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/supporting-adults-with-dmd-a-guide-to-acute-and-long-term-planning/35736/

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Supporting Adults With DMD: A Guide to Acute and Long-Term Planning

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 how we can address unmet needs in adult patients with Duchenne muscular dystrophy. Here's Dr. Quinlivan now.

Dr. Quinlivan:

An emergency care plan is very important because many practitioners in the adult world will not have encountered a patient with Duchenne muscular dystrophy in the past. This is a rare disorder, and because the health needs of these patients can be very highly complex, having an emergency care plan with some emergency guidance and contact details of those key specialists that that patient sees is really important to support local teams, such as general practice, and emergency rooms, into helping them to provide the best level of care.

It can be really helpful to create a treatment escalation plan. In my experience, when I create these treatment escalation plans, I find that all of my Duchenne patients want every level of treatment offered to them. This doesn't necessarily happen if they present to an accident to the emergency department with, for example, a pneumonia. That team will not have seen the patient when he's well, and they will be seeing him at his worst when he's very unwell, and they may not understand the wishes of that patient because he may not be in a position to express them. And so having a treatment escalation plan or being clear about what level of care they would want should they present acutely is really important to make sure that the patient gets the best care that he needs and wants.

I think we need to continue to develop links with adult services. There's a great need to train and educate adult neurologists in this area. In many countries, there is a complete lack of specialists on the adult side, and many patients worldwide are still being looked after by children's services even when they're over the age of 18, so developing better adult care is really important. Some of these patients are going to live well into their 40s, so it really is not appropriate for them to be attending children's services. And while they may be getting expert care, it doesn't help them when they become acutely unwell.

There's an issue here for policymakers because, in some countries, for example, the insurance does not cover the care of adults with Duchenne. It covers their care locally, whereas actually, this condition is so complicated, and these patients can be so difficult to manage, they really need to be seen in specialist centers. So going forward, I think there needs to be policies across countries to develop appropriate services for men with Duchenne. The numbers of patients are growing, and unless this is properly planned, it's going to be very difficult for many patients and their families.

ReachMD Announcer:

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