

DMD Care UK Q+A from 10th Jan 2023: Clinician focus

Physio

Question 1: There is a huge issue around getting access to wheelchairs, especially now everything has been subcontracted out of hospitals. Are we collecting data on this? Could we invite someone from wheelchair services to discuss the bottlenecks to getting people the bespoke wheelchairs that they need when they need them?

Agree – this is a really good idea. We have discussed engaging with occupational therapists from the wheelchair services and think this is one way to tackle the issue. We will take this forward in the physiotherapy working group and look specifically at wheelchair provision alongside the work Duchenne UK are already doing.

As provision has been placed with privatised companies, it can be very difficult to get them together and to cooperate. One centre has the following suggestions that they employ to help:

1. Suggest that providers are discriminating against these young people or adults and preventing them from accessing their environment as their peers do
2. We put parents or teenage boys on to the funders – the CCGs. We suggest that they contact them directly and ask why they have not been provided with an appropriate wheelchair and that their doctor and their physiotherapist has said it is an essential requirement.

Members of the working group are also working on this issue across neuromuscular services with MDUK. We are aware that it is an issue and unfortunately, provision varies across the country. It will take time, but we are trying to address this and will keep the project updated of any developments.

We can also work on template letters for equipment that can be provided within the network to help people gain access.

Question 2: When the chairs breakdown or need servicing, there is no money or set-up to do that. How should we approach this issue?

This requires going back to wheelchair services because we need to have continuity. We should use patient experiences to show the need for this.

Comment 1: Duchenne UK has received a grant to develop a Dream Chair. This would be one that people wanted to use and that met their needs in terms of functionality. There have been some stumbling blocks – including the rising cost of manufacture. However, the project is continuing very positively and would like to further engage with clinicians and the patient community. If anyone is keen to get involved or give their feedback, please contact Emily Reuben: emily@duchenneuk.org about the Dream Chair project.

Comment 2: For MND (motor neurone disease), some centres have a charity-funded wheelchair advisor who talks to patients about their needs and liaises with wheelchair services. Perhaps this is something that we should consider in DMD. It is currently possible to ask the MND advisor for help with particularly complex

issues with DMD patients – especially adults who are so reliant on their wheelchairs.

Question 3: There were plans to revise the online forms in NorthStar for physio assessment. Has this been done?

Yes, there was a plan to make sure that there was one continuous assessment from paediatric into adult physiotherapy. These forms have been implemented in the adult North Star but still need to be done in paediatrics. This is in progress.

We also suggest that, considering the need and interest in, wheelchair service improvement, that a separate group may be needed to look at this in a more focussed and agile way, linking in with the Duchenne UK work on the Dream Chair project. The physio group will follow this up.