Building on the Foundations:

The Cost of Living with Muscle Disease

November 2010

Muscular Dystrophy Campaign

Contents

Foreword

Many patients and their families living with neuromuscular conditions face extreme financial hardship due to the additional costs associated with these rare and very rare conditions.

The financial strain placed on people might be felt due to very expensive wheelchairs, costly home adaptations, or essential equipment such as hoists and specialist beds.

Adding to this burden is the fact that many family members are often forced to give up work due to caring responsibilities; or cannot work themselves because of the severe effect neuromuscular conditions can have on people's health and mobility in the longer-term.

We are in a tough economic climate but our report provides suggestions for considerable cost-savings. For example, providing support for people with disabilities to obtain or retain employment will increase tax revenues, while support for carers helps to reduce the burden on the NHS and local social care budgets.

Adults and children living with these devastating conditions simply cannot afford to go without the support they currently receive from the Government and local authorities. People are worried that the support they receive through the Disabled Facilities Grant and Housing Benefit might be under threat following the 2010 Comprehensive Spending Review.

Existing benefits such as the Disability Living Allowance help to meet some of the huge extra costs associated with having a disability. It is important to recognise that these are not 'out of work benefits' but an essential contribution towards meeting this extra – and sometimes completely unexpected – financial burden.

I have been shocked to hear stories by mums who can't afford birthday presents for their children who have life-limiting conditions; or from families forced into bankruptcy because of the extra costs of essential – but very expensive – equipment.

The Muscular Dystrophy Campaign recognises that many cash-strapped local authorities will have to find savings; but we urge local decision makers to consider the effects that their decisions might have on families with muscle-wasting conditions; and on those individuals who rely heavily on help within the home, on respite care; and assistance to live independently.

We also urge the Government to ensure that the forthcoming changes to welfare benefits – such as housing benefits – do not affect disabled people disproportionately.

Many people living with neuromuscular conditions across the UK are already under huge financial pressure – as this report illustrates – and local and national decision makers must take this into consideration as they decide how to make savings to their budgets.

Robert Meadowcroft,
Chief Executive,
Muscular Dystrophy Campaign
November 2010

Neuromuscular conditions and the Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign supports the 70,000 people across the UK living with more than 60 different types of neuromuscular conditions. These are rare and very rare conditions that can be genetic or acquired, and can present in childhood or adult life.

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

Without multidisciplinary care, most patients experience a reduction in quality of life and, for some conditions, shortened life expectancy.

Action needed

Recommendation 1: The Work Capability Assessment should be reformed to take into account evidence from specialist consultants who have expertise in the rare and complex condition which affects the claimant and ensure that the benefits system correctly identifies people who are unable to work

Recommendation 2: The Access to Work scheme should be made more efficient and responsive to the needs of disabled people in employment, and crucially, sufficiently funded to meet the access needs of every disabled person who is able to carry out paid and unpaid work. This will help to reduce poverty among people of working age with a disability and allow this important group to play a full role in the workplace.

Recommendation 3: Disability Living Allowance (DLA) should be continued as a separate benefit, paid to help cover some of the extra costs of living with a disability. The criteria should remain distinct to those of out of work benefits such as Employment and Support Allowance.

Recommendation 4: The proposal to remove DLA Mobility Component from people living in residential care should be scrapped.

Recommendation 5: We support the adoption of the Lifetime Homes Standard for all new housing developments to help to ensure that people with disabilities have a wider choice of affordable and accessible housing.

Recommendation 6: The ceiling on the Disabled Facilities Grants should be substantially increased or removed altogether. The current maximum grant level does not meet the cost of the complex adaptations required by many people with neuromuscular conditions; forcing families to make up the shortfall themselves.

Recommendation 7: The means test should be removed for disabled adults making essential adaptations to their homes through the Disabled Facilities Grant.

Recommendation 8: Local authorities should take progressive conditions into account when planning home adaptations to make best use of limited funds, and to avoid costly repeated adaptations as a condition progresses.

Recommendation 9: Local councils should have the power to offer Discretionary Housing Payments to people with disabilities before they take up a tenancy, to reflect the restricted choice people with a disability face in finding an accessible home.

Recommendation 10: Families with severely disabled children should be allowed sufficient provision for that child to have a room of their own. A child who requires frequent attention in the night, or has considerable medical equipment, requires their own room to avoid disturbing their siblings, and to allow for harmonious family life.

Recommendation 11: Eligibility for the Winter Fuel Allowance should be extended for people on DLA higher rate for care or mobility.

