



SHINING A LIGHT

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

[www.musculardystrophyuk.org](http://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 in Wales with a muscle-wasting condition were in and out of shielding 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<sup>1</sup> and, for the rest of 2020 and into 2021, 13 percent of all requests for support we received related to COVID-19. People living in Wales sought information and advice on topics such as the faster deterioration of their muscle strength because of shielding, feelings of isolation and a negative impact on mental health, and difficulties accessing routine monitoring, such as lung functions tests and electrocardiograms.

Throughout the pandemic, as government guidance changed, we worked closely with a wide range of health professionals, volunteers, charities, and individuals in Wales to support our community with accurate and up-to-date information and advice.

We also began building a picture of the impact that COVID-19 was having on the people we support and the services they rely upon. In early 2021, we decided to solidify this picture by surveying both neuromuscular services and people living with muscle-wasting conditions, as well as holding discussions at our Muscle Group meetings, Neuromuscular Networks and through our Muscles Matter 2021 virtual seminar series.

We discovered that COVID-19 not only presented new challenges to people living with muscle-wasting conditions and the services they rely on, but it also exacerbated existing challenges. We are also now seeing for the first time expensive, transformative medicines and treatments coming on to the market; the emergence of national and international standards of care for people with a muscle-wasting condition; the emergence of organised but unfunded national and regional neuromuscular clinical networks, and a significant increase in the number of people living well into adulthood and requiring support from a multi-disciplinary neuromuscular service. All of these huge developments continue to take place in the treatment and care of people living with muscle-wasting conditions, improving quality of life and, in many cases, extending lives. But yet it is often still difficult to get access to these services and support.

In early 2021, we ran a survey to ask people living with muscle-wasting conditions about the impact that COVID-19 was having on them and the services they relied upon.

This report reveals the impact of COVID-19 on people in Wales living with muscle-wasting conditions, and highlights pre-existing gaps in neuromuscular services that the pandemic has thrown into sharper focus. The report also identifies priority areas to strengthen neuromuscular care – paving the way ahead.

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<sup>1</sup>Our helpline received 451 phone calls and emails between February and April 2020, as opposed to 333 between January and February 2021.

## Methodology

We have based this report on the results of a national UK-wide survey Muscular Dystrophy UK conducted in the first half of 2021. The survey, which focused on the period between March 2020 and February 2021, looked at the impact of COVID-19 and shielding on people living with a muscle-wasting condition, as well as their families. More than 400 people responded, including people in Wales, providing insight into the impact of shielding and disruption to vital clinical appointments. We also heard of concerns arising because of the pandemic, such as the barriers to receiving physical and mental wellbeing support.

As mentioned, we also consulted Muscular Dystrophy UK's Wales Muscle Group, the Wales Neuromuscular Network, and the Welsh Cross-Party Group on Muscular Dystrophy in the Welsh Senedd, and gathered insights through our Muscles Matter 2021 virtual seminar series. This feedback underpinned our findings and helped develop our priorities.

## Key findings

### Impact of shielding

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

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

- 78 percent of respondents in Wales (75 percent in the UK) experienced disruption to or delays in accessing specialist muscle clinic appointments.
- 19 percent of respondents in Wales (40 percent in the UK) said their access to specialist respiratory care had been affected, disrupted, or delayed.
- 16 percent of respondents in Wales (54 percent in the UK) said that access to specialist neuromuscular physiotherapy had been affected, delayed, or disrupted.

## Analysis

It is estimated that more than 3,400 people in Wales have a neuromuscular condition<sup>2</sup>. Even though significant progress has been made in the diagnosis and management of muscle-wasting conditions, they are nonetheless progressive, debilitating and can frequently be life-shortening.

### The neuromuscular workforce

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

- a neurologist or geneticist with expertise in neuromuscular conditions
- neuromuscular physiotherapy
- neuromuscular nurse and 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 Thomas Report* in 2010 outlined that unplanned emergency admissions of people with a muscle-wasting condition were costing the NHS in Wales over £4 million each year<sup>3</sup>. It pointed out that a significant number of hospital admissions for neuromuscular patients would have been preventable if a multi-disciplinary care system had been in place. Over the past decade, this conclusion has been repeatedly backed up in the findings of NHS-led audits into unplanned hospital admissions across the UK<sup>4</sup>.

