Life With Pernicious Anemia- Discover, Cope, Live

A blog about my life with pernicious anemia as a 20 year-old including the ups, downs, details, and coping methods. From pre-discovery to my present daily life, this is my story. I strive to keep a positive outlook on my condition and my life and encourage others to do the same. Hoping to connect with others who have Pernicious Anemia and also find those who share this condition at a young age. *I am not a doctor and I do not have any medical training or background.

Wednesday, February 6, 2013

Does Anyone Believe Me? -Life Before Diagnosis

Hello all!

Let me begin by saying this is my first blog. I've always been a fan of them; however, I never felt as if I had a topic to write about continuously that others may find helpful or interesting. I needed something to base it on... A purpose, an idea, or some entertaining persona that I could convey to an audience as I went along. Today, it hit me. I found my purpose, my topic. Actually, I should say it found me and began to take over my life about a year ago....

Let's rewind a bit so you can get to know me. My name is Ashley and I'm twenty years old. I'm a small town girl who is extremely ambitious, a go-getter if you will. I've been involved in nearly everything you can imagine from National Honor Society and the Future Business Leaders of America to basketball, golf and gymnastics. Avid athlete and fitness nut, committed student, and family-oriented individual.

In February of 2012, I was in the middle of my collegiate basketball season. To anyone else, I looked like your typical college athlete: physically fit, mentally tough, and ready to take on anything that was thrown at me. I thought so, too. However, almost like the flip of a switch, something began to change internally. I began to feel ill more often than usual. My symptoms began with stomach aches, fatigue, and unusual breathlessness during my workouts to the point of blurred vision and partially blacking out. My coaches would often comment that I looked pale as well. Frequent sore throats also accompanied the other symptoms I mentioned (about twice a month). During the season, I also dropped from approximately 150 lbs to about 133 lbs.

As one could imagine, I was grabbing at straws to figure out what was going on with me (little did I know it would get much worse). I was tested for anything and everything (or so I felt like) having blood drawn or appointments several times a month. The tests doctors gave me ranged from mono, anemia, and bacterial tonsillitis to lymphoma and leukemia. After all of these came back negative (I have fast-forwarded to May), I was told that I was probably suffering from a lack of sleep and severe stress as many college students do. I accepted it as a possibility for my sanity's sake (because I had never been sick for such an extended period of time with no explanation before) because I was going through a tough semester with many projects and homework as well as a couple other life events that put a significant amount of stress on my shoulders. Unfortunately, this was only the beginning.

I had an amazing job at this time that I loved. My work was interesting and I enjoyed the people around me. Yet, for some reason I nearly fell asleep at work every day. My stomach would hurt often, and I noticed that I couldn't seem to focus on anything except for on some days of clarity. Even more unusual symptoms began to accumulate: numbness and tingling in my hands and feet, excessive confusion and forgetfulness, and clouded thoughts. Let me explain further. Once a self-confident and well spoken individual, I now found my thoughts clouded, often trailing off mid sentence forgetting everything I had just said or where I was going with my sentence or thought. Other times when I would open my mouth to speak it was like my own voice or thoughts inside my head was overlapping or conflicting with what was actually being said out loud. I did not disclose this to anyone because I was embarrassed about what was happening and I felt like I was crazy, even though I felt sometimes it was obvious.

No, my issues were not debilitating at this point, but it was frustrating because my original symptoms were getting worse and new ones were popping up. I was going absolutely crazy trying to pinpoint the origin of my symptoms. Maybe I had gotten lazy in school and didn't apply myself

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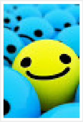
About Me



Anonymous Ashley

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as much as I used to I thought. Hard to believe when you don't have a single "B." And no, I wasn't getting as much sleep as a "sick" person should, but I was taking fairly good care of myself except at this point I had lost almost all motivation to exercise because my muscles already ached for no reason all the time.

Hang with me... We're getting close to the actual diagnosis. I feel there is a lot that many other blogs leave out that could be important or similar to other individuals cases, so I'm trying to cover the "Before Diagnosis" thoroughly.

A family summer vacation to Florida rolled around and I couldn't have been more excited. Prior to leaving, I had another blood test that tested several additional things. Even so, I thought maybe a full week of relaxation and stress free time was exactly what I needed. I began to accept my worsening condition, but the problems continued to pile. A couple months after the last symptoms I discussed, I became easily upset and/or irritable (a symptom which close family members and friends blamed on "PMS..."We now know the real reason). Again, this was not my typical behavior. Typically very light hearted, happy, positive, and easy going. My outlook on life was negative because no one could give me an answer as to why my condition was deteriorating. At the beach was only more disappointment. Waking up at 10 AM to go out to the beach only to find myself back in bed by 2 PM is not my idea of a fun vacation. Nights were spent dragging myself to dinner barely looking presentable (from my perspective) because I had no energy to get ready (dressing up is a favorite thing of mine to do).

Two days before I came home from vacation, I got a phone call from my doctor. My blood results were in, and it turned out I had Pernicious Anemia. I had not even heard of this condition before that moment, but even knowing that something was actually wrong and we were able to pinpoint it was a HUGE relief. I immediately Googled and researched anything I could find (more on my reaction to this in my upcoming posts).

