

## **What to do if your personal physician doesn't know a lot about NF?**

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Your knee hurts. Is it arthritis, or is it somehow related to your Neurofibromatosis (NF)? You have a bad headache that's lasted all week. Is it from that stressful project you've been working on at the office, or is it related to your NF? Your daughter seems distracted and her grades are slipping. Is it just part of being a teenager, or is it part of her NF? You've met "Mr. Right" and he has lots of questions about your NF and how it might affect your future together. Do you have to take a day off of work and drive to see your NF specialist to get the answers your boyfriend wants?

These questions (and a multitude of others) arise all the time for patients and families affected by Neurofibromatosis. But who do you ask? Does every question have to be answered by a specialist in NF - sometimes requiring travel and other inconveniences? Shouldn't your personal physician know some of these answers?

Most NF patients did not start their healthcare journey with a specialist. They started it with their Family Physician, Pediatrician, Obstetrician, or General Internal Medicine Physician. And yet, for a variety of reasons (some better than others), having NF has a way of straining these important primary care relationships. Surely, there are strategies for navigating the healthcare system in order to continue to receive great care from these personal physicians. This will free up time for our great NF specialists to do the work that only they can do AND help the primary care physician in your world do their best work as well - taking care of you through it all.

Neurofibromatosis teaching in medical schools (and in advanced primary care training programs after medical school) is surprisingly cursory for a condition that (in the case of NF-1) occurs in around 1 in 2500 persons. That means that most family medicine practices in this country should average one patient with NF! For all the time that medical schools spend teaching about rare diseases, a brief mention of Neurofibromatosis in a single lecture that includes a half dozen other neuro-genetic diseases is about all most physicians will get.

Remember this, though...doctors are trained to be learners. Just because something is unfamiliar to them doesn't mean they can't or won't give themselves a crash course in it once they know they have a patient with it. Medical training today is more about pattern recognition and keeping an open mind through careful history-taking and examination than about learning "everything about everything" - that just isn't possible to do in modern medicine. It will be your job to remind them why they went to medical school and to give them the challenge of getting up to speed on NF.

As you may already know, most of the time NF is, well, kind of boring. It changes slowly, though not always predictably. It has exam findings that are usually easy to see and for those internal findings the

Provided by NF Midwest [www.nfmidwest.org](http://www.nfmidwest.org)

tests needed to evaluate most of them are common. Some of the common complications of NF are treated in the same way well-trained physicians treat those symptoms for any of their non-NF patients. Since NF has little impact on overall life expectancy, you will still need a personal physician who can do all the stuff they are trained to do for any of their patients – help you through common childhood illnesses, oversee healthcare transitions into adulthood, check blood tests to assess your risk of cardiovascular disease and make sure you're doing all the “wellness” things in order to grow old gracefully. Just as providing very specialized NF care is not the expectation you should have of your personal physician, doing all of these “personal physician” things is not really the expectation of the specialists in Neurofibromatosis. Sometimes patients with specialized needs are their own worst enemy - just because you have NF, doesn't mean that every problem you will have is related to that diagnosis. Be aware that your personal physician should have an agenda about your global healthcare that is bigger than your NF.

Healthcare is a team game now and a personal physician who is smart enough to help you through the common stuff and wise enough to help you use specialists appropriately is what you need most. Your personal physician probably already has a whole team helping him out in his office. Patients with NF will eventually have needs that will involve the nurse, the office manager, the Nurse Practitioner, the social worker, pharmacist or counselor. Many of these can be found at your personal physician's office and they all need to be up-to-speed on Neurofibromatosis.

Not all personal physicians are up to this task - and that's too bad. But for the ones that are, you will find them willing to learn as they work together with you to make sure you are being well taken care of. If your expectation is that they will immediately have a perfect answer to every NF question you throw at them, you'll usually be disappointed. However, if you have an important question about your NF and can give them the time to get you the answers, most of the time within a few days you'll get the answers you need. A physician who really cares about taking care of you and who you are willing to help in that task is what you're looking for.

One way you can help is by being well-educated yourself about NF. While some complications of NF may be treated the same as they are in people without NF, you will want to stay aware of the latest treatments that are being developed for NF patients. You will also want to understand how some symptoms in NF patients could signal a larger problem than that same symptom in a person without NF. Your personal physician may need your guidance to make these connections if they are less familiar with Neurofibromatosis. Pain in all patients (NF and non-NF) deserves to be well-explored and appropriately treated, just like learning, speech or motor delays, back pain or vision problems. The difference with managing these symptoms in NF patients is in the need to see how they are all part of the bigger picture of Neurofibromatosis.

The Internet has both good and bad information about NF, but it's more reputable sites are a good starting point. Attending lectures and symposia, and talking to experienced families and advocacy organizations like Neurofibromatosis Midwest can get you to a place where you at least know the right

questions to ask. Be educated and confident. Your personal physician can help you, but if you feel an issue or complication needs more attention you need make your physician clearly aware of your concerns.

In all honesty, the way healthcare is managed and paid for puts a lot of pressure on physicians to go too fast, focus on the easy stuff, and try to avoid anything that is a little too challenging. That is changing, thankfully and doctors are being held accountable for really "taking care of" populations of patients - and that population includes you.

Here are some strategies for making the most of your office visit:

- 1) Clearly state what you need from your visit when you make the appointment in order to make sure enough time is scheduled for your visit.
- 2) Come prepared with a list of questions that the office staff can give to the doctor to review before entering the room is also helpful. Make sure your list doesn't get piled on with 3 other things by the time the physician enters the room – this will help the visit stay on track.
- 3) Have reasonable expectations for what answers you can get from the doctor today and which she may need to get to you in the days ahead is crucial to not having the visit end with "a guess" or a referral to a specialist every single time.
- 4) Expect that your personal physician will be communicating important new problems to any NF specialists you use is reasonable, but should be verbalized as an expectation of your visit.
- 5) Any non-office visit communication tools your doctor has should be used whenever possible. A well-timed email, the use of a "patient portal" and secure messaging can often give your personal physician a heads-up on what you need and the time to prepare herself to deliver that to you as efficiently as possible.
- 6) NF Midwest has a nice one-page handout about Neurofibromatosis Type 1 for Medical Professionals that you should take along to your visits to share with any new staff members who may need a little more information. Here is the [link to](#) that handout.

Remember, Neurofibromatosis is not that rare, but your personal physician probably has forgotten that fact since medical school. If you can engage your primary care team in a meaningful dialogue about what you need them to be able to do for you, you will find that you are setting yourself up for a long and productive relationship that will lead to your better health.