



## COST OF LIVING

# The Impact of rising costs on people living with a muscle-wasting condition

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[www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org)

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



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# Introduction

Since 2021, the cost of living has drastically increased across the UK, disproportionately affecting disabled people, including those with a muscle-wasting condition. MDUK has become increasingly aware of concerns from our community about the increased costs of things such as electricity for operating ventilation equipment and for charging other equipment, heating to keep warm, and petrol to attend appointments. We have also heard concerns about the inability of people affected by muscle-wasting conditions to build savings so that they can plan for the long-term and prepare for future costs associated with often progressive conditions as a result of the increase in daily costs.

Now is an opportune time to review the additional costs people with a muscle-wasting condition consistently face. This will provide better insight to improve the support available to ensure no person with a muscle-wasting continues to struggle to a point they need to go without food, heating, or access to appointments, especially as the cost of living crisis is predicted 'to get worse before it gets better'.<sup>1</sup>

The UK Government has offered welcome additional support to help with the cost of living for people entitled to certain benefits or tax credits, which will include some people with muscle-wasting conditions<sup>2</sup>, and has also announced some universal support. However, people told MDUK through focus groups and a survey that this additional support still isn't sufficient to cover the rising cost of living, and there is now an urgent need and an opportunity to address some of the longstanding barriers to accessing financial

support, while also navigating the immediate needs to appropriately support people living with muscle-wasting conditions through this cost of living crisis.

This report sets out why there are additional costs associated with living with a muscle-wasting condition; the impact that the rising cost of living is having on people with a muscle-wasting condition; and makes recommendations about the actions that need to be taken by a range of stakeholders and decision makers, including the Department of Health and Social Care, UK Government, Local Authorities, and Integrated Care Systems, and we would value the opportunity to work with you to drive them forward.

Muscular Dystrophy UK would like to thank the hundreds of people living with muscle-wasting conditions who have contributed to this report by responding to our survey and joining our focus group discussions.

<sup>1</sup> Yahoo News UK, Cost of living crisis 'will get worse before it gets better' after interest rate hike, June 2022: [https://uk.news.yahoo.com/interest-rate-rise-worsen-cost-living-crisis-171255233.html?guccounter=1&guce\\_referrer=aHR0cHM6Ly93d3cuZ29vZ2xlLmNvbS8&guce\\_referrer\\_sig=AQAAAJzWmGa3JqAceGyeFMRI1KMQZx-mpGmxoeMSOC5dOhRQ5iTZawmC6QLdWAuXESmAAAdN3ZTL9WhQaMP1iburwMa9AY3NQKh7lgwDMP-ek44yDXgkup177RxishtVjRbhYbACD5rROS5z5XMq1K-d5HZf5\\_xyFN215clBEBEAItpx9UD](https://uk.news.yahoo.com/interest-rate-rise-worsen-cost-living-crisis-171255233.html?guccounter=1&guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2xlLmNvbS8&guce_referrer_sig=AQAAAJzWmGa3JqAceGyeFMRI1KMQZx-mpGmxoeMSOC5dOhRQ5iTZawmC6QLdWAuXESmAAAdN3ZTL9WhQaMP1iburwMa9AY3NQKh7lgwDMP-ek44yDXgkup177RxishtVjRbhYbACD5rROS5z5XMq1K-d5HZf5_xyFN215clBEBEAItpx9UD)

<sup>2</sup> Department of Work and Pensions, Cost of Living Payment Guidance, May 2022: <https://www.gov.uk/guidance/cost-of-living-payment#disability-cost-of-living-payment>

## Methodology

We have based this report on a national survey we conducted which looked at the additional costs associated with living with a muscle-wasting condition. We heard from people living with a condition, as well as their families, between April and August 2022. Over 160 people responded, providing insight into how the increasing cost of living is placing further pressure on those already financially struggling.

We also held a series of focus groups to discuss our findings and to hear in more depth the financial impact of living with a muscle-wasting condition, not just from a budgetary perspective, but also on people's mental and physical health.

Accompanying these findings of our own direct research, we have also drawn on previous MDUK work in this area and on recent work undertaken by other health and disability charities.

At the heart of this report are the voices of people living with a muscle-wasting condition and their families. The report presents clear insight into the additional costs associated with living with a muscle-wasting condition and the additional financial hardships that families have faced due to the pandemic and the increasing costs of living, and what needs to happen in the future to better support them.

*"I'm in a situation at the moment where prices are ridiculous in everything – fuel, paying for car"*  
 Person living with a muscle-wasting condition

*"My partner is my carer who works five days a week and cares, we can't afford outside help"*  
 Person living with a muscle-wasting condition

## Key Findings

Our findings indicate that people living with a muscle-wasting condition already face significant additional costs to manage their condition which leads to many financially struggling. With the cost of living now increasing, these struggles are becoming more exacerbated. The insufficient support in place is not only having a negative impact on their quality of life, but also on that of their families. These findings only offer a glimpse into these experiences, and the issues will worsen unless properly addressed.

### Daily costs associated with living with a muscle-wasting condition

- Over 40% of respondents are in or have previously been in financial difficulty, with over 70% worried about their current financial situation.
- Over 59% have spent up to £10,000 on implementing and maintaining housing adaptations.
- Over half of respondents (51%) have spent up to £2,500 on wheelchairs, with over 65% spending up to £500 on wheelchair repairs and maintenance per year.
- 60% have spent up to £1,000 on installing and running hoists and lifts.

