



SHINING A LIGHT

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

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 a muscle-wasting condition were in and out of shielding in Scotland, 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 percent and, for the rest of 2020 and into 2021, 13 percent of all requests for support related to COVID-19, right across the UK.

People in Scotland sought information and advice on shielding, respiratory care, vaccine safety, access to the vaccine, COVID-19 guidance, emotional support, impact on services, and PPE equipment. Throughout the pandemic, we also worked closely with a wide range of health professionals, volunteers, and individuals in Scotland, to provide accurate information and advice to support our community.

In early 2021, we ran a UK-wide survey of people living with muscle-wasting conditions on the impact that COVID-19 was having on individuals and on the services they relied upon.

This report reveals the impact of COVID-19 on people in Scotland living with a muscle-wasting condition, and highlights priorities for strengthening neuromuscular care and addressing service gaps.

Methodology

This report is based 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 a muscle-wasting condition, as well as their families, between March 2020 and February 2021. More than 400 people responded, including people in Scotland, providing insight into the impact of shielding and disruption to vital neuromuscular clinical appointments. We also heard of other challenges arising out of the pandemic, such as a lack of support for physical and mental wellbeing.

We also consulted the MDUK Scotland Muscle Group, the MDUK Scottish Council, the Scottish Muscle Network, the Scottish Cross-Party Group on Muscular Dystrophy in the Scottish Parliament, and our community, through our Muscles Matter 2021 virtual seminar series. This feedback has underpinned our findings and helped develop our priorities.

Key findings

Impact of shielding

Of people with muscle-wasting conditions who responded to our survey:

- 90 percent shielded during the pandemic in Scotland (86 percent across the UK), regardless of whether they received a letter instructing them to do so or not.
- 85 percent in Scotland (68 percent across the UK) said that lockdown and shielding had had a negative impact on their physical health.
- 70 percent in Scotland (62 percent across the UK) said that lockdown and shielding had had a negative impact on their mental health.
- 25 percent in Scotland (45 percent across 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

Of people with muscle-wasting conditions who responded to our survey:

- 60 percent in Scotland (75 percent across the UK) experienced disruption or delays to accessing specialist muscle clinical appointments
- 50 percent in Scotland (40 percent across the UK) said their access to specialist respiratory care had been affected, disrupted, or delayed.
- 35 percent in Scotland (54 percent across the UK) said that their access to specialist neuromuscular physiotherapy had been affected, delayed, or disrupted.

Analysis

More than 6,000 people in Scotland are living with a muscle-wasting condition¹. Even though significant progress has been made in the diagnosis and management of these conditions, muscle-wasting conditions are in large part progressive, debilitating, and can often be life-shortening.

The neuromuscular workforce

People living with a muscle-wasting condition¹ commonly require complex and long-term management through a multi-disciplinary team (MDT) of neuromuscular specialists. This team provides consistent medical/health monitoring and better access to treatments, which (depending on the condition) should include input from:

- a neurologist or geneticist with expertise in neuromuscular conditions
- neuromuscular physiotherapist
- neuromuscular nurse and care advisors
- specialist psychologist
- Respiratory specialists
- cardiologists
- occupational therapist, speech and language therapist, dietician, orthotist

This care must be well co-ordinated, with strong links between the hubs (specialist neuromuscular clinicians) and the spokes (health professionals supporting people in the community, but in regular contact with the hubs).

Neuromuscular care in Scotland is provided through the Scottish Muscle Network². The Scottish Muscle Network is a national managed clinical network originally established in 1998 with charitable funding from Muscular Dystrophy UK. NHS National Services Division (NSD) now funds the Network.

¹ Scottish Muscle Network, Scottish Muscle Managed Clinical Network Service Description Document And Patient Expectation of Care, October 2015: <https://www.smn.scot.nhs.uk/wp-content/uploads/2017/01/Service-Description-and-Patient-Expectation-of-Care-Final.pdf>

² Scottish Muscle Network: <https://www.smn.scot.nhs.uk>

Although the Scottish Muscle Network is one of only three MDUK-recognised Neuromuscular Networks of Excellence³, there is a need for expansion in the support available to people with a muscle-wasting condition. Improvements in the care of people with a muscle-wasting condition (for example, steroids, non-invasive ventilation, physiotherapy and new treatments) have led to increased life expectancy, but there has not been equivalent investment in the clinical teams who support the families.

From our consultations, we have concluded that there is a need for increased support from neuromuscular specialist nursing, psychology and physiotherapy in the central belt neuromuscular services. We also recommend that there should be better co-ordination of care between the hub and the spokes of the neuromuscular network, by developing a neuromuscular nurse network throughout the country to support specialist consultants at the spoke.

