

Re: I am that patient you love to hate and I need help!!!

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- *From:* [miss.ansari@xxxxxxxxxxx](mailto:miss.ansari@xxxxxxxxxxx)
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On Aug 6, 8:34 pm, christinasbooksh...@xxxxxxxxxx wrote:

I am a walking (though that could change any moment) medical nightmare. I have not seen a dentist in over 10 years because first I was a poor college student and couldn't afford anything. Then my medical problems mushroomed and I have been paying out the wazzoo for medical bills, and I am in a doctor's office a minimum of twice a month. I can't get health insurance because of pre-existing conditions (haven't actually looked for dental insurance), and my husband refuses to get a job with benefits (he is a IT contractor who makes a lot of money, and he would just rather get all that money and take the risk that I won't have any more major problems than I already do.) Plus we make way, way too much money to get Medicaid, and high risk pool insurance \*\*\*\*SUUUCKS!\*\*\*\* (At least in my state) I am not disabled enough to get disability. (And no, I am not going to paper-divorce my husband and then file for welfare, but you can guarantee I have thought a lot about it!!!) Plus my parents almost completely neglected my healthcare from age 0 to 18 because they thought it was ok to do so and they were too proud for charity. (I think I saw a doctor 4 times from age 2 to 15, and probably saw an MD fewer than 4 times between 0 and 2, and then I got yearly 5-minute athletic physicals in HS, plus saw a crappy dentist about 10 times because he was the absolute cheapest. So I know you already think I am an awful patient. (My PCP likes me, but most other doctors when I first see them want to run away because I have a stack of journal articles 7 inches thick. And then they talk to me and get the impression that I know more about my genetic condition than they do and I know more about how my body works than they do. (And it's true...since diagnosis I have only talked to 1 doctor who knew more about EDS than me and she is the world's leading expert, along with her former research partner who left research because she felt so awful about how crappily we are treated by doctors. I have read more journal articles about my condition than 99% of all MDs, though I don't know about DDSs.) Anyway, my intention is a meeting of the minds—I know all of the established medical facts on my condition (what few there are) plus enough anecdotal evidence to make your head spin, but I know \*\*\*ABSOLUTELY NOTHING\*\*\* about how to do the treatments, because I haven't studied for 8 years thinking of nothing but the practice of medicine (well, other than how barbaric

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such practice is—when are they going to get it right?)

Anyway, my current diagnoses include Ehlers–Danlos Syndrome (which is the root cause of EVERY following problem except 1 which should be obvious), asthma, life–threatening allergies to lots of stuff and I know I will develop more, Lyme Disease, hypothyroidism, hypotension, orthostatic intolerance, arthritis, endometriosis, and a few more which I can't remember because of the Lyme Disease—it kills the memory. I currently take narcotics (small dose of one of the most powerful narcotics, but I require massive doses during surgery), antibiotics, fludrocortisone (to raise BP), the pill, fluconazole (because I take antibiotics and the expected happens), Singulair, Claritin, plus comprehensive multivitamin, massive doses of Vitamin C (my doctor really agrees with Linus Pauling), magnesium, CoEnzyme Q10, and ginger PRN to alleviate nausea. Plus a bunch of PRN meds and maybe something else I can't remember ATM.

So you can see I am a disaster, but at least not as bad as the worst EDSers. :P

I need a few bits of suggestions/advice: what pain relief can I use or is there none? I need to have the wisdom teeth pulled, they are horribly impacted, fully bony, but no OS can get me before September, and I have a monstrous cavity/food trap in the worst tooth (looks horizontal to me) which I will be seeing a random DDS about—the first one that said he could get me in less than a week. Like the vast majority of EDSers, local anesthetic has limited effect (I am just glad it has very good effect for about 5 minutes.) My MD says that general anesthetics may only be used on me in the hospital (might make an exception if the doctor has advanced life–saving skills and tools, plus ability to keep BP stable despite my body's desire that it be 30/0 or similar while anesthetized). Nitrous—causes low BP plus opioid–resistance confers partial NO<sub>2</sub>–resistance if what I read is true, triazolam—contraindicated/or extreme caution while taking fluconazole and BCP. What do I have left? Could laser or air abrasion work for all routine dental work? I have a high pain tolerance—I never once hit a nurse or doctor or even yelled or swore—when my pain was 200 on a scale of 1 to 10 and I don't believe that I am exaggerating one bit about that 200—think medieval torture that causes excruciating death and multiply by two. I can just guarantee you that I won't be darkening the door of a dentist's office very often if I have to either put up with the pain of dental work on top of the pain daily living or rent out a hospital surgery spot for 6+ hours (I recover extremely slowly!) every 6 months for general work because EDSers generally have horrible teeth and gums and jaws and TMJs. (I think my gums look great—absolutely no pain or inflammation and they're pink, not red and the teeth other than the 1 humongous cavity are not bad.)

