MUSCULAR DYSTROPHY UK
OUR MUSCLES MATTER

Centre of Excellence experience survey

Contents

Foreword

We’re delighted to present the findings of our - *Experience of Neuromuscular Care* survey, undertaken and analysed in partnership with the Research Institute of Disabled Consumers (RiDC).

We ran this survey alongside our Centre of Excellence awards audit, as part of our commitment to recognising and promoting exemplary neuromuscular care across the UK. The rich data gathered from the survey, will help inform our understanding of the experiences people living with muscle wasting and weakening conditions, their families and carers, have when using UK neuromuscular services. This will help us to further support improvements to the healthcare services our community use.

The responses to the survey highlight the importance of well-coordinated multidisciplinary care. However, it’s clear that across the four nations, many people with muscle wasting and weakening conditions face significant barriers to accessing key specialists and community services.

We’ll continue to work closely with the UK and the devolved governments, NHS commissioners, healthcare professionals, and the community to address the issues identified in this report, to continue to drive forward improvements and access to care for people with muscle wasting and weakening conditions.

We’d like to express our sincere gratitude to RiDC and everyone who contributed to our 2023 experience survey. Your continued support helps us in working towards better health and social care for our community of people living with muscle wasting and weakening conditions and their families.

Andrew Fletcher
Chief Executive Officer
Muscular Dystrophy UK

About Muscular Dystrophy UK

We connect a community of more than 110,000 people 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.

- We share expert advice and support people to live well now.
- We fund groundbreaking research to understand the different conditions better and lead us to new treatments.
- We work with the NHS towards universal access to specialist healthcare.
- Together, we campaign for people's rights, better understanding, accessibility, and access to treatments.

> **"Our experience survey, as part of the Centre of Excellence awards programme, helps provide insight into ongoing service development for neuromuscular centres, to highlight what is working well, and what needs improving in neuromuscular care."**

Abbreviations

BiPap	Bilevel positive airway pressure
CoE	Centre of Excellence awards
COVID	Coronavirus disease
CPAP	Continuous positive airway pressure
CPTs	Changing Places toilets
ECP	Emergency care plan
GP	General practitioners
KAFO	Knee Ankle Foot Orthosis
MDT	Multidisciplinary Teams
NHS	National Health Service
NHSE	National Health Service England
NIV	Non-Invasive Ventilation
NMCA	Neuromuscular Care Advisors
NMCNS	Neuromuscular Clinical Nurse Specialists
NNAG	National Neurosciences Advisory Group
OT	Occupational therapists
RiDC	Research Institute for Disabled Consumers
SHCA	Specialised Healthcare Alliance
SLT	Speech and language therapists
UK	The United Kingdom of Great Britain and Northern Ireland

Executive summary

In 2023, we conducted a survey in partnership with the Research Institute of Disabled Consumers (RiDC) to look at the neuromuscular care experiences of people living with a neuromuscular condition, their family and carers. RiDC, an independent national charity, has been the leading expert in inclusive research for over 50 years.

The survey allowed us to get direct insights from people with lived experience who are using neuromuscular services, complementing our Centre of Excellence clinical audit to provide a fuller picture of the quality of services provided by neuromuscular centres.

While our clinical audit received submissions from 27 neuromuscular centres, the experience survey was open to adults and children receiving care at all neuromuscular centres including those that were not part of the clinical audit.[1] The survey was carried out from March to May 2023, with a total of 859 responses about adult or paediatric care at specialist neuromuscular centres (738 adult responses and 121 paediatric responses).[2]

> **"The results highlighted the dedication of many healthcare professionals who go above and beyond to provide the best possible care. It also made clear there are significant gaps across the country and that wider system pressures are negatively impacting neuromuscular care."**

Some key findings from the survey:

Accessing neuromuscular care

- 72% of adults and 68% of paediatric respondents would like greater involvement of at least one specialty in their care.
- Only 24% adults and 42% paediatric respondents have access to a neuromuscular care advisor.
- 26% of adults and 5% of children who feel they need physiotherapy are unable to access it at all.
- 27% of adults and 14% of children who feel they need occupational therapy are unable to access it at all.
- 79% of adults and 70% of children who feel support from a specialist neuromuscular psychologist would be useful have not been able to access it.
- 95% of adult responses and 88% paediatric responses about assistive devices (such as cough assist, BiPap or CPAP machines) said the equipment had been promptly provided when needed.[3]

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[1] Muscular Dystrophy UK, *Centre of Excellence audit report 2023/24* (Muscular Dystrophy UK 2024).

[2] The survey questions were made optional to promote more honest answers and prevent poor quality responses. Consequently, the number of respondents vary on each question.

[3] Given that people may need more than one equipment in managing their neuromuscular condition, they were allowed to submit responses for each equipment that they use.

Coordinating care

- 15% of adults and 59% of parents/carers of a child with a neuromuscular condition spent more than an hour per week on average coordinating their care (not including time spent receiving / delivering care).
- 22% of adult responses and 33% paediatric responses said centres did not communicate well with community teams to plan their care.* Respondents also expressed concerns regarding the lack of awareness and understanding of neuromuscular conditions amongst non-neuromuscular specialist professionals, such as general practitioners.
- For some conditions an Emergency Care Plan (ECP) is a key resource that can inform non-neuromuscular specialists during an emergency. However, one in 10 respondents (12% adults, 11% children) don't know whether they have an ECP in place.

Accessibility of NHS facilities

- One in two responses rated their centre very accessible (51% adult responses, 49% paediatric responses). However, one in ten found them fairly or very inaccessible (9% of adult responses and 11% of paediatric responses).*
- The survey highlighted that wider NHS hospitals and facilities may not always be fully accessible for services users, due to a lack of disabled parking bays or clinic rooms too small for wheelchair users to move easily around. Many NHS hospitals also do not have a registered Changing Places Toilet.

> **85% of adult responses and 83% of paediatric responses were fairly or very satisfied with the care received at their specialist centre."***

The *Experience of Neuromuscular Care survey* has highlighted several key insights on how neuromuscular care is being delivered and has demonstrated why it's essential our community of people living with neuromuscular conditions, and their families and carers, are given the opportunity to have their say on the standards of care and treatment they receive.

These insights will assist in our work to support healthcare professionals to deliver the best possible neuromuscular care and advance the overall quality of care for people living with neuromuscular conditions.

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* Given that people may attend more than one centre as part of their treatment and management plan, they were allowed to submit responses for each centre they attend for these questions.

Methodology

Following a co-design with our Centre of Excellence awards Sub-Committee and members of our voluntary Content Advisory Group, the survey was run and analysed by RiDC. It ran from March to May 2023.

A variety of questions around neuromuscular care provision were asked, including:

- Satisfaction with neuromuscular care provision
- Types of specialist care received, and the frequency of visits to medical specialists
- Coordination of care
- Provision of mental health support
- Assistive devices
- Accessibility of neuromuscular centres

We asked about the type of care respondents received, and 1,082 people responded to this. From these responses:

Type of care	Number of respondents	Percentage of respondents
Respondents receiving care at an adult neuromuscular centre	738	68%
Respondents receiving care at a paediatric neuromuscular centre	121	11%
Respondents receiving both adult and paediatric care (in transition)	16	1%
Respondents receiving other care[4]	207	19%

Note, percentages on some graphs in this report do not sum exactly to 100 due to rounding.

[4] Most people who selected 'other' said they were receiving limited to no ongoing care, care from community services only, or did not provide any further details.

We have heard from our community regarding the issues around transition in neuromuscular care, especially given that transition goes beyond a clinical scope of transferring care to adult services, it also includes other parts of personal life such as education and employment. Whilst we collected some powerful narratives during this survey unfortunately, following a conversation with RiDC, we were unable to analyse them for the specific purpose of this report, due to a very small sample size of 16. However, combined with the data from clinical audit submitted by healthcare professionals, which can be found in our first report, we are hoping to use the best practice and challenges we identified in future policy discussions around transition care.[5]

Moreover, this survey was primarily designed as a complementary tool to assess the clinical audit on participating neuromuscular centres, as part of our voluntary Centre of Excellence awards programme. Therefore, this report only analysed care received at specialised neuromuscular centres, and their coordination and communication with wider community services. The responses from those who receive 'other' care or did not name a specific centre were not analysed for this report. However, they have provided us with insight into how care is being delivered outside the specialist neuromuscular centres which resonates with the findings of our 2024 Community Survey.[6] We know that lack of awareness of neuromuscular conditions and availability of services outside of specialist centres is an important issue and we will continue to monitor and campaign for raising awareness, including using the insights from this survey.

Our respondents covered a wide range of neuromuscular conditions, as well as a small number (35) who were unsure of their specific condition or who at the time of completing the survey were undiagnosed. The respondents included people attending adult and/or paediatric neuromuscular services, as well as their families and carers responding on behalf of a person living with neuromuscular conditions.

The survey questions were made optional to allow respondents to skip questions if they wished to, reducing the risk of people abandoning the survey. This also allowed respondents to provide more honest answers and prevent poor quality responses. Consequently, the questions received varying numbers of responses which are indicated throughout the report.

Clinical audit

The survey was primarily designed to provide balanced views on the Centre of Excellence clinical audit, to assist our voluntary expert assessors in the scoring. From the survey, we finalised 14 confidential centre-level reports – these centre-level reports were only produced for centres with a minimum of 20 respondents. These were then submitted to the assessors during the assessment period, which ran between July – October 2023. Following the announcement of the audit decision in November 2023, all 14 centres were supplied with the centre-level reports, to provide insight into how patients view their neuromuscular care.

We publish this national-level report to share wider insights into how people living with neuromuscular conditions view their specialist care, and to communicate any gaps in the current provision of care to key stakeholders to campaign for better and more advanced neuromuscular care provision.

12% of adults and 11.5% paediatric respondents received care at more than one specialist neuromuscular centre. This may be due to the complexities of their care, the rareness of their condition or their involvement in clinical research trials. To produce centre-level reports for the clinical audit a small number of questions were repeated for each centre an individual attended. This means that when analysed at the national scale, a small number of questions have a higher number of results than respondents because one individual could answer about more than one centre. This will be clearly marked throughout the report.

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[5] Muscular Dystrophy UK, Centre of Excellence audit report 2023/24 (Muscular Dystrophy UK 2024).