### Treatment and therapeutic costs

- 62% of respondents didn't pay for any medications, but for those who did they would spend up to £125 a year.
- 61% of respondents didn't spend any money on additional therapeutics. Many said this was because they couldn't afford to do so.
- From those who did pay, they spent up to £300 a year to access to treatments such as hydrotherapy, swimming, or chiropractors.
- 95% of respondents also don't pay to access mental health support relating to their condition. The prevalent reason again was because they couldn't afford to do so which has had a profound impact on their overall wellbeing.

*"I attempted suicide and spent 12 weeks in hospital but still don't receive the mental health support I need"*

Person living with a muscle-wasting condition

*"I pay for hydrotherapy twice a month which is a 100-mile round trip. The cost of the petrol alone costs me over £100 per month."*

Person living with a muscle-wasting condition

### Impact of rising costs

- Most respondents (73%) have already noticed an increase in their utility bills, with some noting they require additional heating to help with their mobility and additional electricity to charge their equipment – estimates for this rise varied from £100 - £450 a month.
- To meet their dietary requirements, 56% of respondents are spending an additional £25 to £150 a month, which equates to between £300 and £1,800 extra a year.
- Over 80% of respondents spent up to an additional £100 a month to travel to healthcare appointments.
- Additional costs for carers were variable with some relying on family as they can't afford carers and others spending up to £400 extra per week to access support.
- 68% of respondents said the pressure of these increasing costs is negatively impacting their mental health.

### Accessing employment

- 83% of respondents were unemployed and 20% were in part-time employment.
- Many respondents attributed their employment status to the burden of attending appointments with many also needing to take unpaid leave.
- Similarly, employment impacted carers of people with a muscle-wasting condition with many losing a day's wages to help attend appointments.

*"If my partner needs time off to take me to appointments, they lose a day's wage which equates to about £90/£100 each time"*

Person living with a muscle-wasting condition

*"I am a self-employed single parent, so anytime my daughter is ill, needs to go to appointments or is off school for holidays, I have to take unpaid leave"*

Parent with a child living with a muscle-wasting condition

### Executive Summary

Over 110,000 people are living with a muscle-wasting condition in the UK. Many of these conditions are progressive and some are life limiting, and their impact can lead to a large amount of additional costs to ensure that people can live well for as long and as independently as possible. The financial burden of attending a vast array of specialist appointments, charging specialist equipment and electrical wheelchairs, and paying for private therapeutic treatments that are unavailable through the NHS cannot be overstated. This is now being exacerbated by the increase in the cost of living being felt by the whole population, which is leading to many people living with a muscle-wasting condition having to make tough decisions such as restricting the purchase of groceries or limiting travel. For example, by only using their equipment at home when it is necessary in order to save money on electricity and to reduce the number of appointments they attend to save money on petrol.

Our research has revealed that people affected by muscle-wasting conditions are currently facing an increase of up to £450 a month on their utility bills, up to £150 month on their food bills and an additional £100 a month on petrol to travel to healthcare appointments. This is excluding their daily costs of living with a muscle-wasting condition such as the additional costs for carers, with some relying on family as they can't afford carers and others needing to spend up to £400 extra per week for support. 68% of respondents said the pressure of these increasing costs is negatively impacting their mental health.

The UK Government has launched a range of initiatives to support both the general population and specific groups struggling with increasing costs such as a one-off £150 Disability Cost of Living Payment and a one-off £650 Cost of Living Payment for those on means tested benefits. This is in addition to the Warm Houses Scheme which offered a one-off £140 off the electricity bill for winter 2021 to 2022, and the

Government's Energy Price Guarantee which will mean a typical UK household will now pay up to an average £2,500 a year on their energy bill for the next two years.<sup>3</sup> More needs to be done. As such, Muscular Dystrophy UK has put forward key recommendations which will go a long way to not only support people living with a muscle-wasting condition and their families during this cost of living crisis, but to also better support them in the long-term to enable the muscle-wasting community to better cope with the financial impact associated with their condition.

### Recommendations at a glance

1. Increase benefits in line with current levels of inflation to better support the increasing cost of living.
2. Lift the cap on the Disability Facilities Grant and introduce flexibilities to better reflect the progressive nature of muscle-wasting conditions when assessing applicants.
3. Increase carers allowance to equal 35 hours at National Minimum Wage to better support people living with a muscle-wasting condition and their families.
4. End VAT on energy bills for people living with a long-term condition, including people with a muscle-wasting condition, to make these costs more manageable.
5. Improve access to critical specialist and community services to reduce reliance on private provision and to subsidise private provision of core treatments where delays to NHS appointments are unmanageable.
6. Improve coordination of care and improve access to appointments closer to home to reduce time taken off work and expenditure on petrol.
7. Implement a hospital travel card scheme to provide subsidised, accessible travel to people living with a long-term condition, including people living with a muscle-wasting condition.
8. Improve employer understanding of and flexibility around the needs of people with muscle-wasting conditions

<sup>3</sup> The UK Government, Government announces Energy Price Guarantee for families and businesses while urgently taking action to reform broken energy market, September 2022: <https://www.gov.uk/government/news/government-announces-energy-price-guarantee-for-families-and-businesses-while-urgently-taking-action-to-reform-broken-energy-market>

Table 1 Summary of additional costs associated with living with a muscle-wasting condition

