



7 May 2024

Our Ref: RFI 57483

**Freedom of Information Act 2000
Information in Relation to Trust Services for Patients with DMD.**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above, which you requested on 26 March 2024. Please accept my apologies for the delay in responding to your request. Thank you for your understanding and forbearance.

A response to each of the questions raised has been provided by the Childrens Services and Unscheduled Care, Medicine & Cancer Directorates, and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Caroline Degans
Information Governance Officer

Q1. Does your organisation commission any services for people with DMD?

- A1. There are no dedicated services within Community Children's Services (CCS) for children and young people with DMD. Children are supported across a number of services, depending on individual need and may receive the services of Community Paediatricians, Nurses and Allied Health Professionals (AHPs), AHPs see and support these children and young people through their schools based service. Community Children's Nursing Team (CCN) support children and young people with DMD as required, predominantly through supply of equipment, e.g. profiling beds, hoists, over-bed table, and where airway management is required.

Medical care is coordinated mostly by the Regional Tertiary Neuromuscular Clinic within Belfast Trust.

With regard to Adults with DMD, the Trust do not have a specific neurology clinic for patients.

Q2. If no, does your organisation expect to commission services for DMD in the future?

- A2. No, the Regional Neuromuscular service for Paediatrics and Adults is based in the Belfast Health and Social Care Trust.

Q3. If yes, what services for people with DMD does your organisation commission?

- A3. As the Trust does not commission any services for people with DMD, this question does not apply.

Q4. How many people with DMD does your organisation serve?

- A4. There are fewer than 10 young people on the AHP, Community Paediatrician and CCN caseloads in the Trust, with a confirmed diagnosis of DMD.

With regard to Adults with DMD, the Trust does not hold the data on the number of patients with DMD who reside in the Trust area.

Q5. Does your organisation have any DMD-specific (or muscle-wasting disease-specific) policies or guidance?

- A5. There is the Regional Pathway Guidance for a Child with Duchenne Muscular Dystrophy (DMD/MD) or Suspected DMD/Muscular Dystrophy; Northern Ireland, for Physiotherapists. Paediatric Occupational Therapy Pathways of Care are currently under review by the regional managers' sub-group.

With regard to Adults with DMD, the Trust does not have any DMD specific (or muscle-wasting disease specific) policies or guidance.

Q6. Do any of your organisation's strategies, objectives, plans, performance indicators, audits, inspections, or similar, cite DMD (or any muscle-wasting disease) or use either as a metric?

- A6. No, not within Children's Community Paediatric Services, Community Children's Nursing, Paediatric Physiotherapy, Occupational Therapy, Speech and Language Therapy or Adult Services.

Q7. Is your organisation aware of the work of DMD Care UK (<https://dmdcareuk.org/>)?

- A7. The Trust Community Paediatricians are aware of this work.

The Trust values the work of our charity partners and signposts patients to relevant sources of information.