MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Missing people. Missing support.

How Scotland is letting down people with muscle wasting and weakening conditions

Foreword

The quotes to the right are direct, anonymous statements from people living with muscle wasting and weakening conditions in Scotland and from those who care for them.

These reflections are heartbreaking. But they resonate with me and I know they are, sadly, far too representative of the feelings and experiences of our community in Scotland. We set out to discover where specialist care exists in Scotland and whether it matches local needs. What we found was disgraceful and distressing.

Our findings show NHS Scotland is only accounting for a fraction of our community, so it's no wonder the provision of specialist support doesn't match the need.

We named our report *Missing People. Missing Support*, but we exist and we are fighting to be seen, heard, and to have our basic human rights upheld.

Thank you for taking the time to read this important report, and I encourage our policy makers, and healthcare providers to work with us to overcome the challenges this report exposes.

Sheonad Laidlaw
Chair of Muscular Dystrophy UK's Scottish Council

Front cover photographer: Iska Birnie

"There's a postcode lottery for treatment, or worse – no treatment at all."

"If I don't chase things up, I may never be treated. Shameful."

"All I want is to be cared for and to feel that there is someone to hear and listen to my needs."

The above quotes are from our Scotland survey respondents.

Introduction

Every day we hear from people in Scotland about what it's like living with a muscle wasting and weakening condition. It can be exhausting, stressful and lonely, and the impact is felt beyond the person with a condition – it is also felt by their family, friends, employers and communities.

Sadly, for too many, this experience is made worse by a chronic lack of healthcare provision and service support where it is most needed.

This report is the result of concerns raised by our community in Scotland that there are gaps in the services they need, and that these gaps are widening. It follows our 2021 report *Shining a Light: The impact of COVID-19 and the future of care for people with a muscle wasting condition in Scotland*[1], which recommended priority areas for developments in neuromuscular specialist care in Scotland.

These recommendations included increasing the number of neuromuscular nurse specialist roles; increasing investment in neuromuscular consultant, physiotherapy, nurse specialist and psychology time; and appointing a full-time network manager with administration support for the Scottish Muscle Network. Of greatest note, given the findings and recommendations of this report, are that we called for the strengthening of administrative support for data collection and improved clinic co-ordination.

Since the release of *Shining a Light*, we've heard anecdotally that the number of key health professionals involved in the provision of essential care, such as specialist neuromuscular care advisers, is in fact reducing. Patients and carers have told us they are struggling to have their rights upheld, that waiting times for specialist care are lengthening, and some are losing hope that they will ever receive the support they need.

The Scottish Muscle Network carried out a mapping exercise in 2021 to assess the real level of service provision in Scotland but there has been no repeat of this since. So to understand the true level of service provision available, and make informed recommendations to decision-makers, we have relied on data available under the Freedom of Information (Scotland) Act 2002.

As part of the production of this report and its key recommendations, in 2024 we asked the 14 NHS Scotland health boards to detail the level of provision for key support services required by those living with muscle wasting and weakening conditions.

All 14 health boards responded to our request for this data within the time frames determined by the Act. However, as the report outlines, the level of data and detail held and provided was varied. The lack of data some health boards held was deeply concerning and doesn't correspond to academic research on the prevalence of muscle wasting and weakening conditions in Scotland. This leads us to conclude that only around 20% of patients in Scotland are being accounted for in official reporting.

This report also includes the findings of a survey we carried out with the muscle wasting and weakening community in Scotland about their experiences of accessing neuromuscular services. We used this as a tool to gain a clear understanding of levels of service provision and the challenges faced. Nearly three quarters (71%) of respondents said their daily life is a struggle, and only 14% felt Scotland cares about people with muscle wasting and weakening conditions. This follows a finding from our *2023 Community Survey* that only two-thirds (64%) of respondents in Scotland rated their quality of life as 'good' or 'very good'.

[1] POL14-ScotlandVersion-Impact-of-COVID-report.v4.pdf

Urgent action is needed

As part of this report, we have provided a series of recommendations to the Scottish Government and NHS Scotland health boards to ensure people living with a muscle wasting and weakening condition are first and foremost recognised in the data held by health boards, and that they have access to the services and support they need.

