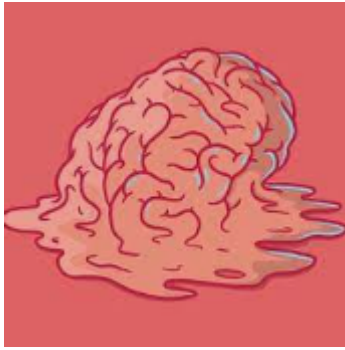




FND Crash Course Guide lol:

Short term solutions:

- Here's another app: <https://apps.apple.com/app/id1515361449> it's called myFND I just recently found it
- For small bathrooms getting a tiny rolling stool can help to get around without getting onto the ground every time. Like these: <https://a.co/d/2xZ0idG>, <https://a.co/d/gfuitpY>
- I use this for grabbing stuff out of the washer and dryer <https://a.co/d/cAbSHco>
- Using a foot sling for your wheelchair is often times more compact and comfier than foot rests: <https://a.co/d/86nqFYP>
- I just bought this: <https://a.co/d/5BG3uzT> and it has made stretching SO much easier. Normally my hamstrings get ridiculously stiff and tight and this has made it so easy that I actually stretch my legs now.
- These can be helpful when your desperate to feel clean but it may not be currently safe to shower, I used them in the hospital a lot. <https://a.co/d/gJye5wY>, <https://a.co/d/2DgPGBJ>
- This is a seizure seat belt for your wheelchair. It's not the most stylish thing ik but when I had seizures everyday it was really important I had this on whether I was just up and about the house in my wheelchair or in public. Saved me from falling out of my wheelchair quite a few times. <https://a.co/d/9XcmRT9>
- Smelling salts to wake up faster after a seizure (only if necessary because it's good to rest after a seizure.) <https://a.co/d/0qD5Faf>
- Anti nausea peppermint stick: <https://a.co/d/chox3jQ> (these actually work really well for me)
- Keep period products upstairs and downstairs, it is the literal worst when you realize you have to go all the way upstairs for one pad lol
- If your family is worried about you during seizures getting a portable pulse oximeter is an inexpensive way to make sure your safe and breathing without going to the ER: <https://a.co/d/gOe6Dy8>
- Make a Seizure action plan with your family. Come up with what you want done when you have a seizure upstairs, downstairs, in public, with a new person etc... because a lot of times it's frustrating when you can't communicate but something is happening that your don't like. Also for an after seizure plan let them know exactly what would be helpful, for me that was giving me space because I would wake up to 4 family member so close to me and it just made things worse.
- When I am in my wheelchair I like to move anything out of our kitchen (because it is so small) including kitchen mats and our rolling island to make it easier to get around.
- I also like to keep a stack of bowls, cups, plates, silverware and anything else you use on a daily basis down in a basket where I can reach them.
- I also like to move a chair out of the way and into a corner so I can just roll up to the table without transferring.
- After my seizures I like to hold something cold in my hands and take sips of water because my mouth is dry and having something cold grounds me. I also like to have my pets nearby because it calms me and it is therapeutic just to have them near.
- I like to have heated socks on a lot of the time because the lack of circulation can make my feet really cold
- Keeping a designated basket or bag on the stairs to bring stuff up and down without trying to carry all the little pieces.
- Keep your preferred food choices in the pantry or fridge at reachable levels.