Neuromuscular services across Wales currently have large staffing gaps and there has been no paediatrician with neuromuscular expertise working across south east Wales since 2018. It is vital that more specialist neuromuscular consultants, neuromuscular nurses, psychologists, care advisors, and additional physiotherapy support for North Wales, be funded and recruited to, as soon as possible.

The specialist neuromuscular workforce is also likely to become even more stretched because of a lack of succession planning, with at least two paediatric and adult consultants in south east and south west Wales set to retire by 2025. The neuromuscular service is already under considerable strain and is provided, in part, on a 'goodwill' basis. We're concerned that if these consultant posts are not replaced, and there isn't a smooth transition, there will be even further disruption to neuromuscular services or that they will even cease to exist.

Investment into this core team will go some way to strengthening the 'hub and spoke' model of working in Wales. The 'hub and spoke' model relies on community neurological and rehabilitation services. However, these services are currently unable to give people with a muscle-wasting condition an optimum service. They would benefit from additional support, education, and training from the specialist teams, including guidance on more complex cases.

With already overstretched staff, the specialist teams don't have the capacity to provide such support. As a result, there is nowhere to refer patients to, so the care advisors and other professionals end up retaining patients and trying to deliver functions and activities beyond their remit. This often leads to an increasing backlog of patients waiting for critical investigations and specialist appointments, and many new patient referrals for adults and children not being addressed.

<sup>2</sup> UK Parliament, Memorandum submitted by The Muscular Dystrophy Campaign, October 2009: <https://publications.parliament.uk/pa/cm200809/cmselect/cmwelaf/memo/crossborder/ucm502.htm>

<sup>3</sup> *The Thomas Report*, CPG on Muscular Dystrophy, July 2010: <https://www.muscular dystrophyuk.org/static/s3fs-public/2021-07/PDF-Wales-Cross-Party-Group-Thom-as-Report-Access%20to%20specialist%20care-2010.pdf?VersionId=XH4i5EiqMwck3iw5kBH74KhaFYSVuZOO>

<sup>4</sup> University College London, *Improving specialised care for neuromuscular patients reduces the frequency of preventable emergency hospital admissions*, <https://pubmed.ncbi.nlm.nih.gov/32005495/>

## Access to new treatments and therapies

Several treatments for muscle-wasting conditions are currently in development, and are undergoing market authorisation or have recently been made available on the NHS. Avoidable delays in accessing these treatments are common, causing people's muscle-wasting conditions to deteriorate further and possibly render them ineligible for these treatments.

In addition, as there is currently no dedicated neuromuscular consultant working with children in Cardiff, children are unable to access treatments or take part in clinical trials unless they travel across the border into England.

It is critical that the paediatric services in Wales are strengthened and children across Wales can access new treatments close to home.

### Dedicated neuromuscular time

Feedback from clinical specialists showed that neuromuscular consultants have only a small proportion of their clinical time dedicated to neuromuscular patients, with as little as 20 percent, in some cases (or one clinic per fortnight), allocated.

This is an inadequate amount of time to provide the comprehensive level of support required by many people. The word 'goodwill' cropped up frequently when describing neuromuscular clinic time as this is often either above and beyond the formal clinic time, or because there isn't any time protected at all, as is the case in south west Wales.

It is clear that 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. This has been

exacerbated by the COVID-19 pandemic and, while telephone appointments may be suitable on some occasions, face-to-face appointments are still vital in short- and long-term plans.

### Neuromuscular networks

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 Cardiff and Vale University Health Board and Swansea Bay University Health Board. As well as providing outreach clinical care, the 'hub' team could also lead change in establishing a more prudent approach to referral and treatment pathways, giving neuromuscular patients better access to cardiac and respiratory care.

