NAVIGATING YOUR EDS JOURNEY: ADVICE FROM THE COMMUNITY

I. Essential to remember and regularly remind yourself:

1. Do not let your health define you. You are more than your health issues. You are still a person with interests, hobbies, and talents, who happens to have health issues.

2. Your health issues are not in your head. You are not a "health imposter." Don't let anyone gaslight you about how you feel or what you've been through.

3. Everyone is different. Just because others with EDS have certain co-morbidities does not mean you will end up with them or have them to the same extent as others. Just because many people go on disability or can't work, doesn't mean you will.

4. EDS people are very compassionate and empathetic. Take advantage of support groups and connecting with others who understand, but also talk about non-health issues.

5. Many with EDS and Dysautonomia have Mast Cell Activation Syndrome (MCAS). Treating MCAS can show which symptoms are from other issues. *A normal tryptase doesn't rule out MCAS.*

6. Every day is different, so life is unpredictable. One day may be good, the next not so great. Things can be unpredictable even within a day – even hour to hour.

7. People can and do improve. We have a number of success stories. It can be a slow, steady effort with a number of different hacks and treatments at times, while a roller coaster at other times. Don't give up hope. Consistency, keeping appointments, and self-care are essential to getting back on track.

8. Everything you do starts adding up: one thing may help 5%, another 2%, another 7%, etc.

9. Once diagnosed and while finding your "new" normal, you will probably go through the grieving process over the life you had and the one you expected. The common five stages of grief are denial, anger, bargaining, depression, and acceptance. Go at your own pace. You may skip stages or repeat stages – it isn't a linear process.

10. Self-care is essential. Listen to your body. Take time to look after yourself, whether it is turning down activities, resting, or watching animal videos. It's ok to say NO.

11. Pacing is part of self-care. On a good day, don't over extend yourself to avoid crashing the next day or so. Plan ahead if you know you need to do something – rest before to make sure you have some energy and plan for down time after the activity.

12. Get to the root of issues to find out what's going on so you can try to resolve them rather than just manage the symptoms.

13. It is ok to set boundaries with family and friends, including ending relationships that are toxic for your physical and mental health. Again, it's ok to say no.

II. Be prepared with information:

1. Write up and keep current a summary of diagnoses, allergies, hospitalizations, blood type, key practitioners, insurance, and medications/supplements, including dosage, when taken, and prescriber. Keep this on your phone or with you in case of emergencies. Make sure emergency contacts have a copy as well as full list of practitioners. The summary and list of medications saves a lot of time when filling out forms with new practitioners and going through medications at appointments.

2. Keep in your wallet in easily noticeable place a basic list with name, address, phone number, emergency contacts, and PCP or a few doctors in case of emergency.

3. Keep the Ehlers Danlos Society EDS information wallet card with your insurance, doctor, and emergency contact information. (https://www.ehlers-danlos.com/download-your-wallet-card or see below for non-QR code card)

III. Practitioner visits/medical records:

1. When you visit a practitioner, go with a list of maybe the top three or so issues you want to discuss and try to go through one at a time – stay as focused as possible. Don't give them a long list that will overwhelm them and get distracted so key issues aren't addressed.

2. It's ok to fire practitioners if you aren't getting what you need from them. Find someone who will listen to you.

3. Ask to record appointments so you can remember what is said. Take someone with you if necessary to advocate and/or take notes.

4. Review your records and correct any errors. This is important for future doctors within that records system and if you ever apply for disability.

5. Keep a copy of all your records and scans/imaging (ask for imaging on CDs).

IV. For friends and family:

1. We tend to like staying as independent as possible and not really ask for help. So we don't feel like we are imposing on you or being a burden, try saying, "I'm going to CVS, grocery store, hardware store, etc, can I pick up something for you while I'm there?" or "I'm cooking and easily make extra," instead of asking us "Do you need anything?".

2. Sometimes all we need is someone to listen to us or quietly hang out - and not advice or suggestions. Please don't be dismissive of what we are going through by saying, "At least you don't have X", "I also have X, but can still X, so why can't you," "You were able to do X yesterday, why can't you do it today," etc.

3. We fake being well, not being sick.


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EMERGENCY ALERT HANDLE with CARE
EHLERS-DANLOS.COM
Ehlers-Danlos Syndromes
CONNECTIVE TISSUE DISORDERS:
Group of 13 genetic disorders that produce complex problems across multiple systems of the body. Can result in:
• spontaneous arterial/intestinal/uterine rupture, including aortic dissection and other cardiac abnormalities;
• hypermobile joints that can dislocate easily;
• fragile and/or stretchable skin and tissue that may readily bruise and tear;
• musculoskeletal pain and fatigue;
• delayed healing;
• dysautonomia, particularly orthostatic intolerance;
• possible neurological and/or spinal involvement.
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EMERGENCY INFORMATION
EHLERS-DANLOS
HANDLE THIS PATIENT WITH GREAT CARE.
• Joints may be lax and dislocate easily.
• Skin tearing, splitting and bruising are common.
• Arterial or intestinal rupture commonly presents as acute abdominal or fank pain that can be difuse or localized.
• Cerebral arterial rupture may present with altered mental status and be mistaken for drug overdose.
• Emergency procedures (especially for Vascular EDS) may require trauma, vascular surgery, ICU. Elective surgery and procedures should be carefully considered. Non-invasive testing is highly preferred.
• Healing may be delayed, with irregular scarring. Use alternatives to sutures whenever possible. Retain sutures/staples for twice the normal period; watch for wound reopening and dehiscence.
• For general anesthesia, use caution when intubating as jaw dislocation is common and GI tissue fragile.
• Local anesthetics are most often inadequate or short-lasting.
• Potential spinal and/or cerebellar involvement may increase general anesthetic and surgical risks.
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