



**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



Below standard: MDUK's assessment of the benefits system

How the welfare system needs to change for people with muscle-wasting conditions

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Foreword

As a passionate advocate for the right of disabled people to live independently, and with a long history of calling the Government to account on this issue in the House of Lords, I welcome this report from Muscular Dystrophy UK – although its findings are of course disappointing.

I would like to thank the hundreds of people living with muscle-wasting conditions who have shared their experiences in order to produce this report, which highlights that there are still major flaws in the disability benefits system three years on from the charity's last major investigation of this issue. People continue to face distressing and stressful situations in the application, assessment and appeals stages of the benefits process, with a shortfall of even a basic knowledge about the progressive aspect of muscle-wasting conditions.

At a meeting in July 2019, which Muscular Dystrophy UK had arranged with Justin Tomlinson MP, Minister for Disabled People, we were encouraged that the Department for Work and Pensions said they were taking steps to tackle problems with Personal Independence Payments and Universal Credit.

However, it will take a considerable amount of change to ensure that the processes work satisfactorily in practice for claimants. This report presents a renewed opportunity for the Department for Work and Pensions and assessment providers to take action in response to the recommendations that have been put forward, and to use information and resources that are shared by Muscular Dystrophy UK.

I will continue to hold the Government to account with Parliamentary Questions and contributions to debates in the House of Lords to try to secure the improvements that are urgently needed to create a fairer and more equitable benefits system for disabled people to lead full and independent lives.

Baroness Thomas of Winchester
Trustee, Muscular Dystrophy UK



Executive summary

Individuals and families affected by muscle-wasting conditions face additional expenses every single day.

These costs pay for care, major adaptations to their homes, specialist equipment and wheelchairs.

Getting the right financial support is vital. It helps people meet the extra costs that living with a muscle-wasting condition brings.

It also provides financial security, independence and a decent quality of life.

Many people with a muscle-wasting condition will be entitled to benefits such as Personal Independence Payment (PIP), Employment Support Allowance (ESA) and Universal Credit (UC). However, we know that many people are facing challenges in getting access to these benefits.

This report is based on an in-depth survey completed by 592 people living with muscle-wasting conditions. Published three years after our last major disability benefit system investigation, the report reveals that individuals and families living with muscle-wasting conditions are continuing to face challenges and are struggling to get the disability benefits they are entitled to.

While we acknowledge that some positive steps have been taken in recent years, there is clearly still a long way to go before people are able to easily and confidently get these benefits.

In collaboration with other disability charities, and through our membership of the Disability Benefits Consortium, we have in the past highlighted glaring flaws in the criteria and implementation of PIP. We also recently raised significant concerns about the way UC is being introduced, based on the findings of a survey of over 500 disabled people.

In this report, we shine a light on key areas of concern and share the solutions we would like the Department for Work and Pensions (DWP) and assessment providers to introduce.

We want to reach, educate and inform more assessors about muscle-wasting conditions, and at the same time ensure that people living with muscle-wasting conditions and their families feel informed and empowered.

Along with offering one-to-one support through our advocacy service, Muscular Dystrophy UK (MDUK) has also introduced a new step-by-step PIP application guide specifically for people living with muscle-wasting conditions, as well as their families. This detailed guide takes people through every step of the application process.

The complicated application process and the consequences of incorrect decisions are causing a huge amount of stress for people living with muscle-wasting conditions.

We must see an improvement in the number of claims being assessed and awarded correctly the first time round.

Through speaking to individuals directly, we know that when the application process is incorrect or delayed, there is not only an increase in financial hardship, but there is also an impact on mental health, quality of life and independence.

Every day counts for people living with progressive muscle-wasting conditions, so it is vital they receive an accurate decision on awarding a benefit at the earliest opportunity.

Key terms

Disability Living Allowance (DLA): for adults aged 16-64, this disability benefit was broken down into a care and a mobility component. It is currently being phased out. The benefit still exists for children under the age of 16 who have care or mobility needs.

Personal Independence Payment (PIP): replaced DLA in 2013. PIP is for disabled adults aged 16-64. It is divided into two components: daily living and mobility. Each of these has two levels: standard and enhanced. Qualifying for PIP also entitles you to other support such as a Blue Badge and Carer's Allowance.

Mandatory reconsideration: the first step of challenging a PIP decision. It is asking the Department for Work and Pensions (DWP) to look at their decision again.

Tribunal appeal: the second step of challenging a PIP decision. It is asking an independent tribunal, called the First Tier Tribunal, to look at the decision. You can normally only appeal after you've received a mandatory reconsideration notice.

Employment Support Allowance (ESA): a benefit designed to provide financial support for people who are unable to work because of illness or disability. It is broken up into two elements: contributory ESA and income-related ESA.

Universal Credit (UC): a new benefit that replaced income-related benefits such as housing benefit, income-related ESA, child tax benefit, income-based job seeker's allowance, etc. It consolidates all of these benefits into a single application process and a single monthly payment process.

Motability: a funding scheme for people who qualify for the mobility part of PIP (either standard or enhanced), which takes part or all of the award to provide the person with an adapted vehicle, scooter or wheelchair.