<b>Cost area</b>	<b>Reason for additional cost</b>	<b>Impact of additional cost</b>	<b>How it needs to be addressed</b>
<b>Petrol</b>	People with a muscle-wasting condition need to attend a range of specialist and community appointments which requires additional travel.	A person with a condition may choose to miss appointments to reduce the use of petrol which may lead to early deterioration of their condition.	The implementation of a hospital travel card scheme to provide subsidised travel. And Improved coordination of care and improved access to appointments closer to home.
<b>Energy</b>	People with a muscle-wasting condition have a range of equipment that rely on electricity such as ventilators and wheelchairs.	People with a muscle-wasting condition are reducing their energy use such as heating their homes which is essential to avoiding stiffening of muscles; or their wheelchairs which reduces their ability to move around.	To end VAT on energy bills for people living with a long-term condition, including people with a muscle-wasting condition, to make these costs more manageable.
<b>Food</b>	Some people with a muscle-wasting condition require soft, pre-cut foods, which are often more expensive than alternative food.	With food prices already rising, people with a muscle-wasting condition may need to cut back on their food intake.	Increase benefits in line with current levels of inflation to better support the increasing cost of living.
<b>Housing adaptations and installations</b>	Muscle-wasting conditions are progressive conditions which makes it difficult for people to walk and can eventually require a wheelchair. As such, housing adaptations provide them with the means to live as independently for as long as possible.	Without the appropriate housing adaptations, people with a muscle-wasting condition rely more on their families which leads to issues around working; and a lack of independence which can lead to mental health issues.	Lift the cap on the Disability Facilities Grant and introduce flexibility to better reflect the progressive nature of muscle-wasting conditions to ensure the appropriate support is provided.
<b>Clothing and shoes</b>	People with a muscle-wasting condition often need to buy specialist footwear, orthotics or clothes that are more suitable.	Specialist shoes and orthotics tend to be more expensive and need frequent re-purchasing resulting in additional costs.	Increase benefits in line with current levels of inflation to better support the increasing cost of living
<b>Additional therapeutic support</b>	People with a muscle-wasting condition may decide to access physiotherapy, hydrotherapy and other treatments privately as these are key to strengthening their muscles and are often unavailable on the NHS.	Few people living with a condition can access private appointments and as such often go without accessing these critical appointments. Those who can often need to sacrifice other areas such as electricity usage to be able to afford such provision.	Improve access to critical specialist and community services and subsidise private provision where NHS delays or lack of provision are unmanageable.
<b>Care and employment</b>	Specialist care and support is not available, which places a greater reliance on family members for support.	As a result, many informal carers either have to reduce their working hours or stop working altogether which places an additional financial burden on them.	Increase the carers allowance to equal 35 hours at National Minimum Wage to better support people living with a muscle-wasting condition and their families.

## The additional costs of living with a muscle-wasting condition

### Background

It is well established that disabled people have a range of additional expenses due to their condition, known officially as disability related expenses<sup>4</sup>. A report by Scope (2019) estimated an extra cost of £583 a month on average attributed to living with a disability.<sup>5</sup> The report also showed that one in five disabled people faced extra costs of more than £1,000 a month on adaptations and equipment. This is unsurprising given Muscular Dystrophy UK's own research has shown many people living with muscle-wasting conditions and their families face extreme financial hardship. This is due to the additional costs associated with living with their conditions, such as costs for wheelchairs, home adaptations, and installations of hoists, as well as the subsequent impact of being able to work less, or family members needing to reduce their working hours due to caring responsibilities.<sup>6</sup> Our 2010 *Cost of Living with Muscle Disease* report particularly highlighted:

- Many families affected by a muscle-wasting condition struggle to find accessible and affordable housing, and often battle for years for home adaptations.
- Severe disability can require a wide range of electrical equipment, such as powered wheelchairs, ceiling hoists, through-floor lifts, and ventilators. All of which can cause a dramatic increase in household electricity bills, which many families struggle to meet.

- Caring for a family member or friend with a neuromuscular condition is a full-time job. This places additional pressure on being able to remain in full-time employment which adds further financial constraints on paying for the needs of the individual living with a muscle-wasting disease.

A decade later and these hardships still haven't been addressed to appropriately support people with a muscle-wasting condition to live as independently as they wish for as long as possible. For example, MDUK's 2020 *Below standard: MDUK's assessment of the benefits system* report showed that barriers to accessing benefits start from application stage and continue throughout each point of the process which can also cause more stress and anxiety.<sup>7</sup> The COVID-19 pandemic has further demonstrated that benefits don't sufficiently support those financially struggling, with disabled people pushed into a more precarious financial position.<sup>8</sup> During the pandemic, the UK Government was offering a weekly £20 uplift to Universal Credit. However, many people were excluded from this uplift which caused further anxiety and stress on their financial predicaments.

