MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Financial insecurity

The ongoing impact of the cost-of-living crisis on people living with muscle wasting and weakening conditions

November 2024

Foreword

We last fully explored the impact of the cost-of-living crisis on people living with a muscle wasting and weakening condition in 2022 – but financial security is never far from our community's minds.

Financial security was one of the key themes to come out of our 2023 *Community Survey*. Between April and September this year financial welfare support requests to our helpline amounted to our third highest number of requests for information and advice. In the same period, access to Personal Independence Payment (PIP) accounted for the highest number of cases dealt with by our advocacy service, which offers support to people unable to navigate or access support themselves.

When we reached out to our community in 2022 and 2023 to help us better understand the experience of living with a muscle wasting and weakening condition, a major theme was exhaustion – both physical and mental.

As this report lays out, not only do many people living with a muscle wasting and weakening condition feel financially insecure, but over half feel they are one change in circumstance or potentially one major expense away from feeling so. This precarious position only adds to the stress and fatigue felt by our community.

We look forward to working with the UK Government and other stakeholders to address the issues this report raises, as we continue to strive to support our community to live well.

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Director of Care, Campaigns and Support
Muscular Dystrophy UK

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1. Introduction

The cost-of-living crisis is not over. While inflation has fallen since the topic recently dominated headlines, many people continue to feel its effects.[1]

Disabled people are disproportionately affected through the unavoidable additional costs that come with living with a disability.[2] Leading disability equality charity Scope estimates that on average the additional costs faced by disabled households amount to £1,010 per month.[3] Basic essentials alone cost disabled households £625 more each year than they do non-disabled households.[4]

For people living with a muscle wasting and weakening condition, these extra costs can include petrol to travel to the large number of specialist and community appointments they need to attend; additional energy needed to power aids and equipment like cough assist machines and wheelchairs; and housing adaptations to maintain independence.[5]

The economic context and provision of government support across the UK has changed in recent years. The increase of many benefits in line with inflation announced in 2023 and the extension of the Household Support Fund in September 2024 are welcome.[6,7] But much needed assistance previously in place, like the Cost of Living Payments or more recently the Winter Fuel Allowance, is ending or reducing and can no longer be relied on in the same way. Energy prices are also once again rising after falling in 2024.[8] The UK Prime Minister warned of a "painful" budget in the run up to it and we're analysing the impact the measures announced around work, welfare and the cost-of-living will have on our community.[9]

As part of the new UK Government's mission to grow the economy, it has promised "radical" and "fundamental" reform to get Britain working.[10] A new white paper is expected, on top of manifesto promises of employment and benefit related reform to support disabled people.[11] There are also still important questions about whether the new Government will take forward potential reforms to Personal Independence Payment (PIP) introduced by the previous Government.

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[1] Joseph Rowntree Foundation, 'The scale of the challenge: JRF's pre-election cost of living tracker' (27 June 2024).

[2] Scope, 'Calling for urgent support with the cost of living for disabled people' (14 December 2023).

[3] Scope, 'Disability Price Tag 2024'. Accessed 11 October 2024.

[4] Scope, 'Life costs more'. Accessed 11 October 2024.

[5] Muscular Dystrophy UK, 'The Impact of rising costs on people living with a muscle-wasting condition' (October 2022), see Table 1. Available at: https://www.musculardystrophyuk.org/app/uploads/2024/05/POL17-Cost-of-Living-report-2022-FINAL-2.pdf

[6] HM Treasury, 'Autumn Statement 2023' (30 November 2023).

[7] Department for Work and Pensions and HM Treasury, 'Government support extended to help struggling households with bills and essential costs over winter' (02 September 2024).

[8] BBC News, 'People told to read meter as energy bills rise' (01 October 2024).

[9] Prime Minister's Office, 10 Downing Street and The Rt Hon Sir Keir Starmer KCB KC MP, 'Keir Starmer's speech on fixing the foundations of our country: 27 August 2024' (27 August 2024).

[10] Department for Work and Pensions and The Rt Hon Liz Kendall MP, 'Getting Britain Working' (23 July 2024).

[11] The Labour Party, 'Labour Party Manifesto 2024'.

All of these factors have led us to revisit our previous work on the cost-of-living crisis to input into this upcoming reform programme. In 2022, we set out our initial recommendations to financially support people living with a muscle wasting and weakening condition in the cost-of-living crisis.[12] Two years later, our *Community Survey* was answered by almost 700 people, who told us financial security was one of their three key policy priorities.[13]

In the following report we lay out the essential costs faced by people living with a muscle wasting and weakening condition. We also explore how financially secure our community feels and whether this has changed over the past two years. We've included an updated set of recommendations for how government and other stakeholders can help our community feel more financially secure and lessen the impact of insecurity.

Ultimately, we want to ensure immediate support to help our community cope, as well as a commitment to the longer-term reform needed to better support people living with a muscle wasting and weakening condition.

Our focus in this report is mainly on the situation in England and the role of the UK Government. Nonetheless, our findings are more broadly applicable. We'll continue to work with our community to take forward these recommendations in our influencing activity across the whole of the UK.

> **I am struggling with paying monthly bills, especially gas. I need to keep warm but it's so difficult if I can't afford to. I have to decide what is more important, eating or heating."**
>
> Survey respondent

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[12] Muscular Dystrophy UK, '[The cost of living with a muscle wasting condition]' (October 2022).

[13] Muscular Dystrophy UK, 'Community survey findings' (09 May 2024), p. 15.
Available at: https://www.musculardystrophyuk.org/app/uploads/2024/05/CommunitySurveyFindingsMay2024.pdf

2. Methodology

This report is based on a three-step approach to update and build on our previous work on the cost-of-living crisis and financial security for people living with a muscle wasting and weakening condition.

Step 1: consultations

We held semi-structured conversations with members of our Content Advisory Group (CAG). This is a voluntary body who reviews our content to make sure it's grounded in the lived experiences of people with a muscle wasting and weakening condition. We spoke with nine CAG members in August 2024. These discussions were designed to find out more about experiences around financial security. In particular, we discussed experiences of employment, benefits, and other forms of financial support. We also asked what would be needed to help people feel more financially secure. Our definition of 'financial security' broadly means having enough money to afford the basics, without feeling anxious. This interpretation was borne out by the CAG members we spoke with. These conversations were used to inform the survey (step 2).