- The best way to get down the stairs for me is to just put both your legs out straight and slide down. However I have carpeted stairs so if you don't then you might want to slide on a pillow or work your way down one step at a time.
- Sometimes I like to keep all of my night time stuff in a ready to go basket that a family member can easily find upstairs and bring down to me if I cannot make it upstairs because I am too tired or I have just had a seizure that has incapacitated me. This makes it easier in case I need to sleep on the couch.
- I wash my face every night and when I'm in my wheelchair it gets a lot harder. So sometimes I will use a bowl of water to bring it down to my level to make it easier to rinse my face or I will use the bathtub faucet. However if I use the sink then I like to put on these: <https://a.co/d/axJXrfq> because it prevents the water from sliding down my arms and getting all over.
- This website is helpful in finding products to make life easier: <https://accidentallyaccessible.com/>
- Some stretches my Physio therapist gave me a while back for when I'm struggling with my legs: Supine hip abductor stretch, Supine hamstring stretch in a doorway and a Seated Hamstring Stretch.
- Make sure you stretch your shoulders and chest because you're using them a lot more now and they can get tight and painful or strained.
- Come up with an action plan if you plan to go back to work like accommodations and ways to get to work
- Getting into the car I put both of my legs in first then I use the folding handle inside the car with one hand and grip the top of the car with the other and hoist myself in.
- Here are some helpful videos for your mom or family to watch to help you better get around safely: <https://www.youtube.com/watch?v=d5W86L-Fk3o>
- Here is a video of transfer techniques for you: <https://www.youtube.com/watch?v=GBSUpj3bsKs>
<https://www.youtube.com/watch?v=tnlyfVUjbP0> (it's super important to do it right otherwise you can do serious or long term damage to your back and shoulders.)
<https://www.youtube.com/watch?v=W7liUY2Xwcw>
- This one involves a slide board which is actually another inexpensive way to make transfers easier: <https://www.youtube.com/watch?v=4wXk1DzaxnQ>
Here is a link to a transfer board: <https://www.amazon.com/TripWing8>
- It is also super important to track literally EVERYTHING, at least at first. It might seem tedious but this is the best way to figure out potential triggers for your symptoms. I use the app Epsy to track auras, seizures, side effects, single doses of medications, significant events, and it also tracks when you have or haven't taken your regular medications. I have lexapro and gabapentin set at 9pm every night and this helps to make sure I take my meds and track any missed or late meds in case it triggers a symptom. After you have used the app for a while you will be able to create a report and this can be shared with your medical providers to track your progress
- For me my biggest triggers after over a year of tracking have ended up being: Family, Hormones (especially around my period I have noticed I have a seizure within a day or two right before my period every single time), Stress and Heat. However you might have different triggers so I will list some things to track to figure yours out: food intake (sugar, and any irregular eating habits), exercise, Weather: hot or cold, stress, blood sugar levels, caffeine intake, hormone fluctuations, medication changes, sleep cycles, screen time, certain food, songs or smells can also trigger my seizures sometimes, Any activity like being around a lot of noise, people or lights and if you have any panic/anxiety/or ptsd inducing things keep track of when those happen and how they affect you. Test everything even if you don't believe it could have an effect. It's important to rule out any contributing factor no matter how small.
- If you have any area rugs in any rooms with hardwood just roll those up if possible because it makes it SO much easier to get around, also any coffee tables or footrests in the living room. (it's only temporary so just make it a little easier for yourself)



Intermediate term solutions:

- Here are some of the best articles and studies I have found related to FND and disability (These are links inside links basically an easy way that I have saved and consolidated these over time):
https://www.one-tab.com/page/SXg7J_zURFa_ciTZvQNXiQ
https://www.one-tab.com/page/YqTzeoEoRGid-JnrWdY_Vw
<https://www.one-tab.com/page/kfGnlqjTT1CGZbx8ziBzww> ,
<https://www.one-tab.com/page/h-kew6ScTfSrWBkTSG8oXA>
https://www.one-tab.com/page/zTSdHMyGTEu5uS47_eMZ5Q
- I'm not sure what your house entrances look like so I'll just tell you what I use for mine. It is almost impossible to get out of my front door by myself so I use our garage entrance. It has one step down when you enter through the doorway. I go backwards and use the doorway to slowly lower myself down till the back wheels touch the ground then I wheel myself backwards and there's only a slight lurch or bump as my front wheels hit the ground. Otherwise if your only option is your front door and you don't have too many steps then a removable ramp like this one: <https://a.co/d/9OpQiwF> is a good option but a little pricey. Finally if none of these are viable, typically if I am going to a super inaccessible place I will bring an old t-shirt or small rug or something to sit on as I scoot because a lot of the time the floors are really dirty.
- Getting a walker helped me transition from my wheelchair to walking a lot easier. Because I am unstable a lot of the time when I am getting my legs back I will use a walker to practice walking everyday till I am stable enough to just use the walker alone then back to walking regularly. Thrifting one is usually pretty easy and affordable.
- For showering I use a shower chair. I have tried three different ones and prefer a smaller one in general; the bigger ones are just too big for a regular tub. I also have a fluffy robe that I lay over my wheelchair whenever I am getting out of the shower and transferring to my wheelchair. It can be hard to keep a towel on yourself and prevent water from getting everywhere. So I dry myself off as best I can then transfer to the robe and wrap that around myself.
- Now I don't really have people that can help me with this because I live with my grandma but it is really helpful when you're in the wheelchair for a while. Have a person wrap their arms around you right underneath your armpits and you grip their shoulders. Then they brace their knees against yours. Then they lift up while pressing their knees into yours till you both are standing straight up and your knees are locked. Now I wouldn't recommend doing this too often because it can injure the other person but once you're up it's nice to just stand like that for a while. Make sure the other person has good form and knows what they're doing as well.
- If your room is upstairs I would get a thrift store wheelchair for upstairs so you don't have to bring the wheelchair up there every time or crawl around lol.
- Getting a 504 plan for school can really help. This allows you extra time on assignments when you need it etc... or whatever other accommodations you may need.



