

## Pain Management for Ehlers-Danlos Syndrome (EDS) Q&A

We will start with providing a few resources that will hopefully help with questions about EDS in adults and non-pain questions.

### Resources

- [www.cincinnatichildrens.org](http://www.cincinnatichildrens.org)
- <http://www.ednf.org/>
- <http://www.hypermobility.org/>
- Pain Management Center:  
513-636-7768
- Connective Tissue Clinic:  
513-636-4760

There are still a few more questions we are working on answering, and we will post those as soon as possible. Thanks again for your questions and attention.

### **Medication**

How do you determine what medication to use for these kids?

FDA approval is missing for many medications in persons under age 18. Pediatric practitioners are used to that. It is a long story, but the fact is that if we are to treat kids with what seems to be logical treatments in a timely fashion, then FDA approval is not something that anyone can wait for. The choice of medications is usually based on what seems to be the appropriate treatment under other circumstances, modified by the practitioner's knowledge of the patient and their diagnosis, tempered by caution, careful dosing and a willingness to monitor the effect and side effects (and interactions with other medications). We are happy to support local doctors who may be nervous about using certain medications –we may prescribe things “all the time” that others rarely do, and are happy to share our experience with them.

Have you had any luck with topical Voltarin gel?

Yes. Some patients have found it helpful. There is literature to suggest some people with joint pain find it helpful. It is an anti-inflammatory medication, so it would need inflammation to work on, which is not always present in EDS.

What do you do when most pain medication causes fainting?

Evaluate the fainting and determine if dysautonomia is present. Treat dysautonomia.

What do you think of medical marijuana use?

We live in Ohio, and this is still illegal here.

Are there muscle relaxers approved for teens? My doctor won't prescribe any for daughter with vertebral stress fracture and resultant muscle spasm.

Muscle relaxants are used frequently in children. I would ask the doctor why he won't prescribe one. We would be happy to work with him/her.

Do people with EDS metabolize narcotics more quickly than "regular" people or build tolerance more quickly?

No, they do not to my knowledge. If the pain is more related to widespread pain or fibromyalgia or CRPS, then opioids often do not work for those types of pain in anyone. Anyone taking opioids for more than a week or so becomes tolerant to them-it varies how much, but EDS is not a specific risk factor.

Can you talk about pain medications for bursitis caused by EDS?

Anti-inflammatory medications, sometimes steroids (either transdermally by iontophoresis or injected) and physical therapy are often used.

Please talk about medication options for people who also have severe GI issue—that rules out the narcotics (constipation, reflux etc).

It depends on the type of pain. Sometimes opioids are not the right thing. When opioids are used for more than a dose or two, then a program to promote bowel health and regular bowel movements is important. Keeping hydrated, lots of fruits and vegetables, exercise, and the use of stool softeners or motility agents are often used.

My general practitioner wants me to cut down on painkillers because he believes I am addicted to them. How can I make him believe that EDS does affect me daily without sounding arrogant?

An open, honest discussion is best. Also, please know that our approach is that the most of EDS pain management is NOT based on opioids, but that opioid medications are a PART of the program for some kids. There may be other medications that could be helpful depending on the type of pain, and if the GP is not prescribing proper PT and psychological interventions, then that should be part of the conversation, too.

If an EDS patient started taking scheduled NSAIDs for pain but then had decreased kidney function, what would a good alternative medication be to start with?

Good question. NSAIDs can reduce kidney function, and the biggest risk is pre-existing kidney problems. Acetaminophen is OK with reduced kidney function, and things like tramadol could be discussed with your doctor. Non-medication treatments are not affected by the kidneys, and a TENS unit might help individual joints (along with rest, elevation and cold packs-or warm, whichever feels better).

Every time I come out of surgeries/procedures under anesthesia, I am in uncontrollable pain and the narcotics never really work. Is there a reason that the anesthesia or narcotics wouldn't work well?

There are genetic differences among people (that have nothing to do with EDS) that change their responses to opioids. There is testing for them, but I do not know how available the tests are, or if they are really even useful outside of research, yet.