We would welcome the opportunity to support the delivery and implementation of these recommendations.

What are muscle wasting and weakening conditions?

Muscle wasting and weakening conditions are a group of rare conditions that gradually cause muscles to weaken and waste. They are usually inherited and are caused by changes (mutations) in the genes which are responsible for the structure and function of our muscles.

They are progressive conditions. This means they will worsen over time. Currently, there is no cure for any type of muscle wasting or weakening condition. However, research advances are being made to find effective treatments and to help us understand the most effective ways to provide care and support to people living with them.

The symptoms of muscle wasting and weakening conditions, and the age at which they occur, are different in each person. Common symptoms could include muscle weakness; muscle stiffness or pain; changes in mobility, such as difficulty walking; difficulty in lifting things; increased occurrence of falls. They are often difficult to diagnose from symptoms alone and a referral will be needed to a specialist for further testing.

Some muscle wasting and weakening conditions can affect the heart or the muscles used for breathing. In severe cases, this means life-threatening complications.

As these conditions are so complex and affect multiple areas of the body, a wide array of healthcare professionals and services are needed to provide the best possible care and support. A range of interventions, including medication, physiotherapy, and adapted aids or equipment can support with symptom management and help to improve quality of life.

The complexity of the services and support needed by someone living with a muscle wasting and weakening condition is illustrated in the *Mapping of Neuromuscular Services in Scotland* undertaken and published by the Scottish Muscle Network in August 2021[2]; the *Optimal Clinical Pathway for Adults with Neuromuscular Disorders* published in September 2024[3], overseen by the National Neurosciences Advisory Group and led by a working group of specialist clinicians, and by our own Muscular Dystrophy UK Centres of Excellence work[4].

[2] MAPPING OF NEUROMUSCULAR SERVICES IN SCOTLAND

[3] https://static1.squarespace.com/static/5f1021faf6248b39f4c64f5d/t/66e1668a6d0c917b7f980f2a/1726047889681/Neuromuscular+Conditions+pathway.pdf

[4] https://www.musculardystrophyuk.org/news/recognising-outstanding-neuromuscular-centres-uk-2024/

Missing people. Missing Support.

Key findings

1. **An estimated 7,300 people in Scotland are currently unrecorded and "missing" from the care records of NHS Scotland's neuromuscular services.**
2. **There is no consistent data collection across NHS Scotland's 14 health boards, leading to an inability to assess the adequacy of service provision against local need.**
3. **The evidence suggests that access to treatment in Scotland is a postcode lottery.**
4. **It is currently impossible to see, or develop, a Scotland wide resource plan.**

"Travelling to mainland Scotland [for care] takes its toll on my body. I want to be able to to access local services when I need them."
Survey respondent

Photographer: Dave Donaldson

Methodology

In July 2024 we sent Freedom of Information (FOI) requests to all 14 NHS Scotland health boards. The requests asked how many people are assessed as living with muscular dystrophy conditions in their area.

We also asked for information about the number of health professionals employed across a range of disciplines and specialties, which were aligned to those covered by the Scottish Muscle Network's 2021 service mapping exercise[5].

The Scottish Muscle Network has produced a Generic Neuromuscular Pathway[6], which provides an overview of the assessment and management of neuromuscular conditions. The range of disciplines and specialties that are included in the pathway is reflected in the Network's 2021 mapping exercise.

Using the Generic Neuromuscular Pathway as guidance, we asked health boards how many people they currently employ to provide services to neuromuscular patients in the roles of:

- Paediatrician
- Paediatric neurologist
- Neurologist
- Rehab consultant

If those roles existed in the health board, health boards were asked to:

- Provide details of the hospital and regional service they work in
- Whether the services provided are for paediatric and/or adult patients

Health boards were then asked whether they employed a range of specific professionals that provide services to neuromuscular patients, and if yes, how many; on a full or part-time basis; the hospital and regional service they work in; and whether the services provided are for paediatric and/or adult patients. They were also asked to specify if the number of professionals employed for each role has increased or decreased in number in the last 10 years. The roles they were asked to provide information about were:

- Respiratory professional
- Cardiology/anaesthetics professional
- Physiotherapy professional
- Neuromuscular specialist nurse
- Neuromuscular care adviser/support services
- Genetics professional
- Neurophysiology professional
- Myotonic Dystrophy Service
- Neuropathology professional
- Allied Health Professionals of other professionals

All 14 NHS Scotland health boards responded to the Freedom of Information request.