[6] Muscular Dystrophy UK, *Community survey findings 2024* (Muscular Dystrophy UK 2024).

Summary of key findings

Satisfaction with care

We are delighted to hear that many of our respondents were satisfied with their neuromuscular care, and that they value the work committed by their specialist neuromuscular teams. Some of these can be found in the responses below:

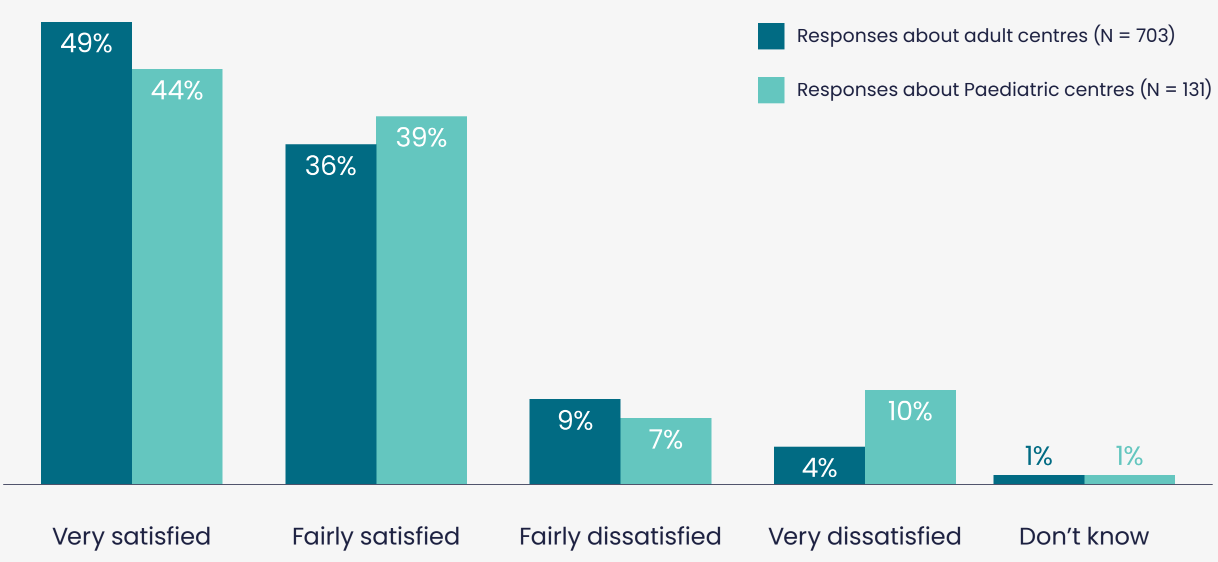
> I have been going there for the last eight years. They have always been supportive suggesting when I need to transfer to using a wheelchair after any falls. Always very supportive when I have had been depressed due to my deteriorating mobility. Always very caring when I am receiving treatment and very professional."

> The neuromuscular team… are all fantastic and go above and beyond to help and ensure our son is receiving the right care. Thank you."

> I appreciate the time and care that staff have taken to ensure that I have felt supported over the last year or so. It has made a great difference."

For each centre they attend, respondents were asked how satisfied they are with their care. 85% of adult responses and 83% of paediatric responses were fairly or very satisfied with the care they receive.[7]

How satisfied or dissatisfied are you with the quality of neuromuscular care you receive at [neuromuscular centre]?



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[7] This analysis is based on number of responses about specialist centres, not number of respondents, as people who receive care at multiple centres were allowed to give an answer for each one.

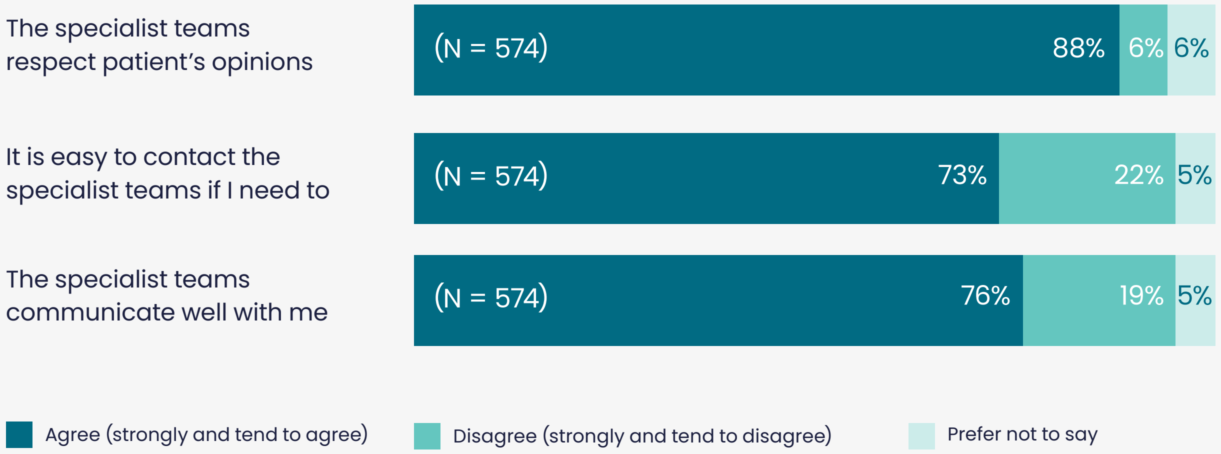
While there is a whole range of reasons for these responses, several respondents provided detail on what they considered to be working well in their care.

> “Our son goes to check-ups at [the centre] a few times per year. They check his progress in great detail and do an excellent job of explaining everything to him and us as parents. They answer all our questions in detail and they have been very good at allaying any fears we have about our son. They are caring, friendly and clearly very dedicated to their jobs and to the people under their care.”

> “I feel that the team explains well what is happening to my daughter which is extremely important as she has learning difficulties and she can become anxious if she does not know this. I feel the team understand this and fully accommodate her needs. I cannot fault the care and understanding at this clinic”

> “I have an annual appointment with my neuromuscular doctor where we speak about everything from muscular dystrophy, exercises, other health issues, it works well because it’s a very open and frank conversation – there’s never a rush to finish even if I have a list as long as your arm.”

The majority of respondents have strong relationships with their specialist teams. However, communication is sometimes an issue. One in 5 responses (19% of adult responses, 21% paediatric responses) felt specialist teams did not communicate well with them. It can also be challenging to get in touch; 22% of adult responses and 23% paediatric responses said it is not easy to contact specialist teams if they need to.[8]



Please tell us to what extent do you agree or disagree with the following statements.
Answers about adult neuromuscular centres

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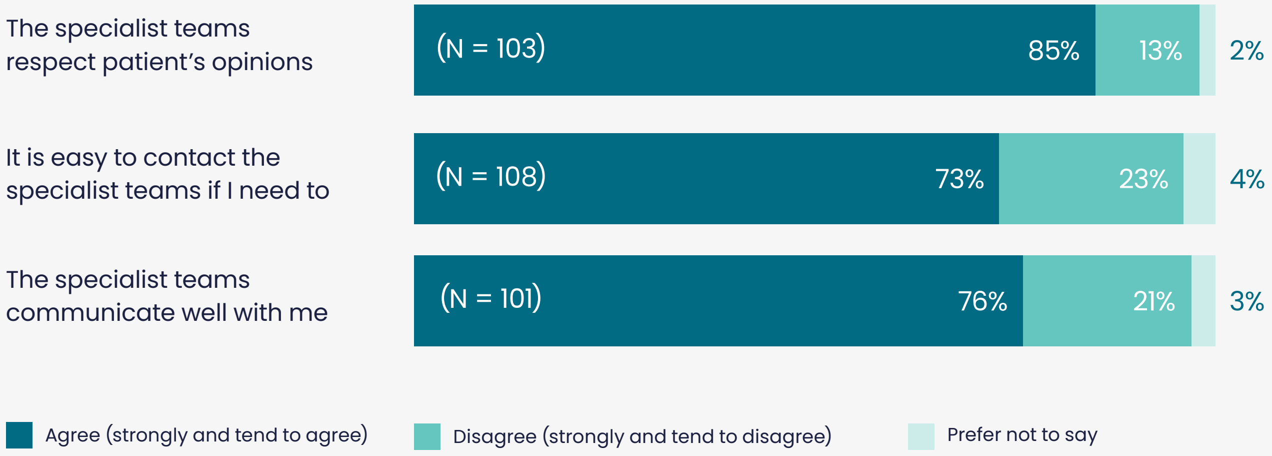
[8] This analysis is based on number of responses about specialist centres, not number of respondents, as people who receive care at multiple centres were allowed to give answers for each one.

Please tell us to what extent do you agree or disagree with the following statements.
Answers about paediatric neuromuscular centres



Whilst our respondents are generally satisfied with their neuromuscular care, some significant gaps remain.

> Whilst it can be good, and has been good, it is still not adequate at times. We have often found it challenging to get the care I need, particularly when I have become acutely unwell. We have had to fight, argue and go in circles many times throughout my life to get things I need."

> I feel that my diagnosis... have been a long time coming. I totally get why there have been delays in the NHS because of the pandemic and I understand the problems, but it has been difficult. I am however very grateful to have obtained the information that I do have and all the investigations that have been made available to me and the attention from the Neuromuscular team... They have been very kind, friendly and helpful."

> When we are in contact they are excellent, but the appointments with the specialist neuromuscular team are too far apart and we don't have access to a care advisor."

> ...the staff I have come into contact with are great, friendly and so hardworking. I cannot fault them. My issue is with the system and not the staff."

We will outline throughout the rest of this report various issues such as coordination of care, accessibility of neuromuscular centres, and access to wider neuromuscular multidisciplinary teams and health and social care support, to demonstrate how neuromuscular care can be improved.