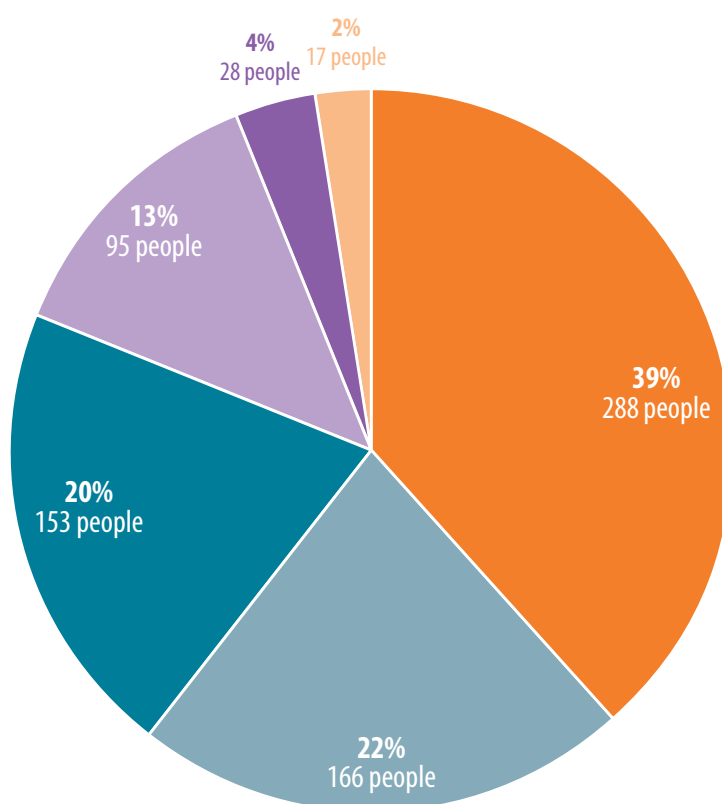
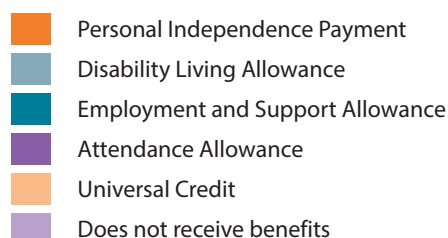
Key findings

In the spring of 2019, MDUK carried out a survey on access to disability benefits, including PIP and the new UC, for people living with muscle-wasting conditions. Nearly 600 people living with muscle-wasting conditions and families took part in the survey.

Not all participants are entitled to the same benefits, so response rates to our questions varied.

The survey responses uncovered the following findings:

What benefits are people living with muscle-wasting conditions receiving?



Loss of independence and financial hardship

- One in three reported financial difficulties when transferring to UC.
- Three out of four respondents had to wait five weeks¹ or more for the initial payment after applying for UC.
- One in 10 respondents had lost their Motability vehicle on transferring to PIP, because of a reduction in the mobility component.
- One in three respondents found an assessment centre to be inaccessible.

Overturning inaccurate decisions

- More than one in three people who went through the PIP mandatory reconsideration process got an increased payment. Over half of respondents who went through the PIP appeals process were given an overturned decision or an increased payment following an appeal.

Delays

- Over half of all respondents had to wait three months or more for a face-to-face assessment to determine their entitlement based on how their disability affected their daily life.
- Two out of five respondents had to wait more than six months for a PIP tribunal appeal.

1. The Government website states that "It usually takes around 5 weeks to get your first payment" of Universal Credit: <https://www.gov.uk/universal-credit/how-youre-paid>



We analysed the 592 survey responses and identified three key parts of the benefits system that urgently need to change:

- application process
- assessment process
- appeals process.

Application process

Recommendation 1

- **The DWP needs to ensure that online and paper application forms are available for PIP and UC.**

Currently PIP applications are available in paper format only. This is fine for some people but completing a form in this way can be very challenging for people living with muscle-wasting conditions. It is vital that people are given a choice of how to complete their application in a way that meets their needs.

Recommendation 2

- **The DWP must clarify the process for people with severe disabilities to request extra time to complete forms.**

Claimants have one month to fill in a PIP application form and return it for the claim to go ahead. Muscle weakness and fatigue can make completing application forms challenging. Reasonable adjustments and a clarification of the process should be made to allow people with muscle-wasting conditions additional time to complete forms without causing undue stress.

Recommendation 3

- **The DWP should regularly review its communications to claimants ahead of assessments and re-assessments.**

It is vital that communication is clear so that there is no confusion about what is required from the claimant.

Assessment process

Recommendation 4

- **Independent Assessment Services (IAS), Capita and other providers must take urgent action to ensure that its assessors have access to 'condition insight reports'.**

These provide a detailed overview of muscle-wasting conditions ahead of an assessment. It is vital that assessors have a basic understanding of someone's condition. At the very least, assessors should understand that muscle-wasting conditions are rare, often progressive and lifelong.

Recommendation 5

- **IAS, Capita and other providers need to ensure that their assessors take medical evidence provided by health professionals fully into account.**

Muscle-wasting conditions are rare. While we would expect assessors to have a basic knowledge of the progressive and lifelong nature of these conditions, we appreciate the assessors are often not from a medical background. It is vital that assessors pay attention to any evidence submitted by healthcare professionals, which will outline the impact the condition has on the claimant's everyday life.