Upon returning home, I received a vitamin B12 shot and felt slightly better, but not a huge improvement like some people report after their first shot. I think maybe the most significant reason I felt a little better at this point is because I no longer felt crazy. Throughout this process, I spoke with some people about my symptoms prior to being diagnosed who acted as if I had "made up" feeling terrible all the time. Yes, this did include some of the people closest to me. I understand now that looking back it must have been difficult to understand the physical and emotional stress I was enduring because I kept much of it to myself. I don't like to complain, and I didn't want people to think there was anything wrong with me. Furthermore, when I did admit I was in pain or questioning something that was going on, it may not have been taken seriously because I had gone out with friends just days before (I'm a try to put on a happy face and try to forget about it type of person).

Having told my story about how my pernicious anemia (PA) came about, I would also like to mention that I have yet to find someone close to my age with it. From what I have read, it is extremely unusual. So, I have a few purposes with this blog:

1) Connect with others who have PA, especially someone my age! Even though the condition is unique to each person, it helps know other people are right there with you.
2) Provide tips I've learned along the way and learn from others as well. **I am not a doctor and I do not have any medical training. Please consult a doctor prior to making any health/medically related decisions.
3) Inspire others to effectively manage their condition, come to terms with it, and retain a positive outlook on life, even on the tough days.

Ok! So, after that ridiculously long post, I feel I was able to get my initial story across. Believe it or not, I cut some stuff out. More posts to come soon. I'd love to hear from people.

Stay positive!

"It is during our darkest moments that we must focus to see the light." -Aristotle Onassis

Ashley

P.S.- Funny fact- I forgot what I was doing when I went to look for a quote. Ha! Guess the forgetfulness/confused symptom still exists. :p

Posted by Anonymous Ashley at 3:15 PM

G+

Labels: B12, Diagnosis, Pernicious Anemia

12 comments:

DeniseL August 19, 2013 at 4:59 PM

Hi, I am going on 20 and have the same condition for almost a year now! Would love to chat perhaps, if you are interested!

Reply

Bruce Sherman February 17, 2014 at 2:26 PM

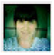
Hello, I am 56 and was diagnosed about 2 years ago. I welcome involvement in your blog. At my age I'm still a bit young for this disease. It's very challenging to live with.

Reply

Darci Gregory July 11, 2014 at 1:53 PM

I loved reading your blog! I am 26 femake college athlete whose is just as competetive outside college doing tournaments and such and traveling. Most of the severe symptoms of PA hit me a year ago when I fractured my L5 vertabrae and casued my L5 S1 disc to buldge posteriorly into my spinal cord. There is nothing worse than almost never feeling at 100% again and some days at only 50%. I would love to share my experience with you if you would like.

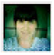
Reply



Browningtown January 10, 2016 at 6:04 PM

This comment has been removed by the author.

Reply



Browningtown January 10, 2016 at 6:04 PM

HI there - I'm now 34 & was diagnosed when I was 25. I found out when I cut sugar out how much i relyed on sweet foods for my energy. I now have 2 kids & make myself have injections every 3 months. The levels were so high for sometime I was told to stop having them until my levels lowered but I always notice i get super unco & can't handle physical contact as my arms & legs feel weakened. Kids present challenges wanting to be carried or even just climbing all over me. I'm glad i came across your blog - symptoms are different for everyone I hope you have achieved what you'd hoped in finding people in the same boat. Shout out any time if you need more support - from one who has gone before!

Reply

Kelli Brady March 1, 2016 at 10:51 AM

Hi, I am a 52 yr old women who just got diagnosed WITH PA. I got lucky while searching for thyroid issues for my shortness of breath. I asked my doctor about it and she doubted it but did test anyway. She was shocked. I am now taking shots monthly but seems to long between. The shots help about an 80% improvement. What do I do about the other 20%? Doctor just seems unconcerned. I am always winded with any effort...cooking dinner , doing laundry ect. Very difficult to handle. It will be nice talking with anyone with same issue.... so sorry it happened so young for you.

Reply

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Reply

Jessica May 11, 2016 at 3:08 PM

I'm 30 and was diagnosed a year and a half ago. I live in America and feel like the doctors in exposed to don't know a ton about it which stresses me out sometimes.

Reply

Jessica May 11, 2016 at 3:09 PM

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Reply

Hannah J Jewellery June 4, 2016 at 5:21 PM

I'm 24 and have been diagnosed with very low b12, it also gave me regular anemia too. I have a bad wheat allergy, which causes inflammation and may be the cause. I've had twice weekly injections for 4 weeks and feel no better! Apparently there are different brands of b12 and some work better than others. She also said for people whose level is extremely low it can take months and months for the bone marrow to regenerate. Starting to think it will never work.

Reply

▼ Replies

Wendy Scotland June 29, 2017 at 5:58 AM

Hang on in there. It can take a frustrating amount of time to work, but it does.

Reply

Wendy Scotland June 29, 2017 at 6:06 AM

I am 16 days post loading doses of b12. For some the effects are instant, but not all. I had a nurse who also suffered from PA and she told me it was a week after her loading dose she started to feel better. I held on to this as no improvement occurred. Thankfully I can now see a parting in the clouds. It takes time for your body to recover from the damage done. This is a horrible disease and exactly as Ashley describes, it takes over your life and any control over it. I was lucky I had a GP who was in it quite quickly when he took the time to look at all my symptoms as a collective. Until then each symptom was dealt with separately and usually dismissed as age related; menopausal; or just put up with it. Including bladder incontenence - the first symptom to disappear! I am now on the right side of normal, I feel I am back. There is light at the end of what is a truly pernicious and horrible tunnel. Just wish more people knew how debilitating it is.

Reply

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