

LET'S TALK DYSTONIA

By Natasha McCarthy

Unless you have it, or know someone who does you likely have never heard of it or have any idea of what Dystonia is. Wikipedia defines Dystonia as:



Dystonia is a neurological movement disorder in which sustained muscle contractions cause twisting and repetitive movements or abnormal postures. the movements may resemble a tremor. Dystonia is often initiated or worsened by voluntary movements, and symptoms may “overflow” into adjacent muscles. Treatment must be highly customized to the needs of the individual and may include oral medications, botulinum neurotoxin injections, physical therapy and/or other supportive therapies, and/or surgical procedures such as deep brain stimulation.

Now that you've read about what a load of fun [dystonia](#) can be you're likely wondering what does this have to do with Parkinson's Disease? Well, as I've said a million times before PD is the gift that just keeps giving. Not only does it hand out the typical motor symptoms of tremors, rigidity/stiffness, stooped posture, slowness of movement and such. It also has lots of fun non-motor symptoms like loss/decreased of sense of smell, bladder & bowel dysfunction, depression, anxiety, insomnia and the list goes on. As if ALL of that isn't enough Parkie's tend to also get dystonia as a symptom of the disease. Yup that's right, because one degenerative movement disorder isn't enough, why not give them two to deal with simultaneously? So those of us lucky enough to get this extra gift must wrap it up pretty and do the best we can with it. You can get dystonia on it's own or as a symptom of PD and for some reason dystonia is also more likely to present in young onset patients with PD than older ones. I guess that's PD's twisted sense of humor kicking in, saying "well, you are in better shape likely than an older person who gets PD so we best throw some curve balls in there for you to make it a tad more challenging!" Didn't you know that Parkinson's is one funny disease, I suppose that's why I laugh so much at it and make jokes of it often. After all one might as well laugh as to cry.

I started to feel the effects of Dystonia first in my hands, when you get it in your hand they call it focal dystonia and sometimes even writers cramp. Initially it only hurt if I tried to hold a pen to write or use my hands for anything. As time went on however they started to ache and pain 24/7 right around the time I started having trouble with my feet and often could barely stand on them the pain was so bad. I had myself convinced I had planters faciatis, subconscious denial perhaps? I get acupuncture

treatments in my hands every three weeks, I highly recommend it. Although it doesn't solve the problem I now only have pain when using my hands for any length of time as opposed to all the time before. That is a HUGE improvement. Not to mention acupuncture from a real acupuncturist can do wonders for a million other things whether you have PD or not. But I digress... A year ago my movement disorder neurologist confirmed that my self diagnosis was incorrect and simply wishful thinking and in fact I had dystonia in my calves and the twisting of the muscles was pulling on my achilles tendon making the pain refer into my feet. He suggested botox injections which is the standard and apparently very effective treatment of dystonia. My mind however instantly goes to that's poison being injected into your muscles and no way am I doing that to myself. He suggested a medication called pramipexole (or Mirapex) which would be effective in helping not only the dystonia but levelling off my crashes from levodopa during the "off" times. I of course refused any more medication yet, you can read about that in the previous post. Long story short by the time last fall hit and I could barely walk let alone exercise I finally listened and added the new medication. It did wonders for my dystonia, I could walk again without being in extreme pain and as he said I was able to get working out again.

Now seven months later I'm still walking pain free, still taking the added medication, still going for acupuncture every three weeks in addition to physio & massage therapy and still working out 5/6 days a week. However, the pain is resuming when exercising and in the moment can be bad enough to bring tears to my eyes. I'm not sure though that it's actually the pain doing that but more so the frustration I have because of it. It seems that dystonia is much harder to deal with and treat than Parkinson's is over all. Now I'm sure I'll have days where the opposite is true, but from my standpoint today PD is managed well with meds & exercise where the other isn't. I've found wearing ankle support braces and working out shoeless helps however that will cause problems in my feet down the road so it is merely a temporary solution. I will be returning to Occupational & Physiotherapy to see if we can try something else, I may up the acupuncture treatments for a while as well and definitely must get those calves as painful as it is massaged more regularly. Long and short is my goal is to find a solution that doesn't involve botox injections into the muscle. Sadly however it seems my cycle is about six months of fighting it and eventually giving in. Whatever "it" may be, new meds, increased meds etc... What frustrates me the most about this scenario is that when it came to new medications or increases my initial response was "not yet, it's too soon" when I would fight it. I always knew I'd need to do it at some point. However with botox injections my mind was set on never, ever, ever... and yet now I'm saying "last resort" and it feels as though that last resort is getting closer and closer. If any of my fellow Parkie's reading this is dealing with dystonia and you have found an alternative treatment to the injections I would love it if you'd take the time to send me a note!

At the end of the day I'm still doing very well, I'm still working out even if some days it frustrates the hell out of me and that is keeping my body working better plus it's helping with sleep issues and stress/anxiety. So giving it up on that is definitely not an option. It keeps me healthy, it keeps Parkinson's in check and from getting worse. Sometimes this broken body's journey hits some forks in the road where I have to find solutions to issues or decide which road to take. These forks are never easy and I suspect as time goes on will become even more difficult, but the important thing I try and focus on is that I still have choices. I can give up, or I can keep being stubborn and fighting. And I have learned to forgive myself for giving 'in' on some of my mindsets knowing that sometimes giving in doesn't mean you've given up, but rather that you have made a hard choice to improve your quality of life even if there's a cost. And although you may have many great supporters in your corner you are on your own and the choice & direction you choose has to be made by you! Struggle with as many of them as you want, but regardless of the frustrations always take a minute to find the joy cause it's there even on a tough journey!

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