

September 12-18, 2011 is National Invisible Chronic Illness Awareness Week. To commemorate this week, I am participating in the “30 things...” meme on my blog. If you are coping with a chronic, invisible illness, I invite you to join in by copying the questions from [InvisibleIllnessWeek.com](http://InvisibleIllnessWeek.com) and posting them on your own blog, MySpace, or Facebook page. A dear friend and colleague recently reminded me that everyone we meet is dealing with something. Let’s bring the invisible into the light and share.

1. **The illnesses I live with are:**

*Classic Migraines without Aura, Chronic Migraines, and Cluster Headaches*  
**Classic Migraine without Aura, chronic  
Cluster Headaches, episodic  
Obstructive Sleep Apnea  
Hypothyroidism**

2. **I was diagnosed with it in the year:**

*1986 (migraines), 2000 (chronic), and 2001 (clusters)*  
**1985 Classic Migraine without Aura, chronic  
2000 Cluster Headaches, episodic  
2012 Obstructive Sleep Apnea  
2010 Hypothyroidism**

3. **But I had symptoms since:**

*As far back as I can remember*

**I’ve had migraines as far back as I can remember.  
Cluster headaches started in late 1999.**

**My family started complaining that I snored about 5 years ago, however, there are reports of me grinding my teeth since I was a toddler. I’ve probably had it all my life. I had trouble regaining my old energy after having H1N1 in October 2009. It wasn’t until I started getting treatment for hypothyroidism that I started to regain my energy in 2010.**

4. **The biggest adjustment I’ve had to make is:**

*Learning my triggers and having the courage/character/strength to change my lifestyle to avoid them*

**I had to learn to accept ideas about my health from someone other than myself. Finding doctors I could trust who would respect my need to understand my options and my choice to make the final decisions was a long and difficult path. I had to put aside my preconceived notions about what I was and was not willing to do in order to be healthier.**

5. **Most people assume:**

*that “being stressed out” causes migraines*

**...that I am just “too stressed out” to handle life.**

6. **The hardest part about mornings are:**

*Waking up a 3:00 a.m. with splitting pain, disoriented and waking up the whole house trying to find my meds.*

**...waking up before the alarm with eye-splitting pain.**

7. **My favorite medical TV show is:**

*House, and ER when it was on*

**My new favorite is The Big Bang Theory. I need something silly to laugh about. This**

**show gives me the chance to enjoy the fun in life even when I can't participate in activities.**

**8. A gadget I couldn't live without is:**

*Ice packs & Heat packs...never leave home without them. In fact, I always carry a "migraine emergency pack" with me that includes medication, ice pack, heat pack, Tiger Balm, Lavender oil, SalonPas patches and water.*

**An full oxygen tank with regulator that goes up to 15 LPM and non-rebreather mask.**

**9. The hardest part about nights are:**

*Waking up from a migraine only to realize it's dark because I slept for the whole day and feeling like I've wasted something very precious*

**Falling asleep too soon, then waking at midnight in pain and having trouble getting back to sleep.**

**10. Each day I take:**

*20 pills & vitamins as preventives, plus 1-6 abortives only when I have symptoms*

**ON A GOOD DAY...**

**250 mg Keppra**

**800 mg Vitamin B2**

**50 mg Vitamin B6**

**1000 mg Calcium**

**600 mg Magnesium**

**5,000 u Vitamin D3**

**500 mg Niacin**

**2 thyroid glandular pills**

**10 mg Zyrtec**

**Flonase**

**ON A BAD DAY, I MAY ADD...**

**2 caplets Excedrin**

**5 mg Zomig**

**25 mg Phenergan**

**up to 800 mg Magnesium**

**2 mg Valium**

**20-60 mg Prednisone**

**up to 60 mg Toradol**

**25-50 mg Benadry (or Ativan)**

**11. Regarding alternative treatments I:**

*Believe in their value and use them as preventive measures. They also help reduce mild symptoms. They do very little to relieve severe symptoms. I use aromatherapy, massage, accupuncture, accupressure, mind/body medicine and see my naturopath on a regular basis.*

**I have become disillusioned about their benefit for me even though I still think they have value for others. Once my health stabilizes, I think I will start using them again.**

**12. If I had to choose between an invisible illness or visible I would choose:**

*I don't know that I would choose another illness. I do wish that my body would show some obvious sign when my symptoms are flaring up so that people would know...then again, I can cope sometimes, so I wouldn't want people to judge me or hold me back based on some outward sign. I guess I just want people (friends, family, co-workers, bosses, clients, etc.) to take my word for it.*

