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## The Complexities of DMD: Optimizing Multidisciplinary Care

### 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 the importance of multidisciplinary care in adult patients with Duchenne muscular dystrophy. Here's Dr. Quinlivan now.

### Dr. Quinlivan:

So the care team for adults with Duchenne muscular dystrophy includes some specialists that they will have seen in pediatric care. For example, the neurologist should be the coordinating consultant, or this could be a rehabilitation consultant. There should also be a respiratory team, so this will include a consultant and also a specialist physiotherapist and respiratory nurses. A cardiologist is key because almost all adults with Duchenne will have cardiomyopathy, and, of course, there should be physiotherapy and bone health specialists or endocrinologists.

But in the adult world, there are other key medical issues that can arise over time, and so we will be bringing in a wider range of specialists. In particular, all adults with Duchenne muscular dystrophy should be supported by a healthcare professional who's got training in psychology, so this should be a clinical psychologist or a nurse specialist with psychology training. They should also have access to an expert gastroenterologist because as patients get older, complications can be very severe and sometimes life threatening.

Unlike pediatrics, in adults, many patients begin to lose weight. So in children, the problem is gaining too much weight, but in adults, the problem is losing weight and becoming malnourished and cachectic. So a dietitian and a speech and language therapist are two very important members of the team. Many people with Duchenne, as they get older, will develop some chewing and bulbar issues, which slows down their eating.

Palliative care consultants can be very helpful in supporting symptom control. Pain can be an issue for many patients. We've seen some other areas where different specialists are needed. For example, about 16 percent of my particular cohort of patients have developed kidney stones that need treatment, so a urologist dealing with renal calculi would be an important member of the team. But in addition, many patients develop bladder symptoms, such as incontinence, and may also need to see a neuro-urologist for that reason. As cardiomyopathy gets worse, the number of cardiac medications prescribed tends to increase, including diuretics, such as eplerenone, and these drugs in combination with ACE inhibitors can result in renal impairment, particularly during acute phases of illness. And so access to a nephrologist is very important to help manage this side of things. Endocrinology is important because many of these patients have delayed puberty and low testosterone levels as well as the indication for bone protection due to long-term steroid use.

And finally, emergency care physicians need to know about Duchenne muscular dystrophy because these patients are going to pitch up to the emergency room with acute infections. And it's very important that the team are also aware of the indications of steroid use and the need to cover sick patients with hydrocortisone. They also need to be aware, if the patient has a fracture, that they might present with a fat embolism syndrome. So I think educating the emergency care physicians is really important as well. I think also, in addition to the patient having an emergency steroid regime, we can really help our patients by making sure that they have an emergency care plan because this will assist the emergency care physicians when they're seen during an acute crisis.

### ReachMD Announcer:

That was Dr. Rosaline Quinlivan talking about multidisciplinary management of Duchenne muscular dystrophy in adults. 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!