Now, with the costs of goods and services rising even further, this same population is facing even more hardship. For example, a survey by Leonard Cheshire revealed around one in four working-age disabled people in the UK are currently struggling to pay for essentials, such as food and heating, with more than 600,000 disabled people in the UK estimated to have £10 or less per week to pay for food and other costs.<sup>9</sup> Similar findings were found by Sense who showed disabled households in the UK are being pushed into debt by spiralling living costs, with 54% of those polled by the charity already in debt, and 38% already skipping meals to save money.<sup>10</sup> Further, 74% will be unable to cope

<sup>4</sup> Independent lives, Disability Related Expenses: explained: [www.independentlives.org/disability-related-expenses-explained](http://www.independentlives.org/disability-related-expenses-explained)

<sup>5</sup> Scope, The Disability Price Tag, February 2019: [www.scope.org.uk/campaigns/extra-costs/disability-price-tag/](http://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/)

<sup>6</sup> Muscular Dystrophy Campaign, The Cost of Living with Muscle Disease, November 2010: [www.muscular dystrophyuk.org/static/s3fs-public/2021-07/PDF-Report-Cost-of-living-with-muscle-disease-2010.pdf?VersionId=INgm7rpYILB\\_3aJ6QnPdmX\\_p9M6GGbd](http://www.muscular dystrophyuk.org/static/s3fs-public/2021-07/PDF-Report-Cost-of-living-with-muscle-disease-2010.pdf?VersionId=INgm7rpYILB_3aJ6QnPdmX_p9M6GGbd)

<sup>7</sup> Muscular Dystrophy UK, Below standard: MDUK's assessment of the benefits system, February 2020: [www.muscular dystrophyuk.org/static/s3fs-public/2022-08/Benefit-report.FINAL\\_EMBARGO.pdf?VersionId=lqHdRiOuhRgAXvR41\\_bEJwPbUOi.uMKk](http://www.muscular dystrophyuk.org/static/s3fs-public/2022-08/Benefit-report.FINAL_EMBARGO.pdf?VersionId=lqHdRiOuhRgAXvR41_bEJwPbUOi.uMKk)

<sup>8</sup> Joseph Rowntree Foundation, Briefing: The financial impact of COVID-19 on disabled people and their carers, December 2020: [www.jrf.org.uk/report/financial-impact-covid-19-disabled-people-and-carers](http://www.jrf.org.uk/report/financial-impact-covid-19-disabled-people-and-carers)

<sup>9</sup> Leonard Cheshire, Rising costs are a catastrophe for disabled people, April 2022: [www.leonardcheshire.org/about-us/our-news/press-releases/rising-costs-are-catastrophe-disabled-people](http://www.leonardcheshire.org/about-us/our-news/press-releases/rising-costs-are-catastrophe-disabled-people)

<sup>10</sup> Sense, Disabled households pushed into debt by rising cost of living, June 2022: <https://www.walesonline.co.uk/news/uk-news/disabled-households-pushed-debt-rising-24288943>

if prices continue to rise, and 68% said the pressure is affecting their mental health. These findings further demonstrate the impact the rising cost of living pressures will have on top of the increased costs disabled people face in their daily lives.

The UK Government has set out several initiatives to provide additional financial support to people living with a disability, such as:

- A £150 Disability Cost of Living Payment, available to those across the UK who receive the following disability benefits will receive a one-off payment of £150 from September: Disability Living Allowance; Personal Independence Payment; Attendance Allowance; Scottish Disability Benefits; Armed Forces Independence Payment; Constant Attendance Allowance; War Pension Mobility Supplement

and

- A £650 one-off Cost of Living Payment for those on means tested benefits for households receiving the following benefits: Universal Credit; Income-based Jobseekers Allowance; Income-related Employment and Support Allowance; Income Support; Working Tax Credit; Child Tax Credit; Pension Credit

In September 2022 the Government's Energy Price Guarantee was announced. This will mean a typical UK household will now pay up to an average £2,500 a year on their energy bill for the next two years – although due to the additional costs highlighted throughout this report, the true cost for disabled people will be higher than this.<sup>11</sup>

However, these schemes aren't enough to address the additional costs associated of living with a muscle-wasting condition as we face a cost of living crisis.

### Why living with a muscle-wasting condition leads to an increase in the cost of living

Muscle-wasting conditions are rare and complex multi-system disorders which require access to a wide variety of specialist appointments and additional equipment to live as independently as possible. Consequently, people with a muscle-wasting condition and their families are faced with a significant additional financial burden whilst struggling to maintain full time employment. This was evident from our findings where 38% of respondents are currently in or have previously been in financial difficulty.

### Cost areas

#### Travel

We have frequently heard that people living with a muscle-wasting condition have to travel many days out of the month to access the variety of care they need. For example, one week they might have to travel to see their neuromuscular consultant and then a week later to see their neuromuscular physiotherapist. It is also often the case that these appointments are far away because they are based in specialist tertiary centres. For the individual and possibly their carer, this places an additional cost burden as they have to take time off work (often unpaid) and spend more on petrol or transport costs. This leads to additional use of petrol, the price of which continues to rise.

In some circumstances, people might not be able to drive or use public transport as they live in more secluded areas, which places a greater reliance on taxis which can become expensive very quickly. However, the alternative is to otherwise not attend their appointments which, as the pandemic has shown, results in accelerated deterioration and the need for more complex care<sup>12</sup>.