Recommendation 6

- **IAS, Capita and other providers should work with MDUK to set up training sessions to help improve their assessors' knowledge of muscle-wasting conditions.**

This will improve the quality of the assessments and ensure that people are awarded the correct level of financial support they are entitled to from the outset.

Recommendation 7

- **The DWP must review the PIP mobility component criteria and create a fairer test of walking distances that is more in line with the former assessment for DLA.**

Under DLA, you could qualify for the higher rate mobility if you could walk less than 50 metres. Under PIP, if you can stand and walk more than 20 metres then you do not qualify for the higher rate mobility. This has meant that people have seen a reduction in their payments following the move from DLA to PIP. Not only has this reduced the level of financial support that people can receive, it has also had a negative impact on people's ability to get additional support, such as wheelchairs or adapted vehicles.

Appeals process

Recommendation 8

- The DWP and Motability must ensure that the claimant retains vital support, such as Motability vehicles, while the mandatory reconsideration and appeal processes are taking place.

Motability vehicles are essential for some people with muscle-wasting conditions to retain their independence. Removal of a vehicle must only happen if all appeals have been exhausted.

Recommendation 9

- The DWP needs to review the environment in which appeals take place. They must find ways to reduce the stress and anxiety felt by many claimants during this process.

Appeals should be a last resort and must not add undue stress and anxiety for claimants who will already be experiencing financial hardship. It is important that appropriate support is offered and that claimants are clear about the appeals process and how long it will last.

Background to the survey and the support we offer

MDUK is committed to tackling the difficulties people with muscle-wasting conditions have in getting access to benefits.

How are we providing support?

Our advocacy service supports more and more people each year, providing them with support in claiming benefits and contesting welfare decisions.

The service caseload in 2018-19 was 127 percent higher than it was in 2016-17. This highlights the breadth of challenges people with muscle-wasting conditions face when they don't get the financial support they not only need, but are also entitled to.

Well over 50 percent of these cases are welfare-related, with the number of PIP cases being consistently high. This shows the many well-documented problems the transition from DLA to PIP has brought to people living with muscle-wasting conditions.

With the rollout of UC imminent, we predict comparable problems and a corresponding growth in caseload to run alongside the current issues we are seeing with PIP.

What issues need to be addressed?

The change from DLA to PIP has caused stress and anxiety to many applicants.

This is mainly because of the changes in the mobility criteria. The lack of knowledge of muscle-wasting conditions among many assessors has resulted in inaccurate assessments and decisions, which then need to be appealed.

MDUK has been pressing for disability benefits to be reviewed and reformed for several years. Many of the challenges and barriers, which we highlighted three years ago, still need to be fixed, as flagged in a recently published Disability Benefits Consortium report, *Has welfare become unfair?*²

2. *Has welfare become unfair?* Disability Benefits Consortium, July 2019 <https://disabilitybenefitsconsortium.files.wordpress.com/2019/07/disability-benefits-consortium-report-has-welfare-become-unfair.pdf>

What progress has been made?

The Government announced in June 2018 that new guidance around PIP would be coming into effect. This guidance would see claimants who are awarded the highest level of support (enhanced rate) and have needs that are expected to stay the same or increase, receive an ongoing award of PIP with a 'light touch' review every 10 years.

The change will mean that claimants who meet the criteria will not have to go through the stress of a regular reassessment.

We have also been trying to improve assessors' knowledge of muscle-wasting conditions by developing a 'condition insight report' for the assessment providers.

We have received positive feedback on this from assessment providers, especially in highlighting the impact of fatigue on individuals' ability to carry out everyday tasks. However, we know that there are many more assessors to reach with this information. We will continue to work with assessment providers in order to achieve this.

How have we produced this report?

In April 2019, we launched an online survey, which was open for two months. We wanted to hear about the experiences of people with muscle-wasting conditions (and their families) when accessing the benefits system.

The survey included a series of open and closed questions about the different elements of the benefits process, such as applications, assessments and appeals.

We also asked questions around the specific welfare benefits that we know many people with muscle-wasting conditions receive. Not all questions were relevant to all respondents, so the response rate varied from question to question.

Close to 600 people responded to the survey.

What follows is a qualitative and quantitative analysis of the survey results.



Application process

What we asked

- How respondents would like to apply for benefits.
- Whether respondents had any physical difficulties in completing the application process.
- How long it took from applying for a benefit to having a face-to-face assessment.

