



# The new integrated care model and muscle-wasting conditions: Supporting community healthcare professionals to care for people living with muscle-wasting conditions

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This report was authored by WA Communications on behalf of Muscular Dystrophy UK



**Muscular Dystrophy UK**

Fighting muscle-wasting conditions



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## Introduction

In July 2022, Integrated Care Systems (ICSs) were formalised as statutory bodies in the health and social care system across England. These reforms will see greater integration of care across the health and social care system and a greater role for community healthcare professionals, which has the potential to will bring positive progress in the management of muscle-wasting conditions.

Muscular Dystrophy UK (MDUK) values our partnership with healthcare professionals and we provide training events and networking opportunities, facilitate regional Neuromuscular Networks, provide educational resources and a wide and comprehensive range of information. We have produced this report to outline what these changes will mean for the management of people living with muscle-wasting conditions, and how MDUK can support community and specialist healthcare professionals to provide best-practice neuromuscular care.

To create this report, we conducted an online survey with 57 healthcare professionals from across England. The full list of survey questions can be found in the appendix of this report. Survey respondents included:

- Speech and Language Therapists
- Neurophysiotherapists and Physiotherapists
- Neurology Community Matrons
- Consultant Neurologists
- Clinical Services Managers
- Occupational Therapists
- Paediatric Community Care Nurses
- Clinical Nurse Specialists
- Community Paediatricians
- Team Leads for Paediatric community care, community physiotherapy, occupational therapy, and Neurology services

This report was also supported by discussion at an All-Party Parliamentary Group (APPG) for Muscular Dystrophy meeting and two workshops attended by seven multi-disciplinary clinicians on what the new integrated care model might mean for people living with muscle-wasting conditions. We are grateful to these clinicians for their time and valuable insights.

## Key findings

We shared an online survey to understand how prepared community healthcare professionals feel to care for people living with muscle-wasting conditions, which they are set to become more involved in. Key insight provided by this included:

- 70% of healthcare professionals feel only 'somewhat' prepared to care for people living with muscle-wasting conditions.
- Nearly half (49%) have not received training with a direct focus on muscle-wasting conditions.
- 70% of surveyed healthcare professionals would like resources on caring for people living with muscle-wasting conditions.

### What commissioning changes are happening and how will these impact people living with muscle-wasting conditions?

The Health and Care Act 2022 was created to facilitate greater integration across the health and social care system, and formally established 42 Integrated Care Systems (ICSs) from 1 July 2022.<sup>i ii iii</sup>

ICSs are made up of two parts: Integrated Care Boards (ICBs), and Integrated Care Partnerships (ICPs).<sup>iv</sup>

- ICBs will have commissioning responsibility for local and some specialist NHS services. They will have their own leadership team, including members from NHS trusts, local authorities, and general practice.<sup>v</sup>
- ICPs are a joint committee of the ICB and the upper tier local authorities and bring together the wider group of organisations involved in an ICS, such as charities.<sup>v</sup>

From April 2023, ICBs will take on commissioning responsibility for a large proportion of specialised services, including neurology services.<sup>vi</sup>

NHS England will continue to commission highly specialised services and other services that were deemed unsuitable, or not yet ready, for greater ICS leadership.<sup>vi</sup> The three muscle-wasting conditions for which diagnostic services will be commissioned by NHSE are spinal. Clinical Reference Groups (CRGs) and national programmes of care will continue to provide clinical leadership to support the development of national standards.<sup>vi</sup> All specialised services will continue to follow national service specifications and evidence-based clinical policies that NHS England will develop, based on the advice of clinical leaders and CRGs.<sup>vi</sup>

With most neuromuscular services now being commissioned through ICSs, there is also an opportunity to elevate the standards of care for people living with muscle-wasting conditions through better collaboration between tertiary, community, and social care services.

Even though the role of specialist healthcare professionals may not noticeably change, in cases where it is appropriate, community healthcare professionals will be more involved in the management of muscle-wasting conditions. As such, additional education and training will be vital to ensure community services are properly equipped to care for this community.

### Case study:

#### My hopes for the new integrated model of care, as a patient living with Limb-Girdle Muscular Dystrophy (LGMD)

My name is Andrew Robertson and I have lived with LGMD since I was diagnosed at 18. The initial symptoms are very subtle, and I was incredibly lucky to be seen by a paediatrician who had had experience with muscular dystrophy during his training and instantly knew where to signpost me. However, I've had to explain to therapists multiple times that I don't have Motor Neurone Disease or Multiple Sclerosis. The lack of understanding in my condition means I have had to speak out to physiotherapists to ensure that I don't damage my muscles with over exercise or in one case receive too vigorous stretching when I needed some level of stiffness in my muscles to aid with my stability (on that occasion after being stretched I got up from the physio bench and promptly collapsed, unable to walk).

Over the years I've experienced disparity of advice between professionals. On one occasion an occupational therapist recommended lots of adaptations and equipment and then a physio, waiting for her to leave the room, told me not to use the equipment unless I really had to, to keep using the muscles for as long as I can. This can leave you quite confused as a patient as to whose advice to follow.

