



SHINING A LIGHT

The impact of COVID-19 and the future of care for people with a muscle-wasting condition in Northern Ireland

www.musculardystrophyuk.org

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**Muscular
Dystrophy UK**
Fighting muscle-wasting conditions



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Introduction

From March 2020 until April 2021, people with muscle-wasting conditions were in and out of shielding in Northern Ireland because of the COVID-19 pandemic. In the early stages of the pandemic, emails, and calls to the Muscular Dystrophy UK (MDUK) helpline rose by 35 percent¹, and for the rest of 2020 and into 2021, 13 percent of all requests we received for support from across the UK were related to COVID-19. General themes for this support included shielding, respiratory care, vaccine safety, access to vaccines, general COVID-19 guidance, emotional support, impact on services, and Personal Protective Equipment (PPE). Throughout the pandemic, we worked closely with a wide range of health professionals, volunteers, and individuals in Northern Ireland to provide accurate information and advice to support our community.

In early 2021, we surveyed people living with muscle-wasting conditions across the UK on the impact that COVID-19 was having on them and on the services they rely upon.

This report reveals the impact of COVID-19 on people living with muscle-wasting conditions in Northern Ireland and highlights pre-existing gaps in neuromuscular care that the pandemic has thrown into sharper focus. It also identifies priority areas to strengthen neuromuscular care.

Methodology

We have based this report on the results of a UK-wide survey MDUK conducted in the first half of 2021. The survey looked at the impact of COVID-19 and shielding on people living with muscle-wasting conditions, as well as their families, between March 2020 and February 2021. More than 400 people responded, including many in Northern Ireland, providing insight into the impact of shielding, and the disruption to vital clinical appointments. We also heard of concerns that arose because of the pandemic, such as a lack of access to physical and mental wellbeing support.

We also consulted with MDUK's Northern Ireland Muscle Group and the Northern Ireland All-Party Group for Muscular Dystrophy in the Northern Ireland Assembly, and through our Muscles Matter 2021 online seminar series. This feedback has underpinned our findings and developed our priorities.

¹ 451 phone calls and emails received in February, March, and April 2020 vs. 333 received in January and February 2021.

Key findings

Impact of shielding

- 86 percent of respondents shielded during the pandemic in Northern Ireland (86 percent in the UK), regardless of whether they received a letter instructing them to do so or not.
- 100 percent of respondents in Northern Ireland (68 percent in the UK) said that lockdown and shielding had had a negative impact on their physical health.
- 100 percent of respondents in Northern Ireland (62 percent in the UK) said that lockdown and shielding had had a negative impact on their mental health.
- 80 percent of respondents in Northern Ireland (45 percent in the UK) experienced reduced access to family carers or care workers because of lockdown or shielding.

Disruption to accessing healthcare services because of the COVID-19 pandemic

- 100 percent of respondents in Northern Ireland (75 percent in the UK) experienced disruption or delays in trying to access specialist muscle clinical appointments.
- 40 percent of respondents in Northern Ireland (40 percent in the UK) said their access to specialist respiratory care had been affected, disrupted, or delayed.
- 80 percent of respondents in Northern Ireland (54 percent in the UK) said that access to specialist neuromuscular physiotherapy had been affected, delayed, or disrupted.

Considering the pandemic is still ongoing, these findings offer only a glimpse of the issues people with muscle-wasting conditions are facing, and the issues will continue to worsen until they are properly addressed.

Analysis

Before the pandemic, there were a number of challenges in neuromuscular care provision because of limited clinic space, stretched staffing capacity, and a lack of flexibility in commissioning pathways to adjust to the growing neuromuscular population. With the focus shifting to recovery from the pandemic, these challenges remain and need urgent addressing to strengthen neuromuscular services in the future.

The neuromuscular workforce

People with muscle-wasting conditions have specialist and complex care needs, which means they require access to several specialist services and (depending on the condition) should include:

- a neurologist or geneticist with expertise in neuromuscular conditions
- neuromuscular physiotherapy
- a neuromuscular nurse and neuromuscular care advisors
- expert psychology
- respiratory
- cardiology
- occupational therapy, speech and language therapy, dietetics, orthotics.

