

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/transitioning-to-adult-care-in-dmd-strategies-for-long-term-support/35735/>

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Transitioning to Adult Care in DMD: Strategies for Long-Term Support

ReachMD Announcer:

You're listening to *NeuroFrontiers* on ReachMD. On this episode, we'll hear from Dr. Rosaline Quinlivan, who's a Professor of Neuromuscular Disease at University College London. She'll be discussing key considerations for treating adult patients with Duchenne muscular dystrophy. Here's Dr. Quinlivan now.

Dr. Quinlivan:

The evidence is that corticosteroids benefit people with Duchenne dystrophy. They delay the loss of walking. Without treatment, boys will lose the ability to walk by the time they are 13 years of age, and the average is 9.9 years. With corticosteroids, depending on whether they are having the steroids intermittently or daily, the median loss of ambulation is 12.5 or 14 years respectively, and some patients are still walking into their late teens. We also know that corticosteroids delay the loss of respiratory function by at least two years, so although the rate of decline might be the same, it's delayed, and so the need to start noninvasive ventilation is much later than in untreated patients. And we know that corticosteroids will also preserve upper limb function, so they delay the loss of upper limb function so they benefit patients in terms of quality of life.

So it is really important that just because a patient transitions from pediatric to adult services, that a new physician coming in looking after this patient doesn't just decide to wean and stop steroids. Sadly, this is a common event. So it's very important that steroids are continued through into the adult population, and it's also very important that the adult physician is aware of the emergency guidelines to prevent an adrenal crisis.

It's really important as well that the family and the young men with Duchenne have a contact number so that, should they become acutely unwell, the adult center managing their care can be made aware of this, liaise with the local emergency room, and offer advice. In addition, supporting patients is really important psychologically. Duchenne adults have a high rate of neurodiversity, and as a consequence, they have a high rate of anxiety and depression. So psychological support for the men, but also for their families, is really important. Supporting them on transport issues is also important. Understanding whether or not they are able to drive is really important for independence. It's certainly possible for men with Duchenne to learn to drive. And if they're not able to learn to drive, then understanding what transport issues they might have and supporting transport is important. Also discussing living arrangements—whether they wish to continue living with their parents or whether it's possible for them to live independently with support. Now, while this is not an option for everybody, there are many men who live very successful, independent lives with support, and so opening this opportunity for young men with Duchenne is very important, and these discussions need to be had by the adult services.

And finally, it's very difficult to talk about relationships and sex in an outpatient clinic when you have your parents or your carers sitting with you, so it's very important that patients with Duchenne in the adult services have an opportunity to discuss these sensitive issues privately with a separate worker. And this could be, for example, a nurse or a healthcare worker. But giving patients the space to have these private conversations is very important.

ReachMD Announcer:

That was Dr. Rosaline Quinlivan talking about special considerations for adult patients with Duchenne muscular dystrophy. To access this and other episodes in our series, visit *NeuroFrontiers* on ReachMD dot com, where you can Be Part of the Knowledge. Thanks for listening!