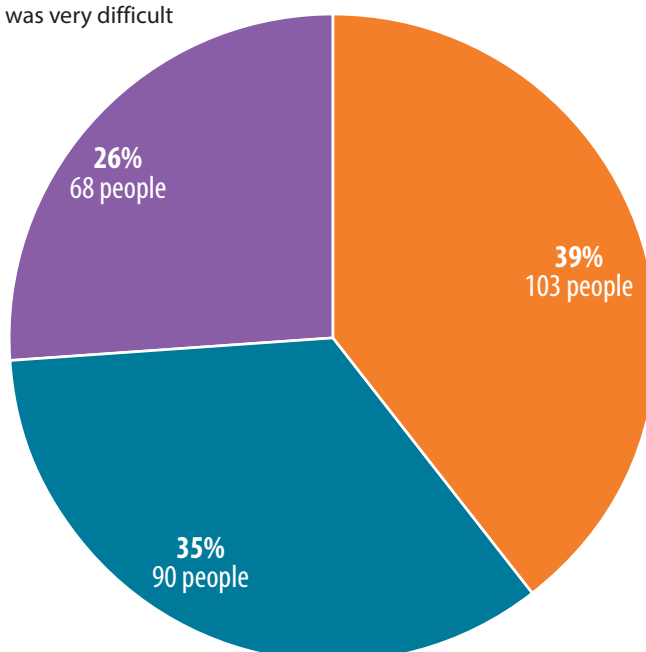
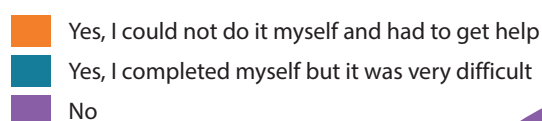
What we were told

People with muscle-wasting conditions have difficulty in completing application forms for disability benefits. This is because they are often physically unable to write or type the amount of information required on the long application forms.

MDUK's advocacy service has received many requests from people asking us to look at the issues surrounding the form and to help them complete it.

Did you experience any difficulty physically completing your PIP application because it had to be completed by hand?

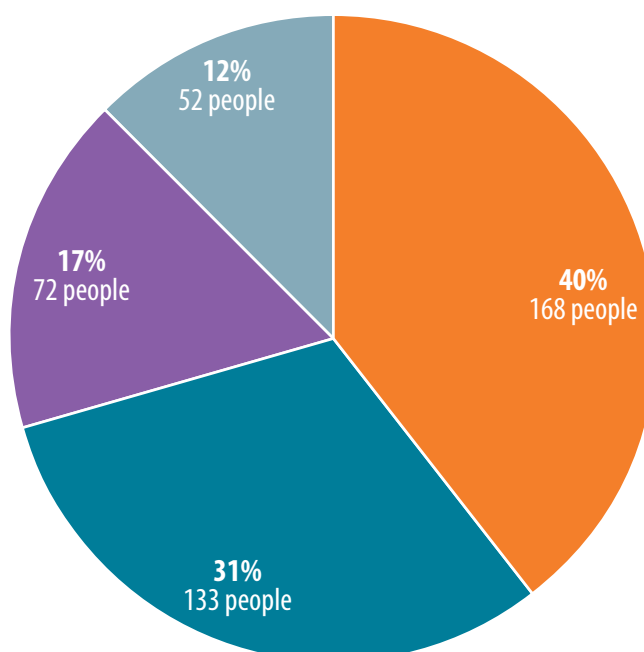
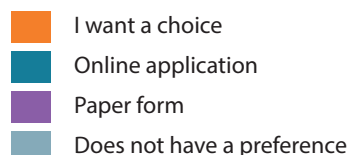
- Three out of five respondents found it difficult to complete the form, either filling in the form themselves (with difficulty) or having to ask someone to write the answers on the form on their behalf.



We asked what preferences survey respondents had for completing application forms – in paper form or online. PIP applications are on paper only, whereas UC is almost exclusively online.

How would you like to apply for benefits?

- Two out of five respondents expressed a preference for having the option of submitting application forms by paper and online.



A worryingly common theme was people telling us they had experienced stress because of the application process.

"I found the application process for Disability Living Allowance extremely stressful and upsetting. The DWP lost forms, then they found them once the form and support letters were re-sent."

Laura McPhail, whose daughter has limb girdle muscular dystrophy

"It's just a long, drawn out, degrading, frustrating, stressful process that people with lifetime progressive conditions should not have to endure! I'm also registered severely sight impaired/blind & the time scale for completing the form is too short when I have to arrange for help from a third party."

Alexander Gosney, who has mitochondrial myopathy

What we asked

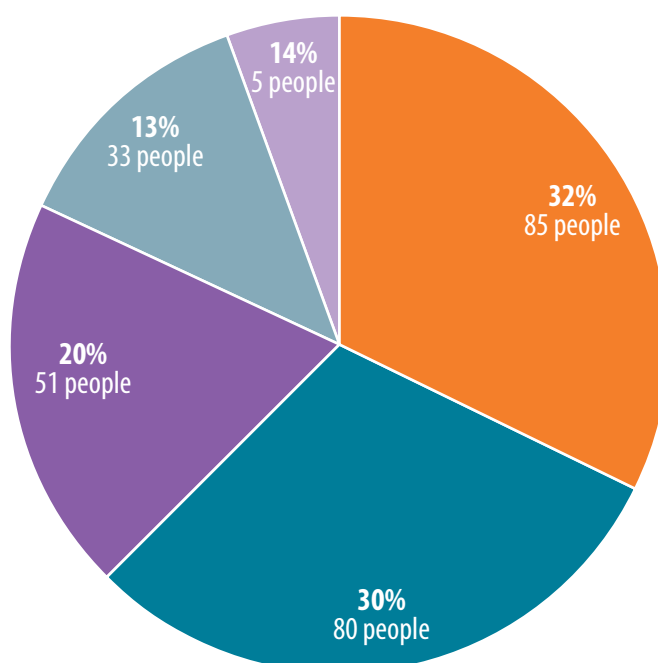
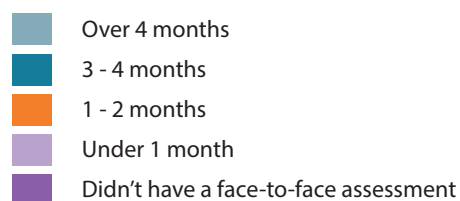
- If the assessment centre was accessible or if reasonable adjustments were offered.
- If respondents had been offered a home assessment.
- How the assessment process made respondents feel.