Long term solutions:

- The way I get around to be more independent is Paratransit as well as regular public transit. However the closest bus stop to me is like a mile away so I mostly use paratransit. Now the downside with these is you might have to wait a while till you've had symptoms for a while. It also costs \$3 and up per one way ride. You have to schedule it

like a week ahead if you want a chance of getting a ride. But it does allow me to get to work on my own since I'm not able to drive.

- I haven't gotten around to doing this but if you are in your wheelchair for an extended amount of time moving your mattress to the floor or getting a lower bed stand is so helpful for getting into bed easier.
- This is the DMV disability placard website:
<https://www.dmv.ca.gov/portal/vehicle-registration/license-plates-decals-and-placards/disabled-person-parking-placards-plates/> I had to wait a while to get mine... I think almost a year but I think you can get like a temporary one till you can get the permanent one. I would also wait till you are diagnosed to apply for this or the paratransit because you need to fill out info on your diagnoses.
- I got my wheelchair through Kaiser and my primary care doctor. However it took me a little over a year to get it. I would wait for a while to see if you have paralysis often and persisting to get a custom one so that you can get your insurance to pay for it. Because otherwise stuff like that can cost upwards of \$500 unfortunately.
- These are the leg compressors I use: <https://a.co/d/f7yBjVf> They relieve a lot of pain and help with the blood flow in my legs. Here is a cheaper option: <https://a.co/d/bG99YDh>
- Some treatment options that I haven't gotten around to trying myself but might be helpful: Acupuncture, Massage, Electrical stimulation, Micro dosing mushrooms (which opens up new neural pathways, which is part of the problem with this disorder is your brain gets stuck in this well traveled brain loop of neuro pathways so opening more has proven helpful for many), CBD oil or other products, heated blanket for pain: <https://www.amazon.com/UpBeatPlus7>
- Some treatment options I have tried: Psychotherapy, medications, physiotherapy, so far these options haven't worked too well for me or haven't shown direct betterment of my condition but don't knock it till you try it one of these might work really well for you.
- Here is the website to the place I am getting my service dog from: <https://canine.org/> I would definitely do a lot of research on what you want in a service dog, what breed, what tasks you want them to do, if your life is in a good place right now to where you can care for one, if you want to train your own or go through a program and if it is worth the effort to own a service dog. It can also take up to 2 years to get a service dog through a program, there is no guaranteed placement and some places it can cost 15k or up. Not the website I have attached though, that's free.
- Cutting out toxic people and reducing my activity level have been the two things that have helped the absolute most for me. I moved out of both my parents' houses and now live with my grandma. I don't speak to half my family and cut out all of my friends. This was super drastic and took like an entire year and not everybody is in my same situation or is able to move out and cut people off. So don't think that this is in any way necessary. I think it's just important to put yourself first and if certain situations or people are making it worse don't give them the chance to.

Alright congrats! You made it to the end :) that was long I know but I wanted everything to be consolidated into one place so feel free to make a copy and reorganize it however you would like if that makes it easier. But I hope that some of this helps and that you get the resources and help that you deserve <3