Question 2 could I possibly use invisalign to straighten out the bottom teeth (they aren't decrepit like all of those extreme

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makeovers, but they are quite misaligned) or is there any other option which doesn't involve pokey things that will shred and horribly scar all of the soft tissue even without getting smashed in the face? I am not self-conscious about a mouth full of metal--after all, you have to swallow your pride just to use an electric scooter or wheelchair as a 29-year old in public, outside of the hospital--though I would rather not wear headgear because it is hideous and nearly as barbaric as a halo for Chiari surgery, which may also be in my future. I don't want to saw off all my teeth nearly to the root just to get a fancy facade, because teeth are valuable and real ones can't be replaced with real ones, and the more intact they are, the better.

Thirdly, could you kindly recommend how I should go about finding a wise and ethical dentist/orthodontist/endodontist who thrives on challenges and learning new things? Or should I just visit the nearest dental school (and I have heard horror stories of students not catching glaring or really serious but subtle problems and professors never looking inside the patient's mouth)? Do dental schools take on patients that aren't in their "charity clinic" where the waiting list for new patients is 4 months out minimum and usually 6 months or more? Should I go to 1 of the free/low-cost dental clinics, even though our income is really high and I will be taking up space that poor people could be using, because money is still an issue? FYI, I live in the Kansas City metro area.

Fourthly, could you refresh your medical genetics skills so that when you have a patient who says "Locals don't work for me and my gums bleed at the slightest touch despite the fact I brush and floss and everything else imaginable", you would tell them "Schedule a visit to the geneticist at your earliest convenience to be screened for Ehlers-Danlos Syndrome"? Nearly every patient I just described or has a health history like mine above has EDS. Don't believe me? Do a journal search and it will become obvious. And I would honestly bet each of you \$5 billion (and I can almost guarantee I would win every single time) that every single 1 of you has treated at bare minimum 1 undiagnosed EDSer (who the odds are that if they aren't desperately seeing 20 to 100 doctors for help, they will be in 20 years) if you have been in practice for 20 years. If I loose, I just find another sucker to fall for my bet. :) I feel confident in saying you probably have 1 who is among your current patients and you think they are hypochondriacs (most common misdiagnosis for EDS and bunch of other things) or they are lying. If your efforts lead to the diagnosis of 1 EDSer, you will be that person's biggest hero after the geneticists who are selflessly working to find the gene and find treatments that actually work and preventative measures to halt progression. Props to Nazli, my biggest hero, and congratulations to myself for accurately diagnosing EDS in myself, my husband, and both of my kids, just from doggedly searching the net and journals for the answer, and demanding that I and the rest of my family see a geneticist when even my favorite doctors had absolutely no clue, and were highly skeptical. Oh yeah, I unknowingly married a man with EDS like me, as have 6 others

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of the far less than 1000 people I know of who have diagnosed EDS.  
Imagine the odds of that when supposedly EDS is a rare, orphan  
disease.

Thanks for reading this far, and feel free to take me up on the bet—  
any amount is fine, though scrounging up a trillion dollars from your  
pocket change might be a bit difficult. Any bet winnings will be  
donated to the Ehlers Danlos National Foundation who will use it to  
educate you [almost free CE credits, though you bet it would be free  
for everyone with a trillion] and the NIH research/Dr. Byers in  
Seattle/any other MD/DDS/PHD ready to jump on our bandwagon, except in  
the case you have a trillion dollars spare, and then I will take a  
mere million dollars as finders fee. (And I also bet that million  
dollars would go to pay for med school for me, so I can research AND  
treat EDS.)

A Thankful Christina  
I am trying to be at least a little funny

helloooo!!!!!!!!!!!! Christina ....the brave girl i hvnt seen b4 in ma  
life.....u seems to b a cute girl and n innocent girl....MAY GOD  
EASEN UR BURDENS ...AMIN.....ok tell me wot r u doing nwadays ..do u  
wan to b ma frnd.....good frnds,....?????????????dn say no  
otherwise i will die,....heheheheheheeh ok do reply...tc  
xoxo  
Mandana iqbal  
Pakistan