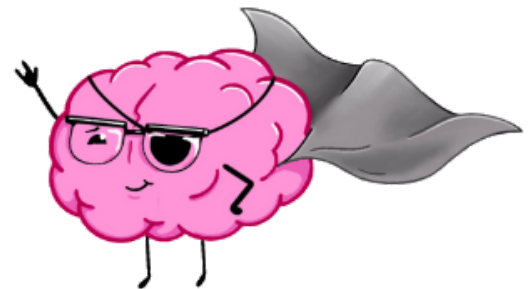




**Hypertrophic Olivary
Degeneration Association**

Living with HOD

Tips and Tricks From Our Community

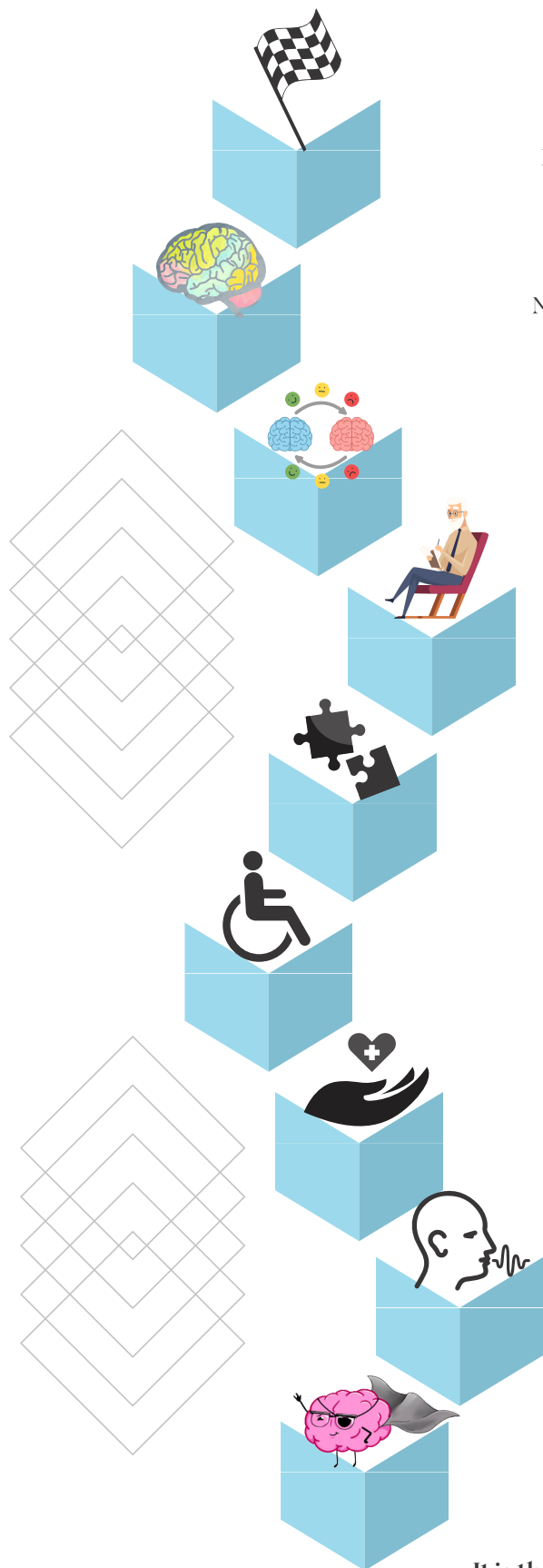




Tips For Patients from Patients



Build your HOD Medical Dream Team!



General Practitioner

Manages all general health (non HOD) medical concerns.

Neurologist

Manager of HOD Symptoms, orders testing and required therapies. Determines Imaging and visit frequency.

Psychologist

We recommend a practitioner that specializes in Chronic illness or Grief .

Psychiatrist (OPT)

Helpful if medication is required. This can be handled by GP as well.

Neuro Physical Therapist

Vestibular physical therapy and other gait/balance therapies as needed.

Occupational Therapy

Supports safety within the home. Suggests accessibility needs.

Movement Specialist

If Ataxia is present. Utilizes Neuro Plasticity to help patient learn how to move safely.

Speech Language Pathologist

Conducts swallow therapy, speech therapy, and cognitive therapy.

Neuro Psychologist

Conducts cognition testing. Frequency determined by patient and Neurologist

It is the patient's responsibility to ensure that all of your providers are connected to each other for optimal outcomes



Hero Tips



Always check with your medical insurance provider for coverage and referral rules.



Word of mouth is a terrific way to find great doctors. Don't be afraid to get multiple opinions before selecting a doctor or a treatment.



