

How to Manage your Health Care Team

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Being diagnosed with a neuroimmunologic disorder such as transverse myelitis (TM), neuromyelitis optica (NMO), acute disseminated encephalomyelitis (ADEM), or multiple sclerosis (MS) is a scary thing. Add to it the fact that navigating your way through the healthcare system today can be very daunting. Unfortunately, whether you have been diagnosed with a relapsing disorder like MS or NMO, or a one-time only disorder such as TM or ADEM, you can expect for this diagnosis to, in some way, impact the rest of your life... so here are some tips to get the most out of your experiences with your healthcare team!

First and foremost, always remember that you are the quarterback of your team... no one else is going to take the initiative to call the plays. Depending on how your diagnosis has impacted your life, potentially you will have several players on your team, including a neurologist, urologist, physical medicine and rehabilitation team, ophthalmologist, primary care doctor, etc., and it is up to you to make sure all the players know of each other's involvement, as well as the game plan – ensure that it is clear who is taking responsibility for prescriptions, acute issues, treatments, etc.

What to Look for in a Healthcare Provider:

TM, NMO, and ADEM are all rare disorders, so finding the appropriate healthcare provider can be challenging. There are, however, a few things to look for in a provider. Ideally, you would see someone who sees a lot of people with your diagnosis. These are the practitioners who will know the most about what therapies might work for what type of patient, and what to try next when something fails. However, depending on access, that's not always easily accomplished. And so, of equal importance is finding a practitioner who is engaged and interested in your case – oftentimes you may be the only patient a practitioner has ever encountered with your diagnosis, but if it sparks an interest in her to learn more about the diagnosis, as well as potential cause, treatments, current research, etc., then that can be just as valuable... especially during that stage where you are trying to discover what in the heck the diagnosis is! You need someone in your corner who stays right there by your side every step of the way through the process. Ideally, having a hybrid of these is best – someone locally who is engaged and dedicated, as well as someone with whom you've consulted at a specialty tertiary center who can offer advice, keep your local doctor up-to-date, and with whom you can check in occasionally. For this reason, communication is key! Your team needs to be willing and able to communicate with you and with each other. Any practitioner who is resistant to receiving input from other practitioners, particularly regarding a rare disorder... that's a red flag that you need to get another practitioner – more information is always better! For those unable to get to one of the few specialty centers around the country, there are plenty of MS Centers associated with medical schools – seeking out one of these in your area is often a great idea; these are often the doctors who are likely to be most familiar with these rare neuroimmunologic disorders such as TM, NMO and ADEM. Also, the practitioners at the two TM Centers in the country, both here at Hopkins and at UT Southwestern, are always eager to offer curbside advice to practitioners who are less familiar with acute treatments that seek out their input!

Preparing for the Appointment:

Doctors are busy. They have a lot of patients, and oftentimes research responsibilities. Depending on their support staff, some are better with communication than others outside of the appointment setting. But during the appointment – that is your time to have your practitioner's undivided attention. It is best to make the most

of that time, and there are ways to prepare for the visit toward that end. First, educate yourself. The more knowledge you have going into your visit, the more time the doctor will be able to spend increasing your knowledge to an even higher level. Second, be aware of appointment timing. Clinic days are busy for doctors – they know they have patients waiting to be seen, and if you had to wait in the waiting room, then you can guarantee that there are patients waiting behind you. Requesting first or last appointment of the day can be a couple of strategies that can reduce the pressure of a backed-up waiting room – if you are the first patient of the day, the doctor can't yet be too far behind, and if you are the last patient of the day, then the pressure is off the doctor to have to worry about potentially angry patients who are waiting... and remember, if you are having to wait for your appointment, please try to keep in mind that this means the doctor is just doing her due diligence in serving the patients that came before you – making sure they understood their diagnoses, treatments, etc., rather than just trying to adhere to a schedule and ultimately do a bigger disservice to the patients by not ensuring that they are receiving all the knowledge they need to be empowered regarding their illness. Next, write out a list of medications, including over-the-counter medications and vitamins, in advance – make sure the practitioner can keep this list! And last, think about what you want to talk about in advance.