What we were told

Respondents shared their experiences of many aspects of the assessment process, including waiting times for a face-to-face assessment, accessibility of the assessment centre and the assessors' knowledge.

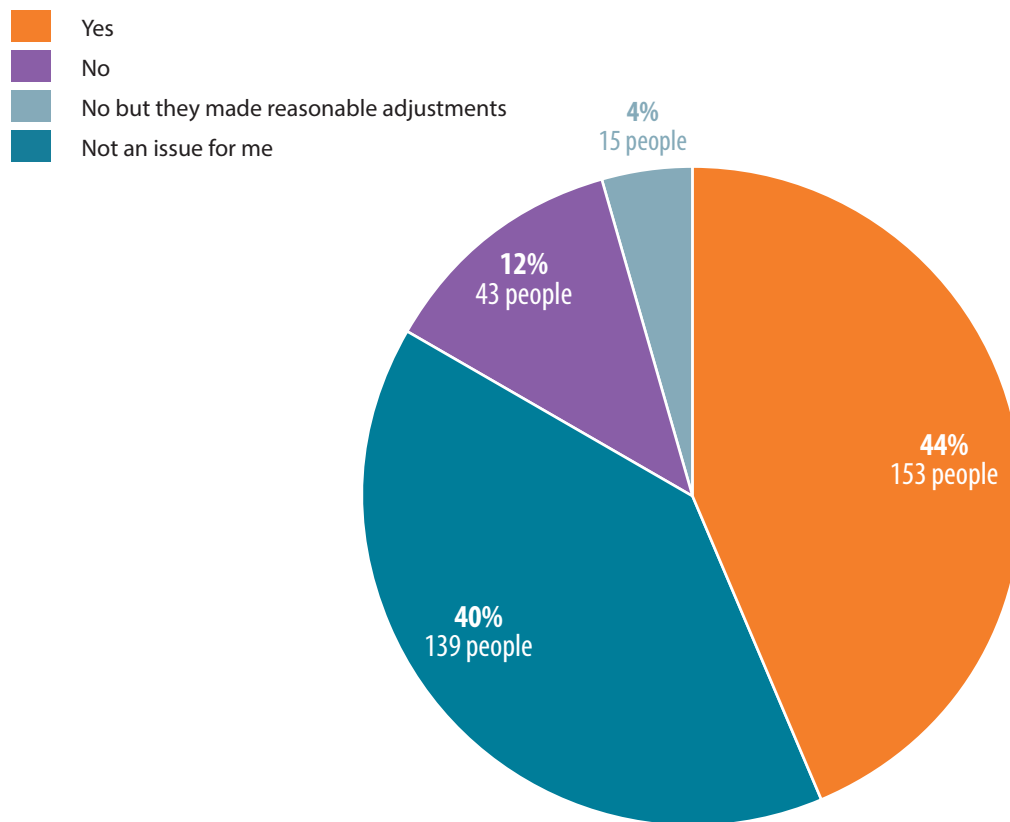
How long between submitting application and getting a face-to-face assessment?

- Almost half of respondents told us they had to wait three months or more for a face-to-face assessment.

