role of the ER is to *stabilize* patients:

☐ So the patient can be referred back to their local doctors

or



☐ So the patient can be admitted into the hospital

The Emergency Room – Go When...

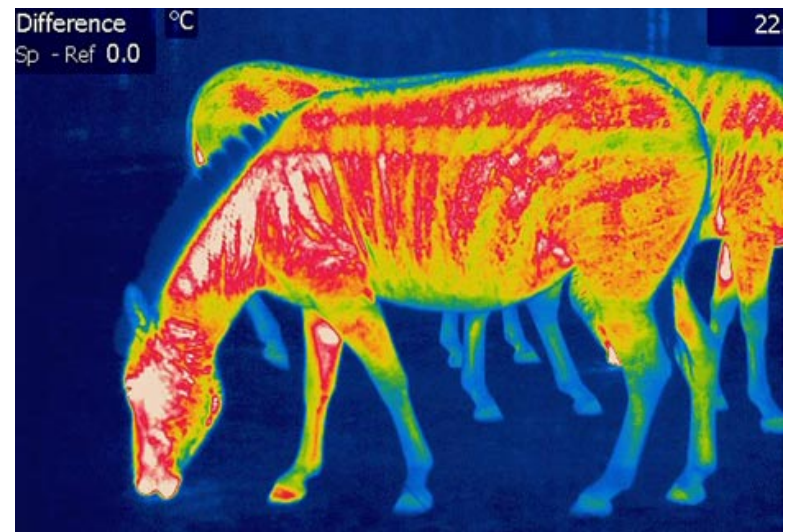
You have these symptoms or other true emergencies:

- ❑ 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



The Emergency Room – Don't Go When...

- ❑ 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(s) has not figured out what the problem is yet so you are hoping Dr. House is in the ER. There is no Dr. House in the ER
- ❑ You are well enough to ask on Facebook or other social media, “Should I go to the ER?”



Hospital Stays



Bring:

- ☐ Your list of doctors, medications, surgeries
- ☐ An advocate ~ family member or friend
- ☐ 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
- ☐ A copy of your directives

Health Information Portability and Accountability Act (HIPAA)



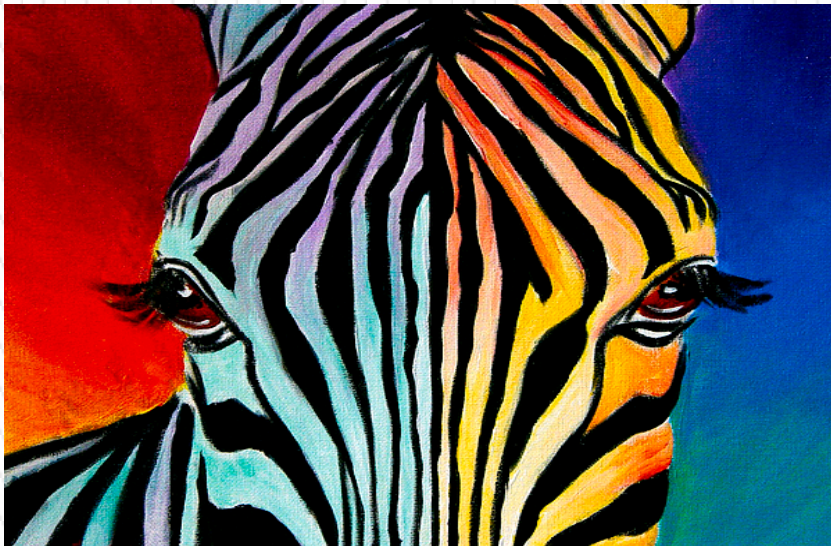
HIPAA controls who can see your medical records and how those records must be stored. It covers paper, electronic, and oral records. It also covers many more rights you have. It is important you understand this act, how it affects you, and your rights under it. <https://www.hhs.gov/hipaa/>

Remember To Do Your Regular Health Check-Ups

- ❑ 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**



Having EDS is not easy. By being educated about your conditions, building a medical team you trust and work well with, preparing for your appointments, and being an active participant in your health care, you can get the medical care you need to live the best you can!



Thank You!

Contact Information



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