Step 2: survey on financial security

We ran an online survey during September 2024, shaped by our discussions with CAG members, to gather more in-depth data and insights about financial security. In total, 407 people took the survey. We heard from people with a condition, carers and those close to them. Although respondents were concentrated in England, we also got feedback from people living in the devolved nations. A variety of employment statuses and of benefits received were covered by respondents. The online survey collected qualitative feedback which we highlight throughout the report.

Step 3: case studies

We also wanted to bring in stories directly from people living with a muscle wasting or weakening condition and conducted in-depth first-person interviews.

3. Key findings

3.1 About our community

We used the survey to explore the employment status of respondents, the type of financial support they receive and the areas of spending that matter most to them. We heard from a wide-ranging sample of our community.

Survey respondent type and demographic

Connection to muscular dystrophy[14]	
73%	Living with a muscle wasting and weakening condition
20%	Relatives
13%	Carers

Employment status of survey respondents	
24%	Full-time or part-time employment
3%	Freelance workers or self-employed
3%	Looking for work and unable to find it
31%	Formally not required to look for work[15]

Demographic	
Geographical location	Respondents were mainly based in England, although 8% were in Scotland, another 8% in Wales, and 2% in Northern Ireland.
Male/female ratio	There was an almost equal ratio of male and female respondents.
Ethnicity	Although most respondents said they were 'English, Welsh, Scottish, Northern Irish, or British', 14% said they were of another ethnic, mixed or multiple ethnic background.
Age	Respondents were spread across the working age population, with the most, 23%, aged 55 to 65. 17% were from above the state pension age of 66.

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[14] Note: responses may not add up to 100%, as respondents were allowed to pick more than one option.

[15] The survey didn't ask the formal reason why respondents weren't required to look for work. However, under Work Capability Assessments for Universal Credit/Employment and Support Allowance, assessments about whether individuals are fit for work include decisions where some people are not required to look for work.

Type of financial support received

We asked about any type of financial (including disability-related) support people receive.

- 53%, over half, of respondents receive PIP.
- 13% receive Disability Living Allowance.

Our community also receive various other benefits, including Employment and Support Allowance (ESA) and Universal Credit (UC). Several people reported receiving multiple benefits, such as PIP and ESA or PIP and UC.

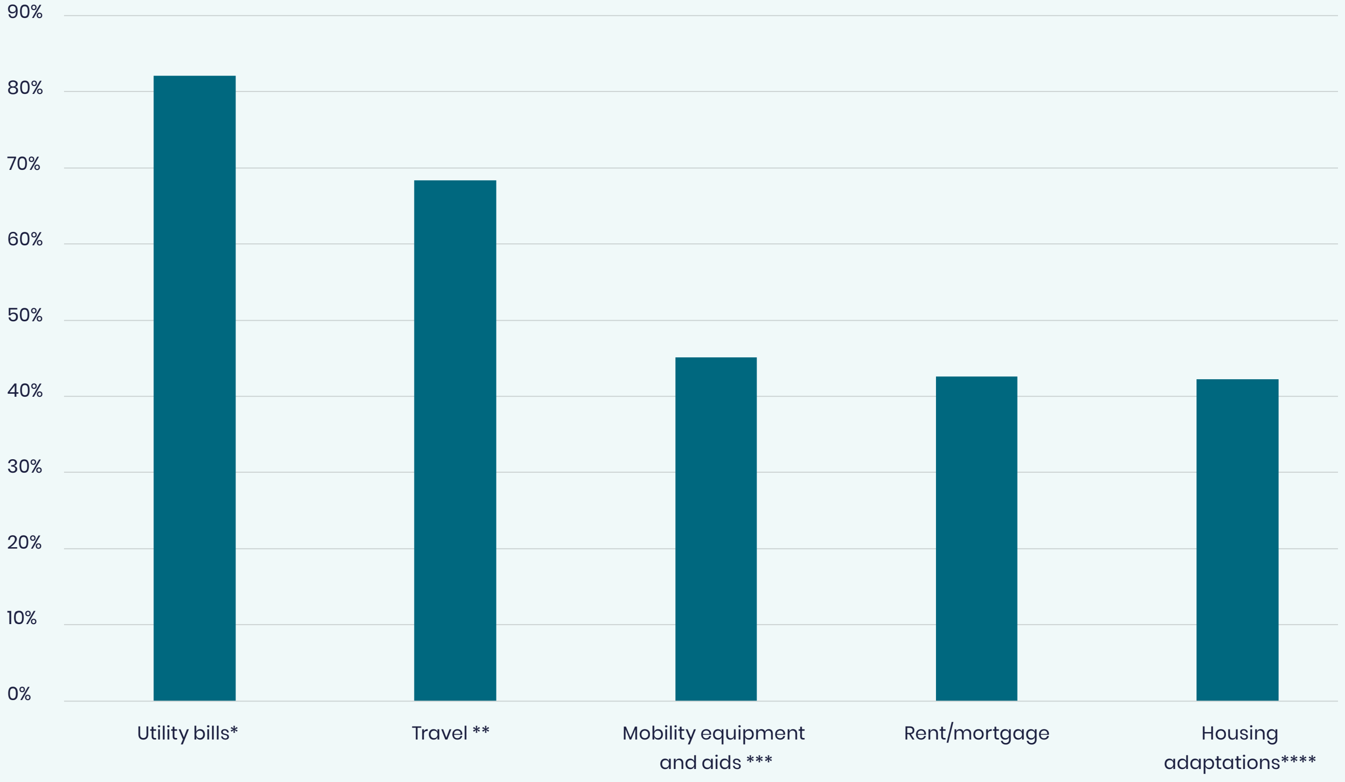
Spending areas that matter most to respondents

To better understand how and where the cost-of-living crisis is impacting on people living with a muscle wasting and weakening condition we asked which spending areas matter most to people.

- Four in five people, 82%, consider paying for utility bills, e.g. heating, water and electricity, their biggest monthly essential spending area.
- The next biggest, at 68%, is day-to-day travel.

Figure 1: Top five monthly essential spending areas

Please select up to five priority spending areas which you/the person you know would characterise as your monthly essentials.