[5] MAPPING OF NEUROMUSCULAR SERVICES IN SCOTLAND

[6] The Scottish Muscle Network is a national managed clinical network (NMCN). It's funded by NHS National Services Division (NSD) but was originally established in 1998 with charitable funding from Muscular Dystrophy UK (then known as Muscular Dystrophy Campaign). It was set up with two aims – to raise awareness of neuromuscular disorders; and to promote the delivery of an equitable, high-quality service to all patients with a neuromuscular disorder across Scotland

Missing people. Missing Support.

Surveying people in Scotland

As well as FOI requests to health boards we conducted a survey of people living in Scotland with a muscle wasting and weakening condition. The survey was open from 15 October to 6 November 2024 and received 77 responses. It was conducted via SurveyMonkey. It asked people whether they had needed to travel to another area/health board to receive services related to their muscle wasting and weakening condition; whether they perceived access to or quality of neuromuscular specialist care to have gotten better, worse, or stayed the same since their diagnosis; and whether they were able to access the following specialist neuromuscular care from the NHS.

- Neurology
- Respiratory
- Cardiology
- Physiotherapy
- Endocrinology
- Neuromuscular specialist nurse
- Neuromuscular care adviser
- Occupational therapy
- Speech and language therapy
- Psychological support
- Wheelchair services

Respondents were also asked to rate the degree to which they agreed or disagreed with a series of statements about living with a muscle wasting and weakening condition and accessing neuromuscular services in Scotland.

In May 2024 we published *Muscular Dystrophy UK; Community survey findings*[7]. The findings in the report were based on the responses of 679 people across two online surveys - one for people living with a muscle wasting and weakening condition and one for people supporting a person living with a condition. The surveys ran between 21 November and 21 December 2023 and were promoted through social media and emails to our supporters. Of the respondents, 6% were from Scotland (compared to 8% of the UK population living in Scotland) and this report has drawn out these Scotland specific responses and trends.

"I've heard of care I can only dream of in other countries and in cities like London, where patients are treated by one team, and have their various appointments in one day."

Survey respondent

The muscular dystrophies are a group of rare conditions that gradually cause muscles to weaken and waste. We mainly use the term muscle wasting and weakening conditions in this report. Although, you may also see the term muscular dystrophy or neuromuscular condition used.

[7] CommunitySurveyFindingsMay2024.pdf

Our findings

1. An estimated 7,300 people in Scotland are currently unrecorded and "missing" from the care records of NHS Scotland's neuromuscular services

- An extensive research study, published in 2022 by Dr Iain Carey of St Georges University of London, found the prevalence of muscular dystrophy conditions was far higher than the previously believed figure of 70,000. Dr Carey's research found there is actually an estimated over 110,000 people living with a condition, which translates into an accepted prevalence figure of approximately 1 in 600 people across the UK living with a muscle wasting or weakening condition[8].
- This prevalence figure against the Scottish population suggests there are around 9,000 people in Scotland living with a condition. However, the FOI returns indicate only 1,750 people are currently being accounted for across the 14 NHS Scotland health board reporting measures.