I know many people with my condition who sadly find that their condition and the impact it has on their daily lives is not understood and so the patient ends up fighting for access to the basic support that they need. I hope with the introduction of ICSs, situations like the above can be avoided with having greater collaboration between the different healthcare professionals I need to see.

### How do community healthcare professionals feel about this change?

We asked community healthcare professionals 11 questions in an online survey to understand how prepared they feel about caring for people living with muscle-wasting conditions in the community. 57 people took part, and we are thankful for their time and valuable insights.

**70%**

feel only somewhat prepared to care for people living with muscle-wasting conditions

**49%**

have not received training with a direct focus on muscle-wasting conditions

**70%**

would like resources on caring for people living with muscle-wasting conditions to be provided

Overall, our survey indicated that community healthcare professionals need and want more education on muscle-wasting conditions. On a scale of 1-10, with 1 having limited to no knowledge of the different types of muscle-wasting conditions and 10 being very knowledgeable, on average clinicians felt at a five for their knowledge of different types of muscle-wasting conditions.

- 63% of respondents had previously cared for a patient with a muscle-wasting condition 'a little', and a further 30% 'a lot'.
- Whilst the majority of respondents have had some experience with these conditions, worryingly only 49% had received training with a direct focus on muscle-wasting conditions.

Community healthcare professionals frequently mentioned that they felt least prepared on their knowledge of condition prognosis and what specific needs people living with different muscle-wasting conditions have, including respiratory, occupational, and medication needs. Some healthcare professionals also mentioned requiring a greater understanding of patients' psychological needs.

Surveyed healthcare professionals stated they would benefit from:

- More regular education and training on each muscle-wasting condition
- Opportunities to meet with specialists to discuss the conditions
- More direct support locally from other professionals
- Sharing of any updates to best-practice methods of care
- Improved staffing levels
- A greater understanding of the role of multi-disciplinary teams (MDTs)

Overall, 70% of respondents noted that they would like their workplace to provide more resources on caring for people with muscle-wasting conditions.

### **In what areas do you feel least equipped?**

"We need some dedicated input from clinical psychology to support families to adjust to these conditions. A lot of families say they don't want their child to know about the condition. I can understand why this might be so, but the reality is the children work it out for themselves and this places us in a really difficult position when discussing treatment plans with children and young people." – A Consultant Paediatrician

"Specific knowledge about conditions. How to best set up communication systems to support a patient if the condition means their abilities will change over time" – A Speech and Language Therapist

"Up to date recommendations and management [...] Forward planning for people with muscle-wasting conditions." – A Speech and Language Therapist

### What would enable you to feel more equipped?

“Education [...] liaison with colleagues (in own service and regional specialist services)” – A Paediatric Physiotherapist

“Some brief training [or] information on key facts about each muscle-wasting condition (including prognosis, cause, current research in that area)” – A Clinical Services Manager and Speech and Language Therapist

It is clear that as NHS England moves to providing further integrated care, community healthcare professionals need additional support with the expertise to ensure they can provide best-practice care to people living with-muscle wasting conditions.

### Support Muscular Dystrophy UK provides to health care professionals

To support and upskill healthcare professionals on muscle-wasting conditions, MDUK have developed online resources including:

- Our condition-specific factsheets<sup>vii</sup>
- Our condition-specific alert cards<sup>viii</sup>
- Our map of NHS specialist services<sup>ix</sup>

MDUK has also worked with leading specialists in muscle-wasting conditions to develop CPD-accredited e-learning modules<sup>x</sup> on neuromuscular conditions, these include:

- OPEN-TACT for paediatric physiotherapists<sup>xi</sup>
- Occupational therapists: how to support patients with activities of daily living, postural management, transfers, and wheelchair needs<sup>xii</sup>
- Nurses: respiratory and cardiology care needs of patients, specialist care for patients with genetic conditions, and specialist care for patients with acquired conditions<sup>xiii</sup>
- General Practitioners: presentation and management of neuromuscular conditions in primary care<sup>xiv</sup>
- Adult physiotherapists: on the management of people with neuromuscular diseases, an overview of neuromuscular conditions, pathology and presentation of neuromuscular conditions, and assessment and outcome measures<sup>xv</sup>
- Palliative care: for any healthcare professional who would like to understand more about palliative care for people with muscle-wasting conditions<sup>xvi</sup>
- Teachers and schools: common problems associated with having a muscle-wasting condition, and how to identify challenges pupils might face<sup>xvii</sup>
- Introduction to muscle-wasting conditions<sup>xviii</sup>

We are constantly updating and adding to our educational resources. If there are areas where healthcare professionals feel further resources are needed, we would welcome feedback on what additional resources they would like to see and how else we can support upskilling and understanding. Please get in touch with us at [campaigns@muscular dystrophyuk.org](mailto:campaigns@muscular dystrophyuk.org).

We also encourage healthcare professionals to participate in opportunities to be upskilled on muscle-wasting conditions. This includes attending local upskilling events that MDUK organises through our Neuromuscular Networks, our online specialist upskilling webinars such as speech and language workshops and our physiotherapy quarterly webinar series, and one-to-one meetings with specialist clinicians.