Investment in the specialist multi-disciplinary team and succession planning

*The McCollum Report*² in 2012 demonstrated that people with muscle-wasting conditions in Northern Ireland experienced inconsistent standards of care owing to a lack of sufficient staffing to provide a fully equipped multi-disciplinary team (MDT). It also showed that there was an alarming reduction in services, such as the provision of physiotherapy and respiratory services, when moving from paediatric to adult care.

² All Party Group on Muscular Dystrophy in the Northern Ireland Assembly, *The McCollum Report*, July 2012: www-stage.muscular dystrophyuk.org/static/s3fs-public/2021-07/PDF-All-Party-Group-Northern-Ireland-Assembly-McCollum-Report-Access%20to%20specialist%20care-2012.pdf?VersionId=1FY5qKLr18mVSGjtjxTUK7.qc7yKXuYS

Our 2011 *Invest to Save*³ report showed unplanned emergency admissions to hospitals cost the NHS £2.27 million per year, with an estimated £908,000 being wasted on unnecessary admissions. A fraction of these costs on unnecessary admissions would have a significant impact on improving services across Northern Ireland for people with muscle-wasting conditions.

In the 10 years since these reports were published, specialist neuromuscular services have increasingly relied on local non-specialist services, the provision of which can be variable depending on service capacity and skillset. This is particularly the case for adult services, which are very different from paediatric services. For example, specialist adult services lack many of the resources generally available in paediatrics, such as community consultants. In general, adults with a neuromuscular condition rely more on self-management as they don't have access to as many appointments compared to paediatrics. This can be quite difficult for people with significant impairment.

The Neuromuscular Service for adults and children in Belfast (the hub) is currently led by two consultants. The adult service is limited to four clinics a month, as only part of the consultant's contract is to support neuromuscular services. This was originally set up as a temporary measure until a full-time consultant could be employed. The Belfast Trust tried to recruit a second consultant but was not successful. The service in Belfast also has two full-time neuromuscular clinical nurses and two full-time physiotherapists. A further four adult clinics are run by the neuromuscular nurse and physiotherapist.

Given the number of people with muscle-wasting conditions in Northern Ireland, these services should have a much larger number of dedicated speciality consultants, physiotherapists, and nurses. Most similar services will have overlapping teams for these disorders, such as muscle disorders,

myasthenic disorders, and so on. Adequate staffing will become even more of a problem in the next 10 years, because there isn't any succession planning; there's no-one to replace the current team in Belfast and no support to start training someone to prepare for this gap. This also places additional pressure on the team. There is no staff to cover when some were redeployed during the pandemic, and when someone takes annual leave or is off sick.

Overall, the Belfast Trust runs a great service. However, people need to travel to Belfast to access specialist appointments, placing a heavier reliance on local community and general services. For example, non-neuromuscular specialists, such as physiotherapists with expertise in complex needs, often provide physiotherapy. All referrals sent to local services do contain the contact details of the neuromuscular clinician, inviting further virtual contact as required, but these non-neuromuscular specialists would benefit from additional support, education, and training from the specialist teams' services. And this, in turn, would give people with muscle-wasting conditions an optimum service.

The Belfast neuromuscular service currently offers telephone and virtual appointments, but the clinical consensus is that in many cases, it's better to assess people with muscle-wasting conditions face to face. We recommend expanding video consultation services so patients can attend appointments in their local area with a community nurse or physiotherapist (skilled in neuromuscular care), who is able to perform the relevant physical tests, with a neuromuscular consultant attending virtually to advise.