Health boards	Total population estimates	Health board FOI figure for local population with muscle wasting and weakening condition	Estimated actual local population with muscle wasting and weakening conditions based on 1 in 600 figure*
Ayrshire and Arran	365,440	17	609
Borders	116,820	0	194
D&G	145,770	0	242
Fife	371,340	15	618
Forth Valley	302,730	0	504
Grampian	582,220	120	970
GCC	1,179,910	1395	1966
Highland	323,630	0	539
Lanarkshire	668,360	0	1113
Lothian	906,190	0	1510
Orkney	22,020	0	36
Shetland	23,020	44	38
Tayside	414,130	130	390
Western Isles	26,120	29	43
Total	**5,447,700**	**1,750**	**9,072**

*See first paragraph above for figure calculation

[8] Carey IM, Banchoff E, Nirmalananthan N, Harris T, DeWilde S, Chaudhry UAR, Cook DG. Prevalence and incidence of neuromuscular conditions in the UK between 2000 and 2019: A retrospective study using primary care data. PLoS One. 2021 Dec 31;16(12):e0261983

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0261983

Stephen Thomas' story

I'm one of the missing

Although I'm 58 and was diagnosed with Facioscapulohumeral muscular dystrophy (FSHD) 22 years ago, it doesn't surprise me that the health board in Dumfries and Galloway, where I live, has no record of me.

The only specialist I see for my condition is a neurologist at the Queen Elizabeth Hospital in Glasgow, which is the nearest specialist centre to me. As this is around 90 miles away, I have my yearly appointment over the phone because it's difficult and impractical for me to travel that far. The support I receive from my neurologist is excellent; I just wish that I was able to see medical professionals closer to home.

"I have my yearly appointment over the phone because it's difficult and impractical for me to travel that far."

The lack of knowledge in Dumfries is isolating

Nobody in Dumfries has any specialist knowledge about my condition. Physiotherapists and occupational therapists don't know how to support me. Sometimes I receive appointments from my GP but realise five minutes into the conversation that they're just using me as somebody to learn from. This is really frustrating and demoralising because I've attended the appointment under the belief they can help me; yet it's the other way round.

"Nobody in Dumfries has any specialist knowledge about my condition. Physiotherapists and occupational therapists don't know how to support me."

The most worrying part about being so isolated and alone in managing my condition is how much I'm deteriorating. Up until 12 months ago I was ambulant and could walk around using a Fischer stick. Now I can't walk more than around 20 metres. I use an electric wheelchair almost full-time as my balance has become so bad it's dangerous to walk. Like most things with muscular dystrophy, we just cope and find a way to adjust, but the deterioration is really hard to process. It would be hard to deal with even if I had the support of medical professionals around me, but feeling like you're navigating the changes all on your own is scary.

Photographer: Julie Broadfoot

2. There is no consistent data collection across NHS Scotland's 14 health boards

- Half the health boards were unable to provide even the most basic data on how many people are currently assessed as living with muscular dystrophy conditions.
- Some health boards still hold diagnosis records on paper or locally in GP surgeries. This makes centralised record keeping problematic and the sharing of best practice both challenging and unlikely.
- In the cases where certain health boards had referred patients to a different health board for treatment, they were unable to provide any data on those patients, including the number referred. The health board they referred to were also unable to identify patients' origin, and in some cases they held no reportable data for either their patients or those from neighbouring boards referred to them.
- It is unlikely that there is effective sharing of experience among health boards.

3. The evidence suggests that access to treatment in Scotland is a postcode lottery

- Over half (59%) of respondents to our 2024 Scotland neuromuscular services experience survey said that there has been a decline in service provision in their area.
- Over one third (38%) of respondents have had to travel to another health board area to receive services related to their muscle wasting and weakening condition in the last 12 months.
- One in five (20%) of respondents said that they have considered moving elsewhere for better healthcare and service provision.
- The FOI returns we received showed that patients in Orkney with muscle wasting and weakening conditions are referred to NHS Grampian which means they and their families need to travel long distances, approx. a 500 mile round trip, by ferry or airplane to attend appointments.
- Patients in NHS Borders who require specialist care can access services in NHS Lothian, however many specialist services are not provided by NHS Lothian leaving patients without access to some specialist services.

[9] POL14-ScotlandVersion-Impact-of-COVID-report.v4.pdf

Vanessa's story

Travelling for hospital appointments

Phoebe, my daughter, is five years old and was diagnosed with Facioscapulohumeral muscular dystrophy (FSHD) in 2023.