Maximizing Your Visit

It's your neurologist's job to throw whatever you throw her way, but it's your job to make it a catchable throw! In other words, there are also things you can do on the day of the visit to help you get the most out of your visit, and they involve your interaction with your doctor. Writing down questions is a good idea, even in the weeks leading up to the appointment so that you don't leave the visit wishing you'd asked just one more thing. And ask questions until you understand. Some practitioners are so great at adapting their explanations according to their audience... others always talk as if they are discussing the disorder to a room full of scientists – way too clinically. Second, PRIORITIZE! If you throw 10 balls at your neurologist, then she gets to decide which one to catch – you need to decide which issues are most troubling to you at this moment. If there are too many issues, then you may need to have more frequent, problem-focused visits with the neurologist. Not all issues can be tackled all at once, though, so decide upfront what you most want tackled at this moment in time. Next, be honest with your doctor. We have this idea that we want to please the authority figure in the white coat. But she can only help you if she has a very honest idea of what is going on with you – if you are not taking the medication, that needs to be explored – financial limitations? Tolerability issues? These may be manageable issues, but not if we don't know what's going on. Also, don't expect to have an answer at the end of the visit. Oftentimes, many of you are dealing with complex issues and hope that by coming to the doctor, particularly to a tertiary center, you will have the answer by the end of the visit. Unfortunately, part of our thoroughness is our thoughtfulness – there may be more tests needed, more diagnoses to explore, etc. As many of you know through your own experiences, TM, for example, can be its own diagnosis, or part and parcel of any number of other diagnoses, including NMO, MS, and neurosarcoidosis. Also, if possible, bring someone with you. The benefit of this is two-fold – you have a second set of ears taking in the ton of information that you are trying to process, plus, if this is someone who lives at home with you, the friend or family member will likely be more invested in helping you to follow through with whatever plans are set into motion with your doctor if he or she was involved from the outset. Last but not least, leave the office with a plan, making sure you and your neurologist are on the same page. For example, if the goal of the visit was to address pain management, such that a new medication was initiated, determine upfront how long it will be before the medication should be effective, what side effects to look for, how to titrate, who to talk to if the medication does not work at the maximum dose or is not well-tolerated, and will there be alternatives at that point? Don't suffer in silence until the next appointment to get these issues addressed. Your doctor isn't going to be thinking about the effectiveness of these medications while you are gone... she is going to assume that if she is not hearing from you, then the medication is doing its job!

After the Visit; Rehabilitation:

No matter what neuroimmunologic disorder you have, the importance of physical medicine and rehabilitation cannot be accentuated enough! Unless you have a completely normal neurological assessment, if you have been told that there is nothing rehabilitation can offer you, then you are quite simply not seeing the correct rehabilitation specialists. A physiatrist evaluates your needs and directs and manages your rehabilitation – deciding what other team members need to be involved. This could include a physical therapist (strength recovery), occupational therapist (activities of daily living, vocational activities), and/or a nurse (skin, bowel/bladder management). Ideally, the team would have a particular interest or expertise in dealing with patients with spinal cord injury or with MS – therapists see a ton of diagnoses throughout the day from a knee replacement, a rotator cuff tear, etc., and the broader their knowledge, the less really detailed their knowledge may be about the very specific needs of TM/NMO/ADEM/MS patients.

After your Visit; Dealing with Insurance:

As mentioned, whether you have a relapsing neuroimmunologic disorder or not, you will be affected by this diagnosis for the rest of your life in some way. As a result, NEVER lose your insurance benefit! That said, ask your insurance company if you can be assigned to a case manager – this is someone who works for the insurance company who helps to oversee and coordinate your case, so that things don't get lost – a good case manager acts as an advocate for you because, over the years, he will learn what medications you have tried, what treatments have failed, etc., and can help to fight the insurance company when things like denials of payment for medications or procedures come up. Also, this person can help you to understand your co-pay and deductible requirements toward your insurance – which is an important thing to know! Some of the medications for the relapsing disorders are quite expensive, as is spinal cord rehabilitation, and understanding your deductible requirements can make a huge impact on your health and your wallet. Lastly, ask if your clinic has access to a social worker you can work with to help you to sort out issues with insurance rejections, applying for disability, or for looking into other resources in the community. Unfortunately, most doctors' offices don't have a social worker, but they are invaluable resources for those clinics that offer them!

Don't forget your Offensive Line:

If your clinic has a nurse, befriend him or her – he or she is there to protect you! Oftentimes, triage is done through the nurse. The nurse is your greatest ally & advocate, and your closest link to the physician.

Stay Connected:

As mentioned, educating yourself is invaluable – better educated patients receive better care. But, you have to know that the information you are receiving is reliable, and the great and awful thing about the internet is just how much information is at your fingertips... and just how completely unregulated it is! Below are sites with trustworthy information for your reference:

- Transverse Myelitis Association www.myelitis.org
- Johns Hopkins Transverse Myelitis Center
http://www.hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/transverse_myelitis
- International Center for Spinal Cord Injury at Kennedy Krieger Institute www.spinalcordrecovery.org
- Guthy-Jackson Charitable Foundation (NMO) www.guthyjacksonfoundation.org
- National Multiple Sclerosis Society www.nationalmssociety.org

Remember, it's your Health – You Call the Shots!

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