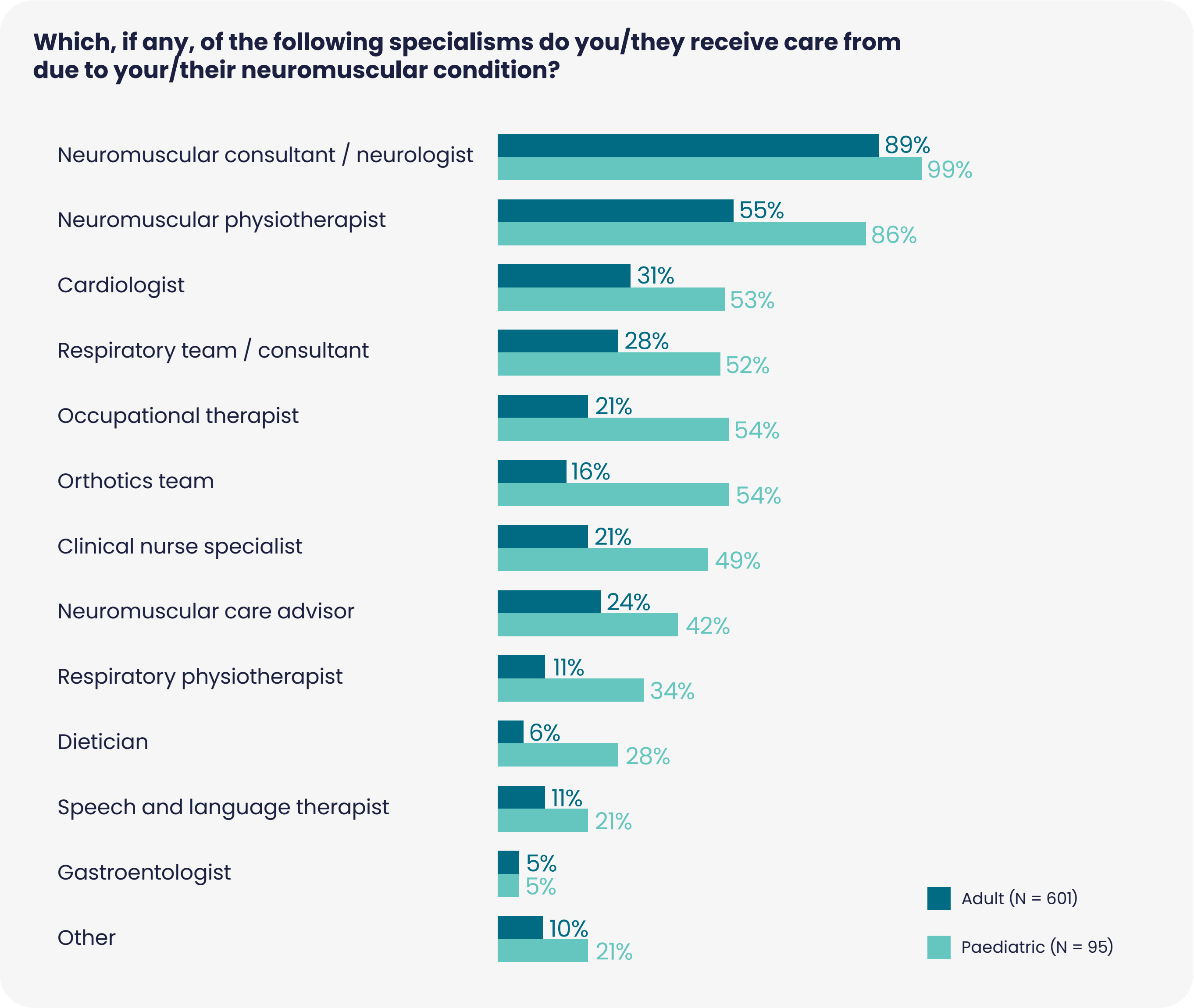
Accessing specialist neuromuscular care

Neuromuscular conditions are a group of rare conditions that gradually cause muscles to weaken and waste, and there are more than 60 different types. For some people, their condition will become more complex as it progresses and they will require input from many different specialties.

Number of neuromuscular specialisms involved in providing care	Adults who named at least one specialism (N = 596)	Paediatrics who named at least one specialism (N = 95)
One	18%	2%
Two	23%	11%
Three	22%	7%
Four	15%	7%
Five	10%	18%
Six	6%	19%
Seven or more	6%	36%

> **“My son has routine appointments at the neuromuscular clinic. They are meant to be six-monthly but are closer to annually He sees the consultant and/or clinical nurse specialist and the physio at these appointments. They organise for regular (annual or biannual) spinal x-ray, dexa scan and blood tests. They also liaise with his local physio team. He also sees a cardiologist annually to monitor his heart function, and he is under a respiratory doctor, although does not currently have routine appointments. We also have access to the regional neuromuscular care advisor… who is excellent. Most of [the] care is good or better than good.”**

The Figure below sets out which services respondents received care from:



For those people who can access a fully staffed multidisciplinary team within a specialist neuromuscular centre it's invaluable. It allows them to be seen by staff with experience and expertise in the management – including proactive management – and regular monitoring of their condition. These staff are able to take into account the complexity of their medical needs, with good lines of communication and information sharing with other relevant staff.

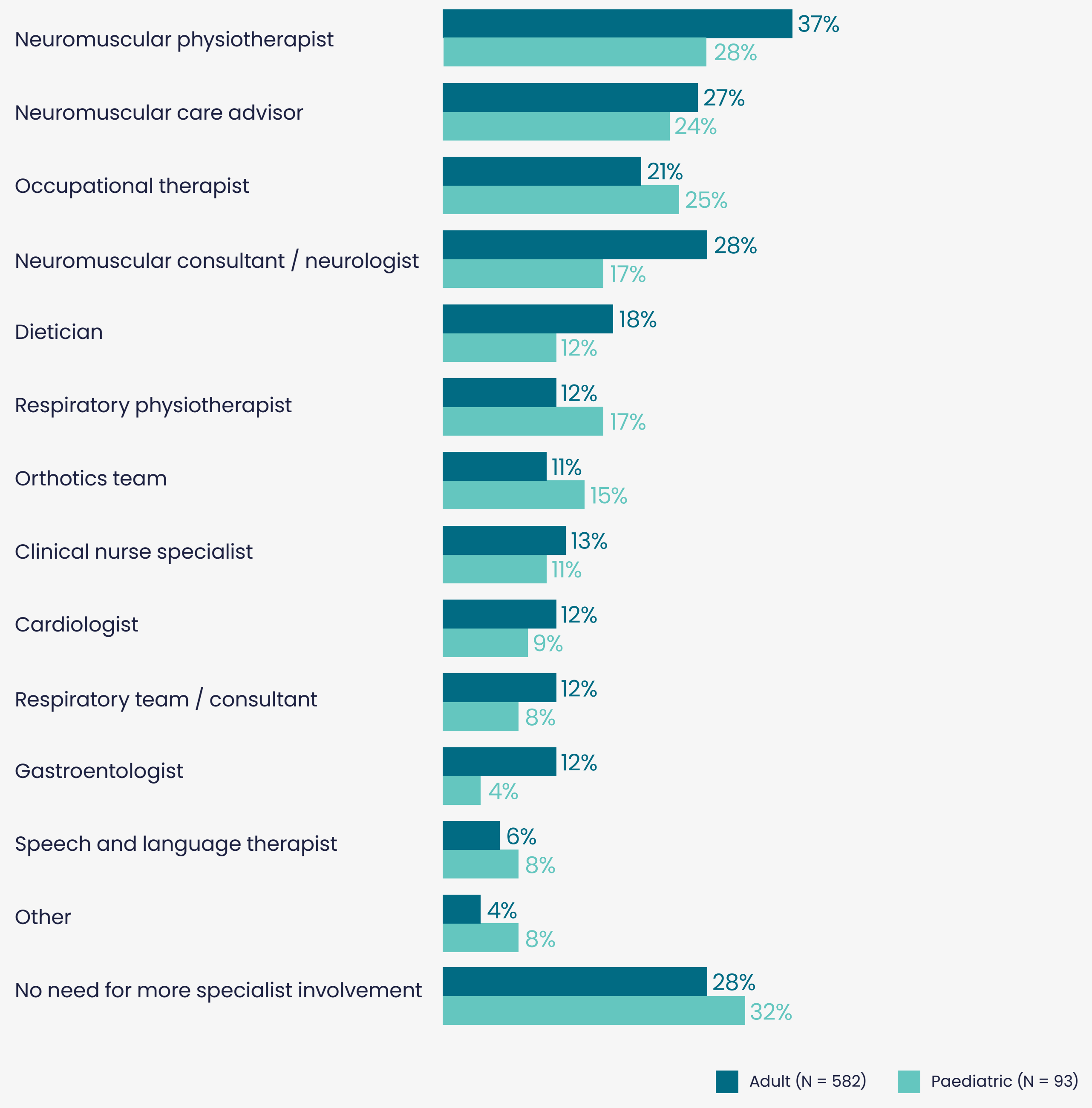
> Respiratory appointments link with speech and language, dietician and care advisor - a complete multidisciplinary team (MDT) approach often [on the] same day same time. All aspects of the MDT are expert / familiar with my muscular dystrophy, and I can contact the team directly as and when needed – this [is] additional to the annual [face to face] appointment."

> It feels very comforting having an MDT team around to oversee all aspects of my condition. I like that I can email the neuromuscular team and get a response almost straight away."

The National Neurosciences Advisory Group set out in the recently published Optimal Clinical Pathway for Adults with Neuromuscular Conditions, that there should be six month or annual review with the neuromuscular multidisciplinary team (MDT) at a specialist neuromuscular service.[9]

However, many people feel they do not have access to the full range of healthcare support that they require. 72% of adults and 68% of paediatric respondents would like greater involvement of at least one specialty in their care:

Which, if any, of the following specialisms would you like to be more involved in your neuromuscular care?



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[9] National Neurosciences Advisory Group, *Optimal clinical pathway for adults with neuromuscular disorders* (NNAG 2024) accessed from https://www.nnag.org.uk/optimal-clinical-pathway-adults-neuromuscular-disorders

Some respondents said they had not been able to access appropriate levels of care, with some people expressing their frustrations over a lack of access to regular specialist appointments, especially given the pressures and resources within the NHS. For instance, for those waiting to see a neurologist, this would be reflected in the current situation of a growing backlog of secondary care, that was disrupted following the COVID-19 pandemic. There were 4.39 million people waiting for consultant-led elective care in England in March 2020, which now stands at 7.57 million people as of September 2024.[10] This also includes a growing invisible backlog, which includes patients requiring care that are yet to be seen by healthcare providers, and the referral to treatment waiting list does not include waiting for non-consultant led treatment, or patients waiting for follow-up appointments, thus not demonstrating the full picture of the backlog. For neurology itself, data estimates backlog of more than 225,000 neurology appointments after the pandemic.[11]

> “I just feel at times we are on our own.”

