

**QUESTION ONE:**      What advice would I give to other people with OT about my journey with this illness?

1. Be overtly honest with your Neuro, no matter how trivial you THINK the matter is. As the condition progressed in me, I found myself having symptoms that had no real consensus with my fellow OT sufferers or the research papers I reviewed, specifically, the pain and the muscle rigidity. There is the standard ache, which most of us agree on, but sometimes it isn't the standard ache, it feels like you tore something, and my brain started getting a tad paranoid, and immediately went back to what I was afraid it was prior to my diagnosis. "What if it's not just OT? What if I'm just that unlucky person who ALSO got MS?" Google is not your friend when this happens. Talk to your doctor. At minimum, they can allay your concerns and rule some things out. Because this condition is so poorly understood, it can get scary.
2. Start prepping your home early in the condition to accommodate you, especially in the bathroom. The moment of diagnosis is probably the early stages and the best you'll feel.
  - a. Tubs become hard to climb over, consider a shower with a seat and grab bars.
  - b. Learn to apply your makeup, blow your hair dry or shave your face sitting on the toilet backwards. Just put a mirror above the toilet tank!
  - c. Gardening is great exercise, but you might want to keep your gardens to a manageable size.
3. Leg and core strengthening is imperative. Consider swimming, a rowing machine, or similar, and get up and walking. Sitting might be safer, but the longer you sit, the worse the pain will get, and the worse your morale will get. It results in a vicious cycle. Better to EARN a little pain doing something, rather than waiting around hoping it will magically get done by itself.
4. Don't cede your independence; it's depressing AND it will/can lead to resentment from others you have become dependent on. There is time enough for that as the disease progresses. Push through until you cannot.
5. Do not assume people are being unkind or unfeeling towards you and your condition—at home or work. It's hard enough to have this condition and articulate it to others—I can't even imagine being on the receiving end of the conversation and trying to wrap my head around it. I can only imagine what goes through their heads, "Really?! You can walk rapidly, but you can't stand? What the hell are you talking about?"
6. Insure all stair railings and door knobs at stairs, in your home, are regularly maintained. You will be putting more weight on those than ever before. I've managed to tear off both.
7. It's fine to have a to-do list—that keeps you moving and no one is happy with a messy house. Be happy if you only manage 1-2 tasks per day. ANY activity leads to physical exhaustion and buckets of sweat—not to mention necessary recovery time.

8. Learn to laugh at yourself. Coping skills are imperative. When something happens, it might not be funny in the moment, but it will be. If you don't have a well-evolved sense of humor after a couple years with this condition, you will be miserable. YOU won't want to hang around yourself.
9. Stay off ladders! Avoid uneven pavement, wide-open spaces, inclines/declines, and curbs. You may not know it yet, but your balance sucks.
10. Avoid emotional outputs. You MUST remain calm. No temper-tantrums; no overwhelming frustration; etc. The more emotional you get, the worse the tremor gets, and the more exhausted you get. That's not to say you can't have a good crying fit, here or there (you deserve it!), but keep it to 5 minutes or less and move on. Feeling sorry for yourself is inevitable, on occasion, but it won't cure you and it won't make you feel better. So take a moment, regain your focus, and move on. Consider breathing exercises and meditation. I find focusing on an object, counting to 10, and slowing my breathing, works.
11. Shopping can be a nightmare. First thing you need to think about is what your standing requirements are (or will be) whenever you leave the house.

Grocery shopping requires sitting to stand (from your car), standing to clear traffic, browsing (think: slow walking), standing in line, and standing to put your bags in your car trunk. All of this is doable, BUT only with a cart to lean on. The grocery cart will become your best friend. Park by the abandoned carts!

12. Remember, you CAN walk "reasonably well". You just CAN'T do it slowly. The slower you go, the more "confused" your brain gets. Then it starts "misfiring" and your legs turn to jelly (or lead) and start shaking.

P.S. Don't EVER try to: stand on your tippy toes; walk heel to toe; balance on a soft surface (e.g., cobwebs on the ceiling fan above your bed)—get a Swiffer duster.

13. It isn't just the legs! It affects any limb that is attempting to bear weight, so whether you are on your hands and knees, scrubbing the floor, or whether you are trying to lift something relatively heavy with your arms, they will shake and spasm.
14. Throw out whatever you previously defined as "strenuous". It no longer fits. EVERYTHING becomes strenuous enough to require recovery time. This is no condition to attempt rising to the challenge. You will regret it. Moderation is key.
15. Get used to naps. I don't know whether it's the drugs or the actual exhaustion, but you will find yourself in the middle of the afternoon unable to keep your eyes open—often.
16. Either get used to explaining yourself or develop one hell of a dirty look that just screams: "Go ahead! Point out the obvious, you buffoon!" People will stare. People will draw their own assumptions. People may glare at you or rudely object, when you park in disabled parking, beg for a seat on the subway, or take early boarding on an aircraft. You can either educate them on this invisible condition or get incredibly snarky. Your choice, but we could really benefit from educating the masses.

