

FOI – 2338

30th April 2024

## **FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST**

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**Do you commission services for people with Duchenne muscular dystrophy (DMD)?**

**Response:**

DMD is managed in the regional neuromuscular clinic in Belfast Health & Social Care Trust.

**SHSCT Children & Young People Response:**

The Children and Young Peoples Directorate (CYP) do not commission services specifically for children and young people with Duchenne muscular dystrophy (DMD)

**SHSCT Adult Mental Health and Disability Directorate Response:**

Adult Physical Disability Teams across the Southern Health and Social Care Trust provide services for adults with a diagnosis of Duchenne Muscular Dystrophy (DMD) and similar muscle wasting conditions. The Physical Disability Team is multidisciplinary consisting of Social Workers, Occupational Therapists and Physiotherapists. Access to Speech and Language Therapists is also available by referral. Service Users with Muscular Dystrophy and similar conditions are assessed by the healthcare professions listed as required. Social work provide support regarding packages of care, nursing or residential placements and direct payments, they liaise with community services and consider alternative social inputs such as day care or day opportunities for clients to attend. Occupational Therapists provide assessment and where required recommendations, regarding home environment, wheelchairs, seating and specialised equipment that will promote independence with activities of daily living. Physiotherapists provide assessment and intervention regarding mobility and respiratory issues and can help identify rehabilitation needs as required.

**If no, do you expect to commission services for DMD in the future?**

**Response:**

Children and young people with DMD are managed by the NI Regional Children's Hospital (RBHSC) and the Neuromuscular Clinic in the City Hospital, Belfast Health & Social Care Trust

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

**Response:**

See above

**How many people with DMD do you serve?**

**SHSCT CYP Response:**

These children & young people are also looked after locally by Community Paediatricians and sometimes by Acute Paediatricians. Information in respect of the numbers of CYP with DMD should be directed to Belfast Health & Social Care Trust.

**SHSCT Adult Mental Health and Disability Directorate Response:**

There are currently 12 adults (18-65) with DMD on the caseload of the Physical Disability Team in the Southern Trust

**Does your organisation have any DMD or muscle wasting disease policies/guidance?**

**Response:**

The Trust follows National Institute for Clinical Excellence (NICE) guidance in relation to DMD. Professionals also utilise best practice guidance issues from their respective professional body. The McCollum Report 2012: Access to specialist neuromuscular care in Northern Ireland, is the most recent report outlining recommendations to improve health and social care for service users in Northern Ireland with muscle wasting conditions.

**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?**

**Response:**

No

**Is your organisation aware of the work of DMD Care UK?**

**Response:**

Individual professionals have an awareness of DMD Care UK and following this FOI request, information about this charity will be circulated to the Trust Clinical Teams.

**Email:** [foi.team@southerntrust.hscni.net](mailto:foi.team@southerntrust.hscni.net)