

Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: <https://reachmd.com/programs/neurofrontiers/comprehensive-care-navigating-neurobehavioral-issues-in-dmd-patients/16502/>

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Comprehensive Care: Navigating Neurobehavioral Issues in DMD Patients

Announcer:

You're listening to *NeuroFrontiers* on ReachMD. On this episode, we'll discuss the management of neurobehavioral aspects of Duchenne muscular dystrophy with Dr. John Brandsema. Dr. Brandsema is a pediatric neurologist and the Neuromuscular Section Head at the Children's Hospital of Philadelphia. Let's hear from him now.

Dr. Brandsema:

The deficient protein from a dystrophin gene mutation is not just expressed in skeletal muscle—it's also expressed in the brain—and so we do have a cognitive phenotype to this disease. About a third of people are fully normal with Duchenne with their thinking; a third are very severely cognitively affected with issues such as autism spectrum disorder, severe cognitive delays, and intellectual impairment; and then the middle range tend to be symptomatic with issues such as attention deficit hyperactivity disorder, and anxiety is also very prevalent; so I would say about 60 to 70 percent of people living with Duchenne have a diagnosable neurobehavioral phenotype when we do careful assessments of them.

It's important to recognize because it's a significant impact on scholastic performance and eventually adult integration into the community with work and further schooling or other community-based connections for the individuals. If they have undiagnosed neurobehavioral issues, they don't tend to thrive as well in those environments, and we sometimes can make interventions, such as medication therapy and other targeted approaches that improve outcomes.

I do find that school-based plans are really important, so having an Individualized Education Plan, or IEP, in the pediatric realm helps because even things like having extra time on tests or an individualized approach to getting the information so that it's not overwhelming or they're not overly distracted in processing it can really help.

Some patients have acute times where they may really benefit from some extra therapy if they've had a significant change in their function or a disease-related stressor or their caregivers are overburdened and may have their own needs for behavioral support, whether it be depression or anxiety or an adjustment disorder, whatever it is. We need to be very respectful and careful in discussing these issues openly in the clinic so that we can get the support that people might need. And then we get to the point where some benefit from medication, and it may be stimulants for ADHD; it may be an SSRI or another related medication for the anxiety or the hyperactivity or other issues that might be coming up. And sometimes we have a psychiatrist involved in the care. Sometimes there's a developmental pediatrician, sometimes this is being managed through the collaboration of the neuromuscular team and the primary care doctor and other resources that are available in the patient's community. So this is really a collaborative effort across different areas of specialty and expertise and takes a careful approach.

Announcer:

That was Dr. John Brandsema discussing strategies for managing the neurobehavioral aspects of Duchenne muscular dystrophy. To access this and other episodes on our series, visit *NeuroFrontiers* on ReachMD dot com, where you can Be Part of the Knowledge. Thanks for listening!