Recommendation 12: Energy companies should increase their provision of social tariffs for people on low incomes and who incur higher electricity and heating bills because of their disability. These tariffs should be promoted and publicised to ensure that people with severe disabilities are taking up the available support.

Recommendation 13: Carer's Allowance should be increased to an equivalent level of Employment and Support Allowance/Incapacity Benefit

Recommendation 14: The earnings premium for Carer's Allowance should be disregarded to allow carers the chance to escape poverty.

Recommendation 15: All local authorities to provide social care to people with a severe disability due to a neuromuscular condition.

Recommendation 16: People over the age of 65 should be eligible to make a new claim for DLA.

Recommendation 17: People claiming their state pension should also be eligible for Carer's Allowance.

Introduction

Disabled people are twice as likely to live in poverty as non-disabled people[1], and many people with a neuromuscular condition experience severe disability, which can leave them unable to work, requiring extensive adaptations to their home, facing higher bills, and not receiving enough support to meet these costs.

Our nationwide survey of 2,000 people living with a neuromuscular condition has revealed a 'postcode lottery' of care and support. Six hundred patients and families responded and we can reveal:

Key findings:

- Over two-thirds of people living with a neuromuscular condition have experienced financial difficulties as a result of living with their condition.
- Two out of five families struggle to pay their bills due to their neuromuscular condition.
- Four out of five families do not think that the benefits system adequately covers these costs.
- Many families are plunged into deep financial trouble due to adapting their homes.

Mrs J from the North East has Facioscapulohumeral (FSH) muscular dystrophy and says:

"I am not even keeping my head above water. It is a choice of heating or eating."

Henry Langen is 58 and lives in South Wales. He is affected by FSH muscular dystrophy, and has struggled with the extra costs of his condition. He says:

"I have lost my home and have been bankrupted twice trying to afford the cost of living with my disease."

Mr M from Surrey says:

"Over the past five years I have had to fund my adaptations, vehicles and equipment. In total, I believe I have spent approximately £100,000 extra because of my disability."

The financial cost of muscle disease

1. Employment and Benefits

Muscular dystrophy and related neuromuscular conditions can be severely disabling, and many people affected by these conditions are unable to carry out any work-related activity. For others, work-related activity and employment is possible through adapted workplaces, part-time and flexible working, and supportive employers.

However, many disabled people who are able to work report that it can be almost impossible to find, obtain and retain employment, due to inaccessible workplaces, transport and employer attitudes.

Our members also report confusion over what will happen if they move from benefits into employment, and due to their medical condition, they are unable to remain in their job. For example, one young man with a progressive and disabling neuromuscular condition currently claims Incapacity Benefit and is reluctant to move into employment in case the job does not work out, as a result of his neuromuscular condition. He would then have to wait six months before being able to be assessed for Employment and Support Allowance (ESA), and would then have to undertake the Work Capability Assessment, which he does not believe would assess his condition fairly.

For people whose disability does not allow them to take part in employment, the level of ESA paid to those in the support group must be paid at a sufficient level to stop people who are unable to work through no fault of their own from falling beneath the poverty line.

Move from Incapacity Benefit to Employment and Support Allowance

The Government has announced its intention to transfer existing Incapacity Benefit claimants onto the replacement benefit, ESA by 2014. Eligibility for ESA is measured through an assessment process, the Work Capability Assessment, which is carried out by a healthcare professional.

We endorse the commitment of the Government to provide more support for people on Incapacity Benefit who wish to move into employment through the migration onto ESA, but this must also be matched by the understanding that many people with severely disabling neuromuscular conditions are unable to take on employment. Reforms to the welfare system must not, in the Government's striving not to "write people off" by keeping them on disability-related out of work benefits, inappropriately place people as ready for work, cutting off their benefits and support.

We recommend structural reform of the Work Capability Assessment (WCA) following the review by Professor Harrington. Further welfare reform cannot be based on the results of a test with such a high rate of failure, and has been found to be dangerously inaccurate for people with complex and long-term disabling conditions.

Under the Incapacity Benefit system, if you were receiving Disability Living Allowance Care Component (higher rate), or you had medical evidence to show that you were affected by a severe and progressive neurological or muscle wasting disease you were exempt from the Personal Capacity Assessment. These are regrettably not exemptions under the ESA rules.

This can mean that very severely disabled people are subject to an assessment by health professionals who do not understand their condition: the health professionals who carry out the WCA are not trained in neuromuscular conditions – rare and complex conditions, with over 200 genetic loci. Many GPs may only see one patient in their whole career affected by a neuromuscular condition, and it is therefore unlikely that the health professionals carrying out the assessment will have experience in these particular conditions.