How often should patients be given pain relief? Only when unbearable? Taking the edge off? It depends on what is going on. Pain should not be allowed to become unbearable. But, two things about that to note: 1. Being pain-free is not possible with medications. The risks of something bad (like overdose) are too high if we try to eliminate all the pain. 2. How a person copes makes a huge difference in what is bearable. Remember my paper cut example. Our thoughts and emotions all play a role in very important ways, and medications can't do much about that. The nice thing about the non-medication treatments is that they are yours any time, any place you need them...and have no side effects. If pain is from surgery or something like that, then keeping on top of the pain with regular dosing is important, until the wound heals. Same goes for something like a dislocation. Medications should be used for chronic pain to help functioning, since so much of healing the pain depends on things beyond medications.

What medications are available for EDS, both something daily to help prevent and something to take just when the pain presents itself? I would love to have some options to make even one symptom better. (Symptoms of everything includes: dizziness, nausea, extreme fatigue, brain fog, joint pain).

There are many medications, each doing something different...too many to discuss here. We would be happy to see you or work with your doctor.

Why do some pain medications tend to have less effect with EDS?

It depends on the type of pain. There is no evidence that folks with EDS react differently than anyone else. However, different types of pain react differently to various medications. As I mentioned above, there are genetic differences, separate from EDS that affect how people respond to some medications. It is quite possible for someone with EDS to also have the gene that makes them more or less affected by a medication. For instance, up to 5-10% of all people do not get the right effect from codeine. It is very likely that some of those folks also have EDS, and then get no relief (or would overdose) from codeine.

## Diagnosing/Testing

Is it possible to have type 3 with cross over vascular, or is it one or the other only?

It's one or the other. If type 3 (EDS-HT) is truly at a 1% prevalence in the population, then 1% of EDS-V could also have EDS-HT. On the flip side, at 1%, EDS-HT would be expected to be 1000 times more likely than EDS-V.

My daughter has been diagnosed with JHS. In your opinion, is this the same as EDS-hypermobility?

I view JHS as a subset of EDS-HT. EDS-HT can be asymptomatic. By definition, JHS is a pain syndrome. Therefore, I consider JHS under the umbrella of EDS-HT.

My geneticist affirmed without a blood test. Is that normal? Shouldn't he have ruled in/out all forms?

Clinical and family histories usually suffice to rule out the other forms. Genetic testing for the exclusion of all other forms is not done routinely.

What kind of testing should happen after a diagnosis of vascular EDS/ EDS hypermobility with suspected vascular involvement when there are vascular issues in the family history?

You would have to define “vascular issues” better. Ruptured large vessels (aorta, carotid)?—I would test. Easy bruising is common to all. Vascular tone instability causing the hands to turn red or blue at odd times is very common with type 3.

How do you test for dysautonomia? Then, what do you do?

There are different kinds of dysautonomia. Most common is a blood pressure regulation problem that leads to blacking out with standing. This is tested with a “tilt table” exam or with blood pressures testing in different positions. The “what to do” part involves increased fluid, increased salt, and potentially medications. There’s more to it than that, but that’s the starting point.

Is upright MRI imperative for cranial settling and retroflexed odontoid which is common with EDS but not see on supine MRIs? Can we make this the standard for testing for EDS patients? The biggest problem is the acceptability of upright MRIs. The closest one to us shut down two years ago and the problem they cited was poor quality of images. To get an upright MRI, our patients must now drive 4 ½ hours away.

Do you notice a difference in patients with a family history of EDS vs. people who don't but still have EDS?

This is a pretty unusual occurrence. When there is truly no family history of EDS, I have to wonder if I’m looking at the right disorder. There are many other disorders that can give you hypermobility that are not EDS.

Is it true that a child cannot be formally diagnosed with EDS until 5? We saw a geneticist for our 3 year old who has had 16 months of pain. She told us to come back in 2 years.

The data show that early on, joint mobility is much higher than later in childhood. We usually use age 5 as a cut-off, since a lot more kids are naturally hypermobile before then. If there is a strong family of EDS and symptoms in the child, then I would treat as if EDS were present, but would call it “probable” rather than confirmed.