Your Neurologist will be the referring doctor for most other specialists and/or testing. Make sure you are open and honest about all symptoms!



Insist that all doctors coordinate care with each other for the best possible outcomes.



The patient always has the final say. If you are not comfortable with a test or treatment, you do not have to agree to it! You are the expert on your body!



Tips & Tricks

From our patient experts

Appointments for HOD Patients



USE AVAILABLE TOOLS

Utilize smart phone calendars or lists to organize and set reminders for appointments, medications, and tasks.



MY MEDICAL INFORMATION

Keep a current list of all medications and supplements that you are taking, along with their dosages and frequencies to share with your medical providers. It may help to include all pertinent medical history, such as Diagnosis and Surgery dates.



FIND CURIOUS DOCTORS

Not all doctors are the same! It is important to have a Neurologist, but you will be hard pressed to find an expert in HOD. We have found that curious doctors who are willing to learn and admit that they may not know everything are our best allies. Word of mouth referrals can be helpful. Ask the HOD community!



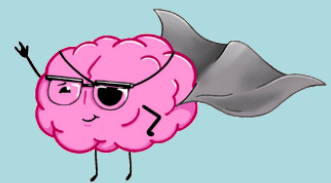
TREAT THE STAFF NICELY

We have found that being friendly with the Physician's staff goes a long way. Good relationships help to achieve ideal outcomes.



BRING SOMEONE TO YOUR APPOINTMENT

Usually, there is an abundance of information shared in our appointments. It is easy to be overwhelmed with everything discussed. A trusted third party can help you to retain and understand everything discussed. If no one is available, perhaps your doctor would grant permission to record the appointment with your smart phone.





Tips & Tricks

From our patient experts

Life Hacks for HOD Patients



FIND GADGETS THAT HELP WITH EVERYDAY TASKS

Having trouble with fine motor function? Try a one handed toothpaste dispenser! Too dizzy to get your shoes on? There are gadgets to help you get socks and shoes on without bending over. Having trouble grabbing things? Get a grabber from Amazon. Make your life easier!



SET A SCHEDULE AND STICK TO IT

Over stimulation can set you back for days. If you have a detailed schedule, with brain breaks built in, you can avoid fatigue and burn out. It is important to not push yourself into exhaustion. Let your brain have a break!



WEIGH THE PROS AND CONS

Just as with everything else in our lives, sometimes certain doctors and therapists are not a good fit. You have to be the judge of who you want on your team. If your Physical Therapist is getting on your nerves, maybe they are not a good fit. This is your life, and you don't have to put up with bad care!



LISTEN TO YOUR BODY

Medications are not one size fits all. Pay attention to how your body responds to all prescriptions. If something is making you more dizzy or feeling bad, talk to your doctor. There are usually more choices available.



KEEP YOURSELF BUSY

Did you know that jigsaw puzzles have been proven to improve short term memory, mental speed, and reinforces connections between brain cells? And they can be fun! Keep your brain working and learning.





Tips & Tricks

From our Patient Experts

Patient Registry for HOD Patients



SCHEDULE AN HOUR

The patient registry is robust. It is important to provide as much information to researchers as possible. This means that it may take up to an hour to complete.



BE HONEST IN YOUR ANSWERS

Research requires honesty. Although some aspects of HOD may be embarrassing, it is important to be completely transparent in your answers. You will not be judged.



REMEMBER YOUR 'WHY'

It is easy to forget why we need to participate in registries, and everyone has their own individual 'why'. Maybe it is for future HOD patients. Maybe it is for your family. Maybe it is for yourself. Whatever the reason, it helps to think about why you agreed to participate.



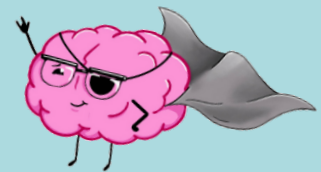
TELL THE COMMUNITY

Sharing your intention with the community helps everyone. Not only are you establishing 'accountability buddies', but you are also inspiring others to participate!



CELEBRATE COMPLETION

Celebrating the accomplishment of completing the task is important. It is not always easy to complete daunting tasks, especially when there is no immediate result.





Tips & Tricks

From our Patient Experts

Maintaining Hope for HOD Patients



DEPRESSION AND ANXIETY

Many of us experience some form of depression and/or anxiety with this diagnosis. Pay attention to your thoughts and feelings. There is no shame in asking for help and being honest with these feelings. It requires bravery, and you are not alone! Tell your doctors and caregiver what you are feeling!



ATTITUDE IS EVERYTHING!