Increased psychological/emotional support

Accessing specialist psychological and emotional support is nearly impossible for people with a muscle-wasting condition and there are long waiting times. As such, clinical teams tend to

³ Muscular Dystrophy UK (previously Muscular Dystrophy Campaigns), *Invest to Save: Improving Services and Reducing Costs*, May 2011: <https://issuu.com/muscular dystrophy campaign/docs/investtosave/2>

refer patients to MDUK and wellbeing websites, as there are no specialist psychological services to refer them to. This is a pre-existing issue as, even before COVID, anecdotal evidence suggested there was a waiting list of several years for a referral to specialist support. Feedback from our community has highlighted how isolating and lonely it can be, when you have a neuromuscular condition; feelings which have only been exacerbated during the pandemic because of shielding and restrictions. Sixty-two percent of people who responded to our survey said lockdown and shielding had had a negative impact on their mental health.

Some clinicians have tried to refer patients to local general psychologists. However, they don't have the specialist knowledge and experience to fully support the specific impact that living with a muscle-wasting condition has on people's mental health, and waiting times for these appointments are still up to two years anyway.

Dedicated neuromuscular clinics

There is a limited number of neuromuscular specialists' appointments available because of a lack of allocated clinic space and dedicated neuromuscular consultant time. During the height of the pandemic, paediatric neuromuscular services in Belfast went almost fully virtual but this meant they struggled with allocating space for urgent face-to-face appointments. As a result, one appointment with an MDT could be spread across the whole hospital, which can be daunting for patients and not always accessible for wheelchair users.

Additionally, neuromuscular consultants only have a short, dedicated time within their role allotted to neuromuscular patients. The clinic teams do what they can in the time available to them, going above and beyond what is expected and funded. But the limited amount of time formally allocated to neuromuscular clinics means there are often long gaps between appointments. As a result, a patient may see their neuromuscular consultant one week

and then will have to travel back to Belfast a week later to see a respiratory consultant or cardiologist. Some travel several hours to attend appointments, which can be frustrating and cause an additional burden on the patient and their carers.

For example, we heard from one individual who cannot drive so relies on her husband to take her to her different appointments, which means taking time off work for both and frequent long days of travel. We believe people with muscle-wasting conditions need a 'one-stop' clinic where they can see each specialist, to reduce this burden.

Increased investment in the neuromuscular infrastructure would allow for the development of a safer and more sustainable national hub and spoke model, based out of Belfast. As well as providing clinical outreach care, the hub team could also establish a more prudent approach to referral and treatment pathways, giving neuromuscular patients better access to cardiac and respiratory care.

Neuromuscular networks

Across the UK, there are neuromuscular networks that focus on identifying both regional best practice and ways to fill gaps in neuromuscular care. The networks ensure that patients have access to a full specialist MDT, offer upskilling events for healthcare professionals to raise greater awareness of muscle-wasting conditions, and develop resources for patients, including condition-specific information and support groups. The current funded networks have led to improved services, while facilitating relationships between stakeholders across the patient pathway.

There isn't currently such a neuromuscular network in Northern Ireland. Having one in place would bring together the key stakeholders involved in neuromuscular care to discuss gaps in services and identify solutions. For example, their initial focus could be on looking at ways to increase investment into the hub and spoke model between Belfast and the rest of Northern Ireland.

But it's also important for the network to be connected to local authorities, the Hub in Belfast, and the Northern Ireland Government to help drive any recommendations forward. One recommendation from *The McCollum Report* was for the introduction of a neuromuscular lead from within Health and Social Care in Northern Ireland (HSC) to identify and fix the gaps in specialist multidisciplinary neuromuscular care that need urgent service development. This neuromuscular lead was appointed and helped implement improvements to neuromuscular services. But when the lead left to another role, they were never replaced. Similarly, Belfast Trust appointed a neuromuscular lead, who was then redeployed during the pandemic and is yet to return to this post. These roles should be re-filled straight away, as they have been a successful conduit between government and the neuromuscular services.