<sup>11</sup> [www.gov.uk/government/news/government-announces-energy-price-guarantee-for-families-and-businesses-while-urgently-taking-action-to-reform-broken-energy-market](https://www.gov.uk/government/news/government-announces-energy-price-guarantee-for-families-and-businesses-while-urgently-taking-action-to-reform-broken-energy-market)

<sup>12</sup> Muscular Dystrophy UK, *Shining a Light: The Impact of COVID-19 and the future of care for people with a muscle-wasting condition*, July 2021: [https://www.musculardystrophyuk.org/static/s3fs-public/2021-07/POL14%20-%20Impact%20of%20COVID%20report.v4.pdf?VersionId=apq4P8Je32l.hgaQFd0h8HyzX\\_DMxWw9](https://www.musculardystrophyuk.org/static/s3fs-public/2021-07/POL14%20-%20Impact%20of%20COVID%20report.v4.pdf?VersionId=apq4P8Je32l.hgaQFd0h8HyzX_DMxWw9)

Over 20% of respondents said they are currently spending between £600 to £3,000 a year on travelling to appointments whilst not working or taking unpaid leave. One respondent particularly told us that they “always travel via taxi, spending over £130 a month”, whilst another told us that “disabled taxis are in very short supply, and if available have to be booked several weeks in advance with fares three times higher than normal taxis due to the vehicle type to take powered wheelchairs”.

### Energy costs

Most respondents (83%) indicated that they are needing to spend more on heating to avoid their muscles stiffening from the cold and more on electricity to charge their equipment. One respondent expressed anxiety about future ventilator running costs given the progressive nature of their condition, where they stated: “I am about to have a trial of a Non-invasive positive pressure ventilation respirator. I am nervous about how much it will cost to run”. Another respondent told us that: “keeping all my equipment, like ventilators, charged was an unexpected and hidden cost of living with a condition”.

About 900,000 people with disabilities are considered to be in fuel poverty.<sup>13</sup> Scope has predicted that if typical domestic bills rise to £3,000 in October 2022 that this number could rise to 2.1 million. This will have a particularly devastating effect on people living with a muscle-wasting condition, with over 70% of respondents worried about their current financial situation and looking to cut costs where they can at the risk of their own health and wellbeing. Many people with a muscle-wasting condition have estimated they so far have experienced rises of £100 to £450 per month on their utility bills. As a result, some are trying to reduce these costs by layering on clothes to keep warm; however, this may not work long term when the colder months return. Similarly, they are trying to avoid charging their electric

wheelchairs until necessary, which reduces their independence and increases their feelings of isolation as they limit leaving the house.

*“My home heating costs are much higher than normal because I have to have a warm environment due to my lack of mobility - it’s hard to cost this, but I would estimate that my heating costs would be approaching double what I would pay if I did not have my condition.”*

Person living with a muscle-wasting condition

*“We have higher electricity use because I need the house to be warmer than most people do, and I use a heated blanket all day and night. Our electricity bill is a worry as it’s gone up £300”*

Person living with a muscle-wasting condition

### Food

People living with a muscle-wasting condition may need to buy pre-chopped foods that doesn’t need to be cut and that is easier to swallow, or they may need to pay more for foods that are packaged in ways that are easier to open. This can be due to weakness of the muscles of the face and neck involved in chewing and swallowing.<sup>14</sup> Weakness in these muscles can make chewing prolonged, particularly if the food is hard, chewy, or textured.

The cost of living crisis is having a significant impact on the cost of groceries, with the cost of food forecasted to rise at the fastest rate in 14 years.<sup>15</sup> Additionally, the current increase in food prices is placing even more pressure on people living with a muscle-wasting condition. 53% of respondents said they are currently spending an additional £25 to £150 a month on food, which equates to between £300 and £1800 extra a year.

### Housing adaptations and wheelchairs

Living as independently as possible for those with a muscle-wasting condition is essential to ensure they can live the life they want and can access all

<sup>13</sup> Scope, Why disabled people are at the centre of the cost-of-living crisis, May 2022: <https://www.scope.org.uk/news-and-stories/cost-of-living-disabled-people>

<sup>14</sup> Muscular Dystrophy UK, Nutrition and Feeding Factsheet: <https://www.muscular dystrophyuk.org/static/s3fs-public/2021-05/Nutrition-and-Feeding-factsheet.pdf?VersionId=ZQEULIApxABegS5dBMtCLqCiOVSsJe9R>

<sup>15</sup> The Guardian, ‘I see price rises of 25-50%’: how inflation is affecting people with a disability or illness, July 2022: <https://www.theguardian.com/business/2022/jul/20/how-inflation-disability-illness-uk>

areas of society. However, this comes with even further costs to ensure they can move around inside and outside of the house. This includes costs such as housing adaptations, electric wheelchairs to move around, and access to hoists and lifts. Almost half of respondents (48%) have spent up to £2,500 on buying wheelchairs, with over 60% spending up to £500 on wheelchair repairs and maintenance per year. Additionally, over half of respondents (59%) have spent up to £1,000 on installing and running hoists and lifts. These costs continue to pile up making it even more difficult for people living with a muscle-wasting condition and their families to not only stay on top of their finances but to save any money for future needs which are likely to incur more costs.

### Clothes and Orthotics

Another area where additional costs originate from is the need for specific clothing and footwear, with 75% of respondents stating that they spend between £100 to £1,000 a year on specialist footwear, orthotics or clothes that are more suitable. For example, those living with Charcot Marie Tooth disease need to regularly buy new clothing and shoes as they frequently fall and damage their clothes and often struggle with feet deformities requiring shoes that fit the shape of their feet, which all tend to be in the higher price brackets. These costs haven't necessarily increased for the moment but do contribute to the financial pressures on those living with a muscle-wasting condition and their families.

