

Muscular Dystrophy UK

Fighting muscle-wasting conditions



Focus on disability benefits

Assessing the impact of Government reforms on independent living

June 2016



FRSB
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Foreword

On 4 May 2016, the House of Lords passed a motion in my name:

“That this House calls on Her Majesty’s Government to hold urgent talks with Disability Rights UK and the Disability Benefits Consortium to identify a mobility criterion in the Personal Independence Payment ‘moving around’ assessment which is fairer than the current 20 metre distance, in the light of the impact on reassessed disabled claimants and the resulting large number of successful appeals.”

The following week, these charities and I met the Minister for Disabled People and his team at the Department of Work and Pensions, and left them in no doubt of our concern at what was happening all over the country, particularly with PIP re-assessments, to those who had lifetime awards for Disability Living Allowance (DLA).

This report explores these issues further, suggesting practical ways forward in a constructive way. I hope the Government is listening.

Baroness Thomas of Winchester
Trustee, Muscular Dystrophy UK



Executive summary

Living with a progressive muscle-wasting condition is expensive. Individuals and families affected by these rare neuromuscular conditions face additional costs on a daily basis for care, major adaptations, specialist equipment and wheelchairs as well as higher utility bills.

Accessing the right financial support therefore assists with some of the extra costs of living with a muscle-wasting condition, and helps ensure financial security, independence and a decent quality of life.

However, following an extensive survey of individuals and families living with muscle-wasting conditions, this report has uncovered a benefits system that is failing to provide people with the support to which they are entitled. It is also inflicting huge stress and anxiety upon them in the process.

Muscular Dystrophy UK Trustee, Baroness Thomas of Winchester, set out significant problems in a recent motion in the House of Lords, which was subsequently agreed to. Concerns have also been expressed by organisations and groups including the Disability Benefits Consortium and Disability Rights UK.

Alarming findings from Muscular Dystrophy UK's survey reveal that people with muscle-wasting conditions are losing access to their Motability vehicles owing to unnecessarily harsh and stringent criteria under the mobility component of Personal Independence Payments. This is having a devastating effect on quality of life and levels of independence.

Others are being subject to short-notice cancellations of assessments and delays in receiving benefits. This is leading to financial hardship and unnecessary use of credit cards and savings until payments come through.

In some cases, people are having to attend face-to-face assessments for disability benefits at centres that aren't accessible for disabled people. These are often done by assessors who have little or no understanding of muscular dystrophy and how it affects day-to-day living.

Key findings

In the summer of 2015, Muscular Dystrophy UK surveyed 300 individuals affected by muscle-wasting conditions on their experience of accessing disability benefits, such as Personal Independence Payments (PIP) and Employment and Support Allowance (ESA). Key findings from the survey include:

- ▶ more than 30 percent of individuals felt they were not treated with dignity or respect by benefits assessors
- ▶ some individuals have had their Motability cars taken away from them owing to changes in mobility award criteria under PIP, compared to that of DLA, which it has replaced. Between 400 and 500 adapted vehicles are currently being handed back each week, many of them from individuals affected by muscular dystrophy
- ▶ nearly 40 percent of people experienced delays in the process, some as a result of application papers being lost by assessment companies
- ▶ more than 30 percent of people with muscle-wasting conditions have encountered financial hardship as a result of delays in receiving a disability benefit
- ▶ around 40 percent of respondents had an assessment for a disability benefit at a centre that was not accessible for people with limited mobility
- ▶ nearly 20 percent had to wait over six months for an appointment to assess their eligibility for a benefit.

Muscular Dystrophy UK is now pushing for urgent action from the Department of Work and Pensions to address this unacceptable situation and improve the assessment and appeal process.

What needs to happen?

“Having a progressive illness is difficult enough without being treated as though you are exaggerating. I struggled not to sink into deep depression.”