If they have type 3, can they get other types as well down the road?

No. This is a common misunderstanding. The numbering system was not supposed to be a grading system (like cancer) where the number designates your personal severity, and you turn from one into another as the disease gets worse.

Do most doctors have your child lay while scanning for Chiara? I think it'd make more sense to have them stand and let gravity work. I worry my son has Chiara, but want to do my research before having scans.

See above for the quality issue for upright MRI. Agree on the point about gravity. Flexion and extension views are sometimes used when an upright MRI is unavailable. However, some of the radiologists I talk to are unconvinced about an MRI being superior to flexion/extension X-ray to look for instability. I can’t comment on how well all these techniques compare.

## Co-morbidities or side effects

My daughter has CRPS and EDS. How is pain management different? EDS symptoms are bad, but CRPS pain is terrible!!!

CRPS pain can be really bad. A full answer is not possible here, but we would be happy to see you or work with your local doctor to help.

What about Ehlers Danlos syndrome and orthostatic hypotension? How does that play a part for our children??

This is a common occurrence. Usually teenagers have it, and it is rare in pre-teen boys. Symptoms including blacking out with standing and heart racing. This can sometimes lead to fatigue. Activation of the sympathetic nervous system may become a more chronic problem which could lead to sleep dysfunction.

I was diagnosed with EDS (I am 53 with Asperger Syndrome). I have nearly all of the Beighton symptoms. I have a son 23 with autism who has extreme low tone with hands, oral motor and gait, but is nearly rigid. Should he be tested if he doesn't have the Beighton issues?

It all depends on what you are trying to achieve by making the diagnosis. A geneticist might be the right place to start.

Is there evidence to support the link with sensory processing disorder and hypermobility syndrome? Also, what are the current standardized tests for clinical observations in the pediatric population?

There is a proprioceptive defect, which is difficulty understanding the inputs from the muscle. For other forms of sensory processing—if there is evidence, no has yet published it. Consistent with some of our patients having fibromyalgia, there could be alterations in the way patients perceive pain—but that is speculative on my part.

What is known of the overlap of HEDS and mitochondrial dysfunction? Is it primarily from deficiencies? What is primary? My daughter and I are both on CoQ10, carnitine, and riboflavin. So far, no one has published anything about mitochondria and EDS. The supplements you are taking all are involved in the metabolism of fat into energy. One could easily suggest that if they work they could be affecting free radical signaling pathways rather than mitochondrial energy production.

Do you have any information on occult tethered cord, or mitochondrial dysfunction primary or secondary to EDS?

There are no published case reports or studies on these topics in relationship to EDS on which to base rational opinions.

Not related to pain, I would love to hear what Cincinnati Children's is seeing in the way of EDS/Mitochondrial disorder overlap. We have a very active mitochondrial clinic. I also trained in Cleveland where there are many mitochondrial specialists and nearly became one myself. I am not convinced that there is any strong connection between mitochondrial disorders and EDS. There may be a few patients out there for whom a mitochondrial diagnosis would be more appropriate, but not many. More often, my mitochondrial colleagues will review a patient who has had multiple mitochondrial investigations, including muscle biopsy, which have all come back normal. They will then go in, perform a Beighton exam, and then ask me to take over the case.

That said, pick any common disease (heart disease, diabetes, Alzheimers, Parkinson disease) and review the medical literature for the interaction of mitochondria with that disease. Mitochondria are essential to just about any process in the body. I would not be surprised if mitochondria are involved with EDS in some way, but not in the classic way in which we define a "mitochondrial disorder."

The other thing to remember is that there are a lot of disorders that can have hypermobility as a finding and could be misdiagnosed as EDS if you are not really paying attention.

Is thyroid disease related to EDS in any way?

From experience and from the literature, there is no evidence of this being true.

Can EDS hypermobility cause severe hypertension or high cholesterol?

No. Low blood pressure is more common. Cholesterol metabolism is unrelated to EDS.