HOD can be defeating, and we know it is very important to feel ALL of your feelings, both 'good' and 'bad'. There will be times when you feel helpless and hopeless. Do not stay in these feelings for too long. Reach out to other HOD patients, think about things that you CAN do, find ways to feel purpose in your new life. Therapies can feel hard and impossible, but your therapists won't ask you to do things they know you can't. YOU ARE CAPABLE!



USE AVAILABLE TOOLS

No one understands HOD better than other HOD patients. Attend group activities. Participate in support groups. Direct Message other patients who seem to be in a good place. Volunteer with HODA.



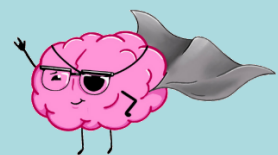
FIND A NEW HOBBY

Using your creativity has been shown to be a healthy way to exercise your brain. Have you always wanted to write short stories? How about painting on a canvas? Maybe creating poetry or handmade greeting cards? We have an HOD patient who is very skilled at rock painting. Finding a hobby that you enjoy can help tremendously with mood.



ACCEPTANCE CAN CHANGE YOUR PERCEPTION

Comparison is the thief of joy. Often when we have life changing diagnoses, we long for the future that we imagined that we would have. Adapting to new future can be literally life saving. Finding a psychologist that specializes in grief and/or chronic illness can help you to get to acceptance.





Hypertrophic Olivary
Degeneration Association

Tips for Caregivers From Caregivers





Tips & Tricks

From our Caregiver Experts

Caring for HOD Patients



SIGN UP PATIENT FOR RECOMMENDED THERAPIES

Physical and occupational therapies may be prescribed by neurology to help the patient learn to navigate life with their symptoms. Patients may be apprehensive, but therapies are necessary for the patient's success.



GENTLY BEGIN TALKING ABOUT A MEDICAL POWER OF ATTORNEY

You may never need to use the POA, but it is better to be prepared should the patient lose the capacity to communicate. It is important to talk to the patient about their wishes, although this can be difficult. Listen to them without interruption or judgment. You may not agree, but honor their wishes.



APPLY FOR GOVERNMENT BENEFITS

Depending on the level of disability, the patient may qualify for government benefits. If accepted by Medicare (in the US), be sure to add a supplemental policy to cover hospitalizations and therapies. Caregivers may also qualify for government aid (varies by state).



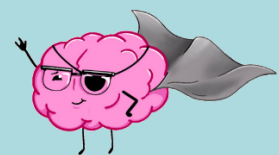
FIND YOUR CARE TEAM

We have found that not all experts are great doctors. The most important characteristic is willingness. If you have a curious doctor who can admit that they don't have all of the answers, but is willing to learn, and the patient likes the doctor, then you have the right doctor!



REMEMBER TO CARE FOR YOU, TOO!

Caregiver burnout is real! Remember to schedule all of your own checkups to ensure that you are healthy enough to continue and take moments for yourself when you can!





Tips & Tricks

From our caregiver experts

Additional helpful tips for caregivers



GET SOME HELP!

Consider hiring a bath aide to assist with personal hygiene. They are trained in helping, and will increase safety all around. (Search Key: Bath Aide)



KEEP THE LINES OF COMMUNICATION OPEN

Technology has come a very long way. A smart watch can alert if the patient is in trouble. It can also be helpful to EMT's if you are listed as the emergency contact. Consider a life alert that calls you first!



ASSISTED LIVING VS ACCESSIBLE APARTMENT

Assisted living in the United States can be unaffordable for most people. If the caree is well enough to manage an apartment, this may be a better option. They can maintain some independence, but you can be close enough to get there quickly if help is needed. Hiring aides to come in and help may be more cost effective. Do your homework!



PALLIATIVE CARE ISN'T A BAD WORD

Palliative care is generally covered by Medicare (always check first!), and can help provide service, medication, and supplies. They do NOT offer any therapies.



TALK IT OUT

Support groups are everywhere, thanks to social media. It can be uncomfortable to speak about your challenges in front of your caree, and vice versa. Take advantage of support groups and talk about it! This life is a tough one, and only fellow caregivers can really understand.





Tips & Tricks

From our Caregiver Experts

Caring for HOD Patients using Walkers



HELP THE PATIENT COME TO TERMS WITH USING A WALKER

We know from our doctors that walking is vital for both brain and body health. Patients may not want to use a walker at first, but if they are able to view the walker as a form of independence, they may be more open to using one. These mobility changes can be hard to deal with.



