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Narcolepsy's Burden of Illness: Its Impact on the Child and Family

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. I'm Dr. Anne Marie Morse. We'll discuss the burden of illness and management of pediatric narcolepsy.

Many times, clinicians really struggle with understanding that the symptoms of narcolepsy far exceed just the pentad symptoms. It's much more than excessive daytime sleepiness or cataplexy, sleep-related hallucinations, sleep paralysis, or even disturbed nocturnal sleep. The symptoms of narcolepsy very much spill into every aspect of life, and many times are going unnoticed, which is contributing to the overarching burden that not only the child experiences, but the entire family. There is this period of a delay in diagnosis, which many times, in addition to that being a burden in itself, is resulting in the cumulating symptoms and diagnoses that the person now is establishing as a part of who they are; may that be depression or ADHD or 'I'm just lazy,' this stigma follows with them for a very long time, and many times, can cause a tremendous amount of stress for the patient as well as the family.

This is occurring at a pivotal point in an individual's life where there are so many expected developmental changes and so many successes that they need to have in terms of milestones that are getting greatly compromised by the fact that the sleepiness is invading into their opportunity to be able to be as successful as they may be able to be. We see this resulting in impaired self-esteem, poor academic success, social isolation and marginalization, not having friends, maybe not even having that first boyfriend or girlfriend, first kiss, from delays in graduation from high school, inadequate success leading to the inability to actually get into the college of their choice, which is going to lead to a lifelong of poor job security and financial security.

As you can see, the symptoms of narcolepsy contribute to this overarching burden that is really important to be familiar with. What is it that you can do for that? First and foremost, one of the most important questions I ask my patients is, 'What can't you do, or what has been impaired because of your narcolepsy?' It's not enough to measure by an Epworth sleepiness scale, it is really important to understand what are the palpable things that the child and the family are experiencing in a daily struggle.

You now have identified your treatment goal. You can utilize this at every single visit to see, how much closer are we? And once we've reached that success, what's the next thing that we're going to knock off that list? Using a simple question like, 'What can't you do because of your symptoms of narcolepsy?,' help you to really personalize your treatment strategy. Never accept the idea that someone wants to be, quote unquote, normal. Normal is a variable that really, truly doesn't exist. I can say for myself, my normal right now is not the same as my normal at 15 years of age.

It's important to think about not only all the things I just described, but also how some of these children may also have other medical and psychological comorbidities that may be present, and also need to be a part of that personalization and consideration of how your treatment strategies are not only affecting the things the child is unable to do or the impairments they're experiencing, but also those

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other areas. You're going to want to make sure you tune into the other sessions where we do talk about the medical and psychological comorbidities, and why a transdisciplinary approach to the care for the child, and really the whole family, becomes incredibly pivotal to being able to have the treatment success that every child with narcolepsy is really reaching for.

Well, I hope this has helped. I know that this was a brief little segment in regards to the overarching burden that individuals experience with narcolepsy as well as their families. But hopefully this is allowing you to add that one extra question to be able to better personalize the treatment for every child that comes across your path.

Announcer:
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