

## Re: Plea for help with diagnosis

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On 7 Jun 2004 15:44:18 -0700, bradedwards@emailaccount.com (Brad Edwards) wrote:

>My apologies if this is too long. I'm posting my story in the hopes  
>that someone will have a clue as to what is wrong with me. I'm not  
>sure which group to post to, so if you have an idea as to a better  
>place for it then please let me know.  
>  
>I am a male in my early 20s and have been underweight my entire life.  
>I've never had much of an appetite or really enjoyed eating. My first  
>meal of the day was usually after 3pm. Four years ago I became  
>severely dehydrated and malnourished, due to my poor eating combined  
>with a lot of stress. During this episode I was extremely weak, and  
>spent maybe a month in bed trying to eat/drink enough to rebuild my  
>strength. Ever since this event I've been trapped in an endless cycle  
>of trying to maintain my health.  
>  
>For some time after the dehydration episode I would wakeup in the  
>morning with an urgent need to defecate, and had explosive bowel  
>movements of strange color/variety. I also felt compelled to eat as  
>much as I could every 2-3 hours beginning immediately after I awoke. If  
>I didn't eat on schedule, my mind would start to feel strange, kind of  
>cloudy like I was spacing out, and then once the hunger pains came I'd  
>feel like there was an emergency and I'd exhibit panic symptoms. Some  
>minutes after filling my stomach with some food I'd start to feel calm  
>again.  
>  
>Since I had such tremendous anxiety all the time, I assumed I just had  
>an anxiety disorder, and that was why my digestive system was behaving  
>strangely. But as time went on, I began to learn how to relax a bit  
>and keep the anxiety from escalating into panic attacks. I also  
>noticed that there were periods of time when for the most part I felt  
>fine. As long as I ate on schedule, then I'd feel good enough for up  
>to 3 months. But this remission never lasted, eventually I'd be hit  
>again with my body behaving erratically, with mind fog, memory  
>problems, difficulty finding words to speak right, darkness when I  
>stretched my arms up in the air like I was going to pass out, stomach  
>pains, weakness and fatigue, etc.

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>I visited a GP and he did some blood tests for general things as well  
>as thyroid hormone levels. Everything was fine except I had an  
>elevated ALT liver enzyme. I did some research on my own and the hype  
>on the Internet led me to Celiac Disease. Unfortunately the doctor  
>said that he couldn't test me for it, so I just went on the  
>Gluten-Free diet instead. I took the diet to an extreme level, using a  
>new kitchen with new pans/utensils, and only ate whole foods such as  
>steak, fruits, vegetables, and nuts. I've been on this diet for over a  
>year now, and despite feeling somewhat better, which could just be a  
>placebo effect, the only other noticeable difference is a change in  
>the way my feces looks. I have not gained weight, and I still get sick  
>every so often. Though I do seem to have longer periods of remission  
>with this diet.

>

>Since I haven't had a miracle recovery after a year of being on a GF  
>diet, I figured I should explore alternatives. I visited a GI doctor,  
>who ordered a bunch of blood/stool tests. He said the results were  
>that I was dehydrated. The sheet shows the following with an H next to  
>it, which I assume means high: C02, BUN, CREATININE, ALT/SGPT, VITAMIN  
>B12. The doctor said the next step was to do some tests like a  
>colonoscopy/gastroscopy in order to rule out Celiac Disease and  
>Crohn's. But I'm already on the GF diet, and I read that there's no  
>treatment for Crohn's, so I decided I'd rather not undergo the  
>invasive testing procedures.

>

>All of the vague symptoms I experience while "sick" seem to be related  
>to my gastrointestinal tract. During the days when I'm feeling pretty  
>good, I can wakeup in the morning and calmly eat some breakfast. But  
>on the days when I'm not doing so well I wakeup and immediately have  
>to run to the toilet, and as I go I'm grabbing some juice or food to  
>put in my stomach since it feels uneasy. Everyday, no matter how I  
>feel, my abdomen distends after I eat in the morning and stays that  
>way all day. On the bad days I have to defecate multiple times,  
>probably 2-6 or more.

>

>The two symptoms I hate the most are when my mind becomes spacey, and  
>when I become fatigued. There are some days when I feel like I don't  
>have the energy to breath. I have to use a chair while washing the  
>dishes I need to eat on, and then I spend the whole day sitting on a  
>chair listening to relaxing music as I kind of just stare into  
>nothing, not moving a single muscle, attempting not to use too much  
>energy so that I have enough to cook my next meal. Those periods  
>aren't fun, but I've always made it out of them and then have a  
>stretch where I have enough energy to do what I need to do.

>

>My guess is that it is something involving the immune system, since  
>when I don't feel well it sometimes feels like when you have a cold,  
>but with none of the cold-like symptoms. It's just the overall feel,  
>like your entire body is fighting something.

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>At this point the doctors I've seen don't have much to say. If someone  
>were to offer me a clever idea as to what might be wrong, it might  
>lead to this mystery being solved, and I would be forever grateful.  
>I'll gladly answer any questions that you might have.  
>  
>Thank you  
>  
>Brad Edwards

Sounds like Crohn's Disease to me. My cousin suffers from it and her history is very similiar to yours. I'd suggest you get tested for Crohn's to either rule it out or learn to live with it. good luck