> “I feel very much left to my own devices as I have such little contact with any medical person. I think this is due to the fact that there is no treatment for my condition so I am just left to cope on my own in whatever way I can.”

> “The Neuromuscular Health Adviser and Physio need additional staff. The workload is too much for them, so they get fed up and burnt out. The whole neuromuscular clinic needs additional investment.”

When people did get an appointment with their specialist neuromuscular team, they reported they were not always listened to, or they didn’t have treatment options explained to them, especially as their appointments could be rushed.

> “I am not listened to when I have concerns about my health. I have no additional support with managing my health other than my yearly appointment with my consultant – no regular respiratory checks despite me raising concerns, no follow up regarding my swallowing concerns, no regular physiotherapy appointments despite the request of my consultant.”

> “I have also occasionally felt that the neuromuscular clinic appointment is a bit of a formality and that there has been a lack of genuine interest/involvement. But that might have been due to scheduling pressures.”

> “More time for discussion about the outcome of investigations and what they mean, e.g. we tend to just get the results of the dexa-scan by letter but would appreciate a fuller discussion about what they mean and how they might change in the future…as parents, we often come away feeling that there is a blurriness/lack of clarity in some of the information we were given.”

The survey results showed that despite the NHS Long Term Workforce Plan[12], there are still unmet needs in the care of people living with neuromuscular conditions, from before diagnosis through to the access of ongoing management and treatment of their condition.

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[10] British Medical Association, *BMA analysis of NHS England Consultant-led Referral to Treatment Waiting Times statistics* (BMA, 15 November 2024) accessed from https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-backlog-data-analysis

[11] NNAG, *Lessons learnt from the COVID-19 pandemic priorities in care for people with neurological conditions after the pandemic* (NNAG 2021) accessed from https://www.nnag.org.uk/lessons-learnt-from-covid19

[12] NHS England, NHS Longterm Workforce Plan June 2023 (NHS England 2023) accessed from https://www.england.nhs.uk/publication/nhs-long-term-workforce-plan

Access to neuromuscular consultants

It’s important for people living with a neuromuscular condition to have regular access to neuromuscular consultants so they can review and evaluate the progression of their condition, and prescribe pharmacological interventions that may treat symptoms, alongside referring people to other services to help them manage their conditions. Our respondents expressed the importance of this access:

[Name] is always delighted to see [his consultant], he feels safe knowing she is on hand, and we both feel she is an excellent consultant in her field and we are very grateful for her and her colleagues.”

I have a yearly (MOT) appointment with my consultant who checks me from top to bottom. She is fantastic and always recommends ideas to make my life as comfortable as possible.”

All aspects are excellent. Detailed assessments taken annually. Clear, respectful communication. Informing us on standards of care and what we should expect. Informing us of relevant research. Interested in wider experiences, such as education, and try to help. Really engaged registrars and consultant who make our son feel welcome and that he matters.”

I have a huge regard for my consultant. Over several years, he has taken a real interest in my situation, and I am very grateful.”

While 89% of those under adult care and 99% under paediatric care received care from a neuromuscular consultant, respondents were not always receiving regular specialist appointments. 28% of adults and 17% of paediatric respondents felt they would like more involvement from their neuromuscular consultants.

I have not seen a neurologist for over two years. I receive no other care, nor does my son.”

There has been a turnover the Neurologists at [my centre] and I have seen the latest one once where she told me that the Trust had told her to reduce the time spent with patients to 20 minutes per appointment, which doesn’t seem much for an annual review. I don’t think [the hospital trust] or the ICS are interested in supporting people with MD and this consultant is not supported to provide a proper service.”

I would like more consultant appointment availability. I should have a review at least once a year. I am worried about succession planning. What happens if he leaves?”

In the last five years I have only seen my NM consultant once.”

Waiting lists to see the consultant can take as long as 2 years, even when you should see them every half a year.”

Respondents were very concerned over the limited amount of clinic time available to them in their specialist appointments, with long waiting times and other pressures within the NHS adding to peoples' frustrations.

> Possibly the frequency with which I am seen, but I think that is part of a wider issue of the NHS being overburdened."

> [I] feel rushed at neurology appointments - believe this is due to sheer volume of patients and from my understanding staff shortages not enough doctors / consultants in the team."

> Annual appointments with the neurologist seem rushed and we [often] have the same conversation as the year before with the same unaddressed issues coming up. For example, in the last three appointments it has been discussed that I could do with [being weighed], and yet this still hasn't happened. The appointments are short and usually running behind, however a significant amount of time is used up with the consultant looking at my notes to see what has happened previously."

This lack of access to timely specialist support can have a significant health impact on people living with a neuromuscular condition and their families – from a potential delayed diagnosis to delays in accessing optimal care and treatments.

It's very concerning that some people living with a neuromuscular condition do not have sufficient access to specialist neuromuscular consultants. While people are generally satisfied with their care, and many of our respondents expressed their gratitude over the high-level of dedication and commitment from the neuromuscular teams, the pressures on health care professionals within the NHS impact the overall care.

Access to neuromuscular care advisors

Neuromuscular Care Advisors (NMCA) are an essential part of a multidisciplinary neuromuscular team to support people with neuromuscular conditions, with significant benefits in preventing unplanned emergency hospital admissions, providing readily accessible support for patients and their families at the time of diagnosis and periods of significant change. NMCAs provide specialist, holistic support in clinical and community settings. For many years, we have been campaigning for increased NHS investments in care advisor roles across the UK.
Our survey respondent say:

> [They] are always available to answer questions on the fly, usually by text or email, and are great at liaising with other specialist teams."

> [The care advisor] has been an incredible source of support, both emotionally and practically. She doesn't shy away from the tough conversations, but she always approaches them with empathy and understanding. I feel like she goes above and beyond to advocate for me and I've no doubt she does it for all her patients. She has offered more real-life practical support than any other healthcare professional since my diagnosis."

> I am treated as a person, not just a number. I feel comfortable to contact [the care advisors] with any concerns I have in between appointments, and they are very helpful, offering support in PIP applications etc, and always get back to you if they say they will. The appointments are always on time and focus on my needs."

Of those who have access to a neuromuscular care advisor, 88% of adults and 73% of paediatric respondents believe they play a very or fairly important role in co-ordinating their care.[13] However, the survey results highlighted that access to care advisors was far from universal, and that there is a great deal of inequity in access. Less than half (42%) of paediatric respondents have access to this support, and only a quarter (24%) of those under adult neuromuscular care.

> We get to see the neurologist once yearly but in between, if we need to see or talk to someone, there is no one we can call except the GP who understands very little about the illness."

Due to variation in roles and funding arrangements, not all regions have access to care advisors. The survey findings are concerning given the low number of people able to access care advisors, as well as concerns regarding the ability of care advisors to manage their workloads due to workforce shortages.

> There is a neuromuscular care advisor in post. Whilst this is a good thing, I feel that she is so overstretched and has so many people on her case load that she has become inaccessible and ineffective."

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[13] From a sample size of 143 adults and 40 paediatric respondents.

Access to specialist physiotherapists

Neuromuscular conditions may affect muscles, the nerves that supply them, or the junction between the nerves and muscles, resulting in weakness, joint tightness, and other functional problems. A core multi-professional neuromuscular team includes specialist neuromuscular physiotherapists.

Regular physiotherapy assessment is an essential part of the overall management of these conditions as it can help identify physical changes over time and prevent any complications through further investigations. Assessments include muscle strength, joint range of movement, posture, and other functional ability. For those who require further assistance, specialist neuromuscular physiotherapists will also refer on to orthotic services for treatment such as Knee Ankle Foot Orthosis (KAFO) rehabilitation and splinting. Specialist physiotherapists also work with mobility and wheelchair services.

> “
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> Physiotherapy has been invaluable to my son in coping with postural changes in his condition and how to manage chest physio while he has been poorly in hospital. Neuromuscular physios have supported parents as well as my child in becoming confident in hoisting whilst ventilated so he can sit up in his chair daily.”

> “
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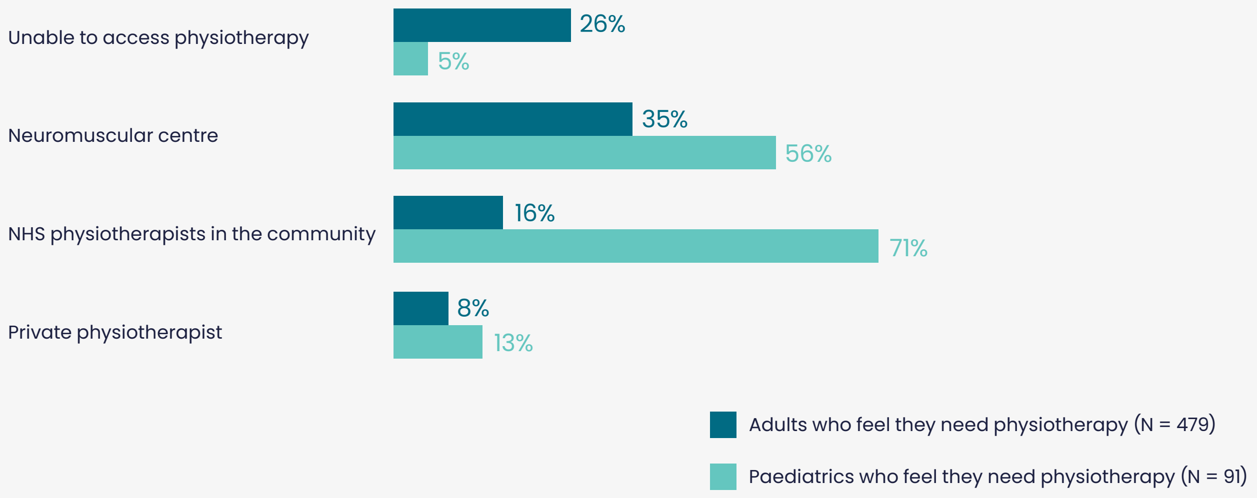
> The specialist physiotherapist] has been instrumental in changing how I go forward and planning how to manage pain and all aspects of condition.”

Unfortunately, the provision of physiotherapy for people with neuromuscular conditions is highly variable and particularly limited for adults. One in four adults (26%) who felt they need physiotherapy said they are not able to access it at all.