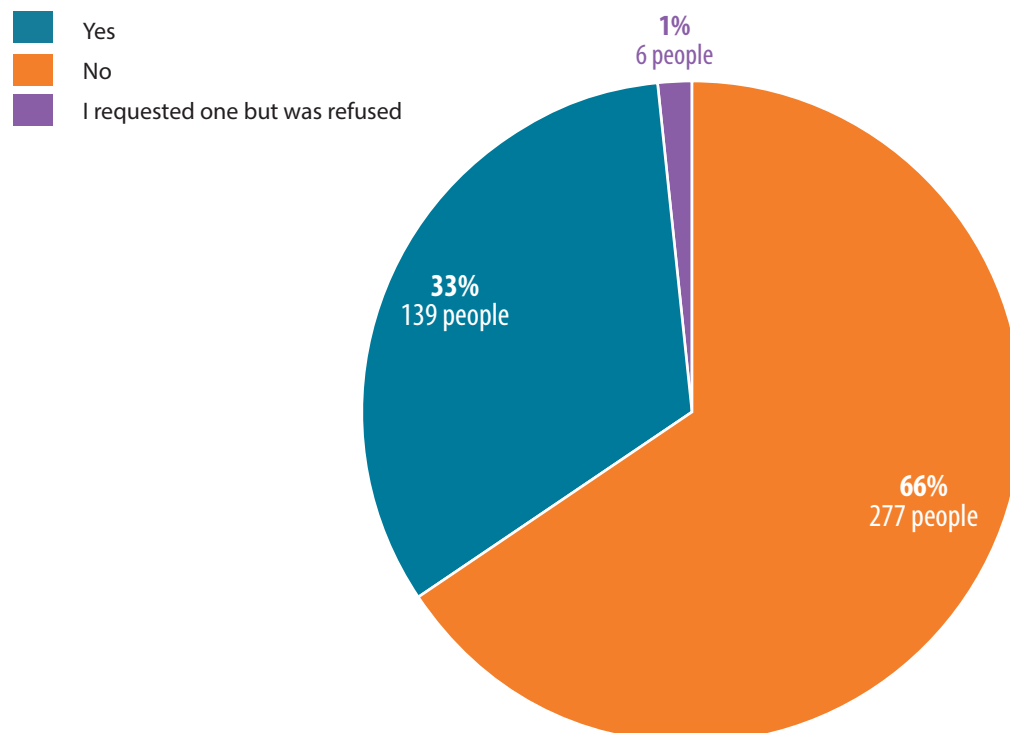


Was the assessment centre accessible?

- One in five respondents said the assessment centre was inaccessible.



Have you had an assessment at home?





"I feel the assessment should be carried out by professionals familiar with muscular dystrophy; by those who understand the progressive nature and the high health risks associated with the condition. There is also no consistent member of staff allocated to individuals, making it extremely difficult to speak to the same person on the telephone more than once."

Alexandra Standen, who has inclusion body myositis (IBM)

"The assessment I received was seriously flawed. When testing my ability to carry pots/pans and if I struggled to cook, I was asked to squeeze the assessor's fingers. The outcome was based entirely on that. On the report the assessor said that I could hold/carry pans. I struggle with this activity quite a lot. It's the difference between adduction and abduction; squeezing fingers does not replicate those movements very much at all."

Mark Farmer, who has limb girdle muscular dystrophy

"I tried to apply for DLA about five years ago but was refused. I haven't applied again, especially since it has changed to PIP, as those I know who have done this have had very bad experiences during assessment meetings and felt they were not taken seriously. I worry that the same will happen to me."

Leah Dore, who has Charcot-Marie-Tooth disease (CMT)

The responses highlight that many assessors still lack even a basic understanding of muscle-wasting conditions. While we would not expect an expert level of knowledge of these rare conditions, we believe there should be an overall awareness and, at the very least, an understanding of the progressive and long-term nature of these conditions.

What we asked

- If respondents had lost their Motability vehicle because of a change in their award.
- If respondents had appealed a decision.
- How long respondents had to wait for a tribunal appeal.
- Whether the appeal led to an increase in respondents' payments or the original decision being overturned.

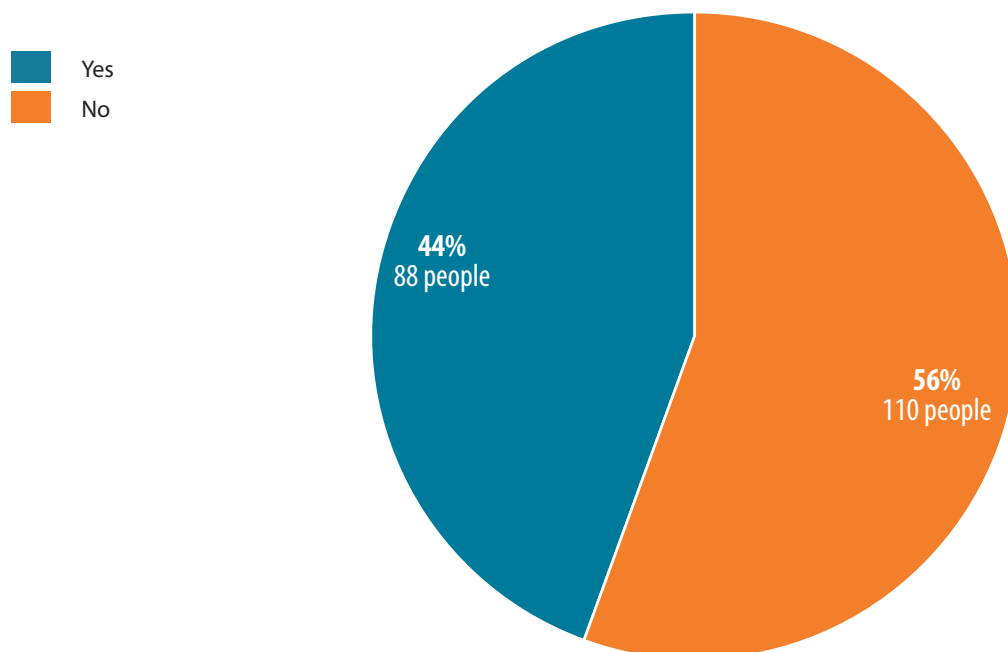
What we were told

If you are unhappy with a decision about your benefits, you can ask the DWP to look at the decision again. This is a 'mandatory reconsideration'. If the DWP does not change their decision, then you can appeal to an independent panel, called a 'tribunal'. A tribunal looks at the evidence from both sides and then makes a final decision.

A significant number of respondents shared alarming experiences of losing their Motability vehicle as a result of the assessment. They also shared the often stressful and lengthy process of going through mandatory reconsideration.

The percentage of negative decisions overturned at appeal stage demonstrates the urgent need for more accurate decisions to be reached first time round.