Can you talk about treatments for gastroparesis?

This is a big area. You are talking medications, diet modifications, and even electrical devices. There are even multiple potential causes for gastroparesis within EDS. I would defer to the gastroparesis specialists out there.

Do u see many patients with EDS, Chiari I malformation and/or tetered cord with spasticity?

We see a lot of patients with EDS and a few of them have Chiari I. Most of our patients do not have those others.

My myopia is extremely bad, does EDS have anything to do with it?

Some connective tissue disorders also have myopia, but not classic or hypermobile EDS. Consult your local geneticist as other conditions may need to be considered.

How much does a mitral valve prolapse play a role in how well or poorly a patient does?

It does not play much of a role, unless there is more significant regurgitation.

Does anyone else have endometriosis? Is it related in any way?

At present, there is no direct link. Some patients have it, but not a lot.

Could you speak to the link between EDS, Chiari and Cranial Cervical Instability?

We see all of these from time to time, but there is not enough data in the literature to suggest how often they occur in EDS. Studies on persons with cervical instability suggest that there are more patients with connective tissue disorders in that population than what they would expect (~12% of their total). However, this does not give us any indication of how often we might see these conditions within the EDS population. It is not common enough to warrant yearly testing unless there are symptoms.

What do you recommend for people with EDS with severe problems in their TMJ joint?

One of our local dentists is very successful with the use of a dental appliance and physical therapy techniques. This is to say, surgical reconstruction or replacement of the jaw joint is not where I would start.

What do you know about keratoconus and EDS?

Keratoconus can be found in some of the rarer types of EDS.

Are there issues with dysphagia as a result of EDS?

Yes. We refer to our GI motility clinic, but there are many causes of dysphagia—so it sort of depends on what you are asking about.

My daughter born with hip dysplasia. Is this EDS related?

One form of EDS can have congenital dislocation of the hips.

I have recently been diagnosed and now have bilateral vitreous separations. Are the two related?

Some EDS subtypes can have more ocular findings. I suggest a genetics consultation.

Can EDS cause issues with the flow of CSF, therefore causing neurological pain?

For the first part of the question: It could. For the second part, it is also possible—although it doesn't cause all neurologic pain. Flow issues usually result in changes in CSF pressure causing headaches.

Why does EDS cause dysautonomia? Is there too much fight or flight? Do you treat the dysautonomia, EDS, or both?

“Why?” No good answer exists. “Is there too much fight/flight?” There have been studies that support this, but they stop short of treatment recommendations. “What do we treat?” Everything is interrelated, so we start with whatever is bothering the patient the most with the goal to work through the rest down the line.

Is it possible to have both vascular type EDS and hypermobility if it runs on both sides of the family?

Yes.

Do you believe autism is camouflaging EDS?

I have to assume that the question is whether autism camouflages EDS related pain. First, not all EDS patients have pain—it is less common in boys. Given that more boys are autistic, the two might combine to have an asymptomatic autistic EDS patient. A few of our patients have had autism—not enough to suspect that there is a strong connection between autism and EDS, mind you. Nonetheless, patients with autism may process sensory signals differently, so perhaps they might not register or communicate their pain in the same way.

## GI

Does anyone else have Inflammatory Bowel Disease? I have Crohn's Disease.  
This is rare in EDS.

What do you do for a child that has acid reflux and can't keep anything down??  
I defer this question to the GI motility specialists.

Could severe constipation in our 10 year old daughter (bowel impaction) be slow motility?  
Yes.

## Fatigue

We opted to delay our 5 year old entering kindergarten due to extreme fatigue. How can we address this?

If your child wakes up a normal kid in the morning, I would say PT and progressive exercise. If not, I would not be confident that EDS was the full answer. Sleep could be an issue. Beyond that, I think a deeper discussion with your physician would be in order.

My child is 6 and is having some extreme pain/fatigue as his days become busier with schools etc. When is it ok to use a wheelchair on the days when pain is unbearable?