Virtual consultations and increased local neuromuscular support

When the pandemic first broke out, almost all neuromuscular services switched over to virtual consultations. To a degree, this has led to improved monitoring of people with a muscle-wasting condition. Feedback we received from Scottish neuromuscular services specifically stated that virtual consultations 'opened up more avenues for the more stable patients, who may not need consistent face-to-face consultations'. However, clinical feedback also highlighted that a lot of vital information was lost through a screen, such as ambulatory function, and muscle strength deterioration, and so those in more advanced stages of their condition would need face-to-face appointments. As such, we recommend using a hybrid approach in the future, based on patient preference, to facilitate critical appointments and treatments that can only be done in person.

With any increase in online neuromuscular multi-disciplinary team clinics, it is important that people with muscle-wasting conditions also have increased access to dedicated neuromuscular key workers in their area. Local neuromuscular nurse specialists can provide a strong link between community-based health teams and the national neuromuscular specialists based in the central belt.

Care co-ordination

The COVID-19 pandemic has exacerbated the challenge of care co-ordination by increasing waiting lists. As a result, some people with a muscle-wasting condition will have missed appointments which has led to reduced monitoring of their condition.

People with a muscle-wasting condition need a wide range of support from a variety of specialist clinicians. Having a number of appointments, including, in some cases, those at muscle, respiratory, cardiology clinics, and so on, can involve a lot of travelling. Improving care co-ordination from a specialist neuromuscular team will go some way to reducing this burden but requires additional administrative support from the MDT.

In Scotland, neuromuscular care is provided through a national network, which makes it especially important that care is well co-ordinated and managed. People can use the 'Near me' video consulting service to attend appointments from home, making it easier to involve the multi-disciplinary team and reducing travel time. We recommend expanding this model to enable patients to attend appointments in their local area, with a neuromuscular nurse or physiotherapist who can perform the relevant physical tests with the neuromuscular consultant attending virtually, to advise.

³ Muscular Dystrophy UK, Networks of Excellence: <https://www.muscular dystrophyuk.org/get-support/health-and-care/muscle-centres>

For the Scottish Muscle Network to thrive and strengthen the neuromuscular care it provides to the people of Scotland, it is critical to increase the network's management, co-ordination and administrative capacity.

We urge NHS Scotland to provide funding for more administrative support to improve co-ordination of appointments for people living with a muscle-wasting condition. This would go some way towards fulfilling one of the objectives in the UK Rare Disease Framework, that 'co-ordination of care is essential to ensure care is effectively managed, the burden on patients and their carers [is] minimised, and healthcare professionals [are] working together to provide the best possible joined up and high-quality care'⁴.

Accessing new treatments and therapies

In Scotland, access to new medicines for rare conditions has improved through a new ultra-orphan medicines pathway, ensuring those with the rarest conditions get faster access to new treatments where appropriate. Through this pathway, the Scottish Medicines Consortium (SMC) has fast-tracked the availability of three new treatments for neuromuscular conditions: Translarna, a treatment for Duchenne muscular dystrophy, and Zolgensma and Spinraza, treatments for spinal muscular atrophy (SMA). Overall, clinical feedback has been positive about this new pathway.

However, without increased investment in the specialist neuromuscular teams (consultant, nurse specialist, physiotherapy and administration time), it will become increasingly difficult to provide and monitor these new and life-changing treatments without potentially compromising the care of other people with a muscle-wasting condition.

Natural history data collection

Collecting natural history data helps document the impact of potential treatments and care throughout a person's life and observe changes to a patient demographic to support them better. It also has the potential to capture the impact of the pandemic and the changing care needs for people with muscle-wasting conditions. The Paediatric NorthStar Database is a UK national neuromuscular database, which has been developed to facilitate research, audit and provide standardised clinical assessment of patients with Duchenne muscular dystrophy⁵.

As new therapies come to market, NorthStar and other neuromuscular databases play a critical role in collecting real-world data for managed access agreements and in understanding the impact on the care needs of people with a muscle-wasting condition⁵. Connecting with this database to link up patient data will help neuromuscular staff, Health and Social Care Boards, and other key decision-makers in Scottish health to understand changes in care provision and ensure people with a muscle-wasting condition continue to get appropriate, safe and high-quality care.

Commissioning of Scottish neuromuscular services

Neuromuscular services in Scotland are funded through block contracts, where each service is allocated an amount for the year. This funding doesn't automatically increase with an increase in patients, which can further strain already-stretched resources and clinic time. If changes to services or staffing are needed, then the hospital manager needs to submit a business case to their regional Health Board. Every service will submit a business case for additional funding, resulting in competition and a reliance on winning bids. This process can place an additional administrative burden on already stretched staff.