Living in the Shetland Islands means we have to travel all the way to Aberdeen for Phoebe's care. This involves either an almost two-hour flight to the mainland or getting an overnight ferry. Phoebe gets tired very easily, so we often have to stay overnight in Aberdeen.

We arrange this through NHS patient travel to get financial support towards the costs, but it doesn't cover everything. The NHS only pays up to £50 for overnight accommodation. It's very hard to find somewhere that cheap, so we often pay extra. It's also a two-day round trip and I have to take time off work, so that has financial implications too.

It took quite a while to get Phoebe's FSHD diagnosis; at one point we felt we were spending more time travelling than at home! Due to how fatigued Phoebe gets, I worry the healthcare professionals don't get an accurate representation of how she usually is as she's exhausted by the time we arrive.

Educating healthcare professionals in the Shetlands

It's frustrating when so many of Phoebe's tests could so easily be done on the island. We recently had a breathing assessment done at Aberdeen hospital. The test only took ten minutes, but it was still a two-day journey. We know it's possible to have more specialists where we live as there is an adult respiratory consultant in the Shetlands, but we were told they couldn't do the tests on a paediatric patient.

One of the improvements I'd like to see is more education available for non-specialist healthcare professionals like GPs. I work in a health centre and recently asked our GPs to join the upskilling webinar run by Muscular Dystrophy UK. We added it to our local newsletter as there's a real need for better understanding of muscle wasting and weakening conditions like Phoebe's in our area.

Photographer: Dave Donaldson

4. The evidence suggests it's likely there is a considerable unmet need

- Given the categories of health professional and specialty used in the Scottish Muscle Network's 2021 mapping of neuromuscular services in Scotland, which were echoed in our FOI requests, there appears to be a considerable unmet need in terms of services and support available to people living with muscle wasting and weakening conditions in Scotland.
- Even in Scotland's largest health board, Greater Glasgow and Clyde, where there is some provision of service, this is still not adequate.
- No health board has a dedicated member of staff for each of the roles outlined in the FOIs.
- No respondents to our 2024 Scotland neuromuscular services experience survey have access to a full range of specialist neuromuscular care. Half of respondents (49%) do not have access to a specialist neuromuscular care adviser, and half (51%) do not have access to a neuromuscular specialist nurse.
- Over one third (35%) do not have access to specialist physiotherapy and 41% do not have access to specialist psychological support.
- Almost half (47%) of respondents said that access to neuromuscular specialist care has gotten worse since they were diagnosed. The same number said it had stayed the same. 6% said that access had improved.
- Over one third (35%) said that the quality of specialist neuromuscular care had gotten worse since diagnosis. Over half (56%) said that it had stayed the same and 9% that it had gotten better.
- Over half (53%) of respondents from Scotland to our 2023 Community Survey told us they do not feel in control of their physical healthcare, and a quarter (25%) of survey respondents told us that they do not feel in control of their mental healthcare.

5. It is impossible to see, or develop, a Scotland wide resource plan

- Services will not improve unless all health boards begin routine collection of standardised, detailed data as a basis for understanding demand, planning to resource it, and sharing expertise and learning.

Claire's story

Being diagnosed with Charcot-Marie Tooth (CMT) at 12 years old was a hard thing to deal with.

But at least I was having regular paediatric appointments and physiotherapy sessions. I'm now 40 and haven't had any consistent appointments since moving to adult services 22 years ago.

Living in Wick, in the Highlands, resources and knowledge about conditions like mine are limited to say the least. I've had numerous falls over the years, due to my CMT, resulting in me being on crutches. I'd get referred to a consultant for a couple months after and then be left on my own again.

My son is 16 and also has CMT. He was diagnosed at nine years old and is still doing really well thanks to his amazing physio team.

I worry about him having to soon transition to adult services as I hope he doesn't have to face the same abandonment of care I have. He should be transitioning to a rehabilitation specialist in adult services. So I'm cautiously hopeful he will be able to continue receiving support as it makes the world of difference for conditions like ours.