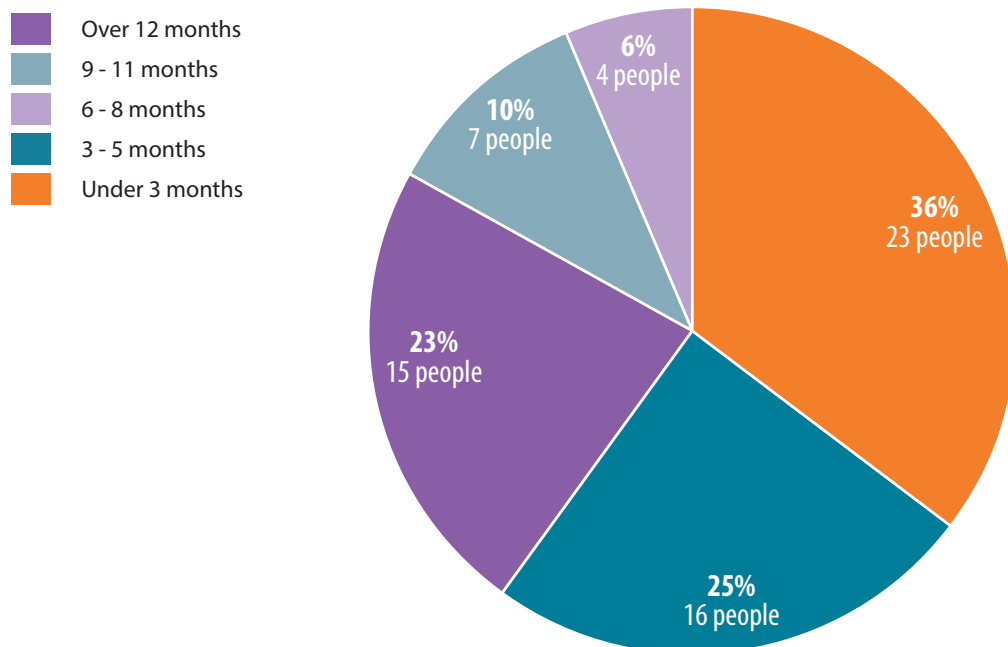
Did you challenge your PIP decision?



- Over half of respondents who went through the PIP appeals process obtained an overturned decision or an increased payment following an appeal.

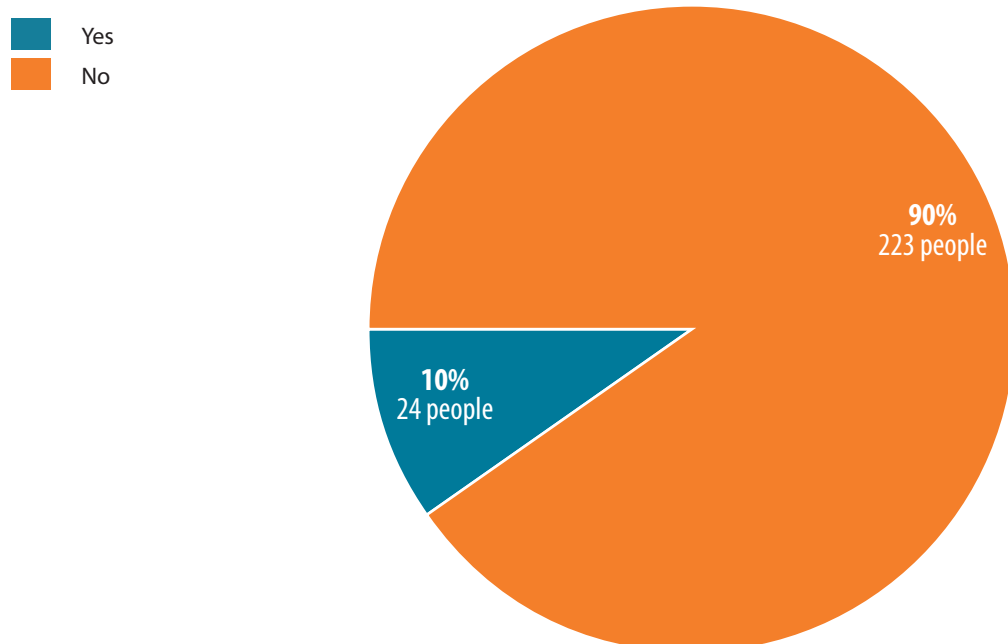
How long did you wait for a tribunal appeal?

- Two out of five respondents had to wait more than six months for a PIP tribunal appeal.



Did you lose your Motability vehicle?

- One in 10 respondents had lost their Motability vehicle on transferring to PIP because of a reduction in the award for the mobility component.



Many felt that submitted medical evidence had not been taken into account.

"I had a nightmare with PIP because when I applied for mandatory reconsideration I was still downgraded for mobility. When I called the DWP, I was told that my doctor's statements hadn't been looked at so a second mandatory reconsideration was done and I then got the enhanced rate of mobility. It was an extremely stressful time."

Lynne Earthy, who has spinal muscular atrophy (SMA)

Anyone getting the enhanced rate of PIP qualifies for a wheelchair-adapted vehicle via the Motability scheme. However, we heard from 24 respondents who had lost their Motability vehicle because, they were told, they were no longer eligible for the enhanced rate of the mobility component under PIP. Losing a Motability vehicle can be devastating, taking away your independence. You then have to appeal to get your vehicle back. This can be extremely stressful.