Where, if anywhere, do you access physiotherapy to help manage your neuromuscular condition? Select all that apply.



Although 95% of paediatric respondents who felt they needed it were able to access some form of physiotherapy, 28% of all paediatric respondents would like more involvement from a specialist neuromuscular physiotherapist. This compares to 37% of adult respondents.[14]

As the above Figure shows, some people go outside the NHS to meet their needs, whether to private providers or elsewhere, including through charitable means. As a case study, 5% of our adult respondents received care at the MD Support Centre in the Midlands or the Neuromuscular Centre in Winsford, charities which provide specialist regional support.

> Accessing physio would be a great help to me, or access to aqua therapy or any therapy really would be of great benefit, but [I'm] just left for another year [to] then go back and [be] asked how is it progressing."

> I only get seen yearly and although I see a physio I am not able to do a lot of the exercises alone. I feel that once you're seen that's it and there is no follow on process from it. I never get any help from any other service in my area and due to lack of resources availability cannot get access to any facilities near me who have disability exercises classes. Unfortunately gyms in my area have no knowledge about my disability and have no understanding of what I can and cannot do."

> Given that there is no cure or medication it is difficult to see how more than an annual appointment with the consultant [would help]. But more regular access to physio and assessment by a physio I think would be good. I saw the registrar in December and to date have not got a physio appointment yet."

> I need more physical support and personal training support. I am willing to pay for [a] local personal trainer but all the support I have been offered is once a year and is over one [hours drive away] – the other side of [a] big city. This is not practical for anyone."

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[14] Given the variation of resources and access in any given region, and individual's physiotherapy management need, respondents were able to select multiple options due to variety of ways they can access physiotherapy.

Access to specialist occupational therapists

Occupational therapists provide advice and information on the management of daily living activities and carry out further assessments for equipment and housing adaptations, to help support patients in being as independent as possible and to be able to participate in meaningful everyday activities. Some of the services they provide are in giving advice on postural equipment, strategies to address fatigue and pain, and advice on assistive technology and devices.

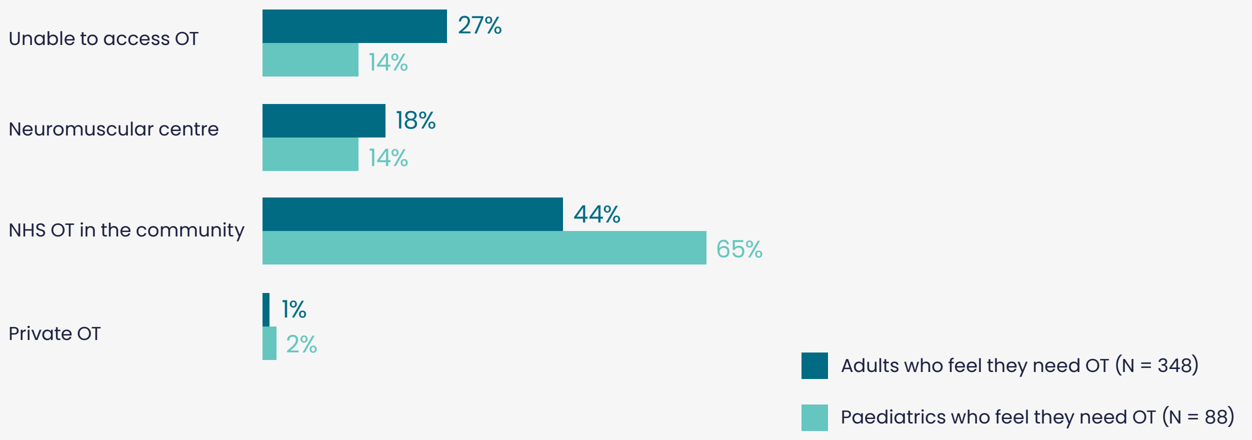
> The support team have been instrumental in helping to get the aid needed to continue as normal a life as possible."

> Since a referral to [the neuromuscular centre] last year, I've been blown away by the care... [The OT's] fatigue management course has helped me to understand the ups and downs of my condition and techniques to help. I now feel for the first time that I am managing my condition rather than just soldiering on."

> They have provided several devices and home adaptations that make things easier for me at home. They have provided a walker and a wheelchair."

While for those with access to neuromuscular occupational therapists the support has been valuable, the survey found that 27% of adults and 14% of paediatric respondents who feel they need this care are not able to access it.[15] Of those who can access it, the majority of support comes from community therapists.

Where, if anywhere, do you access occupational therapy to help manage your neuromuscular condition? Select all that apply.



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[15] Given the variation of resources and access in any given region, and individual's occupational therapy management need, respondents were able to select multiple options due to variety of ways they can access occupational therapy.

Those who struggled to access neuromuscular occupational therapists expressed their frustrations and what they hoped could be improved:

> Waiting time for OT and physiotherapy services seems much longer than it used to be. More staff needed."

> More practical help on how to manage conditions and navigate the overwhelming medical information. Less focus on cure and more on living day to day with [a] condition."

> I would like to see some assistance and support with daily living, recognising and managing symptoms."

> No access to Occupational Therapy for adults at [the neuromuscular centre] - my children have previously benefited a lot from OT support at a different paediatric centre."

Access to mental health professionals

Access to appropriate mental health professionals is critical to good quality care. A key issue identified in the survey findings was access to psychological support. Many people living with neuromuscular conditions have a range of mental health needs, including for things like social isolation, social anxiety, relationship difficulties, and neurocognitive problems – all of which require appropriate support.

The 2018 All-Party Parliamentary Group (APPG) for Muscular Dystrophy report, Access to psychological support for people with neuromuscular conditions, demonstrated that psychological support brings significant benefit not only to people with neuromuscular conditions, but also to their wider multi-disciplinary team as it reduces the burden on other key healthcare professionals such as care advisors and clinical nurse specialists. People living with a neuromuscular condition may feel anxious or isolated as they adjust to their diagnosis, and there are also impacts on their family and carers. The importance of access to mental health services is also highlighted in the Optimal clinical pathway for adults with neuromuscular disorders, which notes evidence that mental health problems increase the cost of care by 45%.[16]

Unfortunately, there is a significant lack of access to specialist neuromuscular mental health professionals across the UK. 63% of adults and 82% of paediatric respondents felt support from a specialist neuromuscular psychologist would be useful. However, of these only 17% of adults and 26% of children had been able to access this support.

Do you feel that psychological support from a specialist neuromuscular psychologist would be useful?	Adults (N = 576)	Paediatric (N = 93)
Yes	63%	82%
No	30%	15%
Prefer not to say	7%	3%

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[16] National Neurosciences Advisory Group, *Optimal clinical pathway for adults with neuromuscular disorders* (NNAG 2024) accessed from https://www.nnag.org.uk/optimal-clinical-pathway-adults-neuromuscular-disorders

Have you been able to access this psychological support?	Adult (N = 365)	Paediatric (N = 76)
Yes	17%	26%
No	79%	70%
Prefer not to say	5%	4%

> Psychological services is the gaping hole in an otherwise very good service. This should be provided as standard for families experiencing serious and life limiting conditions such as muscular dystrophy. We have tried for years to get support, and nothing has been offered that fits our needs in this space, yet it could be one of the greatest positive impacts to quality of life.”

> More support from other specialties available, e.g. dietitian, psychologist. Psychological support, none available for child or parent.”

> I feel that more psychological support should be ongoing after genetic counselling and diagnosis.”

> I wasn’t aware there were neuromuscular psychologists.”

> There needs to be better support in mental health, and [for] professionals to have a better understanding of the challenges that come with complex needs and treatment. The services that are attached to neuromuscular should have [a] better understanding or listen to the patient rather than thinking they know better, considering the consultant can struggle to give treatment.”

While workforce shortages remain a serious issue that must be addressed in the longer term across the wider NHS, access to specialist neuromuscular mental health professionals must be a key part of that, with sustainable investment needed to ensure the expansion of a specialist workforce. This resonates with the latest report by the Specialised Health Care Alliance on the unmet mental health needs of people living with a rare condition, who found that there is inequitable access to mental health support across the UK and is often poorly integrated into their wider health and social care.[17]

Our survey findings showed that many people with a neuromuscular condition are struggling to access the psychological support they need to manage their condition.

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[17] Muscular Dystrophy UK is a member organisation of the Specialised Health Care Alliance. See further: *SHCA survey: unmet mental health needs of people living with a rare or complex condition* (SHCA 2023) accessed from https://shca.info/wp-content/uploads/2024/04/SHCA-survey-%E2%80%93-unmet-mental-health-needs-.pdf

Assistive devices in neuromuscular conditions

People living with neuromuscular conditions can sometimes have chronic respiratory failure. To help manage their lung function and prolong survival, often assistive equipment such as non-invasive ventilation (NIV) or mechanically assisted cough may be needed.

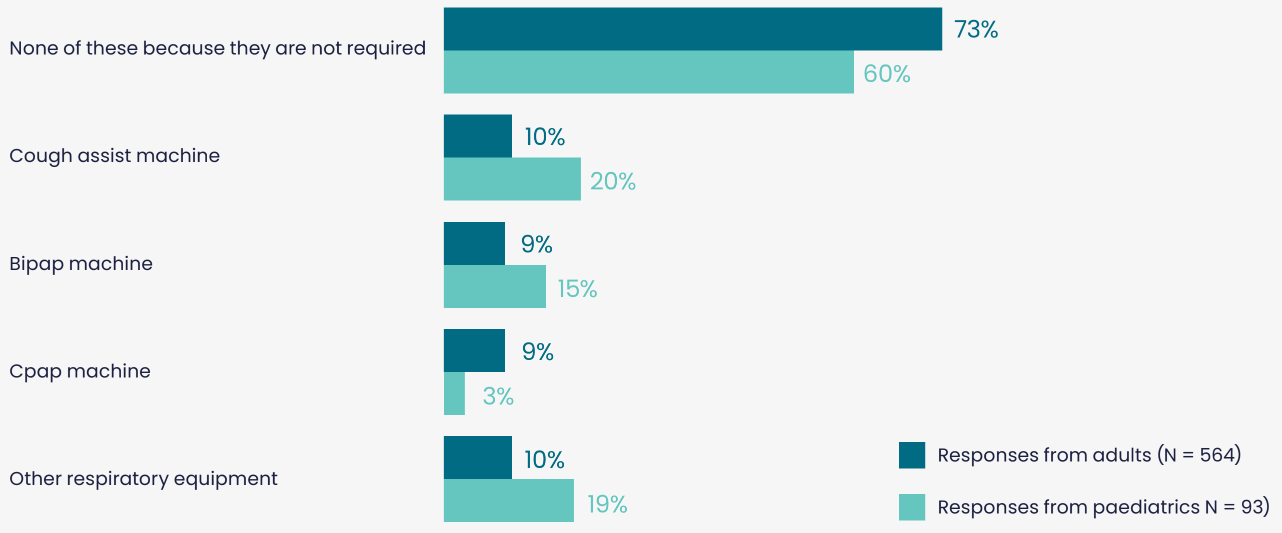
NIV supports breathing by using a machine and tight-fitting mask that sits over the nose and mouth, which improves lung effectiveness. Bilevel positive airway pressure (BiPap) is a trade name that is often used interchangeably with the term NIV, which is commonly used in the UK.