A WALKER OR ROLLATOR WITH A SEAT IS THE BEST CHOICE

The seat is helpful when rest breaks are needed. The patient may not need rest breaks today, but they may need them three months from now. It is more economical in the long run to purchase the higher quality mobility aids that can handle any stamina changes.



GAIT BELTS INCREASE PATIENT SAFETY

A gait belt can be used to help steady the patient as they transfer from standing to sitting and vice versa. They are also handy to help steady the patient while walking without other mobility aids.



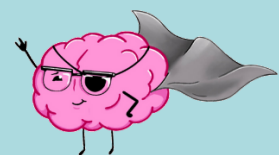
HAND BRAKES ARE HANDY!

HOD patients are known for their dizziness and unsteady walking. Walkers and Rollators with hand brakes can help to avoid falls.



EXERCISE WILL HELP TO KEEP THE PATIENT STRONGER FOR LONGER!

Lowered stationary bikes with arm involvement is essential to help work the lower and upper extremities. (the coordination exercise helps too!) Patients don't always want to exercise, but unfortunately for us, it is a "Use it or Lose it" scenario. Movement and activity are of monumental importance to the Neurodegenerative Brain Disease crowd.





Tips & Tricks

From our Caregiver Experts

Caring for HOD Patients using Wheelchairs



MAKING HOME ACCESSIBLE

In general, our homes are not automatically wheelchair accessible. You may need to add ramps to entryways, add door pulls to assist with closing doors, and making sure that flooring material will work with the chair.



COMFORT IS KEY

Wheelchairs can be uncomfortable! Be sure that the seat has a comfortable cushion, and consider adding a cup holder for a beverage. If you are able, you can remove the legs on the chair to allow the patient to scoot around and exercise their legs.



GET EXERCISE IN THE CHAIR

A wheelchair is an extension of the patient's freedom. It is not a prison! Patients can practice yoga, light hand weights, or even get a work out with a foot pedal exercise bike. Large wheeled chairs can help to work out the upper body too! Make it fun, not a chore.



BATHING...WITH A CHAIR?

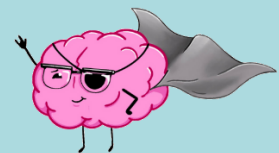
Shower chairs with extensions are available to help slide the patient in and out of the shower. Adding grab handles in the shower are also a good idea. The shower can be dangerous, so best to make it as safe as possible.

(Keyword search: Shower Chair with Extension)



UPGRADES TO HELP WITH EVERYDAY ACTIVITIES

- Replacing toilet seats with handled seats (Keyword Search: Toilet Seat with Handles)
- Installing grab handles on the inside of car doors (Keyword Search: Car Door Grab Handle)
- If the patient uses oxygen, a plastic cord wrap can be added to the side of the chair to wrap the oxygen tubing so that the patient can move around the house with ease.

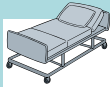




Tips & Tricks

From our caregiver experts

Bed bound tips for caregivers



COMFORT IS KING, SAFETY IS QUEEN

Hospital beds are convenient since they are adjustable, but can be very uncomfortable. It may be worth it to invest in a bed with an adjustable base. Bed rails can be purchased from medical supply companies or even from Amazon.



HELP ME HELP YOU!

An overhead bed trapeze can be installed for the caree to help pull themselves up and transfer to a wheel chair. This can help keep the caree and the caregiver safe from injury.



ACCIDENTS HAPPEN

Bed bound folks will need a way to use the restroom safely. Layered pads can be laid in the bed to catch accidents, a bedside commode can be added, and bed pans and urinals can be used.



WATCH OUT FOR BED SORES

Keep barrier lotion on hand to apply to skin to help avoid bed sores.



BEDSIDE TABLES

Patients want to be able to do things for themselves. Bedside tables are terrific for a lamp, books, tablets, water, rescue medication, etc. If they can reach it, they can help themselves!





Tips & Tricks

From our caregiver experts

Life Hacks for caregivers



DO THINGS TO KEEP YOU MENTALLY AND PHYSICALLY WELL

Chat with a friend, read a book, go to the park. Try to keep some flexibility in your schedule, and surround yourself with people that will understand if plans need to be modified or cancelled at the last minute.



WATCH YOUR CAREE FOR OVER STIMULATION

Over stimulation is very hard for folks with HOD to recover from. You can help them to avoid this by offering to help manage appointments, or gently telling them that they may need a break. Make sure to get permission first!



SOME DAYS ARE BETTER THAN OTHERS

On rougher days, don't be afraid to lighten the mood by breaking out into a silly dance, or call a friend together, or ask the caree what might make them feel a little better. We have heard that laughter can be the best medicine!