"I think it is unfair that the changeover to PIP meant I lost my car. When I was on DLA it was an award for life, as we all know these conditions do [not] right themselves."

Georgina Armes, who has facioscapulohumeral muscular dystrophy (FSHD)

"I received DLA higher rate mobility and got a car through Motability scheme. I then had to apply for PIP, only to be told I no longer met any criteria. I have asked for a mandatory reconsideration and I have now started the appeal process. It looks like I may lose my Motability car. This will greatly impact upon accessing services and appointments. Despite not being independent with travel, the DWP say they can't award PIP for mobility even though I have to use a wheelchair for anything more than a very short distance. It has been an extremely stressful experience, which has been going on for eight months and is still not resolved. How can DLA be awarded to me for so long and then I suddenly get nothing despite no improvement in my condition?"

Michelle Morgan, who has congenital muscular dystrophy

The respondents' experiences of ESA assessments and appeals signal a stark warning for the rollout of UC.

"I had to fight two years to be put into a support group for ESA. In my first assessment, I scored zero points. It went to a tribunal and I was put into the 'work-related group'. It was very stressful. With the help of Muscular Dystrophy UK and a new assessment, I received the points I should have done to start with and was put in the support group."

Sue O'Brien, who has FSHD

While it is still too early to fully assess the impact of the rollout of UC, the initial signs indicate that further significant changes are urgently required to improve this process.

"Universal Credit is dreadful. They didn't send a letter explaining why I had been turned down. We waited for months. Still nothing. So I have done the mandatory reconsideration without the letter! That was four weeks ago and I am still waiting to hear! I have had no money for a year..."

Corinne Clifford, whose son has myotonic dystrophy

Impact of not accessing disability benefits

Every day counts for people living with muscle-wasting conditions.

People have a right to live as independently as possible. Benefit decisions have a profound effect on financial and daily life.

"I have lost my Motability car. I've lost my independence. I also have a child with the same condition and she's missed school due to us not being able to travel or get around independently. I'm in debt and it is awful."

Aamayah Mohammed, who has central core disease

"My husband has Duchenne muscular dystrophy. Before we got married, we were living separately and both receiving PIP at the maximum rate. We were both in the support group for income-related ESA, receiving the maximum possible amount with the severe disability premium. We needed this level of financial support because we both have very complex medical needs, which come with hidden additional cost to life. We were heavily penalised for getting married. My partner had to close his ESA claim and move onto my claim as a joint claimant. This left us over £100 a week worse off."

Charlotte Hardwick, who has myofibrillar myopathy

The stress and anxiety caused by the many stages of the disability benefits process should not be underestimated. It can have a huge impact on your mental health.

"It's so crazy having to consistently 'jump through hoops' because the progressive nature of FSHD isn't understood nor believed. Lost count how many times assessors have been adamant that there's a pill I could take to improve or cure me. It's an incredibly frustrating attitude based solely on ignorance. It takes considerable time to feel better in myself again. Horrendous."

Louise Beattie, who has FSHD



Conclusion: what next?

MDUK will be sharing this report with the Government, devolved administrations and assessment providers.

We will be enlisting support from our parliamentary supporters to highlight our findings and to press for the recommendations put forward in this report to be implemented.

Nobody living with muscle-wasting conditions should have to experience such a difficult benefits process.

PIP: a comprehensive guide to making your application

MDUK has a new detailed guide, offering applicants living with muscle-wasting conditions step-by-step support through the PIP application process. *Applying for PIP: a comprehensive guide to Personal Independence Payment (PIP) for anyone with a muscle-wasting or associated neuromuscular condition* will help people navigate the benefits system independently by providing them with all the information they need in one place.

The process can feel daunting, and MDUK has designed the guide to make the application easier to complete.

This benefit is key for people living with muscle-wasting conditions. It covers the additional associated costs that living with a disability brings. It also helps to promote equality and independence.

Lack of understanding of rare conditions is a real issue. This is why a strong and detailed application is vital for people with muscle-wasting conditions. We've designed the guide to offer helpful and detailed guidance on filling out the forms, along with advice on other aspects of the application process. A detailed guide for people with muscle-wasting conditions didn't previously exist; this is the first of its kind.

MDUK's advocacy service

Our advocacy service is here to help anyone with a muscle-wasting condition to get the care and support, services, benefits and equipment they are entitled to.

If you're struggling to access these services, we can help by providing advice or intervening on your behalf.

You can get in touch with us by calling our Freephone helpline on 0800 652 6352 or by emailing us on info@musculardystrophyuk.org



About Muscular Dystrophy UK

Over 70,000 young children and adults live with a muscle-wasting condition in the UK today. There's no cure, it limits and, in many cases, shortens lives. MDUK funds pioneering research into treatments and cures to improve lives today and transform those for future generations.

We're here with information, advice and support to help people with or affected by the condition to live well with muscle-wasting and associated conditions. And we're driving change to see better care so that people can stay active, independent and connected.

To find out more go to:



Helpline: 0800 652 6352



Research Line: 020 7803 4813



info@musculardystrophyuk.org