**13. Regarding working and career:**

*I am a very driven person. I work hard...sometimes too hard. I know I miss a lot of work days because of my illness and it bothers me. I also know that I would be foolish to try working through a migraine that is not responding to treatments. Sometimes I just have to stop and take care of me.*

**14. People would be surprised to know:**

*I often have symptoms and no one can tell. I am very good at hiding my pain. I don't offer information but will respond honestly if I am asked. I don't want people to worry about me.*

**15. The hardest thing to accept about my new reality has been:**

*I've been living with it all my life. It was a relief when I finally accepted that I would have to learn to cope rather than stressing myself out trying to find a cure. I still want a cure. I just can't put my life on hold waiting for something that may or may not come in my lifetime.*

**16. Something I never thought I could do with my illness that I did was:**

*Worked full time and finished graduate school.*

**17. The commercials about my illness:**

*They're a joke. The only ones I have seen leave the impression that taking "their pill" always stops the migraine and that if you take it you will never miss important events again. WRONG! Abortives don't always work. Even when they do, they have side effects and they only relieve the pain, not the 24-hour "hangover" you feel when the pain subsides. The commercials about preventive meds make it sound as though taking their pill or treatment will completely eliminate all migraines forever. That's just not true.*

**18. Something I really miss doing since I was diagnosed is:**

*I've lived with this all my life. I do occasionally crave the idea of being able to skip meals, eat junk food, stay up all night, and be outside during a thunderstorm and not suffer with days of pain afterward.*

**19. It was really hard to have to give up:**

*Popcorn, flavored chips, veggie dip, Pepsi (that was the worst!)*

**20. A new hobby I have taken up since my diagnosis is:**

*Neurotically tracking my symptoms and triggers on a calendar*

**21. If I could have one day of feeling normal again I would:**

*I do have symptom-free days. I enjoy them to the fullest...even if that just means deep breathing and enjoying work. If I knew I would never have a migraine again, I think I would be more careless at taking care of myself. Having migraines helps remind me to be good to myself.*

**22. My illness has taught me:**

*Patience...the pain does not last forever and it hasn't killed me yet. If I just stay calm, I can get through anything. Slow down, take care of myself, enjoy the good moments in life, breathe deeply, drink lots of water, and never take the day for granted.*

**23. Want to know a secret? One thing people say that gets under my skin is:**

*"So-and-so had migraines and they stopped them by doing X" (usually something I've*

*already tried that failed). It also annoys me when people say that stress causes migraines...GRRRR!!!*

**24. But I love it when people:**

*Validate how debilitating migraines can be...hours in bed in the dark, intense sensitivity to light and sound, irritability, restlessness, anxiety, poor concentration...and yeah...the PAIN.*

**25. My favorite motto, scripture, quote that gets me through tough times is:**

*My favorite scripture is II Corinthians 12:19 "...My grace is sufficient for you, for my power is made perfect in weakness." Therefore I will boast all the more gladly about my weaknesses, so that Christ's power may rest on me.*

*My favorite quote is "What doesn't kill me, makes me stronger."*

**26. When someone is diagnosed I'd like to tell them:**

*Take charge of your care. No one knows your symptoms like you do. Keep asking for help until you get what you need. Don't let anyone tell you that you just "need to relax" or that it's "all in your head". There is hope.*

**27. Something that has surprised me about living with an illness is:**

*Symptoms change over time. So do treatments. New information is available. Sometimes I need ice, sometimes it's heat that helps, or certain smells, or pressure, or new meds, or supplements...I don't have to be stuck with only one treatment.*

**28. The nicest thing someone did for me when I wasn't feeling well was:**

*There are so many! Bringing me hot or cold packs, finding my medicine, massaging my head until their hands fall off, driving me home or to the hospital...and most of these have been in the middle of the night so the sacrifice is so much bigger when my loved ones lose sleep to help me.*

**29. I'm involved with Invisible Illness Week because:**

*People need to know that it is possible to be happy and successful while living with migraines. People also need to know that successful people with migraines sometimes need to take a break. We can't be there for everyone all the time. Our illness takes over at times and doesn't give us a choice.*

**30. The fact that you read this list makes me feel:**

*Hopeful. The more people know, the better we will all be.*