### Treatment costs

People with muscle-wasting conditions require consistent medical/health monitoring, fast access to treatments and access to a specialist multidisciplinary team. Even before the COVID-19 pandemic, access to these fundamental services was unequal across the country, resulting in a postcode lottery of services. This is particularly evident for services such as physiotherapy, as shown in our *Overstretched* report which found that 60% of people with a

muscle-wasting conditions are unable to access appropriate physiotherapy to support them with their condition<sup>16</sup>, and hydrotherapy, as shown in our *Hydrotherapy in the UK* report which found over two thirds of people with a condition are unable to access a suitable hydrotherapy pool.<sup>17</sup>

From those who were able to pay for private provision, our results revealed this could result in spending £300 extra a month to access such services. Even more concerning is that some of those who can't access hydrotherapy in their area have resorted to spending money on the running and heating of a hot tub (in lieu of regular hydrotherapy), which can cost £800-£1,000 a year with additional electricity costs. This is on top of the yearly prescription cost which results in people with a muscle-wasting condition cutting back on their medication.

Lack of access to these core services can lead to longer term concerns such as accelerated deterioration which may make them unable to work or undertake day-to-day activities. It will also result in needing additional and more complex care later which can mean more appointments (and therefore more petrol) or turning to private providers at a later date requiring more appointments.

### Employment challenges

Employment is a key aspect to managing any financial burden. Yet, it is well established that disabled people struggle to maintain employment or need to reduce their working hours.

Between July and September 2021, only 53.5% of disabled people aged 16 to 64 years in the UK were employed compared with 81.6% of non-disabled people.<sup>18</sup> Even though the disability gap is closing, unemployment continues to be an issue for those living with a disability. From our survey, 54% of respondents were currently unemployed and approximately 20% were in part-time employment. Many of those who were unemployed

<sup>16</sup> Muscular Dystrophy UK, *Overstretched: improving access to physiotherapy for people with muscle-wasting conditions*, July 2016: [https://www.musculardystrophyuk.org/static/s3fs-public/2021-07/PDF-Report-Overstretched-Access-to-Physio-July-2016.pdf?VersionId=a9tU61.e4g\\_qIAcyXz001mq45zoGuYxM](https://www.musculardystrophyuk.org/static/s3fs-public/2021-07/PDF-Report-Overstretched-Access-to-Physio-July-2016.pdf?VersionId=a9tU61.e4g_qIAcyXz001mq45zoGuYxM)

<sup>17</sup> Muscular Dystrophy UK, *Hydrotherapy in the UK: the urgent need for increased access*, December 2015: <https://www.musculardystrophyuk.org/static/s3fs-public/2021-07/PDF-Report-Hydrotherapy-in-the-UK-2015-compressed.pdf?VersionId=me6HM8rOAIrDwDxwI5nUmZtIIdpJ1VE>

<sup>18</sup> Office of National Statistics, *Outcomes for disabled people in the UK: 2021*, February 2022: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2021#:~:text=The%20employment%20gap%20for%20disabled,it%20was%2034.7%20percent-age%20points.>

had medically retired as they were physically unable to work. Many respondents attributed their employment status to the burden of attending appointments as many had to take unpaid leave.

People with a muscle-wasting condition often depend on carers to help with their daily activities. Some people living with a muscle-wasting condition require carers to support them 24/7 whereas others may only depend on their carers for a few hours a day. Many people with a muscle-wasting condition cannot afford a carer to cover their full needs, which places a greater reliance on their families to provide such care. These unpaid carers of people with a muscle-wasting condition are impacted in terms of their own salary potential, with many losing a day's wages to attend appointments. Where carers do take time off work to help an individual with a condition attend their appointments, this often needs to be taken as unpaid leave and requires understanding from their employers. Due to the volume of appointments and the demand of being a carer, they often as a result eventually go part-time or quit their job altogether which adds a further financial strain on the household.

*"Our key concern is not being able to afford carers which is preventing my husband from working."*

Person living with a muscle-wasting condition

*"My wife is my carer and is not paid for her caring services which includes facilitating and helping me wash and cloth myself, prepare meals, driving me to appointments, washing and ironing my clothes, and cleaning up the bathroom and toilet after my use."*

Person living with a muscle-wasting condition

Overall, these different areas of increased cost demonstrate the overwhelming financial impact of living with a muscle-wasting condition.

### Case Study

Sheila, Living with Facioscapulohumeral muscular dystrophy (FSHD)

*"By the time I was 50, twenty years after receiving a diagnosis for FSHD, I was starting to see a real impact on my mobility, as I started using a walking stick and could no longer use a bicycle. Our terraced house would be difficult to adapt so my partner and I decided to buy a rundown bungalow to renovate to improve access as my condition progressed."*

*"We spoke with a Disability Adviser at the Red Cross who came and looked round the bungalow before we started building work. They advised on the size of the bathroom, which is often the room that creates the most problems for individuals with reduced mobility in the long-term. We had to make general renovations such as a new boiler and re-wiring, and specific renovations including widening door frames, which required bespoke doors and ensuring external doors had no threshold, installing a wet room in the large bathroom, a ramp at the front of the house and decking at the rear of the house to enable external access. In total the renovation cost about £60,000, about half of which was on adaptations due to my increasing and anticipated lack of mobility. These adaptations have been useful and definitely a good investment as we can't fully predict what the future holds with regards to deterioration. I transitioned to a wheelchair three years ago which was relatively easy in this property. One of the main things we have to recognise about having a progressive condition is you might be managing fine but then another muscle deteriorates and something that used to be quite easy becomes quite difficult."*

### The Mental Health Impact of Rising Costs

Financial concerns often lead to a worsening of physical and mental health. Research undertaken by Scope revealed that for disabled people whose living costs have increased over the past three months, half (48%) reported such rising prices as having a worsening effect on their long-standing health condition, with a similar proportion (51%) saying their mental health had worsened.<sup>19</sup> Our findings have similarly shown the impact financial struggles can have on mental health, with 80% of respondents stating they are worried about their current financial situation. One respondent particularly told us that her husband is cutting back on eating to reduce the cost of food as he is concerned that they will run out of money.