The Wales Neuromuscular Network was established to advise and support patients, carers, the NHS, and Wales Government to make sure people with neuromuscular conditions get the best care. However, without sufficient funding and action by NHS Wales on the recommendations they put forward, the Network can only deliver limited improvements to neuromuscular services. MDUK has seen the benefits of NHS-funded managed neuromuscular networks across the UK, which focus on identifying both regional and national best practice, as well as ways to fill gaps in neuromuscular care.

With adequately resourced and co-ordinated networks, patients are more likely to access a full specialist multi-disciplinary team, who can also offer upskilling events to raise greater awareness of muscle-wasting conditions among fellow healthcare professionals, and develop resources for patients, including condition-specific information and support groups. Such networks have been

essential in improving neuromuscular care across the UK, but they need to be embedded into and funded by the NHS.

We recommend NHS Wales invest in the Wales Neuromuscular Network by funding a national neuromuscular network manager post, who can work with the dedicated neuromuscular health professional clinicians, and the families living with these conditions to build robust neuromuscular care across the country.

### Priority areas for developments in neuromuscular specialist care in Wales

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, and care advisor posts.
2. Secure NHS funding to support the Wales Neuromuscular Network to appoint a network manager to help identify local service gaps and implement more timely solutions.
3. Provide access to specialist psychology and mental health services for people with a muscle-wasting condition.
4. Provide timely and local access to new treatments and therapies for people in Wales.
5. 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.

## Conclusion

With the pandemic having a truly damaging impact on both the physical and mental health of people with muscle-wasting conditions, many will now require 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 the recommendations and priorities outlined in this report can be life-changing for a person living with a muscle-wasting condition. It could also give every person living with a muscle-wasting condition access to appropriate, high-quality care.

MDUK is committed to working with the Wales Neuromuscular Network, the Welsh Government, NHS Wales, 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 have had one appointment with a neuromuscular physio by phone, which has been my only appointment since September 2019.”*

Feedback from a person with a muscle-wasting condition on Welsh neuromuscular services

*“I was admitted into hospital in April 2020 due to a cardiac Afib episode. I was due to have a follow-up appointment following discharge, only to be advised that unless I have further episodes I will not be seen.”*

Feedback from a person with a muscle-wasting condition on Welsh neuromuscular services

*“I have been waiting so long for surgery that my muscles are wasting to a point that surgery might be pointless as I will not have the muscle to walk. Clinics have just run so slowly that it’s hard to see when appointments will become available again.”*

Feedback from a person with a muscle-wasting condition on Welsh neuromuscular services

*"I was due to have an operation which has been cancelled twice. For now, I am left to just sit it out and wait for clinics and surgeries to re-open. Due to my CMT and muscle wastage, I have not stood for over a year, which might mean I'm unable to walk in the future."*

Feedback from a person with a muscle-wasting condition on the impact of COVID-19 on access to neuromuscular services

*"I have found that I have experienced a lot more pain due to being less active. I have found that I am a lot stiffer when I get up in the morning, or getting up from a seat after a prolonged period of being still."*

Feedback from a person with a muscle-wasting condition on the impact of COVID-19 on access to neuromuscular services

*"I was going to a hydro-gym, which was a great way to exercise all my muscles. I was going four times a week, then it changed to only being able to walk (slowly with a rollator) and do a few gentle exercises due to movement issues. I feel I had muscle wastage because of this."*

Feedback from a person with a muscle-wasting condition on the impact of COVID-19 on access to neuromuscular services

*"My breathing has deteriorated a lot, as I used to be on the go all the time. My mobility has worsened due to not being able to breathe when I am on my feet."*

Feedback from a person with a muscle-wasting condition on the impact of COVID-19 on access to neuromuscular services

*"I have been in for nearly a year. During this time, I lost both my parents. I have tried to keep on top of things but am struggling now. My full-time carer has not had her vaccination yet, and it hasn't helped that I have had to chase them up and nothing is happening."*

Feedback from a person with a muscle-wasting condition on the impact of COVID-19 on access to neuromuscular services

## 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 require 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 Michaela Regan on [m.regan@muscular dystrophyuk.org](mailto:m.regan@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](mailto:info@muscular dystrophyuk.org) or call **0800 652 6352**.