Dr. Neilson: My concern with wheelchairs is that once a person starts sitting in one, it becomes easier and easier to spend more time in it. Having seen that pattern on multiple occasions, I never feel comfortable telling parents that a child using a wheelchair is “ok.” We spend a lot of effort trying to get people out of wheelchairs, not into them. The decision to pursue a wheelchair would have to be made in context of what the treatment plan is, where the child is in that process, and what factors are present that cannot otherwise be modified. (Continued on next page).

Dr. Goldschneider: A good evaluation to see if he/she would benefit from shoe inserts, and working with him/her on walking mechanics will help. This will be an ongoing process. I cannot say about the wheelchair for your son, as that varies from kid to kid. Overall, I would rather have a wheelchair available in school and have the child attend, than not and have them learn to avoid school. A second set of books, a few extra minutes to pass between classes and that kind of accommodation can be helpful (perhaps when is he older and has to walk and carry books more).

## **Working with Schools**

Please discuss getting accommodations for college entrance exams for a graduating homeschooler whose last IEP is years old  
You'll have to contact the testing agency directly to determine what they need.

What is the best way to educate a school who doesn't seem to "get it" when it comes to the limitations EDS involves, specifically with writing and hand fatigue? Our 7 year old son is having difficulty.

We typically provide letters to the school for our patients in anticipation of this. We also use occupational therapy to address the hand issues.

We were hoping to obtain assistive technology but are unsure if that's the answer.

We're not sure exactly what you mean by assistive technology—there is a broad range of interpretation.

What do I tell my sons school on how to help him physically?

I would need more specific information, so I will answer this in general. The first part is to document any physical problems and work with a physician to provide a letter to the school. The next part is to work the school to determine how those problems can be addressed. If physicians or therapists can provide more directive advice, that will help the school know what to do.

## **Physician Therapy**

What is your opinion on Bowenwork for PT?

Sorry, that's a new one to me.

Does physical therapy with EDS patients have to be year-round? Is there ever a time when it is okay to stop?

I view it like going to the dentist. You might start with a big cleaning, but after that it's checkups and making sure you're not falling behind. Once you have met your goals, it is a good idea to check in on a yearly basis or so. To be clear, though: your home exercise program should be every day from now on (just like brushing your teeth).

How do we find a local PT that can safely do exercises on the neck and shoulders in Chiari patients?

You have to interview your PT and determine their comfort level. Not all Chiari's are the same, and some may remain asymptomatic for a lifetime.

### Miscellaneous

Have you had any experience with children having toxic levels of copper? My granddaughter has six times normal.

There are a number of non-EDS causes. The most common cause is birth control pills which stimulate the liver to produce copper carrying proteins. Liver specialists and geneticists both know how to further evaluate this.

My mom had antiphospholipid syndrome during her pregnancy with me, what does this mean? OB/GYNs know this very issue very well. I would not expect this to affect you.

Is it UNSAFE to do colonoscopy/endoscopy on EDS patients, even if there is failure to thrive?? When does risk outweigh benefit?

Only with the vascular type. Our EDS-HT patients get scoped all the time for GI problems.

Any suggestions for getting Illinois to recognize EDS and granting parking permits for people who have difficulty walking but don't use a wheelchair to get around?

I am not familiar with the process in Illinois. In Ohio, a physician just has to write a script, and the patient takes it to the license bureau.

How do I lessen pain from climate/weather changes?

One of my patients moved to Florida for just that reason. I told her to be sure to get out of the way of hurricanes. I do believe this is a real problem, but I have never seen a solution offered. Usually, it seems related to low pressure systems, so perhaps increasing the pressure with water (i.e. a bath or pool) might help.

We see people "die from EDS" frequently on groups. Is this a real risk? Why isn't it stressed more if so?

The vascular type has a real risk of death, and we always evaluate for that. We take a detailed family history of multiple generations for each patient. I have not noticed any patterns of persons dying prematurely due to EDS-HT. The medical literature also does not suggest an increased risk of death.

What is cap age for your consultations if in college?

For genetics (Connective Tissue Clinic), let's just cap it at 100. For pain management, we see children through college age, approximately 21.