We recommend that Scottish Health Boards

⁴ UK Department of Health and Social Care, UK Rare Disease Framework, January 2021: <https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework>

⁵ Paediatric NorthStar UK Neuromuscular Database: <https://www.northstardmd.com>

consider introducing flexibility into the funding reimbursement process so neuromuscular services can best support the growing neuromuscular population, especially given the complex multi-disciplinary care they need and the roll-out of new treatments. For example, we recommend NHS Scotland engages with NHS England to understand the cost of supporting an individual neuromuscular patient, and consider this in the yearly allocated block contract so that the amount can grow as the neuromuscular patient population increases. Similarly, given the low numbers of neuromuscular staffing in Scotland, we would recommend expanding this and investigating how many patients should be assigned per consultant to ensure safe staffing, and the delivery of appropriate and safe neuromuscular care.

Priority areas for developments in neuromuscular specialist care in Scotland

1. Increase the number of neuromuscular nurse specialist roles to ensure every neuromuscular team has at least one of these vital roles.
2. Increase investment in the national neuromuscular teams with more neuromuscular consultant, physiotherapy, nurse specialist and psychology time.
3. Appoint a full-time network manager with administration support for the Scottish Muscle Network.
4. Reduce waiting lists and address the growing backlog of new and follow-up appointments, by implementing virtual outreach clinics in local areas.
5. Strengthen the administrative support for data collection and improved clinic co-ordination.
6. Consider introducing flexibility into the yearly growth of block contracts to accurately reflect the growing neuromuscular population and the resulting increase in complex care needs.

Conclusion

With the pandemic having had a detrimental impact on both the physical and mental health of people with a muscle-wasting condition in Scotland, 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 Scottish Muscle Network, the Scottish Government, NHS Scotland, key health and social care decision-makers, and clinical stakeholders to support the implementation of these priorities and, where appropriate, to provide patient insight.

“We have felt completely isolated as we couldn’t access the usual services that we would have been able to if it wasn’t for lockdown.”

[Feedback from a person with a muscle-wasting condition on the impact of cancelled specialist appointments](#)

“I am worried about the long-term consequences in terms of my physical health, and I am also worried about how long it will take for my husband to get a vaccine as this is the only thing that will allow us to finally be able to gain some normality back (albeit with continued social distancing, mask wearing etc.)”

[Feedback from a person with a muscle-wasting condition on the impact of the pandemic and shielding](#)

“I really struggled with pain and weakness when I returned to work after shielding last year and I don’t think I have fully regained the stamina I had before this. Being able to go outside to keep

a bit more active has helped this time around.”
[Feedback from a person with a muscle wasting condition on the impact of shielding](#)

“I live in a third floor flat so have no access to a private outdoor space to exercise (and limited space indoors) - being told to shield significantly impacted the amount of physical activity I have been able to do. I eventually spoke to my specialist who advised (prior to shielding being paused) to go out for walks at times when it was quiet - it would have been beneficial to have had the opportunity to speak to my specialist when she first decided to add me to the shielding list to discuss my individual situation and lack of access to outdoor space. The blanket ban on travelling for exercise was also not helpful to those of us shielding in city environments with no access to private gardens - it would have been much better from a physical and mental health point of view to be allowed to travel to a quiet outdoor area to exercise away from busy city streets.”

[Feedback from a person with a muscle wasting condition on the impact of shielding](#)

“Before lockdown, I was always up and out attending hospital appointments. I drove my electric wheelchair without much hassle. Due to my severe scoliosis, I got my wheelchair seat remoulded last February before this COVID-19 kicked off. Unfortunately, we went into full lockdown, and everything was shut down and left in limbo. So, I had no wheelchair to sit in and now it's going to take a long time to get used to driving again. My body has also become very stiff because the physiotherapy hasn't been able to come round and do my stretches.”

[Feedback from a person with a muscle-wasting condition on the impact of shielding](#)

“My two-year-old son got diagnosed with Becker muscular dystrophy at the beginning of the first lockdown in April 2020 and we had to wait five months for a face-to-face appointment, we got his diagnosis over the phone which was very upsetting.”

[Feedback on the impact of cancelling specialist clinical appointments in Scotland](#)

“The endless juggling of working from home, home-schooling, and caring for a child with a neuromuscular disease has left me depleted and low. My needs are so far down the list that I have forgotten to care for myself. Sometimes I don't think I can go on doing all that I do.”

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

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@muscular dystrophyuk.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@muscular dystrophyuk.org or call **0800 652 6352**.