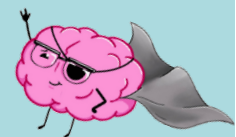
YOU ARE AN ADVOCATE!

Remember, you may need to step in and advocate for your caree. Be sure to ask for permission from the caree first. Your caree may need for you to intervene so that they don't become a science project.

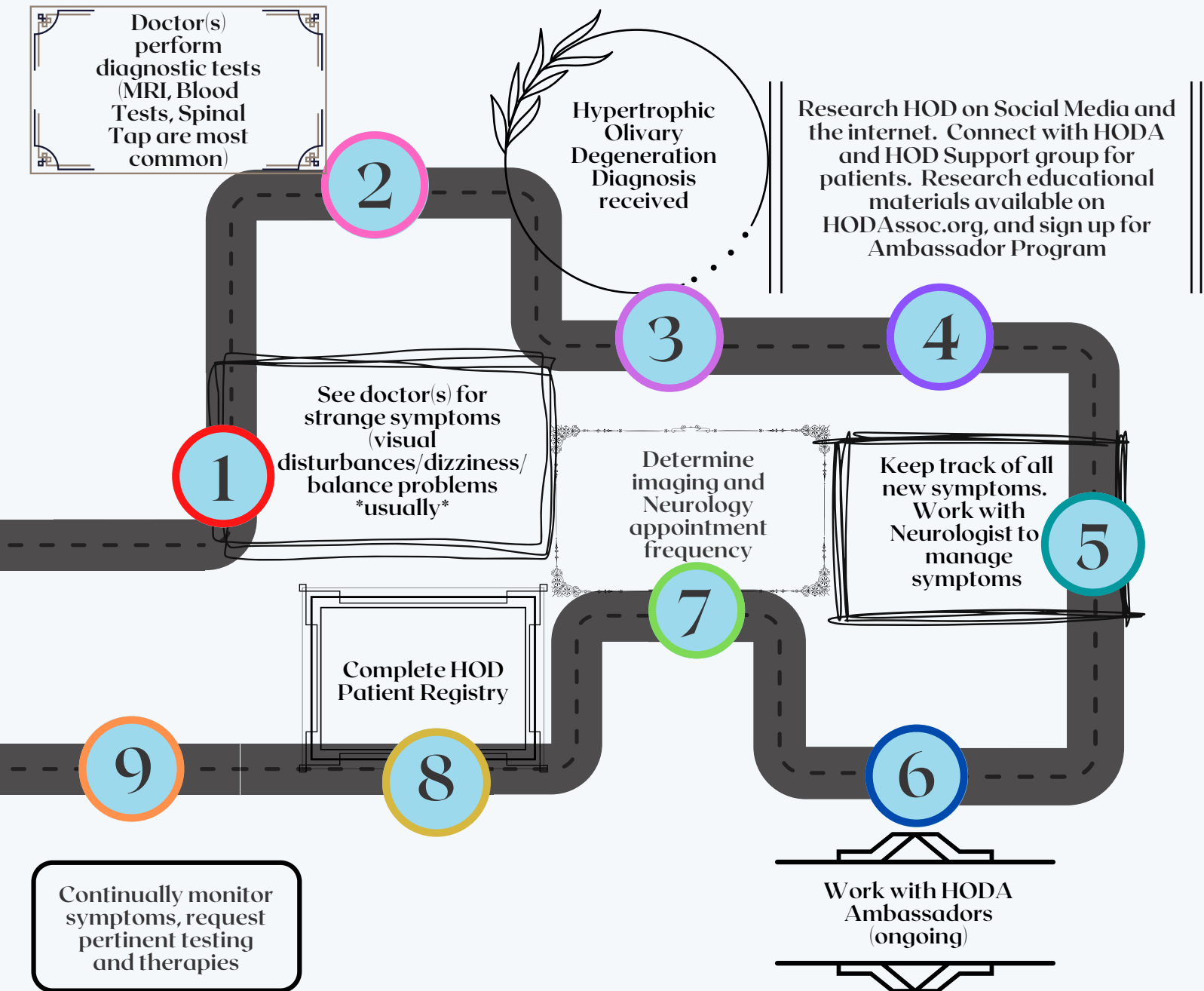


DON'T TAKE IT PERSONAL

Try to remember that we are all human and we all have and bad days. People are generally good and mean well. If your caree gets over stimulated, they can very easily lash out for no apparent reason. Try to remember that it is not YOU.



HOD Patient Journey Map





Hypertrophic Olivary Degeneration Association

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🌐 HODAssoc.org

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