I'm concerned about where we will be POST puberty when were already having a problem at 7 years old! What are we looking at for the future? Can you address the progression expectations? Symptoms can progress in girls, but tend to get better with boys—This is not a hard and fast rule. It makes a good case to work hard on the physical therapy now.

Do you ever use service dogs or emotional support dogs?  
I have no experience with this.

So because that this has to do with collagen, then can it also effect hair?  
There are no known hair problems that are related to EDS.

Also, when my daughter was born within 12 hours of life she turned ash white. No one could explain to us why. They had all the different specialists there to check her out. The good thing about genetics is that in dealing with extremely rare disorders, I am often faced with situations that no one has ever seen before. As such, I have a high comfort level in telling you I have no idea what that is about.

### **Treatment/Therapy Options**

Have you heard off Alexander technique and would this therapy help with hypermobile type EDS?  
Postural education and control are skills that are developed in PT for hypermobility. So, the Alexander technique (which I know only a little about) could be helpful. It is unclear if it would be enough by itself.

What do you think about prolotherapy for EDS children?  
Dr. Neilson: What I have seen is that it works for a few months and then the effect goes away. The platelets seem to work better than the saline or sugar solutions. You will have to have repeated therapies, and it is unclear if there will be a lasting benefit. Usually a shoulder joint will require 30 or so injections during a single session. You will have to pay out of pocket

Dr. Goldschneider: The evidence for prolotherapy in general is not good, so I do not even consider it in my general practice.

If doctors suspect a shoulder tear would you recommend surgery for someone with EDS or just continuing therapy? I have pain in my shoulder every night.  
Sometimes a torn labrum needs to get “cleaned up” to help reduce the pain.

Should Chiara 1 Malformation be fixed with surgery?  
Chiari malformations get fixed should they start causing neurologic problems. We have patients with this who we have followed for years without intervention.

Is Botox a viable treatment for spasticity with a combination of these 2 or 3 disorders?  
Our therapy is to make strong muscles. Botox goes the wrong way on this. Still, it depends on what spasticity you are talking about.

What do you think about acupuncture or myofascial release?  
They are fine and good.

A number of integrative health options are available to folks with EDS. We talked about acupuncture, Yoga, meditation, Tai Chi, Pilates and massage as being helpful for lots of folks. With all of them that involve manipulation or possible extreme postures (especially chiropractic) one needs to assess what might happen to the joints by doing the activity. Several are very relaxing, so if you already get lightheaded standing up, then stand up carefully after these! ☺

Do you recommend an overall whole body PT and OT regimen being started for EDS or should PT and OT be added as certain areas become problematic?  
Overall body.

What do you think about spinal surgery (fixation) when there is L4-L5 Listesis Grade 1?  
The indications for surgery for spondylolisthesis are related to progression of the listhesis/instability and neural compromise. As long as things are not progressing, then surgery is not usually done.

With chronic subluxation related pain in a specific joint how successful is joint tightening surgery in reducing pain?  
Some surgeons have been able to take steps to improve the lifespan of the repair, and some joints may do better than others. Overall, there is a high risk that these repairs will fail over time. As a general rule, therefore, we cannot advocate for tightening of joints through surgery.

What do you think about a cortisone injection for shoulder pain?  
It depends on what is going on.

## **Research**

Are there any studies to help EDS or dysautonomia?  
Yes, but I think we still have to do a lot of basic groundwork to help convince the medical profession (and hence, the grant funding agencies) that this syndrome is something to take seriously. Most of the studies that we base our medical decisions on are small, and there may be only one or two studies done. Instead, a lot of what is currently getting done in EDS is based on word-of-mouth successes. Combined with the Internet, we are essentially applying a 19<sup>th</sup> century process with 21<sup>st</sup> century technology and finding out that it's still not good enough.

## Diet

Many POTS patients are on a high salt diet, but would a POTS/EDS patient benefit from that since their blood vessels don't constrict? We haven't seen any change by adding salt or high sodium foods.

The idea is to increase the total body fluid. The rule is that water goes where the salt is. Some patients with POTS have ineffective release of hormones that retain salt and reabsorb water. For that reason, the salt could end up being wasted in the urine. We start with increased salt and fluid—if that doesn't work, medications come next. It is incorrect that blood vessels don't constrict—but they do seem to have a mind of their own and will often constrict or dilate inappropriately.

## Sports

Is it safe on the knees to run 2 miles a day?

Yes, it's okay if your muscles are strong enough to stabilize the joints and alignment is maintained.

Hula hooping, we heard, was great for EDS/POTS but be very aware of where your knees/hips are (dislocations/subluxations).

Positional and postural awareness is always a good thing.

Will the repetitive work from playing sports do damage?

Depends on the sport, I suppose.

## Biology

How does EDS cause dysautonomia?

Dysautonomia: There are lots of causes, but the exact cause in EDS has not been delineated. It may not be the same from person to person. Please refer to our blog, the video and the resources posted above

My daughter who is 14 was just diagnosed with EDS. I don't know anything about it.

Please refer to our blog, the video and the resources posted above.

Can a child have EDS-Hypermobility without dislocations?

Yes, fortunately. EDS is defined by hypermobility—extra motion of the joints. Dislocations are one possible outcome, but not necessary for the diagnosis.

Wouldn't that mean that hormone changes contribute to worsening EDS problems? I started getting pain at 14, and it has only progressed.

You are spot on. That seems to be the case. Exactly how is not known, but hopefully will be studied soon.

Can you explain why there is a connection between hormone changes with puberty?

I can make up a good story about why such a connection might exist, but it is pure speculation until we can prove it. The first thing we're trying to do is prove that such a connection actually does exist.

## **Headache**

Can EDS cause chronic headaches ?

Yes. Headaches are frequently seen in folks with EDS.

Why are headaches common with EDS? What causes them and when should you go to ER for migraines? Please address chronic headaches/migraines, vertigo and EDS. What kind of break through medication is best for long-term headaches?

See up top for resources, and I cannot make specific recommendations for your situation. However, it is important to have an overall plan for headaches, which includes good posture, neck care, stress management, possibly certain long-term medications, as well as certain medications to take for breakthrough pain (pain the pops up for not good reason when things have been OK for a while).

My daughter gets severe headaches. No pills work. It feels like she might blow a blood vessel. Can you help?

We would be happy to. Either you can come to see us, or we can work with your doctor.

Our 13 year old was recently diagnosed with pain in the knees and headaches, but they are not bad. What should we expect in the coming years?

It depends on boy or girl, how much proper PT is done, whether he/she has good coping skills, can pace themselves and care for their joints and anything else that bothers them.

## **Abdominal Pain**

Chronic headaches and abdominal pain: how do you manage pain them?

A holistic approach is the best, as we discussed in the presentation. A combination of psychological interventions (which has the best evidence for abdominal pain than everything else combined) includes exercise, lifestyle modifications and certain medications. The good: Many of the medications used for headaches help for abdominal pain. The bad: The evidence for them is not great, so some work and others do not.

## **Hand Pain/Fatigue**

How can you easily explain hand fatigue and fibrous pain?

Altered mechanics would explain pain and fatigue in the hand and wrists, as it does for other joints, but I am not familiar with "fibrous pain." I assume you mean something else, sorry. Adaptive equipment can be helpful, and using a keyboard in class instead of writing, often with wrist supports can be helpful.

## Symptoms

Do you usually see young children (age 7) who cannot walk more than 200 feet without pain, subluxing?

Yes. Many times getting a good shoe inserts makes walking a lot better, both in terms of pain and fatigue.

My daughter has pain in knees and hips. How can I tell she is having a subluxation?

It depends on her age, what she was doing at the time you suspect subluxation, and how she acts and feels after. Sorry, I can't be more specific.

**Specific medical advice is best done with a proper history and physical exam. For anyone with specific medical questions or those looking for a physician, please call the Pain Management Center at 513-636-7768. We would be happy to see for an appointment or work with your local physician.**