* For example, heating, water, electricity
** For example, petrol, personal vehicle, accessible taxis, parking
*** For example, wheelchairs, including maintenance and repair costs
**** Including, assistive equipment and managing wear and tear

3.2 People feel financially insecure

Over half, 53%, of people living with a muscle wasting and weakening condition feel financially insecure.

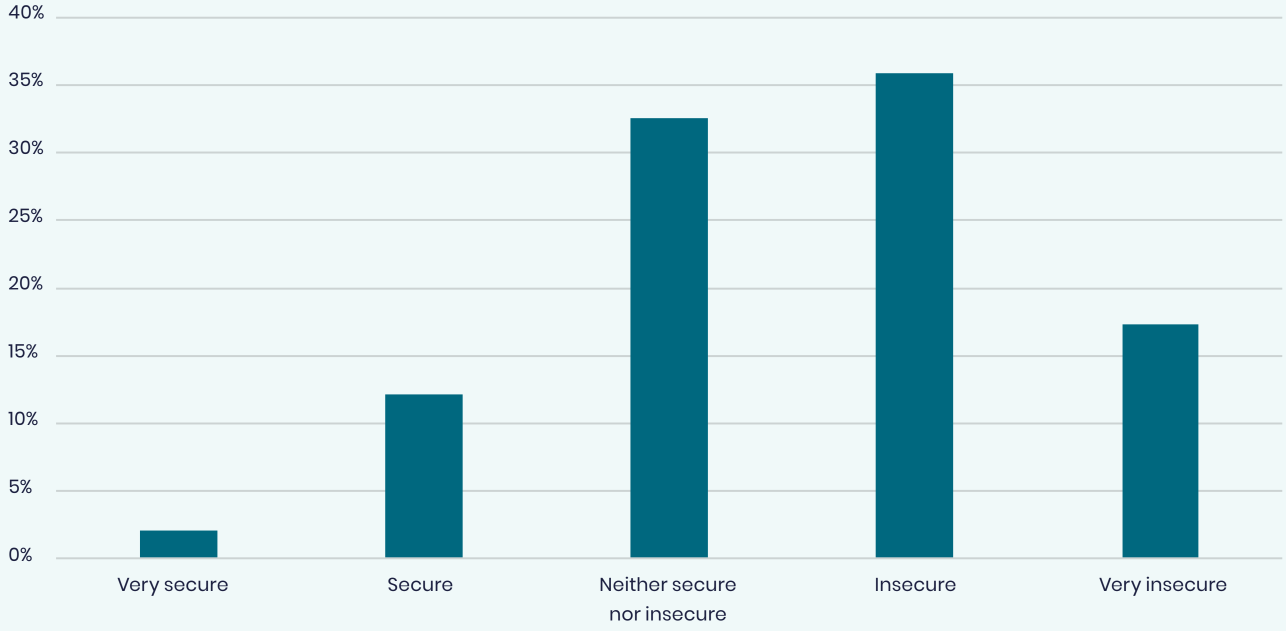
17% of those who feel insecure reported feeling very insecure.

Although not directly comparable, these findings suggest the situation has worsened since a year ago, when 24% of our community said they felt financially insecure.[16]

How financially secure people currently feel

Figure 2: Levels of financial security

How financially secure do you/the person you know currently feel?



Even more concerning is just how many people feel they are just one change in circumstance or potentially one major expense away from feeling financially insecure.

Half of our survey participants said they had recently experienced significant one-off costs and/or expected them sometime soon. A lot of these were about managing growing needs in the face of declining health. The main cost areas were for housing adaptations, and mobility aids and equipment (e.g. wheelchair, mobility scooters).

Of those who said they felt financially secure, 52% said there were one or more caveats to this. Many people said they lived in single/near single-income households, which can be worrying when they might rely so much on their partners and family for income, caring and help with the bills.

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[16] Muscular Dystrophy UK, 'Community survey findings' (09 May 2024), p. 19. Available at: https://www.musculardystrophyuk.org/app/uploads/2024/05/CommunitySurveyFindingsMay2024.pdf

The meaning of financial security

The survey also explored the meaning of financial security in more detail, revealing how harshly the cost-of-living crisis has been impacting on our community over the past two years.

- 27% of respondents said they always came close to or used up all their available income at the end of the month. 27% of respondents said this was often the case. This leaves little room for savings.
- 36%, over a third, of respondents said they were never able to put money into savings at the end of the month.
- 56% of respondents said they had to borrow money or take out additional debt to manage at the end of the month at some point in the past two years.

> **"Everything has been stripped away from us, you are just surviving not quite drowning but treading water. You are constantly worrying about the cost of everything you spend, it is always at the forefront of your mind."**
>
> Survey respondent

3.3 Financial insecurity has a widespread negative impact on lives

How people feel about their financial situation can impact every part of their lives. Figure three shows that across the board, financial insecurity has made survey respondents feel worse.

Of survey respondents, 48% said their physical health has worsened. This rises to 66% when asked about mental health. Over a third of respondents, 35%, said it has negatively impacted on their ability to work, with 16% saying it has made it much worse.

> **“As the condition progresses, I know I won’t be able to work much longer and then I will either require carers or my wife will need to work less to care for me. Very worrying in the current climate with two children depending on us.”**
>
> Survey respondent