Joyce Matthews, who has myotonic dystrophy

To ensure that individuals with muscle-wasting conditions are able to get the support they need, Muscular Dystrophy UK is calling for:

- 1. The Department for Work and Pensions (DWP) to assess the impact of the ‘20-metre rule’ in the mobility component of Personal Independence Payments (PIP), in light of the forthcoming PIP review set to be completed next April.** Muscular Dystrophy UK also believes this review should be brought forward, given the severe impact the ‘20-metre rule’ and loss of Motability vehicles is having on the independence and quality of life of many disabled people. Latest statistics show that 400 to 500¹ Motability vehicles are currently being handed back each week. This evidence is backed up by an increasing number of calls to Muscular Dystrophy UK’s helpline and advocacy service from people adversely affected by these changes. With many individuals still waiting to migrate from DLA to PIP, this figure can only be expected to rise, given the tougher PIP eligibility criteria.
- 2. The DWP, along with Motability, to ensure an individual’s Motability vehicle is not taken away from them until a final decision has been reached on their eligibility for the enhanced rate mobility component of PIP.** Currently, individuals deemed not eligible for enhanced mobility PIP have a maximum of seven weeks to return their vehicle to Motability if the vehicle is adapted and an appeal is lodged immediately. However, it takes far longer than seven weeks to request a Mandatory Reconsideration and, if necessary, hold an appeal hearing. This can leave individuals without a car – housebound, unable to work or travel – for months. Some have no option but to purchase a new car in the meantime, at a significant personal financial cost, and for which there is no reimbursement.
- 3. The DWP and Atos and Capita to ensure all applicants are prompted to consider the ‘reliability criteria’ at assessment.** The DWP says it specifically asks assessors whether or not they have mentioned these criteria to claimants. However, there are alarming reports from individuals with muscle-wasting conditions stating they are not being prompted to consider the ‘reliability criteria’ at assessment. These criteria determine whether they can perform an activity ‘safely, to an acceptable standard, repeatedly and in a reasonable time period’. This is reflected in PIP decisions that bear no resemblance to the individual’s mobility or ability to carry out day-to-day

¹<https://hansard.parliament.uk/Lords/2016-05-04/debates/16050467000595>
PersonalIndependencePaymentMobilityCriterion

activities. Assessors are required to prompt individuals to ensure they fully understand these criteria and can apply them to real-life situations. This should ensure the most accurate and comprehensive information is obtained. In addition, creating audio recordings of assessments should become standard practice so that reports sent to the DWP by assessors can be properly corroborated.

4. The DWP and Atos and Capita to ensure that all claims are processed within the specified 13-week timeframe.

Although there has been some recent improvement, there are still delays in processing claims, sometimes owing to frequent, short-notice cancellations. These delays, particularly if significant, can cause stress and anxiety, as well as significant financial hardship and reliance on savings and credit cards.

5. The DWP and Atos and Capita to ensure that assessors are adequately trained and have knowledge of progressive conditions such as muscular dystrophy.

Through Muscular Dystrophy UK's advocacy service², there have been a number of cases where assessors have completely misunderstood the nature of progressive conditions such as muscular dystrophy. In one case, an individual was told his condition would improve with time. Assessors must be trained to have a basic knowledge of such conditions, and take into account all supporting evidence from health professionals to avoid decisions being taken, based on false assumptions.

6. The DWP and the Department of Health to work with medical centres to ensure that further medical information can be obtained by claimants for free, right from the first PIP assessment.

While most Muscle Centres give medical evidence for free, there are some cases – especially via GP surgeries – where charges of nearly £100 are made. This can prohibit applicants from producing further supporting evidence, which can increase the risk of wrong and misinformed decisions being taken on their PIP award.

7. The DWP and Atos and Capita to ensure that premises are fully accessible for disabled people.

Forty percent of people responding to our patient survey reported they had an assessment at a centre that was not accessible. In some cases, individuals had even been sent home and appointments rearranged for this reason, delaying the process even further. Issues individuals may have, such as difficulty walking up slopes, problems with balance, as well as the number of Blue Badge parking spaces at the centre, should all be taken into account when adapting a centre.

“I wish they would take into account what the word ‘progressive’ means and that muscles do not come back. It’s demeaning and embarrassing to have to lay your personal needs out for someone to decide whether you are disabled or not.”

Michelle Goldthrite, who has facioscapulohumeral muscular dystrophy

²Muscular Dystrophy UK's advocacy service supports people with muscle-wasting conditions who are having difficulties getting the care and support, services, benefits and equipment they are entitled to.

The PIP '20-metre rule' and access to Motability

Shortly after the Coalition Government assumed office in 2010, they announced plans to replace Disability Living Allowance (DLA) with Personal Independence Payments (PIP). Both are non-means-tested and non-taxed, in- and out-of-work benefits designed to meet some of the additional financial costs faced by disabled people.

A higher rate mobility award under DLA, and an enhanced rate mobility award under PIP, both qualify the applicant for support under the Motability scheme. Access to an adapted vehicle makes all the difference to levels of independence and quality of life. Many disabled people are only able to travel outside of their homes and engage with the community because of their access to the scheme.