### Case study:

#### My hopes for the new integrated model of care, as a Specialist Neuromuscular Physiotherapist

My name is Jo Reffin and I am a Specialist Neuromuscular Physiotherapist at King's College Hospital NHS Foundation Trust in London. In over ten years working in this area, I have seen many changes to health and social care provision in England, and I have always felt that building and maintaining strong networks with community teams is essential to improve care and support for people living with muscle-wasting conditions. The integration of healthcare through the creation of ICSs presents a great framework to further develop these links.

The creation of ICSs means people living with muscle-wasting conditions may be treated by community physiotherapists more regularly. To support this, I feel it is very important that community teams receive increased education on muscle-wasting conditions to empower them in their role.

Even as a specialist, I regularly refer to educational resources, such as Muscular Dystrophy UK's online courses, and attend educational conferences, in order to build my network with fellow healthcare professionals. I also strongly encourage healthcare professionals to reach out to community teams and vice versa, to share resources, best practice and to build networks.

Service managers and local health systems have an important role to play in facilitating the integration of care practically and preparing healthcare professionals to more frequently care for people living with muscle-wasting conditions. Community healthcare professionals should be formally upskilled on muscle-wasting conditions. However, as staff are extremely time constrained, it is important that managers allow for dedicated study time. To support efficient communication within neuromuscular networks and ICSs, which I believe is central to integration, better quality integrated technology is needed.

I am hopeful that the move to integrated care will be a positive change for the management of muscle-wasting conditions. To achieve this, it is essential that steps are taken to ensure that the workforce is upskilled and neuromuscular networks are in place. This will give clinicians confidence and ensure the best possible care for patients with muscle-wasting conditions.



## Recommendations

From our survey, it is evident that there is variation in experience and understanding of how to care for those living with muscle-wasting conditions. ICS commissioners have a responsibility to maintain the quality of care in this restructuring, but also have a key opportunity to enhance it and to upskill their workforce. We have identified the following recommendations to ensure that healthcare professionals receive the information and training they need to provide optimal care:

- Integrated Care Boards should directly communicate with healthcare professionals in their region on commissioning changes and what they mean for people living with muscle-wasting conditions.
- Health Education England should share MDUK's factsheets and eLearning modules on muscle-wasting conditions to support community healthcare professionals to care for people living with muscle-wasting conditions.
- ICS commissioners should actively engage on how to improve care for people living with muscle-wasting conditions. This includes attending local neuromuscular network meetings and one-to-one meetings with specialist services.
- ICS commissioners should access and share educational materials provided by MDUK within their region.
- NHS England should ensure that appropriate resources are provided to healthcare professionals and ICS commissioners on disease management. This includes updated service specifications and condition-specific standards of care.

## About Muscular Dystrophy UK

Muscular Dystrophy UK is the charity for the 110,000 people living with muscle-wasting conditions in the UK. We bring together people affected by more than 60 rare and very rare progressive muscle-weakening and wasting conditions. We provide vital information, advice, resources, and support for people with these conditions, their families and the professionals who work with them.

We have created condition fact sheets for all the muscle-wasting conditions that we serve.<sup>vii</sup> We also have a service where you can find your Regional Neuromuscular Forum and Clinical Network.<sup>xv</sup>

Please get in touch with us at [campaigns@musculardystrophyuk.org](mailto:campaigns@musculardystrophyuk.org) if you have any comments, questions or require further support on topics relating to this report.

## Appendix – Survey Questions: Community preparedness to support people with muscle-wasting conditions

1. **What region do you work in?** [London / North East / North West / Yorkshire / East Midlands / West Midlands / East / South East / South West]
2. **What is your job title?** [Open for respondents]
3. **Have you received training with a direct focus on muscle-wasting conditions?** [Yes / No / Don't know or Unsure / If Yes, how many estimated hours have you received in total?]
4. **On a scale of 1 – 10, how knowledgeable do you feel around the different types of muscle-wasting conditions?** [1 to 10]
5. **Do you know where your nearest specialist neuromuscular centre that provides care to people with muscle-wasting conditions is?** [Yes / No / Don't know or Unsure]
6. **Have you previously cared for patients with muscle-wasting conditions in your role?** [Yes – a lot / Yes – a little / No / Don't know or Unsure]
7. **Do you feel equipped to care for patients with muscle-wasting conditions in your role?** [Yes – very prepared / Somewhat prepared / No / Don't know or Unsure]
8. **In what areas of your work do you feel least equipped when caring for those with muscle-wasting conditions?** [Open for respondents]
9. **What do you think would enable you to feel more equipped to care for patients living with muscle-wasting conditions?** [Open for respondents]
10. **Are you aware of any (online) resources to support healthcare professionals to care for people living with muscle-wasting conditions?** [Yes / Yes, but would like some extra resources to be provided by your workplace / No, but would like some extra resources to be provided by your workplace / Don't know or Unsure]
11. **If provided, what online resources would be beneficial for you to feel more prepared when caring for patients with muscle-wasting conditions?** [Open to respondents]

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