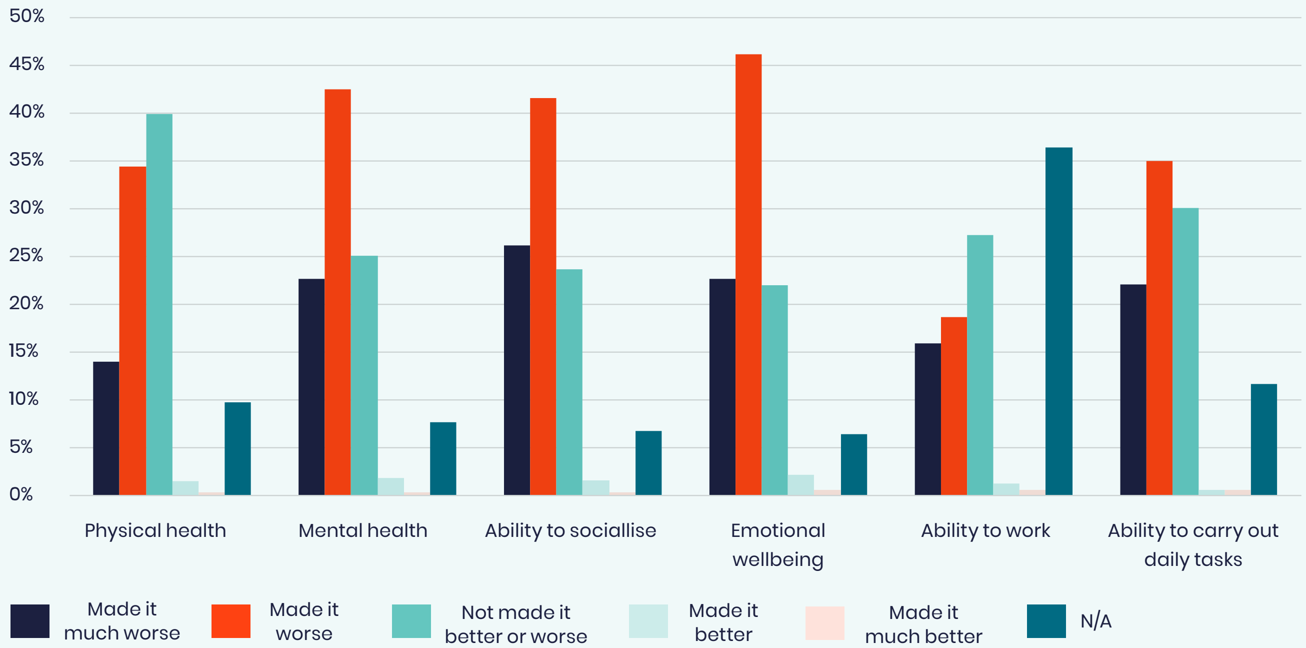


Figure 3: The impact of feeling financially insecure

Thinking back over the past two years, how has your/the person you know’s financial situation affected your . . . ?

Although this report looks at the spending areas considered to be monthly essentials, feeling financially secure shouldn't only be about being able to afford your essentials or just surviving. Figure three also illustrates how much of a strain financial insecurity can place on our social and home lives. The survey also asked how someone's financial situation had affected their quality of life. 64% said it had worsened, and 19%, one in five, said it had been made much worse.

> **"Having muscular dystrophy has affected my life considerably. I have had to increase my antidepressants to help my mental health. And I have had to give up a job that I loved due to my physical disability and chronic pain that I suffer with it."**
>
> Survey respondent

Charlotte's story

Both Charlotte, 33, and her husband Tom live with a muscle wasting and weakening condition. As well as experiencing increased financial costs due to their disabilities, they also have to cope with receiving less benefits because they are married and live together.

We use four ventilators between us, which are running or charging 24 hours a day, two wheelchairs which need to be charged regularly, and wash dry toilets to name just a few things that require energy.

Another thing we spend a lot of money on is hot water. We both get a lot of muscle pain and circulation problems, so having regular hot baths and showers helps with this. But it all adds up.

We have 24-hour care, including waking night shifts, which means the carers need the heating on overnight to stay warm. They're also charging things like their phones and laptops, making hot drinks and having lights on, so that's another expense we need to factor into our budgeting. Food is also an issue as we both have swallowing difficulties, so we make smoothies quite often, but fruit and vegetables have really gone up in price.

> **"One of the biggest expenses for us is our energy bills which we spend roughly half our income on."**

Tom and I have been married for six wonderful years, but our happiness has come at a price. When you get married and live together, your benefits are given to both of you as a joint award rather than being assessed individually, so we lost a considerable amount of our monthly income.

We both want to work so we're not under so much financial pressure and feel like less of a burden on society, but the benefits system puts so many barriers in the way. Even when we've tried to do work that's permitted within the benefits we receive, we've had difficulty getting the Department for Work and Pensions to agree it. They argue we shouldn't be able to work if we need the level of support we receive. If we could get around this and work part-time, other financial support such as Housing Benefit and Council Tax Reduction could be affected, and we may actually struggle more financially.

We've tried to extend our Motability car leases for as long as possible, but we know we'll have to get new ones soon. The initial payment for a new Motability car is always a lot.

Having all these additional costs inevitably adds another layer of stress and puts a strain on your mental health.

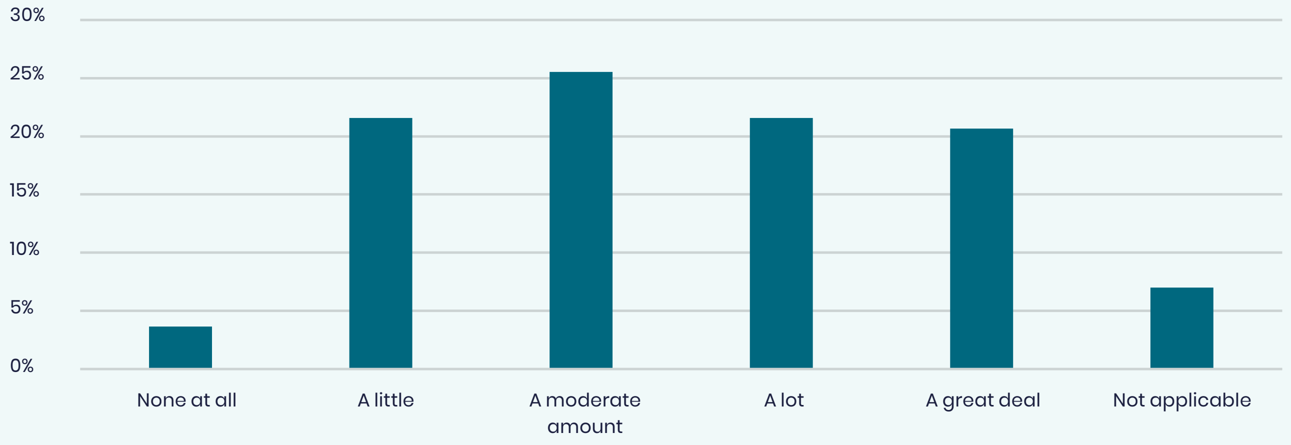
3.4 Worry about being able to afford the essentials

More of our community is worried about their financial situation now than they were two years ago.

