



The Confident Patient:

A Self-Advocacy Guide for Narcolepsy

Your diagnosis

- How do my test results, like an EEG or sleep study, support my specific diagnosis?
- What is the difference between narcolepsy type 1, type 2, and idiopathic hypersomnia in my case?
- What signs should I look for that indicate my symptoms are changing?

Improving quality of life

- If my insurance denies a treatment you prescribe, what is the process for an appeal or pre-authorization?
- What kind of financial support services are available for this treatment?
- What can I do if my medication is out of stock at the pharmacy?
- Are there lifestyle changes, like scheduled daily naps, that could help with fatigue?
- Where can I find a support group for people my age living with narcolepsy?

Treatment options

- How do we decide when it's time to switch to a different treatment plan?
- What are the different goals of stimulants and oxybates?
- What is the dosing schedule for these different treatment options?

Symptom check-in

- Sudden muscle weakness (cataplexy)
- Intense daytime "sleep attacks"
- Brain fog or trouble focusing
- Restless or disrupted sleep
- Headaches or migraines
- Anxiety or depression
- Difficulty keeping up with work or social life

Notes: