

UNDERSTANDING

ATAXIA

*for dummies,
smart people,
and everyone
in between*

by Jonas Cepkauskas

OK, first things first. Most will NEVER fully understand ataxia, but knowing how and why it affects YOU will prove invaluable. It probably took several years before the problem was finally figured out, and like parenting, it never gets easier...

I am in the USA, so that's what I know, so I use it as an example. Ataxia is considered a rare disease. There are approx. 150,000 people in the USA affected by this rare neurological condition. That may sound like a hefty number, but with a population of 330 million, that comes out to about 1/20th of 1 percent. I for instance, am SCA15 (type), which may have a frequency rate of 1 in 100,000. Friedreich's ataxia has a frequency rate of about 1 in 50,000.

There are over 100 types (now) of 'hereditary' ataxias, and many more that seem to come out of nowhere, which are called 'sporadic' (acquired). These can be caused by head trauma, stroke/heart attack, toxins/chemicals, substance abuse, even vitamin deficiency. Needless to say, there are a

plethora of ataxia woes, when you add age, lifestyles, attitudes, family history, etc.

What I'm getting at is YOUR ataxia is probably NOT the same as mine, his, hers, or theirs. You may learn that ataxia is a symptom of something else. That is true sometimes, but ataxia is a symptom AND its own condition, which refers to a group of cerebellar dysfunctions.

Ataxia is very hard to explain in depth to anyone. The easiest way to somewhat get your attention is to say it's like being drunk with no buzz. YES, liquor is 'ataxia in a bottle'. Most ataxians drink very little, as it's pouring gas on the fire. Picture the very inebriated person standing (sort of) at the front door, trying to insert a key in the lock.

Most ataxias are PROGRESSIVE, which means it will increase in intensity as time goes on. One good thing is nothing happens overnight. It may take a long time before you can notice a difference. It all depends on many

factors which I mentioned, but it's better understood if you compare a beer or two to consuming half a dozen shots of tequila.

In your travels, odds are pretty good that you will be told that you need to know your type. To ME, that is only partially true... I think that the 'knowing' part needs to be whether or not your ataxia is 'dominant', (meaning it comes from one parent), or 'recessive', meaning BOTH parents must have the defective gene. This info will come in very handy in the future.

ALSO, it is important to know that 'hereditary ataxias' run in the family. If you are diagnosed with an ataxia, it's probably 99.9999% sure that ANYONE in your blood family that HAS ataxia, has the same type. Of course there are exceptions to all rules, but there is no need to lose sleep over this one.

Another reason ataxia is hard to explain to you is that you have no experience. You haven't lived it, and therefore have no idea what I'm talking about.

The common symptoms in ALL ataxias are

- 1) Lack of balance and walking ability
- 2) Slurred or slow speech
- 3) Vision problems
- 4) Poor overall muscle coordination and control
- 5) Very poor penmanship or drawing skills

I think that no matter what type you have, you have ATAXIA. Whether it's an SCA, Friedreich's, dominant or recessive, etc. you have ATAXIA. Sure, each type may have different quirks, severity, rate of progression, etc. but the bottom line is you have ATAXIA. Compare it to a car. You may have a Ford Focus, a Dodge mini-van, a Cadillac Escalade, etc. They all have four wheels, an engine, brakes, and get you from point A to point B, They are all similar, yet very different. Ataxia is like that....

Ataxia is very complicated, but simple at the same time. Your main brain (cerebrum) contains gigs and gigs of information. Much of

that information is commands from your cerebrum funneling through your cerebellum, and distributed through your nerves, telling your body what to do. When you have ataxia, the cerebellum is defective, and therefore your body can't do what your brain wants it to.

The cerebellum has many purposes, but the main is muscle coordination and overall function which is probably related to the fact that your cerebellum controls TIMING. It also has something to do with mood, anxiety/depression, and it can be somewhat of a factor in regulating temperature in your body.

What you must realize is that there is NO cure or viable treatment. In your daily existence, you may come across ads for stem cell treatment, posts about trying acupuncture, various exercises, alternative medicines, gadgets, etc. The thing is that if ANYTHING worked, thousands of us would be lining up.

What you need to do is EXERCISE to your capacity. ANY movement is exercise. Ride your bike, walk if you can, swim if you can (water will keep you up), housework, etc. It

won't 'cure' your ataxia, but may help keep your body limber, because ataxia can stiffen your movements. You don't want to put yourself in more of a flux than you already are.

Another thing is eat healthy, and stay away from junk food. Many people automatically go to "What about an ataxia diet"? There may be some suggestions, but I put no stock in it.

Sooner or later, chances are, you may find that the medical community is your friend, but you need others. You need the experience of those that know, that have been there. That is invaluable.

Ataxia is a journey that you will be on for the rest of your life. It's no one's fault, it just happened. The more you know, the better off you'll be.

You must also understand that 'ATAXIA' is a very serious neurological disorder, like Parkinson's, MS (multiple sclerosis), cerebral

palsy, etc. Several symptoms are quite similar. I even sell a t-shirt that says 'ATAXIA – it's kind of like Parkinson's and MS had a baby'... Basically, it is NOT going away anytime soon, so you NEED to learn the ins and outs. You have to manage it, and learn to live with it. You REALLY have no choice.

After reading this, start watching my videos and webinars. Read my book 'Life with ATAXIA'. ALL are filled with info, tips, tricks, and advice. Much of this info, you can't get anywhere else, REALLY.

Please go to www.lifewithataxia.com Hit the 'BIO' button.

My name is Jonas Cepkauskas, and I was diagnosed some 28 years ago. Most of the info I'm giving you is stuff I learned along the way. See, I pretty much try to do what almost no one else does. You will find that MOST doctors, nurses, physical therapists, etc. are extremely limited as to what they know about ataxia. Very, very few actually have any experience. It is sort of like asking someone about Quantum Physics. You'll get many opinions and misinformation, but very few actually know.

Ataxia is an 'ELITE' condition, so you will need an 'ELITE' neurologist.

Basically, whether you have ataxia, ANY other condition, your career/job, responsibilities, etc. life is what you make of it. If you are 'sick and disabled', the world is out to get you, and everything sucks, GOOD LUCK!!! Don't let that happen.....

Absolutely NO ONE wants to be here, but that is where we are. It is very very far from how we anticipated life. It is a MAJOR challenge that we simply don't have time for, BUT.....

As I always say, "The more you know, the better off you'll be". Read the book, watch the videos and webinar presentations...watch any videos on the subject. Start putting together bits and pieces. Use any tools you can access. Be someone that others can relate to. It takes time, but you will learn and adapt....and NEVER GIVE UP!!!