Priority areas for developments in neuromuscular specialist care in Scotland

1. Allocate sustainable and consistent funding for neuromuscular services to accurately reflect the care needs of the neuromuscular population, including more neuromuscular consultant, physiotherapist, nurse specialist, psychologist, speech therapy, occupational therapy, and care advisor posts.
2. Increase the number of trained neuromuscular staff who can work with community services, and bridge the gap between specialist neuromuscular teams and their surrounding areas.
3. Improve access to specialist psychology and mental health services for people with muscle-wasting conditions.
4. Reduce waiting lists and address the growing backlog of new and follow-up appointments by implementing virtual outreach clinics in local areas.
5. Establish a Northern Ireland NHS-managed regional neuromuscular clinical network and re-appoint neuromuscular leads to connect government and the network.
6. Provide specific clinic space where people with muscle-wasting conditions can access an appointment when they need to.

Conclusion

With the pandemic having had a detrimental impact on both the physical and mental health of people with a muscle-wasting condition in Northern Ireland, many will now need more complex and time-intensive care. As such, it is important to consider the future of neuromuscular services post-pandemic, so that services are more resilient and adaptive to this population. Implementing our recommendations and priorities outlined in this report will mean every person living with a muscle-wasting condition will have access to appropriate, high-quality care. That will be life-changing for people with muscle-wasting conditions.

MDUK is committed to working with the Northern Ireland Government and NHS, MDUK Northern Ireland Council, key health and social care decision-makers, and clinical stakeholders to support the implementation of these priorities and, where appropriate, to provide patient insight.

'I'm fed up completely not getting to see any health professional at all.'

[Feedback on the impact of shielding](#)

'I really struggled with the lack of contact with friends and family. I was also terrified of getting COVID-19. Shielding was extremely difficult, especially given that there are already many limitations with living with Duchenne muscular dystrophy.'

[Feedback on the overall impact of the pandemic](#)

'The first lockdown was the hardest as I thought I would definitely die if I caught COVID-19. This made me very depressed, and I started just eating and drinking as I figured I was going to die anyway.'

[Feedback on the impact of the pandemic](#)

'Scared to go too far outside as lots of people without masks and lack of social distancing.'

[Feedback on the impact of the pandemic](#)

'Unable to access my physical activities, such as my swimming pool, which was good for my muscles, has significantly impacted my physical health. I also haven't been able to work or socialise with friends and family which has impacted me mentally.'

[Feedback on the impact of shielding](#)

'Unable to access any type of care including my GP, which has been devastating. I feel so neglected by the NHS.'

[Feedback on the impact of the pandemic on access to healthcare services](#)

'Loneliness, I miss chatting to people. I am also very worried about extra costs associated to shielding such as gas and electricity bills.'

[Feedback on the impact of shielding](#)

About Muscular Dystrophy UK and muscle-wasting conditions

Muscular Dystrophy UK is the charity bringing individuals, families, and professionals together to fight muscle-wasting conditions. Founded in 1959, we have been leading the fight against muscle-wasting conditions since then.

- We bring together more than 60 rare and very rare progressive muscle-weakening and wasting conditions, affecting around 70,000 children and adults in the UK.
- We support high quality research to find effective treatments and cures and will not stop until we have found them for all muscle-wasting conditions.
- We are leading the drive to get faster access to emerging treatment for families in the UK.
- We ensure everyone has the specialist NHS care and support they need – the right help at the right time, wherever they live.
- We provide a range of services and resources to help people live as independently as possible.

Muscle-wasting conditions can cause muscle weakness or wasting. They are multi-system disorders that require complex long-term care. There are currently no known cures and few treatments. People will need vital multi-disciplinary care from specialist neuromuscular consultants, physiotherapists, nurses, care advisors, psychologists, and other therapists and – where necessary – support from specialist respiratory and cardiac consultants. Without this level of care, people experience a reduction in quality of life and in some cases, shortened life-expectancy.

Get involved

If you or your care have been affected by the COVID-19 pandemic and you would like to share your story with us, then please get in touch with the policy team at campaigns@musculardystrophyuk.org.

If you are struggling to access the support you need, our advocacy team is here to help. Please get in touch with them at info@musculardystrophyuk.org or call **0800 652 6352**.