There is also a card that may be printed to “silently” advise people of your condition.

17. Get good shoes. Not too heavy and not too light. I prefer hiking boots. They provide ankle support and mine have amazing gel foam cushioning. If your shoes are too heavy, you’ll trip and driving becomes more difficult, especially with a manual transmission. If they are too light, you’ll misjudge where your feet are and impair your balance. Give up heels. That day came and went if you prefer to remain upright. My fine motor skills have gone to hell, as has my dexterity; I recommend zippers or “no tie” shoelaces over standard shoelaces where possible.
18. Magnesium baths ease the pain and stiffness, but you’ll likely need something more. Essential Oils last much longer than a tube of Icy Hot, Mineral Ice or Biofreeze and they ultimately cost less—one small bottle lasts for months. Clove oil will heat up your muscles; Peppermint will cool them down. And, best of all, they smell good and leave no disgusting residue.
19. The right alcohol works. Most OT sufferers, within the support group, agree that alcohol can be a miracle “cure”. However, I recommend triple-distilled vodka. I hate the taste of alcohol with a passion, it mixes well, and there is no hangover. One to two cocktails reduces the tremor to almost nothing and increases standing time. THIS is how I maintained a social life. Just don’t make it a habit and tell your doctor what your rate of consumption is. There IS such a thing as too much.
20. Your memory will be in short supply when on anti-epileptics or Clonazepam. Learn to leave yourself “bread crumbs” for important reminders. This includes conversations with your doctor. If it’s important, write it down. I use sticky notes and a digital calendar.

For example, traumatic events should be highly memorable, right? In 2015, I took my cat to the veterinarian for her annual exam. He determined she had a terminal illness. A year later, he was surprised she was still alive and had gained weight and repeated the diagnosis to me. I had no clue what he was talking about—though I tried to play along. 2015 is a complete blur to me. It also turns out vets make misdiagnosis too. 😊

**QUESTION TWO:** What would I advise doctors to improve on when they see a patient with OT?

1. Start with minimum drug dosages. Only if, and when, your patient brings up difficulty managing should the dose be increased. If they aren’t complaining yet, do nothing. I felt I was doing pretty well. My confidence was not impeded and my doctor increased my dose due to “gait change” (I’ve got a bulging disc which wasn’t helping my gait). I moved directly into an allergic reaction and the need for DBS within 6 months of diagnosis.
2. Clonazepam should not be prescribed as a first-line drug. If and when it IS prescribed, be VERY clear about how to take it and the dangers/difficulty trying to get back off it.

3. Anti-epileptics and Diazepines have a purpose. However, please know that taking these drugs impair our memory. So, if you have something important to tell us, you might want to write it down, tell a caretaker, etc. Insure we know AND understand what you are saying. Try having us repeat back what you said. At some point, we're just on auto-pilot and we don't know what we don't know.
4. Understand the life and social limitations that accompany this condition and explain them to us. Leaving us to our own devices to struggle through daily activities leads to Google which, often times, due to lack of research and information on the condition, leads to more frustration on BOTH our parts.
5. Please refer us to resources like the National Tremor Foundation, National Organization for Rare Disorders, OT Support Forum. Having no one else to talk to leaves us a bit isolated, not to mention, since so little is known or published about the progression of the condition, you develop additional challenges and have no way of determining whether it's part of OT or whether you are just extra lucky and developed something else. It never even entered my mind, initially, that a forum existed to talk with other sufferers and compare symptoms/discuss challenges and coping skills.
6. Be open to suggesting or trying new things. We're frustrated and desperate, and just as capable of determining the risk/benefit ratio for ourselves, given the right information and feedback. Don't knowingly feed me rat poison... but please, I've got a rare condition just screaming to play guinea pig.
7. For better or worse, this condition makes you go through the 5 stages of grief. Either you rise to the challenge or dig a very deep hole for yourself. After the diagnosis provides the affirmation that you aren't nuts, the relief wears off as you get worse. This condition affects and *infects* you physically, emotionally, and socially. It is a slow rollercoaster ride through hell to a lack of independence, lack of confidence and near-total social withdrawal and avoidance. If the OT person languishes in this, at some point, the doctor and/or caretaker MUST get involved and send them to a grief counselor. I've seen quite a few folks in the forums just sink into a funk. There's little any of us can do for them except superficially attempt to raise their spirits.
8. FGS, would you please start researching/testing CBD + THC for this condition? There is some anecdotal evidence that it is providing the relief we so desperately crave. It is an excellent CNS depressant. Additionally, I was able to avoid medical professionals for a good year using Valerian Root. Might make for some interesting research—it's safer than Clonazepam (I used it to get off Clonazepam quickly).
9. IN RE: DBS;
  - a. DO NOT just throw "You need brain surgery..." at a patient without prefacing it with some kind of foundation. It's kind of a terrifying thing to just have thrown at you out of the blue.
  - b. DO NOT turn on one side pending implant of the second. It's a lot like putting an outboard motor off-center on a boat. Suddenly, your rudder and steering is skewed and you feel like a drunk sailor. I ended up fracturing my eye socket walking into the corner of a picture frame. No falls! Just turned into a wall for no reason.
  - c. DO explain that DBS does not require me to "challenge" myself to get to the highest setting. It doesn't make you better; it just results in worse facial numbness, speech problems, and throat