Continuous positive airway pressure (CPAP) is a machine that blows air through a mask into the nose or mouth, which helps people to breathe while they are asleep.

Having chest secretions in the airway can impair breathing and can also increase the risk of pneumonia. However, for some people with neuromuscular conditions, muscles that are needed to cough may weaken. To assist with this, some people may also be using cough assist, which is an equipment used to help effectively mobilise and clear chest secretions to cough.

27% of adult and 40% of paediatric respondents who answered this question use at least one piece of assistive equipment. Of those, over one in three use multiple pieces of equipment, and were allowed to submit responses for each piece of equipment that they use.

Which, if any, of the following equipment do you use due to your neuromuscular condition? Select all that apply.



It is important for people who are using assistive equipment, as well as their families and carers, to be provided with information on how to care for the equipment, and to be able to contact their NIV team for any enquiries or issues they might have. Some of our respondents shared their experience, which has largely been positive:

> Respiratory care is the best aspect. I feel confident that knowledgeable and timely support will be available should I experience any acute respiratory issue or infection. The home ventilation service has been good… I am able to access the ventilation equipment I need fairly easily."

> The respiratory care is very good and the nurses are easily accessible."

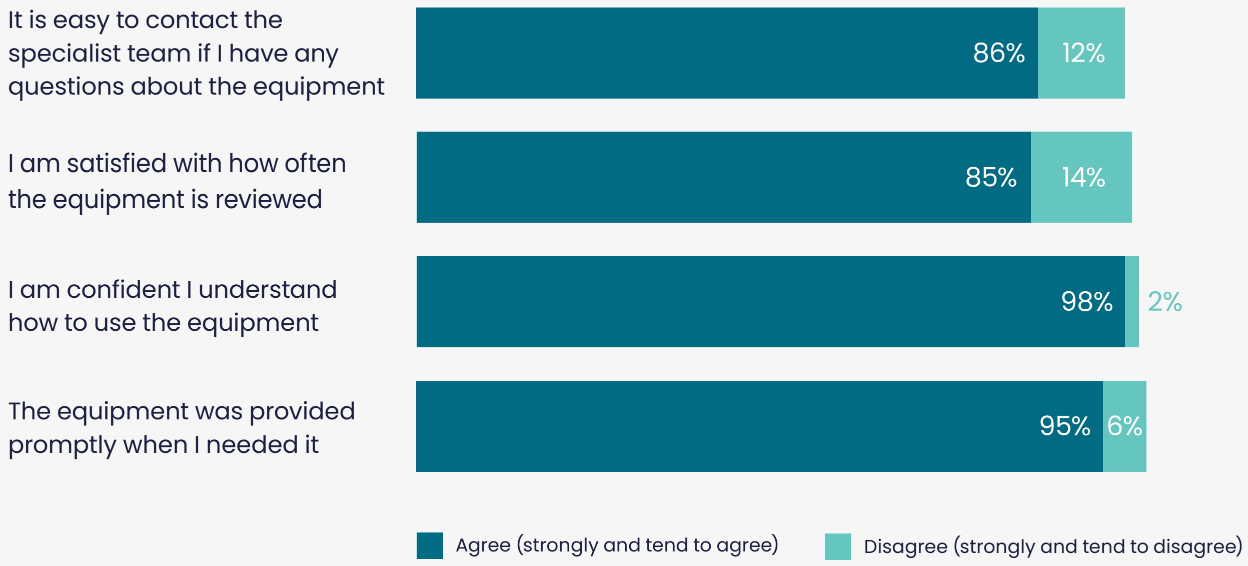
> They have kept me alive and provide me with the necessary equipment to support my breathing. The team provides support when the settings on my equipment need adjusting."

Some people, however, noted difficulties around communication with their respiratory team and coordination of appointments – which demonstrates an impact of a neuromuscular care coordinator:

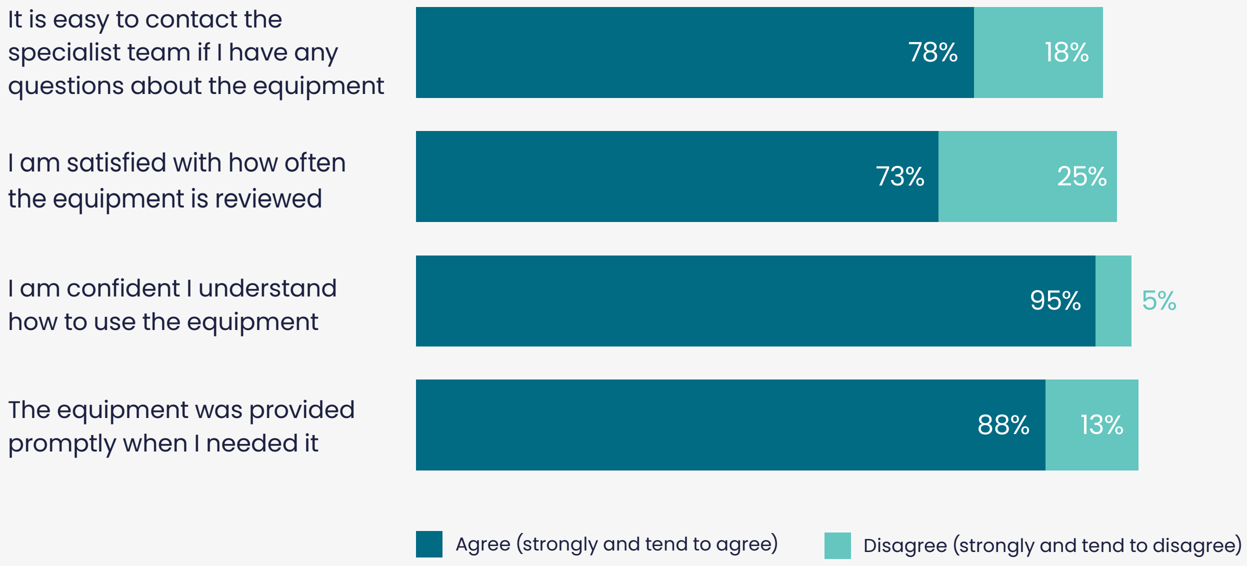
> It is not always easy to contact the respiratory team if I need equipment or advice."

> Respiratory care (although respiratory physio excluded) is not great. Appointments changed without notice, they continue to be on video call and not in person…"

Please tell us to what extent you agree or disagree with the following statements.
Answers about cough assist, bipap and cpap equipment from adult centres (N = 160)



Please tell us to what extent you agree or disagree with the following statements.
Answers about cough assist, bipap and cpap equipment from paediatric centres (N = 40)



Emergency Care Plan

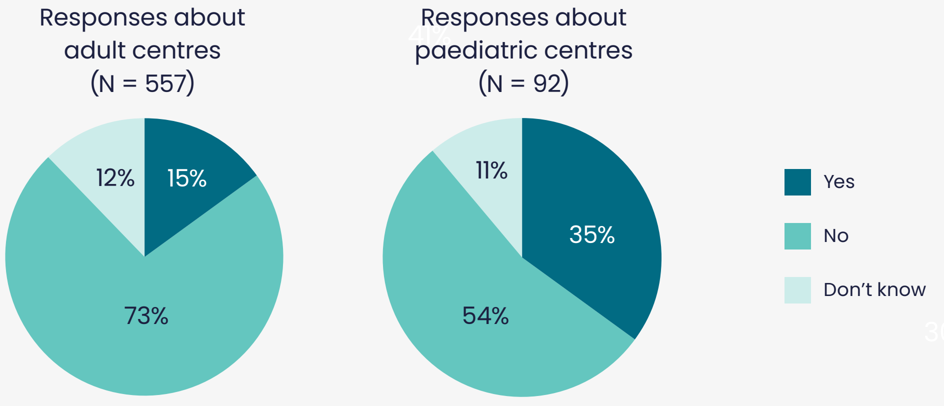
Neuromuscular conditions are rare, and in some cases, due to a heightened risk of medical complications, people living with a condition can be at an increased risk of requiring acute and emergency care. Some people will have specific care needs due to their condition, and when emergency care personnel do not hold information about these needs it can result in poorer quality or even unsafe and dangerous care.

Healthcare professionals who do not specialise in neuromuscular conditions may not have the necessary knowledge and expertise to provide the right care. It's therefore important that people with neuromuscular conditions have a clear and well-documented emergency care plan in place, which can be easily and effectively accessed by ambulance services and A&E staff. Emergency care plans are an important measure in preventing unplanned hospital admissions.

> It needs to be communicated with hospitals especially A&E departments as when attending my local urgent care or A&E department they have no idea what to do with me."

> I have a home ventilation care plan in place outlining the steps that should be taken if I develop an infection and this helps make admission into hospital smoother."

Have you/they been provided with an emergency health care plan for your/their neuromuscular condition?



The survey respondents cover the 60 neuromuscular conditions, and it's important to note that not everyone with a condition requires an emergency care plan, for example in conditions where there are no issues of a cardiac or respiratory nature. For people with complex conditions, it's essential neuromuscular services ensure patients have a clear and well-documented emergency care plan to ensure that they get the care they need, one which can be presented on admission. It is also important to ensure there is an accessible copy for when a patient is seen by peripheral hospitals and clinics, with contact numbers made available should they wish to contact the neuromuscular team directly.