Lianne Harris, who has spinal muscular atrophy type 2, describes the importance of her adapted vehicle to her independence and quality of life:

"I live in a village which is four miles from the nearest town and 10 miles from a larger town. There is no way that I can get around to other places or to hospital appointments without my vehicle which is adapted to take my electric wheelchair. My vehicle is expensive and contains adaptations that address my needs and keep me safe when I travel, which are not available on public transport. Public transport is simply out of the question as it is unsafe for me. If I don't get out of the house then my mental health suffers. If this is to be a long-term thing due to having no vehicle then it will end up that my physical health suffers which will result in medication being required, and could even result in hospital stays. This will cost the government even more money."

For DLA, an individual would qualify for the higher rate of the mobility component if they were unable to walk for more than 50 metres. The distance of 50 metres is well recognised, and is used as a measure in Department for Transport guidance on inclusive mobility.

In early drafts of PIP regulations, 50 metres was considered the qualifying distance for an enhanced rate mobility award.

But at the last minute – and without consultation – the Government announced that the qualifying distance would be 20 metres. The Government then consulted on these changes and was inundated with responses highlighting the damaging impact these more stringent criteria would have on disabled people.

However, the Government responded by arguing that because there was no uniform agreement on what the distance would be,

it would press ahead with implementing the '20-metre rule'. This, despite the fact they were unable to produce any evidence in support of the change.

'20-metre rule' – the impact

Muscular Dystrophy UK warned the Government repeatedly that pressing ahead with the '20-metre rule' would have a devastating impact on individuals requiring access to suitable vehicles.

As a rapidly increasing number of individuals are having these vehicles taken away, Muscular Dystrophy UK does not believe that the Government is dealing with this alarming situation with the seriousness that it deserves. Its response has not been adequate, and has been to deny there was a problem at all, despite mounting evidence to the contrary.

The Minister for Disabled People, Justin Tomlinson MP, said in a Westminster Hall debate on Motability on 23 February 2016:

"Numerous speakers mentioned a 50-metre rule becoming a 20-metre rule. There never was a 50-metre rule. It is not that if someone can walk 20 metres and 1 cm, they get no benefit, but if they can walk only 19 metres, then they get the full benefit; it is about moving safely to an acceptable standard repeatedly and in a reasonable time period. **The rule is a bit of an urban myth."**

In another instance of confusion regarding the Government's own policy, Baroness Ros Altmann said in a House of Lords debate on 4 May 2016 on 'Personal Independence Payment: Mobility Criteria':

"To reiterate for the noble Baroness, if a claimant cannot walk up to 50 metres safely, reliably, repeatedly and in a timely manner, they are guaranteed to receive the enhanced rate of the mobility component. **Therefore, there is not a strict 20-metre rule."**

The Minister subsequently wrote to Baroness Thomas to apologise for any misunderstanding her remarks caused – given that a claimant is not guaranteed enhanced rate mobility if they cannot walk up to 50 metres, taking into account the 'reliability criteria'.

Fifty metres was a clear qualifying distance for a DLA higher rate mobility award, and it was also put forward as the qualifying distance in the draft regulations for PIP in 2011. It was not until after publication of the regulations that this was changed to the current 20 metres. It is deeply unfair to the thousands of individuals who have lost their Motability vehicles to argue that the policy responsible is a 'myth'.

Muscular Dystrophy UK is calling for the DWP to assess the impact of the '20-metre rule' in the mobility component of PIP, in light of the forthcoming PIP review set to report next April.

Muscular Dystrophy UK also believes this review should be brought forward, given the severe impact the '20-metre rule' and loss of Motability vehicles is having on the independence and quality of life of many disabled people.

Muscular Dystrophy UK calls for the DWP, as well as Motability, to ensure that an individual's adapted vehicle is not taken away from them until a final decision has been reached on their eligibility for the enhanced rate mobility component of PIP.

Reliability criteria

The impact of the '20-metre rule' has been exacerbated by the failure of PIP assessors to make adequate use of the 'reliability criteria' in their decision-making.

These criteria were adopted by the Government to ensure that assessors took into account whether or not an individual could perform an activity 'safely, to an acceptable standard, repeatedly and in a reasonable time period'. These criteria are in the published PIP guidance and therefore must be included in assessors' decision-making. The DWP says it asks assessors if they have mentioned these criteria at assessment.