- In 2022, 17% of our community said they weren't worried about their financial situation.[17]
- In 2024, just 4% said they weren't worried about their financial situation.
- 43% of people living with a muscle wasting and weakening condition say they are worried either a lot or a great deal about their current financial situation.

Figure 4: Levels of worry around current financial situation

If you/the person you know currently feel financially insecure, how worried are you about your current financial situation?



> **My daily costs living with a severe physical disability are astronomically high and bills just keep on getting bigger… It is a nightmare. Costs on cost never ever stop."**
>
> Survey respondent

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[17] Muscular Dystrophy UK, 'The Impact of rising costs on people living with a muscle-wasting condition' (October 2022). Available at: https://www.musculardystrophyuk.org/app/uploads/2024/05/POL17-Cost-of-Living-report-2022-FINAL-2.pdf

Increasing costs over the past two years

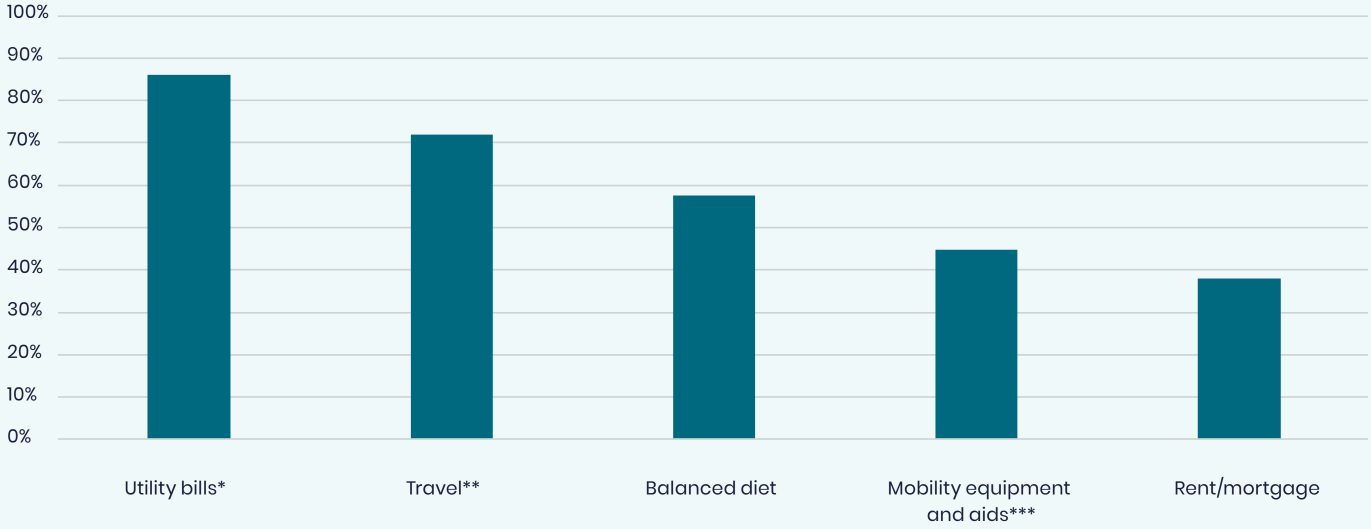
Survey respondents were most worried about being able to afford the essentials. Utility bills, day-to-day travel, and mobility equipment and aids are all in the top five areas in which people have seen costs increase.

Top of people's concerns was also eating properly. 36% of survey respondents were worried about being able to afford a balanced diet.

We hear of many people living with muscle wasting and weakening conditions significantly cutting down on holidays and buying clothes, as well as reducing spending on essential and other areas of their lives, just to get by. In some cases, these things are simply unaffordable.

Figure 5: Cost areas people have seen the biggest rise in

Thinking back over the past 2 years, for which areas have you/the person you know seen costs increase?



* For example, heating, water, electricity
** For example, petrol, personal vehicle, accessible taxis, parking
*** For example, wheelchairs, including maintenance and repair costs

Looking ahead at future financial security

Any hope of short-term relief is looking unlikely.

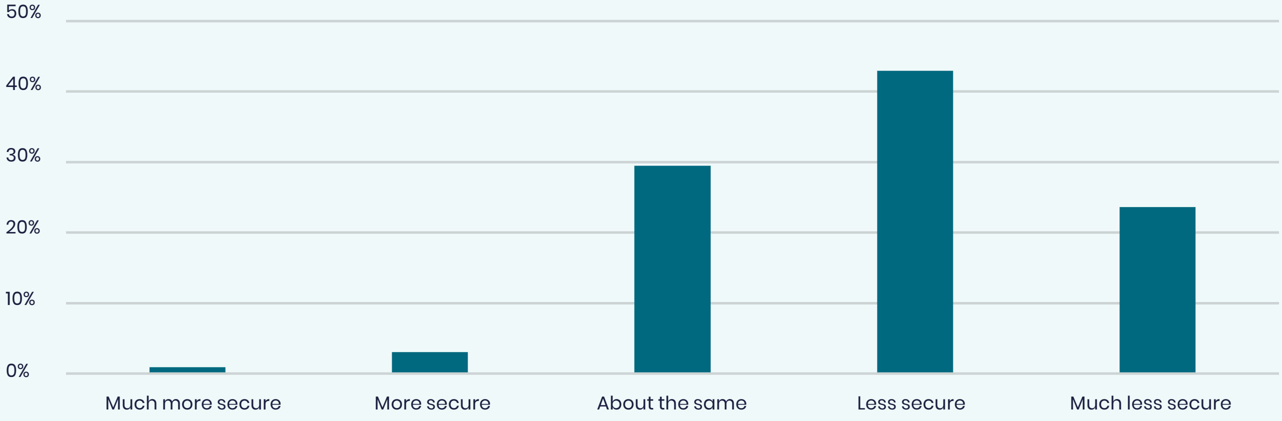
- Only 4% of our survey respondents said they will feel more financially secure in a year's time.
- 67% said they will feel less secure.
- 24% said they will feel much less secure.