tightening. You want to start your day at the absolute bare minimum you can tolerate, and then only up yourself, as needed, throughout the day. My neuro was a little low in the explanation of expectations and overall intent and use. Fortunately, Medtronic was great about explaining the best method for use. So now I don't feel like I'm having a stroke every morning.

**QUESTION THREE:** Please write down anything else that you think might be helpful to others to help in the general understanding of this condition.

1. Don't stare at me and don't make me explain myself. Whether it's why I'm supporting myself at the check-out counter by leaning on something; why I cancelled a planned activity; or simply did not complete my house cleaning, you have no clue what is lurking in my body or the amount of effort I go through to provide you the pretense of "normal" so YOU feel better. YOU get the luxury of judging, while never having to walk in my shoes—literally. Tread softly.
2. Adjust your expectations of me. I have. You might be right that I could do more, but then again, I know my body better and I'm erring on the side of less, not more. It isn't just me who needs to accept my limitations (THAT took long enough)—you should also. That said, if I'm just sitting around moping, refer to item 5.

My family is completely ignorant of my condition. My mother thinks it's just like her Essential Tremor (in her neck)—it's not really an impairment in her view—she ought to try getting it in her legs! It makes me angry sometimes. My brother keeps buying me REI gift cards, as if I'm going on a wilderness hike in the near future. I try to laugh it off, be courteous and remember it's the thought that counts, but it hurts and I, instead, try to overdo it because I remember my good old days when I was that tough, vibrant, active person (I'm only 43!) that HE remembers. It really isn't their fault; I've made no substantive effort to change their perspective or educate them, there is little research to direct them to, and I live across the country, so they don't SEE how challenging it can be.

I think I may be fortunate that I recognize this contradiction—some don't realize how unrealistic their expectations of others may be. This is a weird condition! As much as WE struggle to want others to understand what we're going through, for them to sympathize or empathize, how could they? I can't imagine the struggle of others to understand this condition. I barely understand it!

My friend asked me to explain it. I repeated verbatim what I read online, that "it's load-bearing and gravity-induced" and "I can walk, but I can't stand"...what the heck does that mean to your average person?! That doesn't even come close to describing this condition! It merely serves to minimize what it truly is—life-altering and life-limiting; painful and anxiety-inducing; exhausting and progressive: all terrifying terms. Sure, I can walk! But, I'm incredibly conscious of how I likely appear to others. I walk like a drunk sailor most days, and, following DBS, I sometimes slur (or just trail off)! I joke about what might happen if I got pulled over by the police, but it's not that funny.

3. I have reasonably good days and downright terrible ones. I know as soon as I wake up in the morning, THIS is the absolute best I'm going to feel for the rest of the day. It's a down-hill train wreck from

there! By 7pm, I just want to crawl back into bed, good day or bad. I find holding myself to rituals/habits works best, no matter how I feel. You absolutely have to get out of bed and commit to the activities that will begin your day.

Really, most days aren't that bad anymore. I now get more good days than bad. If I need to renew my perspective, I just try and get to the kitchen, with my DBS off, to remind myself what it could be like. That said, there is this precious few minutes before I sit up and turn my DBS on that I feel great. No pain; so relaxed; normal. It makes it so difficult to crawl out of bed...lol.

4. I feel like I'm carrying around bags of concrete in my legs, on bad days. They get heavy; they cramp and spasm. It gets hard to pick up my feet. It feels like I've got bursitis in my legs (closest analogy I can come up with). On the absolute worst days, it spreads to my arms and the muscles in my hands and arms grow rigid, spasm/twitch, and are painful.