Muscular Dystrophy UK is concerned, however, that assessors are not prompting individuals to fully consider these criteria when answering questions at PIP assessment. This is resulting in inadequate decision-making, which is not providing people with the support they should be entitled to.

Many individuals with muscle-wasting conditions would answer 'yes' if asked 'can you walk 20 metres?' But if prompted to consider whether they would be in pain afterwards, would be able to walk the same distance again shortly afterwards or would be left fatigued, many would have to answer 'no'. This is equally true for walking in adverse weather conditions or on an uneven surface.

It appears, however, that it is not the policy of Atos – one of the companies responsible for PIP assessments – to prompt individuals to make these considerations. Muscular Dystrophy UK believes that this runs contrary to the Government's own PIP guidance.

Judging from calls to our advocacy service and information helpline, Muscular Dystrophy UK is concerned that PIP assessment companies are failing to encourage applicants to respond in sufficient detail.

Jane is a manifesting carrier of Duchenne muscular dystrophy. Not having been given clear guidance on questions regarding her mobility, Jane confirmed that she could walk 65 metres. In reality, if Jane were to attempt to walk this distance, she would need to take several breaks, and would therefore be unable to complete this in a timely manner. She would be greatly fatigued, highly prone to falls, and would be unable to repeat this or any other activity for the rest of the day. Owing to the paucity of information and lack of prompting for these key criteria, Jane was awarded the incorrect level mobility component and lost access to her Motability vehicle.

It is deeply concerning that rules designed to make PIP assessments fair and sufficiently detailed are not being enforced.

The DWP and Atos and Capita must ensure that all applicants are prompted to consider the 'reliability criteria' at assessment.



Sarah is 29 years old and has myotonic dystrophy. She and her husband live in Norfolk, and she is six months pregnant. Being pregnant, she cannot take the medication that helps with her fatigue. Her mobility, which is already affected by her condition, is further impacted.

Sarah was one of the first people to be assessed for PIP when it was initially introduced. However, when her award expired, she was reassessed and subsequently awarded the standard rate.

She was also told that her Motability car, which she relies on to travel long distances safely, would be taken away. Sarah is devastated – she will lose her independence and may not be able to get to work. She is highly prone to falls and becomes fatigued very quickly. A fracture or break resulting from a fall could cause an irreversible deterioration in her mobility. Owing to the weakness and wasting of the muscles in her limbs, as well as the fatigue associated with her condition, the health and safety of both Sarah – and potentially that of her child's – could be at risk.

Sarah says:

"The '20-metre rule' does not assess how someone's mobility is affected by their condition. Occasionally I may be able to walk 20 metres, but on other days my weakness and balance would be more affected – I could fall and twist my ankle (or worse), decreasing my mobility further. Walking around or even just to the shops is 20 metres or more. The criteria are unrealistic. I could easily choose not to work, but my job is not just any job. As a nurse, I make a difference in my role, but it seems like the DWP is trying to prevent me from doing so."

A man with inclusion body myositis (IBM) is currently receiving DLA: middle rate for care and higher rate for mobility. This was awarded in 2010 and renewed in 2012.

Having been asked to apply for PIP, and following an assessment by ATOS, he was awarded PIP – daily living at standard rate and mobility at standard rate. When this change took place in March, he lost his Motability vehicle. He needs this to drive to work each day – a 70-mile round trip. He has asked for a mandatory reconsideration, however his vehicle will still be taken away in the meantime.

Muscular Dystrophy UK's advocacy service has been supporting him in his reconsideration, in pushing for this decision to be overturned.



“To say I was devastated is an understatement. My adapted vehicle is my lifeline and my independence: without it, I’m housebound and isolated.”

Darran has myotubular myopathy and lives in Doncaster:

“I applied for PIP in November 2015. After a lengthy process, I was finally informed by the DWP that I only qualified for a standard rate mobility award for PIP. Having been on higher rate mobility on DLA, this meant I would lose my Motability vehicle.

“To say I was devastated is an understatement. My adapted vehicle is my lifeline and my independence: without it, I’m housebound and isolated.

“I requested a reconsideration from the DWP, but this took so long to arrive that Motability had to take my car away, as we had gone over the maximum extension period they allow whilst waiting for a DWP reconsideration or appeal.

“With no certainty on when I would hear from the DWP – and potentially facing months stuck indoors – I put forward a £2,000 deposit on an adapted vehicle.

“Some time afterwards, the DWP contacted me to inform me they had mistakenly assessed me as qualifying for standard rate mobility, and in fact I had now been awarded higher rate mobility. This meant my Motability vehicle could be returned to me.