This worry is due to several different things, including the growing inability to afford rising bills. People are worried about their deteriorating health condition and the need for them or their carers to reduce working hours. There is also considerable uncertainty over the UK Government's plans around the benefits system and how these might take away the lifeline that many people in our community consider PIP to be.

> **I can't bear to look forward. I'm afraid for my future."**
>
> Survey respondent

Figure 6: Expected change in how financially secure people will feel in the short-term

Thinking one year ahead, do you think you/the person you know will feel more or less financially secure?



People living with a muscle wasting and weakening condition are telling us that things have got worse in recent years, are bad now and are set to get worse. Too many of our community feel financially insecure, struggling on their current income to afford the essentials for daily living. Even though people are cutting down on any and all their expenses, they're still having to take on debt just to get by at the end of the month.

People are unclear about how things will go in the coming year. But in the meantime, the health, wellbeing, and quality of life of our survey respondents are suffering. There is an urgent need to find solutions to the cost-of-living crisis so that people living with a muscle wasting and weakening condition can afford the essentials. More importantly, given the wide-ranging effects of the cost-of-living crisis, such as on quality of life, further support should ensure people are thriving, and not just surviving.

> **The cost of food and heating makes it difficult to have money for anything else."**
>
> Survey respondent

Daniel's story

Daniel, 49, lives with Duchenne muscular dystrophy. He shares his experience of financial insecurity.

I have a lot of medical equipment which means our energy bills are very high and have increased a lot in recent years. Using a ventilator and regularly charging my electric wheelchair uses additional electricity. Because I'm unable to move independently, I also have to keep my flat quite warm.

We've been on the waiting list for a new property for the last seven years. We've recently been accepted for a new flat, but the Disabled Facilities Grants (DFG) process is very stressful – whether my basic human needs will be met are in the hands of a single person.

> **We've been trying to reduce the heating bill by putting extra blankets on me. But this makes it even harder for me to move due to the weight on my body."**

I enjoy going out in nature and taking photographs, as well as attending comic conventions. I've started reducing this though, to ensure we have enough money for the essentials. There's always the worry in the back of my mind about unexpected additional costs that may have to be dealt with.

My wheelchair is now 13 years old and has started needing a lot more repairs. It recently needed new tires and a battery, which on its own was £500. I had to borrow money from my mum just to be able to move around my own house.

Paying for transport and tickets for my carers is something I always have to think about. I avoid going to venues that don't offer a free carers ticket. Supposedly, this is what the mobility part of Personal Independence Payment (PIP) is for, but having a Motability car means you don't receive any of that income.

> **The company will soon stop making parts for my wheelchair and I will need to self-fund a new one which will cost around £20,000. This is a huge concern for me as I don't have that kind of money."**

3.5 What would help people feel more financially secure?

What the UK Government is doing

The UK Government is looking to address the rising number of people out of work to support its national ambition around economic growth. Some of their plans have already been outlined, including a new national jobs and careers service, a new youth guarantee, and devolving more powers to local leaders to support disabled people and those with long-term conditions into work.[18] We've largely welcomed their approach to both improve people's health and provide tailored employment support, including facilitating a more localised approach.[19] However, we are still waiting to hear about the wider directions of employment and welfare reform, some of which will be detailed in an upcoming white paper.

Inputting into government thinking and reform agenda

To input into ongoing government thinking, we set out to explore what type of support our community would most like to see. Through our financial security survey we've heard directly from people living with a muscle wasting and weakening condition about the employment and financial support measures that would increase their sense of financial security. This report is an opportunity for us to share what our community has told us at this critical moment so we can all work together to shape the solutions in, and delivery of, the UK Government's upcoming reform agenda.

The top employment-related measures people would like to see

Figure seven, on page 21, shows the top employment-related measures people living with a muscle wasting and weakening condition say would improve their financial security.

- 39%, four in ten, of our survey respondents said not feeling at risk of losing benefits is at the top of their list, and that it would have the biggest impact.

We consistently hear that losing benefits is a major cause of insecurity, whether it's anxiety around the potential outcome of benefit reviews or the stress caused by uncertainty over potential government reforms to PIP and being at risk of losing your benefits. In fact, one in four (26%) say more certainty over upcoming changes to the social security system would help them feel more financially secure (see figure eight).

Three of the top five employment measures people would like to see relate to the role of employers. These are:

- 33% of survey respondents said employers need a better understanding of disabled people.
- 23% said there needs to be more opportunities for disabled people.
- 23% said there needs to be greater flexibility when it comes to managing their conditions – for example attending hospital appointments.

Working from home is the most important flexible working arrangement our community would like to see, not least because of the control it allows people to keep around managing their condition and independence.

> **"More help required to secure a job with a degree of challenge, it's my arms and legs that don't work very well, but my brain is very alert."**
>
> Survey respondent

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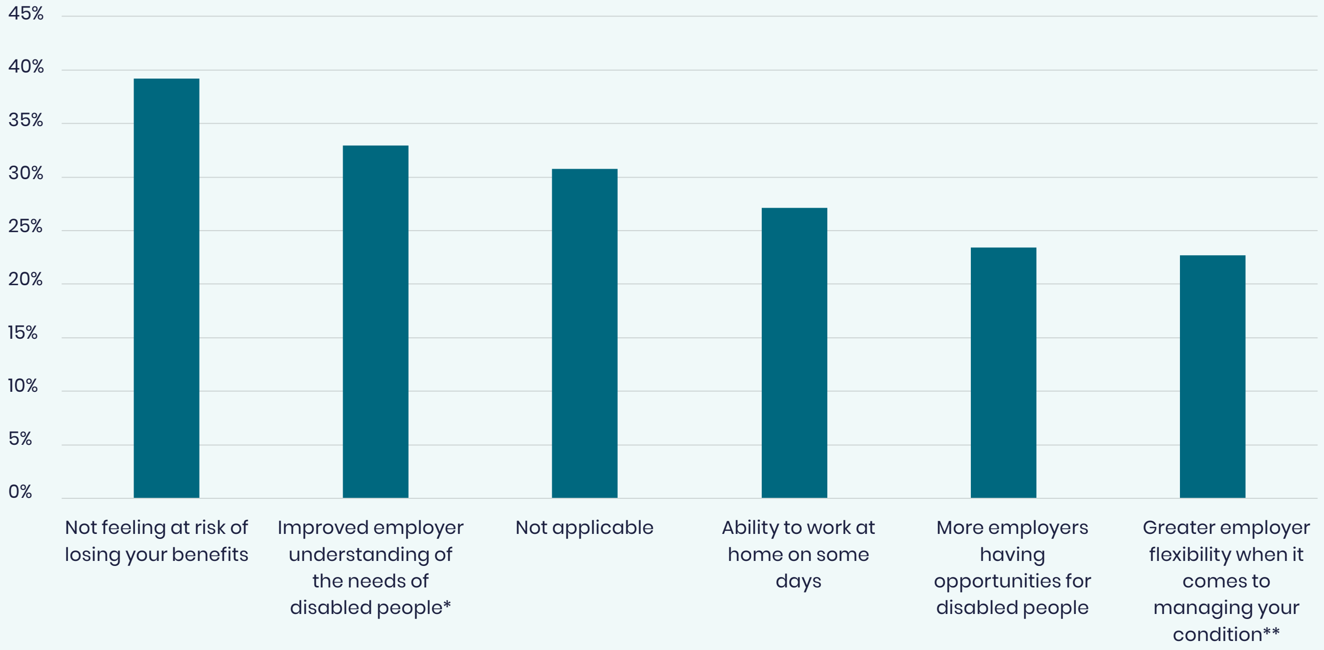
[18] UK Department for Work and Pensions, 'Back to Work Plan will help drive economic growth in every region' (11 July 2024).