However, the experience survey highlighted the challenges that remain about emergency care plans. All respondents were asked regarding the provision of emergency care plan (this question was open to all respondents to answer, and not just those with specific medical circumstances where an emergency care plan would be required). 15% of adults and 35% of children were sure they had an emergency care plan in place. Of those, the majority had been involved in the development of their plan (65% of adults, 63% paediatric respondents) but more than a third (35% and 38% respectively) were not.[18] Given the importance of patient-centred care, with patients being partners for decisions of care, it is important to ensure that they participate in this development, as well as their families and carers, with the emergency care plan being developed before any crisis occur. We have worked alongside neuromuscular health care professionals to develop a care plan that everyone in our community can use, which include background information, contact details of neuromuscular teams, care advisors, and GP, details about the neuromuscular conditions, any medications in use, acute trauma care in the event of injuries, and, where appropriate, cardiac, respiratory, and anaesthetic management.[19]

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[18] From a sample of 82 adults and 32 paediatric respondents.

[19] Muscular Dystrophy UK, 'Care plan' accessed from https://www.musculardystrophyuk.org/support/information/your-condition/care-plan/

Co-ordination of care

As is clear from the above, neuromuscular care is highly complex requiring coordination between many different specialties – within the same hospital, across multiple specialist centres and between specialist and community services.

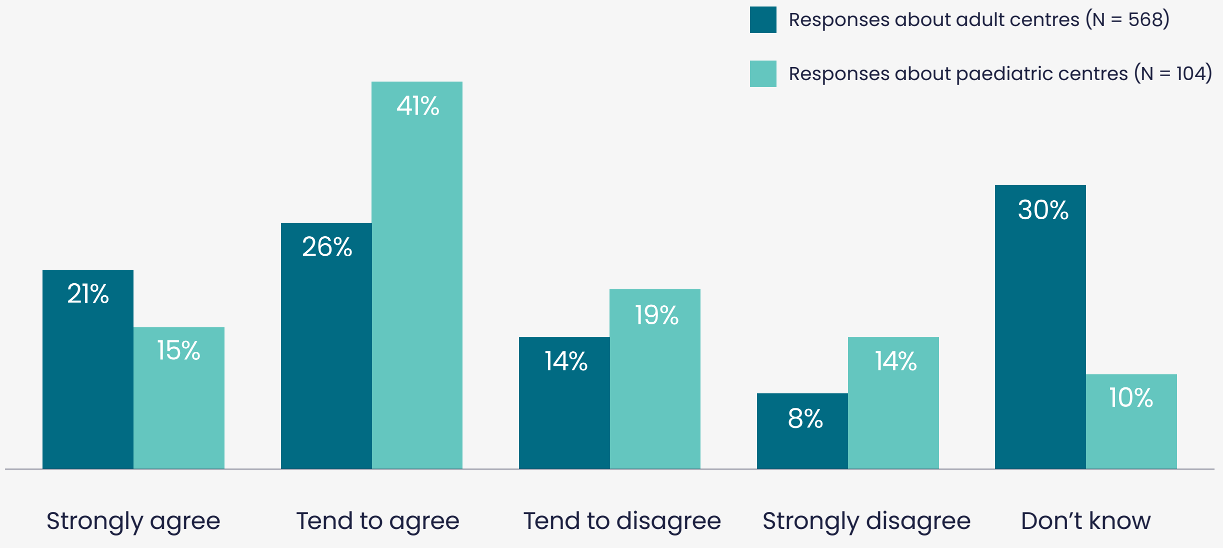
> I wish that different hospitals could access each other's notes. I receive cardiology care from [one centre], and neurology at [another]. It is so difficult, as the neurologist does not have access to cardiology notes so has previously requested lots of heart tests, when I didn't need them. This wastes NHS time and money, and my time. It is so frustrating that hospitals cannot access my notes."

> Could be more coordination across various departments involved. Cardiology / respiratory / endocrinology/ bone team and neuromuscular team could coordinate better appointment times, blood tests, advice etc…"

> The individuals within teams are all wonderful but the systems by which they communicate need a lot of work. It feels very disorganised since we first started attending (4 years ago)."

Coordination between neuromuscular centres and community teams is a particular challenge. 47% adult responses and 56% paediatric responses agreed that centres communicated well with community teams. However, one in five (22%) adult responses and one in three (33%) paediatric responses felt their centres did not communicate well with local teams.[20]

To what extent do you agree or disagree that [neuromuscular centre] communicates well with community teams to plan you/your child's neuromuscular care?



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[20] This analysis is based on number of responses about specialist centres, not number of respondents, as people who receive care at multiple centres were allowed to give answers for each one.

This communication is particularly vital as many of the non-neuromuscular specialist services people with neuromuscular conditions require have little experience in managing their complex needs.

We often hear stories of people living with neuromuscular conditions, and those who have yet to receive a confirmed diagnosis, where healthcare professionals have been unable to help as they've never heard of, nor understood, a similar case presentation to identify or manage rare conditions.

> Overall, it has improved since I was diagnosed over 50 years ago. Now there is so much more info available and there is more communication. However, I think GPs need to have more training with lifelong conditions. Services need to be brought together more."

> GPs just do not know enough about the condition, and in mine and my son's experience, have been an active barrier into access to services... Access to service is incredibly difficult via primary care."

> Better coordination with local services [is needed]. Referral to local services are made but the appointment never happen."

> It would be good if there was a better link with local services. They recommend things but [it's] not always possible to receive the treatment support locally that they would like me to have. I.e. physio & hydrotherapy."

> Better communication between medical professionals, e.g. faster or clear plan between GP and consultant."

Given that the NHS is made up of various organisations, from GP surgeries, ambulance services, to NHS Trusts, it is crucial that clinical information in electronic patient records is shared effectively between relevant services. It also reinforces the need for sustainable investments to retain and increase neuromuscular care advisors, given the importance of their role in coordinating care.

Time spent coordinating care

One in 10 (9%) adults and one in four paediatric respondents (26%) felt they spent too much time coordinating their neuromuscular care.[21]

The burden was particularly high amongst paediatric respondents, of whom 59% spent more than an hour per week on average coordinating their care, and 7% spent more than five hours per week.

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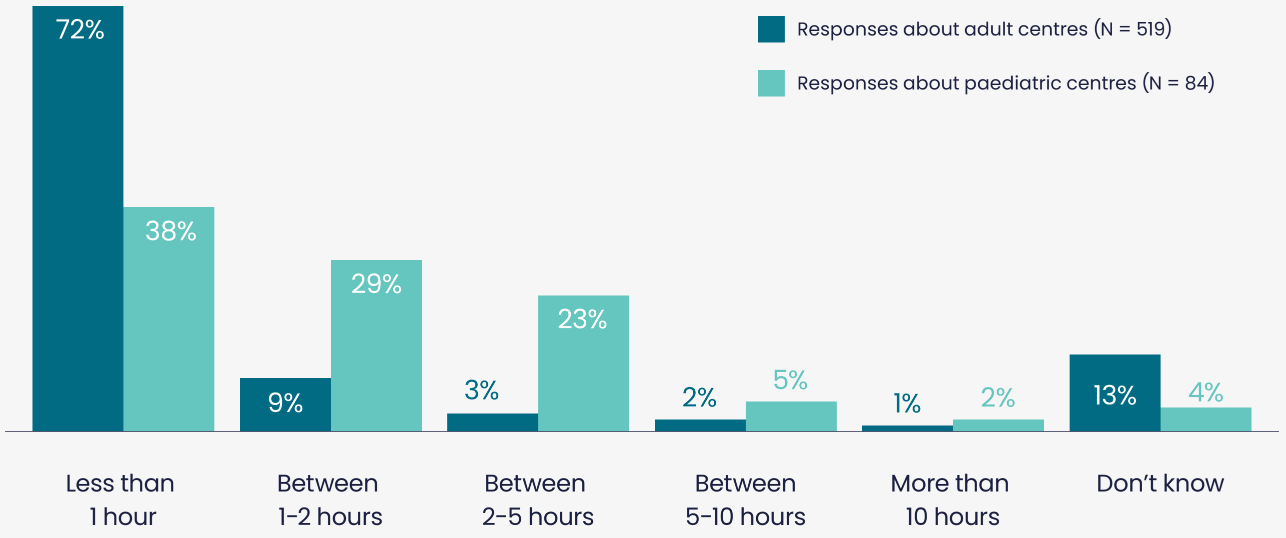
[21] By co-ordinating care, we mean activities such as booking appointments, organising treatments, filling out forms, writing relevant letters or reviewing results. This excludes time spent at appointments or time spent receiving care due to a condition. The adult figure includes only those who were answering on behalf of themselves to allow more accurate recall.

On average, how much time each week would you estimate that you spend coordinating you/your child's neuromuscular care?



> I feel I receive good care but by a lot of different departments and at different NHS trusts. I don't know how much they talk to each other and it feels disjointed sometimes so I feel I have to coordinate it myself...lots of services that I'm very grateful for but all feel very separate."

> There isn't enough staff, clinical or admin. Communication used to be good but now it isn't. Simple requests aren't actioned unless chased by me."

> Just more nurses so we are dealt with sooner, feel like I'm forever chasing people..."

> Because there is no treatment for Inclusion Body Myositis I feel it is very much up to me access help. I need to chase referrals to physio and OT locally and constantly come up against service providers who do not understand this condition."

> [I would like] more joined up support. Rather than independently seeing each team maybe have multiple specialist all together with a common aim and discussions about plans moving forward. Also working with all effected family members together rather than multiple separate appointments."