“However, my £2,000 deposit is non-refundable, meaning I have lost this money. Not to mention lost months to stress and anxiety thanks to the flawed PIP assessment.”

Delays, cancellations and lost forms

“The whole process was very upsetting and stressful and the finances were very, very tight, sending us into arrears.”

An individual with centronuclear myopathy, who was turned down for a PIP award

One of the key features of the roll-out of PIP has been a number of significant delays to the process. At one stage in 2015, 3,200 individuals had been waiting over a year and 22,800 had been waiting over 20 weeks for their assessments³. Muscular Dystrophy UK's advocacy service has also seen delays in the assessment process for other disability benefits, such as ESA.

While waiting times for PIP have improved, many claims are still not processed within the set 13-week period.

In our recent patient survey, nearly 40 percent of those who applied for a disability benefit experienced delays in the process. These included delays owing to application papers being lost by assessment companies.

Comments included:

- ▶ “loss of papers”
- ▶ “it took a very long time as they lost the paperwork. They don't talk to each other”
- ▶ “I waited just short of 12 months due to a clerical error”
- ▶ “they lost my applications twice”
- ▶ “everything seemed to involve a delay”.

Delays in the process and the need for back-dated payments can also cause financial hardship for individuals with muscle-wasting conditions. A third of individuals told Muscular Dystrophy UK they had experienced financial hardship as a result of delays when applying for a disability benefit.

Muscular Dystrophy UK calls for the DWP and Atos and Capita to ensure that all claims are processed within the specified 13-week period.

“The whole experience was a nightmare and has left me with emotional scars.”

An individual with facioscapulohumeral muscular dystrophy (FSHD) applied for PIP and told Muscular Dystrophy UK:

“My first three PIP home assessments were cancelled without informing me. I had arranged for a social worker to be at each one and no apology was given by Capita on any of the three occasions.

³<http://www.bbc.co.uk/news/uk-33020987>

“Having finally gone through the Capita assessment, I was contacted by the DWP to tell me that they were awarding me lower rate daily living and no support for mobility. We disagreed with the decision but weren’t allowed to see the Capita report then. The DWP refused to change its position after a mandatory reconsideration (over a year after I originally filled the forms in).

“We went to tribunal, before which we were allowed to see the Capita report. We realised they had mixed mine up with someone else’s: even my basic family details were incorrect. After reviewing the evidence, the tribunal awarded me enhanced rate daily living and mobility. Without the support of Muscular Dystrophy UK’s advocacy service, I would have given up and surrendered long before.

“Financially it was very hard, and family had to help out. It’s also had a terrible effect on me emotionally. I am under a mental health team, suffer very bad panic attacks, and no longer leave the house.

“PIP is meant for people who are unwell and struggle, but my experience proved the exact opposite. I shouldn’t have had to wait more than 21 months for the correct decisions to be made. The length of time everything took and having to resort to the court of appeal meant the whole experience was a nightmare and has left me with emotional scars.”

“The whole process has been incredibly stressful.”

Diana’s son, Josh, has Duchenne muscular dystrophy and lives in Norfolk:

“Josh completed his PIP claim form in January 2016, and an appointment was set for a medical consultant to come to our home the following March. We arranged our schedule so that we were available, and also arranged for our local Neuromuscular Care Advisor to join us for the appointment.

“However, after waiting two hours, I contacted Atos only to be told the assessor was sick and the appointment had been cancelled. They had left a message on my mobile – which gets no signal in the house – but made no attempt to call my landline.

“A second appointment was scheduled for April and was again cancelled by Atos. This time, no reason was given.

“We set a new date – not ideal, as it was very close to Josh’s GCSEs – and I was called the night before to be told that this appointment too had been cancelled.

“At the fourth time of asking in May, an assessor did turn up (although two hours late).

“The whole experience has been incredibly stressful.”

Going for assessments

“The Occupational Therapist was not trained in the symptoms of myasthenia gravis, so was not aware of the intermittent nature of the condition. She insisted her job was to record what she saw at the time of testing, not to subsequent deterioration in functioning over three to four hours, or weakening of muscles over time. It was a disrespectful discussion.”

Iris, who has myasthenia gravis

Being assessed for a disability benefit can be a stressful experience. People with muscle-wasting conditions will often be required to outline very difficult and personal details to a complete stranger, and many find the assessment process traumatic.