[19] Muscular Dystrophy UK, 'What do the Work and Pensions Secretary's priorities tell us about the new UK Government's plans for supporting people into work?' (15 July 2024).

Figure 7: Employment measures that would increase financial security

Please select up to three employment-related arrangements or resources that would help you/the person you know feel more financially secure.



* Including those with complex needs but who still want to work
** For example, surrounding attending hospital appointments

The top financial and other support measures people say would improve their financial security

Figure eight, on page 22, shows the top financial and disability-related support measures people living with a muscle wasting and weakening condition say would improve their financial security. Directly increasing the funds available to people would be the most important step governments could take towards this.

- 64% of survey respondents said increasing the level of benefit allowances would help.
- 45% said increasing the provision of additional one-off payments to help with the cost of living, such as the previous Disability Cost of Living Payments of £150, would help.
- 53% said implementing wider changes to the social security system to better meet the needs of people living with muscle wasting and weakening conditions would help.

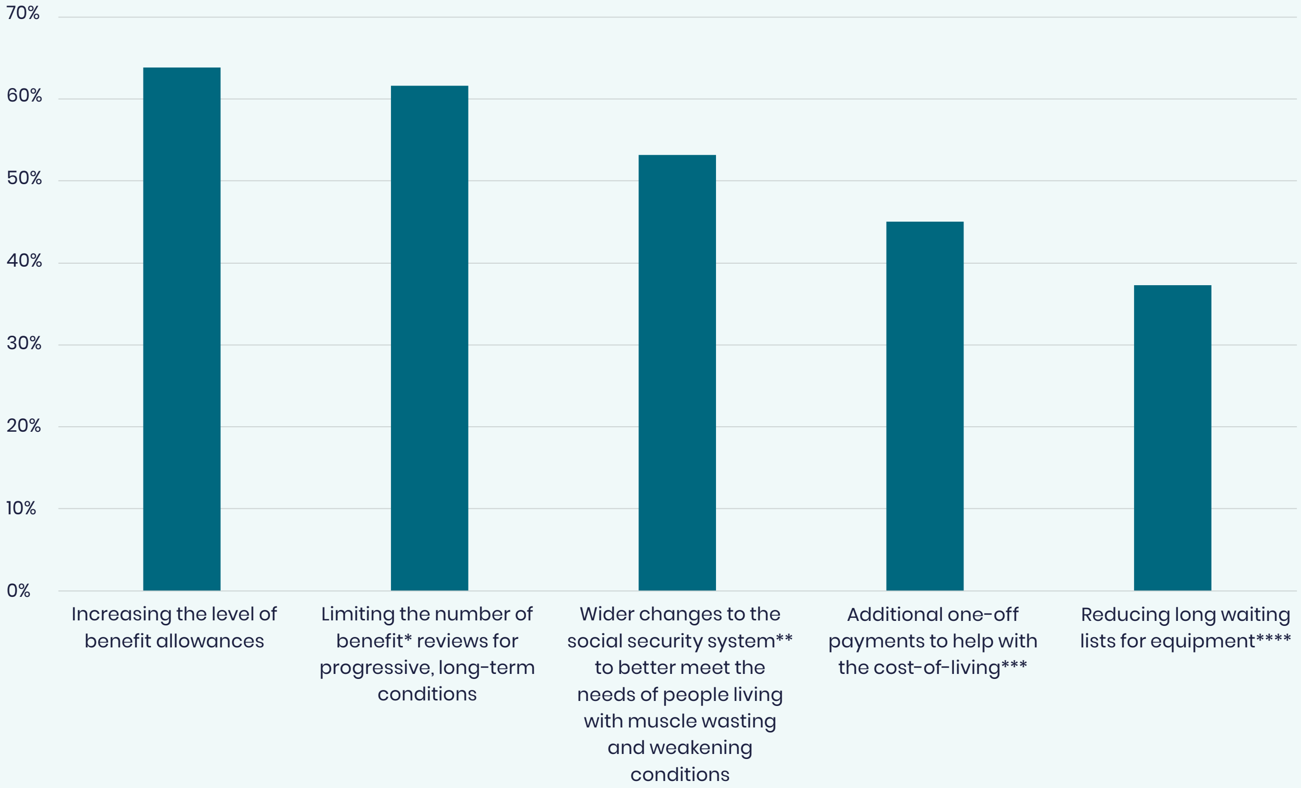
We've previously mentioned the worry brought about by the possibility of losing your PIP allowance when it is being reviewed. But our frustrations with the system, and in particular with PIP, do not end there. We repeatedly hear from people on benefits who say that assessors lack condition-specific awareness and training; how difficult the application (including appeals process) can be; and how it can often feel like the system is trying to catch them out.