The above experience demonstrates the importance of care coordinators in ensuring a more joined-up care and better overall patient experience. Indeed, the UK Rare Diseases Framework put as one of the priorities that there needs to be a better coordination of care to ensure it is effectively managed, with less burden on people living with rare conditions and their families and carers, and allow health care professionals to work and collaborate together.[22]

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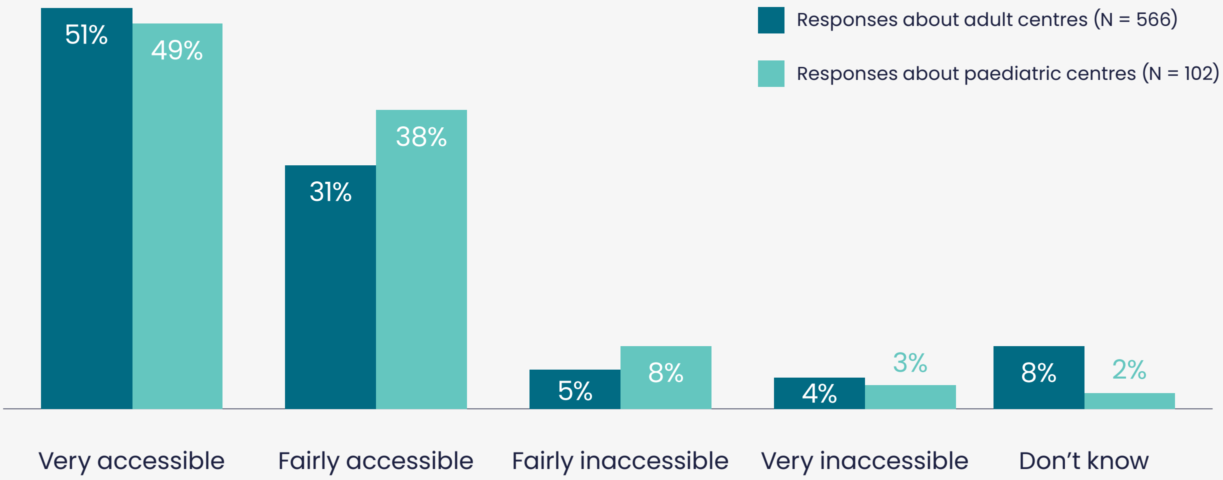
[22] Department of Health and Social Care, 'The UK Rare Diseases Framework' (2021) accessed from https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework

Accessibility of NHS facilities

How accessible do you/they find [neuromuscular centre]?



82% of adult responses and 87% of paediatric responses rated their centres as fairly or very accessible.[23]

However, some respondents said that NHS facilities were not always accessible for disabled people due to things like a lack of hoists, unsuitable room sizes for wheelchair users to move easily, as well as a lack of disabled parking bays. Parking was a considerable barrier for many respondents, who reported a lack of parking facilities made attending NHS appointments difficult.

> We have had appointments in tiny rooms… where it has been difficult for my son to turn his wheelchair. Getting through some doors in the hospital and through corridors is sometimes hard. Larger rooms, with electronic doors, and less clutter in corridors would be good."

> Like almost all hospitals I have dealt with, I feel I always need to plan ahead for things such as hoists. Not readily available and always need to make phone calls prior to visits to ensure they are there."

> Parking facilities would be extremely helpful, as currently there are none. This makes it very difficult to attend appointments."

> More parking for disabled people who can't use tram/public transport and so have no choice but to drive and park. Sometimes it's impossible to park or it's a long way from where I need to go."

> More space for wheelchairs in consulting rooms."

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[23] This analysis is based on number of responses about specialist centres, not number of respondents, as people who receive care at multiple centres were allowed to give an answer for each one.

Also affecting accessibility at some NHS facilities, the survey findings indicated that some NHS hospitals do not have registered Changing Places toilets (CPt).

Between 2017 – 2025, we were a Co-Chair of the Changing Places Consortium. It was set up in 2005 to campaign for CPts to be installed in all large public spaces so more people can access their community. CPts are different from standard accessible toilets in that they provide an adult-sized changing bench, an overhead hoist system, a larger space, height adjustable wash basin, and a peninsular toilet.

There are currently over 2,507 registered CPts in the UK. Unfortunately, only 123 out of over 900 NHS hospitals have a registered CPt with the Changing Places Consortium.[24] While this has been an increase from 20 CPt in 2014, this still results in difficulties for disabled people when attending medical appointments. Some of our respondents highlighted these issues.

> “On our visit in February I did not see a suitable wheelchair friendly, high disabled toilet for people with muscle disabilities, unable to transfer from low seating back into their wheelchair.”

> “It would be great if there was access to a hoist in toilets as this would enable someone like myself to use the toilet. As it is, this is impossible.”

> “We were not made aware of a Changing Places toilet in the hospital despite asking for a year.”

It is a major concern that some NHS facilities continue to lack the vital infrastructure necessary to support medical appointments being as accessible as possible for disabled people. We'll continue to work with the NHS and the Government to ensure inclusive facilities are available at NHS hospitals.

Only 123 out of over 900 NHS hospitals have a registered CPt with the Changing Places Consortium.[23]

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[24] For further information, please refer to the Changing Places Consortium's website: https://www.changing-places.org/find

Improvement of services

At the start of this report, we began by highlighting the commentaries from our respondents regarding things that are working well with their care, and the positive differences that their specialist neuromuscular team has made to their neuromuscular care. Significant gaps, however, remain, and throughout the survey, respondents also detailed areas they considered in need of improvement. These ranged from a better joined-up and coordinated care, better communication between different health and social care teams, and better provision of care, such as mental health provision or therapy provision.

> “The care has become more joined up over the years, for example having clinic, physio and heart scans on the same day, which is good, but this could go even further to minimise the number of visits people have to make. This would mean longer days but would negate more than necessary stressful commutes.”

> “More communication in transitioning from paediatric to adult care.”

> “I feel they should carry out annual checks to compare year on year and to make sure I'm functioning at my best. If I have any concerns they just seem to get brushed off. Communication needs to be improved too. And more time spent with each individual.”

> “It would be helpful to have greater commitment from the health trusts to outline what an expected care plan could look like and what options are available post diagnosis, including counselling.”

> “I would love to be able to access hydrotherapy regularly. I have had sessions but when the course finishes I have to get put forward again and go on the waiting list again and it can be over a year before I get another chance.”

> “I would like more information supplied in regards to trials.”

> “Perhaps, some connection with others with the same condition might be helpful. Maybe we could help each other, and therefore, not feel quite so alone with this rare condition. It impacts so much, in so many ways on our daily lives.”

Many healthcare professionals, with their high level of dedication and commitment to provide care, are struggling with pressures on their clinic time and workload in supporting their patients.

Recommendations

There remains a significant gap for people living with neuromuscular conditions to access the right care, treatment, and support, with a variation across the UK and in some cases, disjointed care. Many healthcare professionals, with their high-level dedication and commitment to provide care, are struggling with pressures on their clinic time and workload in supporting their patients. To ensure that people living with neuromuscular conditions, as well as the neuromuscular workforce, to receive the best possible care, we call on:

- NHS commissioners, Integrated Care Boards, and health boards to utilise the optimum clinical pathways for neuromuscular conditions to commission and improve services to meet the needs of people living with neuromuscular conditions.
- The UK and the devolved governments to ensure sustainable investment to increase and retain specialist neuromuscular workforce to ensure it is fit for the future, as well as increasing investment in research into neuromuscular conditions.
- NHS Trusts, health boards, and commissioners to formally recognise neuromuscular care advisors as a core role within multi-professional team to help reduce unplanned emergency admissions and ensure holistic, well-coordinated support for people living with neuromuscular conditions.
- The UK and the devolved governments to ensure that rare conditions, including neuromuscular conditions, are embedded within medical school curricula to increase understanding and knowledge of the care, treatment, and management of these conditions.
- Changing Places Toilets to be installed in all NHS sites and buildings, as these toilets provide extra space and equipment to allow people living with neuromuscular conditions to use them safely and comfortably.

Our charity works with healthcare professionals and researchers who have high-level dedication and commitment to deliver the best possible care for their patients, and experience such as the above has expressed the importance of their roles in advancing the overall quality of life of people living with neuromuscular conditions. Given the increasing pressures within the NHS on workload, available resources, and time, it is thus important that policies and sustainable investments are made to ensure a strong neuromuscular workforce that is fit for the future.

Next steps

The findings of the 2023 *Experience of Neuromuscular Care* survey provide an insight into the lived experiences of people with a neuromuscular condition in accessing neuromuscular care. These findings will further enable us in continuing to campaign for improvements to healthcare services for our community of over 110,000 people living with a condition. As part of our mission to work with the NHS towards universal access to specialist healthcare we are committed to working with all neuromuscular centres across the UK.

It is a major concern that some NHS facilities continue to lack the vital infrastructure necessary to support medical appointments being as accessible as possible for disabled people. **We'll continue to work with the NHS and the Government to ensure inclusive facilities are available at NHS hospitals.**

List of centres in the survey

The following NHS hospitals are included in the survey. Whilst 27 neuromuscular centres participated in the Centre of Excellence awards audit, the survey recorded a wider number of NHS hospitals attended by people receiving neuromuscular care.

- Aberdeen Royal Infirmary
- Addenbrookes Hospital Cambridge
- Aintree University Hospital Liverpool
- Belfast City Hospital
- Betsi Cadwaladr University Health Board, Wales
- Birmingham Heartlands Hospital
- Bradford Royal Infirmary
- Gloucestershire Royal Hospital
- Hull Royal Infirmary
- John Radcliffe Hospital, Oxford
- John Walton Muscular Dystrophy Research Centre, Newcastle
- King's College Hospital, London
- Leeds General Infirmary
- Leicester General Hospital
- Musgrove Park Hospital, Taunton
- National Hospital for Neurology and Neurosurgery, London
- Ninewells Hospital, Dundee
- Norfolk and Norwich University Hospital
- Nottingham University Hospital (Queen's Medical Centre)
- Mount Gould Hospital, Plymouth
- Queen Elizabeth Hospital Birmingham
- Queen Elizabeth University Hospital Glasgow
- Robert Jones and Agnes Hunt Orthopaedic Hospital Oswestry
- Royal Brompton Hospital, London
- Royal Cornwall Hospital
- Royal Derby Hospital
- Royal Free Hospital, London
- Royal Hallamshire Hospital, Sheffield
- Royal London Hospital
- Royal Stoke University Hospital
- Royal Victoria Hospital, Belfast
- Salford Royal Hospital
- Southampton General Hospital
- Southmead Hospital, Bristol
- St. Bartholomew Hospital, London
- St. George's University Hospital, London
- St. Luke's Hospital, Bradford
- St. Thomas' Hospital, London
- Swansea Morriston Hospital
- University Hospital of Wales
- Western General Hospital, Edinburgh

List of contributors

The successful running of the 2023 Centres of Excellence Awards and Experience of Neuromuscular Care Survey were the results of the contribution from the following individuals and organisations:

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