



# Accessing Care: How to Advocate For Yourself Living With Narcolepsy

Obtaining high-quality medical care can be challenging. There can be a lot to juggle between finding a qualified specialist, navigating insurance complexities, and getting to and from doctor's appointments.

People with Narcolepsy may face even more difficulty advocating for their medical needs given the rare nature of the disorder and have likely spent years navigating the healthcare system just to get to their Narcolepsy diagnosis.

The following is a list of steps you can take to make the most out of your medical appointments and ensure you get the best care possible.

## 1. Understand (at least somewhat) health insurance

Health insurance plans in the US dictate where you can go for specialty care, and you should always aim to see an "in-network" provider.

In-network means that the office or provider you will be getting medical services from is contracted with your insurance plan. This way, when that provider submits a claim to your health insurance, your insurance will reimburse them for the care you received.

Medical offices are typically really good about making sure they accept your insurance before seeing you for an appointment, but it's never a bad idea to call your insurance and double-check for yourself.

Also, a lot of insurances require a referral for specialty services from your primary care provider, so be sure to get help with this if needed.

**Pro tip: always ask the office you are going to whether or not they take your insurance.**

## 2. Bring a list of questions

To get the most out of your doctor's appointments, come prepared. Making a list of questions is a great place to start. You might want to consider bringing these written down on a piece of paper. Some questions that may be relevant to someone with Narcolepsy include:



- What is Narcolepsy?
- What medication options are there?
- What are the side effects of these medications?
- Can I take medicines for Narcolepsy with the medications I am already on?
- How quickly do these medications start working?
- When should I return for a follow-up?
- If I have questions before my next appointment, what is the best way to get in touch with you?

If you are about to have a sleep study, you can ask things like:

- What should I expect during a sleep study?
- What can I bring?
- Are there any medications I should stop before coming to my sleep study?
- What time should I arrive and what time does the study end?
- What exactly are you looking for in a sleep study?
- How long does it take to get the results of the sleep study?
- Do you call once the results are ready or should I schedule an in-person appointment to discuss the results?

**Pro tip: Come prepared to your appointments with questions and any other concerns you may have.**

### 3. Keep your follow-up appointments

You should always follow the advice of the provider you are seeing for care. This involves scheduling follow-up appointments so that you and your provider can discuss how your treatment is going and make changes as needed. It also allows you time to ask questions that may arise and clear up any confusion related to your care.

For people living with Narcolepsy, keeping your follow-up appointments is especially important since many patients are on stimulants or other various scheduled drugs. These are also commonly referred to as “controlled substances.”

Healthcare providers may therefore ask you to return to the office on a frequent basis to monitor your drug therapy and make sure the medications that are being prescribed to you are working as desired with minimal side effects. If you feel like things are going well with your medical therapy and wish to lengthen the time between follow-up appointments, you can always ask your provider directly and make that decision together.

**Pro tip: Keep your scheduled follow-up appointments, and if you are confused at any time regarding the timeline of your follow-up appointments, just ask your provider.**

### 4. You can schedule appointments sooner rather than later

For people with Narcolepsy, there are a number of drugs and treatments that are available. As mentioned above, your healthcare provider should lay out a plan to follow up with you. This shows they care and want to make sure they monitor you closely.

Even if you aren't starting a new treatment, many individuals don't realize that you can always request an appointment sooner than your routinely scheduled follow-up appointment, especially if you have new questions or concerns that you want to address in person and not necessarily over the phone.

**Pro tip: you can always ask for an appointment sooner than your regularly scheduled appointment if you want.**

## 5. Arrive early for your appointment if you can

Many people view doctor's offices as places that tend to run behind schedule. However, it is in your best interest to be on time, if not early, for your appointments. This will help ensure you have the most time with your provider that day to discuss your treatment and get your questions answered.

**Pro tip: arrive early to your appointments whenever possible!**

## 6. If you feel like you aren't getting the care you need, do these things

Not every patient-provider relationship works out. If for some reason you feel like your provider is not listening to you, or if you are having difficulty getting through to them outside of appointments, there are several things you can try.

Firstly, try and be patient. This can be difficult especially if you have been to multiple providers already, but it is worth trying to get through at least a few visits in order to gauge whether your relationship will be positive and therapeutic. Treatments for Narcolepsy can take a long time to work, so patience is incredibly important. No treatment is one-size-fits-all, and there will likely be some trial-and-error as you and your provider try to figure out what works best for you. So try to stick it out for at least a few appointments with your doctor.

Second, as mentioned, when you see your provider in person, be sure to ask them how you can contact them between appointments. Depending on the doctor's office, questions via phone call can sometimes take a while to get answered. Other offices may accept secure email messages via confidential patient portals and may get to these messages quicker. So always ask how to get in touch.

If you feel like you aren't having needs and questions addressed, it may be worth scheduling an appointment on your own accord. This way you know you have a dedicated appointment time with your provider during which you are the sole focus of their attention.

If you are really unhappy with the care you are receiving, you can also try these things:

- Ask your primary care provider to advocate for you. They should be able to communicate directly with your specialist and ask them to take steps to move forward with your care.
- You can ask to switch to another provider in the office.
- You can choose to switch offices entirely (not ideal, but if there is another provider who is in-network, this can technically be an option).

While accessing healthcare can be complex, especially with rare disorders like Narcolepsy, these tips can help you make the most out of your doctor's appointments and advocate for your needs. You can also check out our [newly diagnosed checklist](#) for more resources if you or someone you know has just been diagnosed with Narcolepsy. Further resources can also be found [here](#).