A massive overhaul of the welfare system is needed. In addition to increasing allowance levels, a system that would make our community feel more financially secure would also include longer benefit awards; fewer medical reviews (especially for people with progressive long-term conditions that will not get better); reform to application criteria to better account for fluctuating and mobility-impairing conditions; and more.[20]

> **Currently waiting for my PIP renewal to come back (has been 13 months since forms sent back so far) and the worry of losing my PIP fills me with dread everyday as I rely on this to support me and for my independence as I have a motability car."**
>
> Survey respondent

Figure 8: Financial and other support measures that would increase financial security

Please select up to three financial and disability-related support measures that would help you/the person you know feel more financially secure.



* For example, PIP

** For example, PIP assessment and application process

*** For example, the previous Disability Cost of Living Payments of £150

**** For example, so you don't have to buy your own to prevent your condition worsening

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[20] For further exploration of the benefits system, see Muscular Dystrophy UK, 'Below standard: MDUK's assessment of the benefits system' (2020). Available at: https://www.musculardystrophyuk.org/app/uploads/2024/05/Benefit-report.FINAL_EMBARGO-compressed.pdf

How can we all make our community feel more financially secure?

Living with a muscle wasting and weakening condition affects people differently. This means the employment situation for those living with one of the over 60 muscle wasting and weakening conditions may look different. For example, over a quarter of our survey respondents are working, while almost a third are not formally required to look for work.

Our findings show how not feeling at risk of losing benefits – for example if people try to work but things don't work out – would be the most significant employment-related step to improving financial security for our community. As such, we support the position put forward by the wider disability sector that "claimants with a realistic prospect of employment can and should be offered high-quality, tailored employment support. Such support should be voluntary and sold on its merits, not imposed by benefit cuts and sanctions."[21] As part of supporting disabled people into work, we recommend the UK Government clarify how it will give people "the confidence to start working without the fear of an immediate benefit reassessment if it does not work out."[22]

We also look forward to working with local leaders around the delivery of tailored plans to help disabled people and those with health conditions into work.[23]

But our findings also demonstrate how a wider approach to work and welfare needs to go further in improving a sense of financial security for people living with a muscle wasting and weakening condition. Specific measures around building skills and confidence or improving access to employment are needed. But so too are broader changes in attitudes around, and opportunities for, disabled people at work. Repeated piecemeal reform of the benefits system and unnecessary periodic reviews for medical conditions that won't improve are detrimental. Instead, we advocate for a more holistic overhaul of the social security system to better suit the needs of people living with muscle wasting and weakening conditions. To this end, we urge the UK Government to engage with organisations like ours to deliver their manifesto commitment to publish "a proper plan to support disabled people to work."[24]

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[21] Disability Benefits Consortium, 'Work Capability Assessment: Submission by the Disability Benefits Consortium to the Activities and Descriptors consultation' (October 2023), paragraph 2.4. Available at: https://disabilitybenefitsconsortium.com/wp-content/uploads/2023/11/work-capability-assessment-2023.10-dbc-response-to-consultation.docx

[22] The Labour Party, 'Labour Party Manifesto 2024', see chapter: 'Kickstart economic growth'.

[23] UK Department for Work and Pensions, 'Back to Work Plan will help drive economic growth in every region' (11 July 2024).

[24] The Labour Party, 'Labour Party Manifesto 2024', see chapter: 'Kickstart economic growth'.

4. Summary and next steps

We already knew that disabled people were disproportionately affected by the cost-of-living crisis. But our report has found most people living with a muscle wasting and weakening condition feel financially insecure. This situation has worsened over the past two years, with more people today feeling worried about their financial situation. Lots of people in our community struggle to afford the essentials – utility bills, everyday travel, a healthy diet, and getting necessary mobility equipment and aids – on their current income. All of this has a profound negative impact on people's health and wellbeing, as well as on their ability to work.

These findings come at a time when the UK Government is aiming to get more economically inactive people into work to promote national growth. They are readying fundamental employment and welfare reform. We've heard directly from people living with a muscle wasting and weakening condition about the measures that would most help them feel more financially secure, and with this be better able to support these ambitions.

On employment:

- The UK Government should ensure that people living with muscle wasting and weakening conditions, and other disabled people, do not feel at risk of losing their benefits.
- The UK Government and employers should work with expert organisations to improve employer understanding of the needs of disabled people. This should also look at how to develop more opportunities for disabled people.
- Employers should implement flexible working practices, in particular the ability to work from home on some days.

On welfare:

- The UK Government should increase the available income of people with muscle wasting and weakening conditions (for example by raising the level of financial and disability-related benefit allowances, or additional one-off payments).
- In the longer-term, the UK Government, in consultation with disabled people and patient organisations like Muscular Dystrophy UK, should implement wider changes to the social security system to better meet the needs of people living with muscle wasting and weakening conditions.
- In the shorter-term, the UK Government should limit the number of benefit reviews for individuals who have progressive, long-term muscle wasting and weakening conditions.

We'll closely monitor government activity and hold the UK Government to account on its manifesto promises. We'll also continue advocating for the needs of our community to ensure the voices of people living with a muscle wasting and weakening condition inform these upcoming proposals. Finally, we want to work with the UK and devolved governments, employers, disabled people, local leaders, and other actors, to see the above recommendations delivered. Together, we can best support people living with muscle wasting and weakening conditions to enter and stay in work, deliver a successful programme of reform to the benefits and employment systems, and support the national ambition to kickstart economic growth.

5. About Muscular Dystrophy UK

We're the leading charity for over 110,000 people in the UK living with one of over 60 muscle wasting and weakening conditions.

We connect people living with muscle wasting and weakening conditions, and all the people around them, friends and family, healthcare professionals and scientists. So that everyone can get the healthcare, support and treatments needed to feel good, both mentally and physically. We support people through every stage of their life, from the point of diagnosis to living the best life possible.

- We share expert advice and support so people can live well now.
- We fund groundbreaking research to understand the different conditions better and to 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.

If you need support, call our helpline on **0800 652 6352** (Monday to Thursday, 10am-2pm) or email **info@musculardystrophyuk.org**.

To speak with our employability helpline, call **0800 652 6352** (Monday to Thursday, 2pm – 4pm) or email **employability@musculardystrophyuk.org**.

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