This can be made worse by problems encountered when going for the assessment, such as assessors who have no knowledge or understanding of muscle-wasting conditions and assessment centres that are not accessible for many disabled people.

In our recent survey, a third of individuals with muscle-wasting conditions told us they did not feel they had been treated with respect and their needs were not taken into account at their assessment.

Comments include:

- ▶ “I don’t feel they understood the pain and how it affects my confidence and strength”
- ▶ “the assessor knew nothing about Duchenne – even down to the pronunciation”
- ▶ “inability to walk up stairs or inclines not taken into account because I am able to walk the minimum distance”
- ▶ “I was made to feel small – like I was troubling him”.

As well as making the experience of assessment an unpleasant one, the assessors’ lack of knowledge is leading to wrong and inaccurate decisions being taken.

Muscular Dystrophy UK is calling for the DWP and Atos and Capita to ensure that assessors are adequately trained and have knowledge of progressive conditions such as muscular dystrophy.



Chris has facioscapulohumeral muscular dystrophy (FSHD) and lives in Peterborough. He applied for ESA because he had had to give up work owing to deterioration in his condition. Chris was initially refused ESA. The assessor stated in her report that while Chris's condition was progressive, his condition would improve over time with physiotherapy.

This is an inaccurate assessment. While physiotherapy can help relieve discomfort and improve posture, there is no evidence that it would improve overall levels of disability. Muscular Dystrophy UK helped Chris to appeal the decision successfully.

Chris was told by the DWP two months later, however, that he would receive no mobility support under PIP. This, despite the fact that the same Government department had decided his mobility was so limited he was unable to work. Chris again successfully appealed the decision, but the process caused him significant stress and it went on for nearly a year.

Other individuals go for assessments, only to find that the centre isn't fully accessible for disabled people: this was true for nearly 40 percent of individuals who responded to our patient survey.

Muscular Dystrophy UK is calling for the DWP and Atos and Capita to ensure that premises are fully accessible for disabled people. Issues individuals may have, such as problems with balance, as well as the number of Blue Badge parking spaces at the centre, should all be taken into account when adapting a centre.

“It was totally and utterly exhausting. No thought at all was given to mobility needs.”

An individual with myofibrillar myopathy, who applied for PIP, told Muscular Dystrophy UK:

“There was not enough Blue Badge parking, and all spaces were occupied. I waited a while, but had to park in the short-term parking further away and on gravel with kerbs, to make the appointment. The distance to the building was too far from the parking and the building’s entrance was at an elevated height, with many steps – it was only accessible through long zigzagged sloped pathways which was an even greater distance to cover. Inside the building, there was a massive open space in the reception area which was very difficult to manage with balance problems (and no handrails or walls to walk against).

“Totally and utterly exhausting – no thought at all to the type of individual needing an assessment and their mobility needs. After all that, the appointment was cancelled on the spot, due to the assessor being sick. They told me the assessor had been ill all week, but no attempt had been made to cancel the appointment before I made the journey.”

How to get involved

If you have been affected by any of the issues raised in this report, and would like to share your story and get involved with our campaign, please get in touch with Peter Sutton on p.sutton@musculardystrophyuk.org or call **020 7803 4838**.

If you are struggling to access the support you need, our advocacy team is here to help you. Please get in touch with them at info@musculardystrophyuk.org or call **0800 652 6352**

What is muscular dystrophy?

There are about 60 forms of muscular dystrophy and related muscle-wasting conditions. These conditions cause muscles to weaken and waste over time, leading to increasing disability. The conditions may affect not only the muscles in the limbs, but also those of the heart and lungs, sometimes significantly shortening life-expectancy.

Many of the conditions are low-incidence, rare conditions, with some regarded as very rare or ultra-orphan. Muscular dystrophy and related muscle-wasting conditions are genetic and can be inherited or acquired. With few exceptions, there are currently no effective treatments or cures available.

Clinical trials in some forms of muscular dystrophy and related muscle-wasting conditions are now underway and it is hoped that these may lead to the introduction of new treatments that can slow or arrest the progression of these often devastating conditions.

About Muscular Dystrophy UK

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

- ▶ We are supporting high-quality research to find effective treatments and cures, and leading the drive to get faster access to emerging treatments for UK families.
- ▶ We are ensuring everyone has the specialist NHS care and support they need, with the right help at the right time, wherever they live.
- ▶ We are providing a range of services and opportunities to help individuals and their families live as independently as possible.

We operate a free advocacy service, which is available to anyone with a muscle-wasting condition who needs support.