Nowadays, I have to wear orthotic splints to help my drop foot. Without them I can only walk holding on to furniture around the house. I get a lot of pain in my calves and back due to the way I walk, and I have restless leg syndrome. I get sciatic pain in my lower back that travels down my legs, as well as pain and weakness in my hands – this means I struggle to do chopping or open things. My most recent symptom I'm really struggling with is fatigue. Not having any regular appointments to receive guidance on how to manage my symptoms is very hard.

Photographer: Iska Birnie

David's story

The lack of support after diagnosis was shocking

When I moved to Glasgow in 2021 at age 32, I pulled loads of muscles in my back. The pain wouldn't go away so I went to see a physio. The exercises she gave me didn't fix it, so she contacted my GP who referred me to a spine specialist for an MRI scan.

They told me they couldn't see anything wrong, but my partner was adamant they needed to run more tests. Five months after a neurologist had done some blood tests, I got an unexpected phone call at work to tell me I had Becker muscular dystrophy.

They couldn't give me an appointment for another four months and I'd never even heard of muscular dystrophy. I had no idea where to turn.

Finding knowledge in clinical trials

I started a clinical drug trial at the John Walton Muscular Dystrophy Research Centre in Newcastle a month after being diagnosed. We still hadn't seen a consultant since I'd had the phone call, so my partner found this, and we thought it would be a good way to gain knowledge about the condition. I've travelled to Newcastle every month since August 2023 for the trial.

Leaving Scotland in search of better healthcare

We moved to Newcastle this summer so it's easier to take part in other clinical trials and receive more healthcare support.

"When we lived in Scotland, I had my first and only appointment with a neurologist seven months after receiving my diagnosis over the phone."

They sent me for an echo cardiogram and a lung capacity test a few months later, but other than that, they were clear there wasn't much they could offer me.

Looking to the future

I'm now taking part in my second clinical trial in Newcastle at the John Walton Muscular Dystrophy Research Centre. It's amazing to get information and support from the team of specialists there.

Photo source: David

Recommendations and next steps

Scottish Government

1. The Scottish Government should mandate the collection of standardised data on muscle wasting and weakening conditions by Scotland's health boards, including the number of people diagnosed and the service provision per health board. An audit of the data should be reported each year.

2. The Scottish Government should include, as part of the review of the neurological care and support framework, a comprehensive Scotland-wide resource plan to ensure equal and equitable access to care and support for people living with a muscle wasting and weakening condition.

3. The Scottish Government, along with health boards, must develop a long-term succession and sustainability plan for expert, full-time care advisers in every health board area. Working towards a target of 2034 to ensure every person living with a muscle wasting and weakening condition reports their needs are being met by healthcare and support services.

Health boards

4. Scotland's 14 health boards must commit to collating and sharing data on the wide range of muscular dystrophy conditions, and best practice for managing patient care from diagnosis to bereavement. They need to commit to an annual audit of best practice implementation. .

5. Data on muscle wasting and weakening conditions should be recorded electronically and in a consistent way across Scotland.

6. The experiences and recommendations of people with muscular dystrophy and those who care for them should be regularly sought and implemented.

7. Every health board must have an accountable muscle wasting and weakening conditions champion, responsible in particular for ensuring smooth transitions for people with muscle wasting and weakening conditions, and those who care for them.

8. Health boards should work collaboratively with Muscular Dystrophy UK on upskilling, training and professional development about muscle wasting and weakening conditions.

Support available from Muscular Dystrophy UK

We understand that living with a muscle wasting and weakening condition can be both overwhelming and isolating for those living with a condition and their families.

This is especially true if people don't have access to the right information and support to help them to live well. We're here to listen and provide information and advice about all aspects of living with a muscle wasting and weakening condition.

For information or support on muscle wasting or weakening conditions:

Call our free helpline on **0800 652 6352**

Email us at **info@musculardystrophyuk.org**

We're committed to working in partnership with the health professionals who support our community, providing upskilling training and networking opportunities, while ensuring NHS neuromuscular services receive appropriate attention from commissioners and decision makers.

We connect a community of more than 110,000 people across the UK living with one of over 60 muscle wasting and weakening conditions, and all the people around them. So everyone can get the healthcare, support and treatments needed to feel good, mentally and physically.

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