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Can We Talk? Optimizing Patient and Parent/Caregiver Buy-in to the Management of Pediatric Narcolepsy

Announcer:
Welcome to CME on ReachMD. This episode is part of our MinuteCE curriculum.

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Dr. Morse:
This is CME on ReachMD, and I'm Dr. Anne Marie Morse. We will discuss optimizing patient outcomes and management of pediatric narcolepsy.

You've heard me earlier discuss the fact that the one question that you can incorporate into your practice today is, 'What can't you do because of your narcolepsy?'. This gives you the starting point of understanding what is important in your patient's life, and how can you treat to that goal and make them feel successful in their own way.

Now, that is a great starting place, but just like any good outcome, you need more of an instruction manual than just that one point in time. This is where it becomes really important to understand the full picture of what an individual is experiencing. If we want to optimize the day-to-day of every person who has narcolepsy, we need to understand what every day looks like. This is where, many times, I'll encourage my patient to use something like a symptom diary. A symptom diary is going beyond your sleep diary of just understanding what sleep-wake schedules are, as well as what napping is. Very frequently, it's not necessarily the person coming in and describing that the naps are the problem, they're describing the fact that the naps intrude into what they want their life to look like.

It is important to understand: What do those compromises look like? What are the things that are being traded off? Is it their social activities? Is it because of the fact that if they don't nap, that they're experiencing a migraine, and therefore they need to nap in order to head that off? Are they struggling with the fact that, despite watching what they're eating and trying to incorporate exercise, they're still experiencing increasing weight gain?

By developing a symptom diary, it allows for you to have a better understanding of what does the continuous symptoms look like over the course of many days. Very frequently, I'll ask my patients to complete these for 1 to 2 weeks. This now, in addition to that, 'what can't you do because of your narcolepsy,' gives you a more comprehensive view of what potential progress can look like.

Based on the symptom diary and based on that response of 'what can't you do,' I'm able to sit down with my patients and really discuss the development of a progress map. What do I mean by that? Well, we all know that no matter what I prescribe, no matter what lifestyle modifications I introduce, no matter what social supports or introduction to another individualized narcolepsy, the change that the person who is going to experience with narcolepsy is not instantaneous, and therefore we need to be realistic and give very good anticipatory guidance that is individualized to where they're starting. Being able to understand that a person is napping four times a day for 40 minutes at a time, and measure success by not necessarily just a reduction in total naps, but maybe a reduction in the duration of naps. Maybe it's that we are identifying we want to be able to spend time with our friends, instead of it being zero times a week, seeing that it's twice a month, that is a positive movement in the right direction.

It can be really hard to understand those palpable changes when it doesn't feel so palpable, because they're subtle. It also is really important to have this type of baseline when you are making tremendous success, because sometimes it feels like medications or strategies are losing their effectiveness, but not because they're not effective anymore, but because of how successful we have been, and now the goals have changed. That is not something to dismiss. That is something to celebrate. It allows for you to not only keep track, keep progress, and make goals, but allows for you to continue to have those integral celebrations of all the progress that is made.

It is really important to give your patient this type of encouragement and these types of tools so that they can be an active participant in their own care and really be put, literally and figuratively, in the driver's seat to be able to achieve that goal of whatever the ultimate success is that you are identifying together.

It's important to not only get this information selected from the individual, but in pediatrics, definitely getting it from school as well as friends and parents, can be really informative to understanding where there's still opportunity and where there has been the meaningful success that is so important.

So this has been another brief but hopefully important and really great discussion. I hope you have found this information useful and some gems that you might be able to incorporate into your practice today. Thanks for tuning in.

Announcer:
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