

Saw three doctors before anyone being convinced I had anything but anxiety. EoE is scary. I describe it to people as asthma of the esophagus, for complete lack of another way to do so. The only way to be diagnosed at this time is to be put under and a snip taken from the inside. My first experience with this condition was a terrifying food impaction, during the off hours of my local hospital's GI Center. No one was available to administer certain anesthesia meds and I woke up during surgery. There needs be be another way for (potential/probable) EoE patients to be identified so they may be made aware of this condition's symptoms before they're in a predicament.

Nobody knows it exists

I feel like it could have been caught at least 5 years earlier if ER staff had been either better aware of it's existence, or less dismissive of me.

I feel like I still know very little, and I mainly believe that is because the research is not there.

Lack of information, detail and support

Almost all the knowledge I have on the subject is from my research. Very little help from GI or Allergist other than to treat symptoms and do endoscopies.

Scoped 11 years ago to look for the problem. Only recently diagnosed with EoE after they looked at the same scope results from 11 years ago again.

My doctor first blamed my disorder on Marijuana use (which has actually helped, and I am now a medical patient in the state of Florida -- it has definitely helped me gain weight). After 3 different doctors, I was finally tested via endoscopy due to my organs shaking violently in spells and rapid weight loss. I was not well informed about my elimination diet, and nearly a year later, I feel like I'm walking on eggshells to find anything that isn't a raw fruit or vegetable to eat.

Was dismissed a lot by different doctors. Current GI doctor isn't very helpful in treating it. Doctor hasn't officially diagnosed me but symptoms align and endoscopy results indicated this existence

I feel as if Doctors do not believe me and I get written off all the time. No matter how hard I try to voice how miserable I am and that these medicaitons are not working, I get nothing in return. My allergist cares and puts more effort into me than my GI ever did. I'm still standing because of my allergist, but still suffering because of my GI

It took a while to receive a diagnosis and now even when I have one, it has been difficult to manage.

I was labeled an anorexic (even though I have never had issues with my weight/body dysmorphia) and was treated very poorly. No one believed my symptoms until I lost 1/3 of my BW in 3 months. I had an ER doc tell me, "anorexics don't belong in my ER.", even though I had passed out in public and didn't choose to go to the ER.

After years of tests and restricting foods, there remained no real solution or treatment outside of avoiding 5 out of the 6 most common food allergies for the rest of my life.

Years ago I had radiation therapy and a neck dissection for metastatic tonsillar cancer.

Assumed for years that dysphagia resulted from that, especially due to loss of saliva. As symptoms worsened I was referred to a speech pathologist and given oral exercises.

Continued to suffer for years until a food impaction incident landed me in ER and an endoscopy diagnosed EoE.

I found out at 16 with a ruptured, infected esophagus that was apparently infected for years :) My doctor(s) did not really explain my diagnosis very well. Nor did they explain what exactly I should do to help myself. My GI doctor prescribed me an anti-reflux medication and said I should take it for 6 months to see if it improves my reflux, and my allergist suggested that I should attempt to find my triggers. I got conflicting statements from both of them on which works better since this is such an understudied and recently discovered disease. My GI

doctor said that my consistent burping would pass after 4 weeks on my anti-reflux medication. It has been nearly 8 and I still have issues.

It took 9+ years to be diagnosed even after having abnormal biopsies, I hope this disease will be more well known in the future

They told me I had GERD for years before diagnosis. Now that I am diagnosed finding the causes are challenging. More research needs to be done to help people find out what allergians they are reacting to.

The doctor was dismissive

Years and years of trouble swallowing, after diagnosis treatment prescribed with no explanation.

I swallow Flovent (instead of inhale) and take protonix which limits my symptoms but it wasn't until my sophomore year of high school (15 yrs old) that I was able to get a proper diagnosis. From the age of 10-15 almost anything I'd eat would make me throw up. There seems to be a lack of diagnosis for children which I believe to be a problem.

It took many years to get a diagnosis and a doctor thinking it was all in my head. Finally got a doctor to listen and got a diagnosis

After diagnosed with EoE, the strategy for treatment is basically: keep on PPI and swallowed steroids indefinitely. It feels like treating symptoms without understanding or addressing the underlying issue.

I was an adult when diagnosed however I had symptoms since childhood

Delays in diagnosis with COVID. I have spoken to doctors for perhaps a total of 25 minutes regarding the diagnosis.

It's taken too long. Much is still unknown.

Took a decade, missed for other things.

I had a poor specialist whom I stopped seeing. A year later my esophagus popped and almost killed me. Thumbs down. Trying to see a specialist now with Covid is impossible.

Even after diagnosis, treatment, and a strict diet I am still ill most of the time

I was diagnosed as a child and it took many doctors to figure out what the problem was. I was diagnosed at approximately age 13 but my parents knew something was wrong and were seeing doctors about it for 4 years prior. I feel that EoE is something that too many doctors are unaware of or at least were unaware of when I was a child (10 years ago).

I had symptoms my whole life and didn't find out it was a medical condition until I ended up in the ER. I just thought I was weird for always needing water handy when I eat.

My family doctor has brushed off my symptoms (he told me it was anxiety related) and it was only after I pressed that he finally sent me for an endoscopy and I was finally diagnosed. I've had serious choking episodes and I felt like I wasn't taken seriously until now

concern it would get worse.

Worsening symptoms, choking to death

Not being able to clear an obstruction in the future is always a fear of mine. I'm not sure anything will change this.

Mostly wanting to halt the damage so I don't end up worse off in the long run.

Long-term effects of EoE and the medication.

I suppose the biggest concern is it worsening. Second biggest is saying farewell to the joy of good food I used to love.

Quality of life

Just clarity into why

I don't know if it will ever get better and it's awful.

Medication seems to be working, just worried about staying on top of it or things worsening.

I worry that my poor health will effect my ability to get pregnant and keep a healthy fetus concerned about long term side effects of nexium and lack of good alternatives

Yes. Future damage to esophagus. Symptoms not improving.

Getting sick

Figuring out all allergns

It all too often gets regarded as anxiety or an emotional problem. No one took me seriously until I couldn't drink water.

Obviously. I am wary of long-term ppi use, and am now learning about how to do an elimination diet. I do not want a feeding tube, and I'm suffering from the social disconnect necessitated by my slow eating habits

Not really, if drugs stop working then it forces me to be healthier even if it is limiting

I am fearful of making mistakes that will lead to future food impactions, inflammation of the esophagus, and other EoE related problems simply because I cannot get a straightforward answer on how to manage my disease.

Treatment options! My EoE affects my entire sinus system and stoumach as well and its been so hard to get under control

Preventing further damage to my esophagus. Afraid of choking and not being able to clear the obstruction.

Where I live finding qualified specialist is limited.

Whether I have to keep getting dilated. Problems swallowing again.

Being sure I identified my triggers

Return of benign strictures (more dilations required), symptoms persisting despite trying medications, diet, and dilation

I have concerns mostly around jobs. At times my symptoms keep me from going to work which often makes me worry that when I'm out of college and in my chosen career that is more rigid with scheduling, I won't be able to go home early or take the days off I need. Any other concerns are very minimal such as vacation or sporting events where I could possibly have a flare up

I worry I won't ever enjoy eating again. Is life without dairy even really life?

That it will progress into something worse.

No. I was diagnosed as a child, and it has been well managed.

Long-term side-effects of medications.

Yes. Even though my scope is improved i still have pain.

Long term damage. Symptoms not improving. Concern that I will not be able to identify a clear cause.

Yes. I don't like it.

What is the long term prognosis

EoE is so complicated with the branches within it. I wish more information was accessible about conditions like Mast Cell Disease, Connective Tissue Disease, etc.

Currently taking 20mg of Omeprazole as treatment for EoE. Concerned about the long term implications of taking medication.

Yes, my symptoms aren't managed. I worry about cancer or esophageal rupture

I'm concerned it will kill me.

I'm concerned that I'll only be able to eat 3 ingredients for the rest of my life and will still feel sick

Yes, I wonder how this will impact my life in the future if I can't figure out my trigger foods. They started me on a gluten free diet to see if I'm allergic to wheat, and I really miss some of my favourite foods so I hope it's not wheat

Severe stricture management. Stricture location at c4-c5. Two separate series of multiple dilations and it keeps closing back up. Also concerned they can't identify what is causes it to close up even with biopsies showing inactive EoE.