Given that the pandemic and shielding have already had a negative impact on the mental health of people living with a muscle-wasting condition, the cost of living crisis is only further exacerbating these issues with 68% stating the pressure of the crisis is affecting their mental health. Given people with a muscle-wasting condition already struggle to access adequate mental health provision, we also found 95% of respondents don't access mental health through private providers as they can't afford to. This further demonstrates the need to drive forward our recommendations to alleviate the current financial burden on people with a muscle-wasting condition and their families.

## Recommendations

### 1. Increase benefits in line with current levels of inflation to better support the increasing cost of living.

With the costs of living now continuing to rise, this impact is becoming unsustainable with many people in our community struggling to cope. The Government has introduced a number of measures to specifically help disabled people and also some universal measures, which is clearly welcome. However, more

needs to be done and we are calling on the UK

Government to increase the cost of living support that is available by increasing benefits in line with current levels of inflation to help stop the cost of living crisis becoming a poverty emergency.

### 2. Lift the cap on the Disability Facilities Grant and introduce flexibilities to capture the progressive nature of muscle-wasting conditions.

The Disabled Facilities Grant (DFG) is available to support the cost of providing adaptation and facilities to enable a disabled person to continue living in their property. The maximum grant payable under the DFG is £30,000 in England, £25,000 in Northern Ireland and £36,000 in Wales. However, the actual amount of DFG varies from person-to-person depending on their specific circumstance. As a result, most people with a condition receive insufficient funds to cover the required adaptations. We have also frequently heard that the process to receive the grant is arduous and rarely considers the progressive nature of the condition. As such, the UK Government needs to consider lifting the cap of DFG and introduce further flexibilities to better assess people living with a muscle-wasting condition by liaising with specialist neuromuscular healthcare professionals (such as neuromuscular care advisors) to understand the debilitating progression of the disease and additional equipment and adaptations that may be required in the future to better estimate support needed.

### 3. Increase Carers Allowance to equal 35 hours at National Minimum Wage to better support people living with a muscle-wasting condition and their families.

The lack of affordability of carers can place a significant burden on families, and yet the impact this has on them is too often overlooked. Unpaid carers are eligible for carers allowance which is £69.70 a week for 35 hours a week. This equates to £1.98 per hour, whereas national minimum wage for those over

<sup>19</sup> Scope, Disabled People Hit Hardest in the Biggest Cost of Living Crisis in a Generation, February 2022: <https://www.scope.org.uk/media/press-releases/energy-and-cost-of-living-crisis/>

18 is currently £6.83 per hour (up to £9.50 when over 23). Additionally, Carers Allowance may be taxed and affect means-tested benefits such as Housing Benefit and Universal Credit. With costs rising, we are calling on the UK Government to increase Carers Allowance to equal 35 hours at National Minimum Wage.

#### **4. End VAT on energy bills for people living with a long-term condition, including people with a muscle-wasting condition, to make these costs more manageable.**

In terms of the costs of energy bills, we appreciate the UK Government has tried to support those on low incomes through the Warm Home Discount Scheme, however this only provides a £140 one-off payment to support people with their electricity bill for winter 2021 to 2022. The Government's September 2022 Energy Price Guarantee will also help in this area. However, more needs to be done to properly support people living with a muscle-wasting condition to cover the increase in bills. As such, we are calling on the UK Government to end VAT on energy bills for people living with long-term conditions, including muscle-wasting conditions. This would go some way to reducing the financial burden and provide more long-term support to people living with a muscle-wasting condition.

#### **5. Improve access to critical specialist and community services to reduce reliance on private provision and implement support to supplement private provision where delays to NHS appointments are unmanageable.**

As noted, treatments such as physiotherapy and hydrotherapy are critical parts of care a person with a muscle-wasting condition requires. Improving access to specialist and community services will go some way to ensuring they stay well for longer, which will allow them to work for longer whilst reducing these additional costs. We are therefore calling for the Department of Health and Social Care, local authorities, and Integrated Care Systems (ICSs) to tackle the barriers in place in accessing these critical services, and in areas

where this isn't possible, to implement support to subsidise private provision.

#### **6. Implement a hospital travel card scheme to provide subsidised, accessible travel to people living with a long-term condition, including people living with a muscle-wasting condition.**

And

#### **7. Improve coordination of care and access to appointments closer to home to reduce time taken off work and costs on petrol.**

Addressing the daily travel costs that our community faces requires a two-pronged approach; the first is for the UK Government to work with local authorities, NHS Hospitals and Patient Representative Organisations to implement a hospital travel card scheme, as proposed by the Cystic Fibrosis Trust.<sup>18</sup> This scheme would provide subsidised, accessible travel to people living with a long-term condition. Secondly, improving the coordination of care and providing services closer to home would go some way to reducing travel to appointments and thus significantly reduce travel costs and negate the need to take as much time off work.

#### **8. Improve employer understanding of and flexibility around the needs of people with muscle-wasting conditions**

In our focus groups, attendees stated they may still be able to work if there was better support in place from employers, such as access to parking, being able to work from home, and better flexibility from managers to attend medical appointments.

By law, every disabled person or a person living with a physical or mental health condition has the right to reasonable adjustments in the workplace, such as access to specialist equipment or flexible hours. A key barrier to improving adjustments offered is a lack of understanding of specific long-term, progressive conditions, such as muscle-wasting conditions. We appreciate that an employer cannot be aware of every condition and specific support these

<sup>18</sup> The Cystic Fibrosis Trust, Cost of Living with CF, June 2022: <https://www.cysticfibrosis.org.uk/sites/default/files/2022-06/Cost%20of%20CF%20report.pdf>

individuals may need. However, we would encourage employers and managers who have a person with a muscle-wasting condition working for them to learn more about the condition to better understand what flexibilities may be needed. Muscular Dystrophy UK has an eLearning introduction course to neuromuscular conditions, which we would encourage people with a condition to share with their employers. Further, we have a factsheet on the reasonable adjustments a person living with a muscle-wasting condition is entitled to and our helpline is available to anyone who needs any further information.

## Conclusions

The financial burden of living with a muscle-wasting condition cannot be overstated. With the cost of living drastically increasing, this burden is creating an unsustainable situation where many people living with a muscle-wasting condition are at risk of going without food, heating, and access to appointments.

With the cost of living crisis predicted to get worse before it gets better, now is the time to address the additional support that needs to be in place for people living with a long-term condition, and to consider how to better support this community in the future to ensure they have access to the support they need. Implementing the recommendations outlined in this report will go some way to better supporting a person living with a muscle-wasting condition.

The UK Government has set up several initiatives to support those currently financially struggling, such as the Warm Home Discount and the Cost of Living Payments. However, more needs to be done to ensure people living with a muscle-wasting condition have access to the appropriate support to ensure they don't face a detrimental impact to their physical and mental health and wellbeing. Ending VAT for utility bills, increasing benefits in line with current levels of inflation, and lifting the cap on the Disabilities Facility Grant will go a lot further to alleviating the financial burden for people living with a muscle-wasting condition than these one-off payments.

Improving available support throughout this crisis can't be achieved in isolation and the onus isn't only on the UK Government, but also on the NHS and local authorities to better support people with a muscle-wasting condition living in their areas. Working together, local authorities and the UK government need to implement a hospital travel card scheme to provide subsidised, accessible travel to people living with a long-term condition. Additionally, the NHS needs to work with ICSs to improve coordination of care and improve access to appointments closer to home. Having such measures in place will help people living with a muscle-wasting condition attend their specialist appointments and avoid delays in attendance due to concerns around petrol prices and taking unpaid leave from work. In areas where there are long waiting times to access critical specialist and community services, or where some services aren't available, such as hydrotherapy, it is imperative that the Department of Health and Social Care, local authorities, and local ICSs consider implementing schemes to supplement private provision of core treatments.

Further, the UK Government needs to consider the impact that the cost of living crisis has on the families and carers that are essential to helping people with a condition to access appointments to stay well for as long as possible. Increasing costs and financial struggles have a significant impact on a carer's life, many of whom are trying to juggle their caring responsibilities with full-time employment. As such, the UK Government needs to increase Carers Allowance to equal 35 hours at National Minimum Wage.

These outlined changes will not only help support people with a muscle-wasting condition through this cost of living crisis but will provide long-term improvements to ensure people living with a muscle-wasting stay well for longer and live as independently as possible.

Muscular Dystrophy UK is committed to working with the UK Government, local authorities, NHS decision-makers and clinical stakeholders to support the implementation of these priorities and, where appropriate, to provide patient insight.

## About Muscular Dystrophy UK and muscle-wasting conditions

Muscular Dystrophy UK is the charity bringing individuals, families, and professionals together to fight muscle-wasting conditions.

Founded in 1959, we have been leading the fight against muscle-wasting conditions since then.

- We bring together more than 60 rare and very rare progressive muscle-weakening and wasting conditions, affecting around 110,000 children and adults in the UK.
- We support high quality research to find effective treatments and cures and will not stop until we have found them for all muscle-wasting conditions.
- We are leading the drive to get faster access to emerging treatment for families in the UK.
- We ensure everyone has the specialist NHS care and support they need – the right help at the right time, wherever they live.
- We provide a range of services and resources to help people live as independently as possible.

Muscle-wasting conditions can cause muscle weakness or wasting. They are multi-system disorders that require complex long-term care. There are currently no known cures and few treatments.

People will require vital multi-disciplinary care from specialist neuromuscular consultants, physiotherapists, nurses, care advisors, psychologists, and other therapists and – where necessary – support from specialist respiratory and cardiac consultants. Without this level of care, people experience a reduction in quality of life and in some cases, shortened life-expectancy.

## Get involved

If you or your care has been affected by the cost of living crisis and you would like to share your story with us, then please get in touch with us at [campaigns@muscular dystrophyuk.org](mailto:campaigns@muscular dystrophyuk.org). If you are struggling to access the support you need, our advocacy team is here to help. Please get in touch with them at [info@muscular dystrophyuk.org](mailto:info@muscular dystrophyuk.org) or call **0800 652 6352**.



[www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org)

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