We recommend that during the assessment process, additional information is requested and taken into consideration from medical professionals who have expertise in rare conditions so that the assessor can fully understand the impact of these complex, multi-system disorders on a claimant's capacity for work. This would work in a similar way to claims for Disability Living Allowance, which do not compromise the doctor's relationship with their patient.

The WCA further fails to take into consideration real-life context – it does not measure the availability of accessible and appropriate work, only functionality. The failure to assess real-life context when assessing

> "I have lost my home and have been bankrupted twice trying to afford the cost of living with my disease."

ESA claimants points to a wider issue with the proposed reforms: for many disabled people who are able to work, it can be almost impossible to find, obtain and retain employment, due to inaccessible workplaces, transport and employer attitudes. For example, research by *Trailblazers* – the Muscular Dystrophy Campaign's Young Campaigners Network – earlier this year found that:

- almost three out of four young disabled people believe the job application process puts disabled people at a disadvantage;
- seventy percent of young disabled people believe their job applications have been rejected due to the perception of disability;
- almost three out of four young disabled people feel physical access to the workplace is a major obstacle to getting into employment;
- more than half of respondents cite an employer's aversion to risk as a major obstacle in finding work;
- almost half of young disabled people think inaccessible public transport is a major factor in finding work.

Recommendation 1: The Work Capability Assessment should be reformed to take into account evidence from specialist consultants who have expertise in the rare and complex condition which affects the claimant and ensure that the benefits system correctly identifies people who are unable to work

Helping people into work

Access to Work: The complexity and limited budget of Access to Work also acts as a disincentive to those who would like to work but have significant care needs. Research by *Trailblazers* earlier this year highlighted a number of further concerns with how Access to Work works in practice:

- A candidate must have already been offered a job before an Access to Work assessment is carried out.
- When starting a new job there is an initial delay in funding while assessments are carried out thus increasing anxiety during the first few weeks.
- If adaptations are required for the building, theoretically the funding is available, but the time delay between applying for a job and starting a job could be months if major alterations are required which reduces the likelihood of securing the job.
- A disabled employee must have the money in advance to pay for added cost. Reimbursement may take weeks to arrive, compromising cash flow.

Recommendation 2: The Access to Work scheme should be made more efficient and responsive to the needs of disabled people in employment, and crucially, sufficiently funded to meet the access needs of every disabled person who is able to carry out paid and unpaid work. This will help to reduce poverty among people of working age with a disability and allow this important group to play a full role in the workplace.

Concerns about the future of Disability Living Allowance

Disability Living Allowance (DLA) is intended to help meet the extra costs of living with a disability. It is split into two sections:

- a care component – if you need help looking after yourself or supervision to keep you safe
- a mobility component – if you can't walk or find it very hard to walk, or you need help getting around

A number of proposals to reform the welfare system have suggested that DLA could be absorbed into a new Universal Credit when the welfare benefits system is reformed. We believe that it is crucial to retain Disability Living Allowance as a separate non-work related benefit, to be paid to both children and adults in and out of work, to cover at least part of the extra cost of disability.

The 2010 Comprehensive Spending Review proposed the removal of the higher rate of the mobility component of DLA for people living in residential care. We oppose this measure which seems to suggest that disabled people in residential care don't want to go to the shops, visit friends or family and or just leave the place that they live.

We also note that the current eligibility criteria for DLA are greatly different to those of Incapacity Benefit and ESA and that this difference must be maintained. We are deeply concerned that on repeated occasions since the 2010 General Election, both in the 21st Century Welfare paper, and more widely, DLA has been referred to as an "out of work benefit" or that this has been implied. This is clearly incorrect – DLA is intended to go some way towards meeting the extra costs people living with a disability face. These include for example, adapted vehicles and higher transport costs, paying for their own wheelchairs, higher heating and electricity bills, and often being forced to spend thousands of pounds to make their homes accessible. We strongly urge the Government to ensure clarity in future statements on this matter: **DLA is not, and never has been, an out of work benefit.**

Medical tests for DLA

In the June 2010 Budget it was announced that claimants for DLA will undergo medical tests to assess their eligibility from 2013.

We believe that accurate and appropriate medical tests for DLA are not, in principle, unwelcome. By ensuring that only those who meet the criteria for DLA receive the benefit, greater funds will be available for those who rely on this support to meet the real and substantial costs of living with a disability. However, we would be greatly concerned if the medical tests were on the same grounds of the flawed Work Capability Assessment. In addition, we recommend that people should not be required to be tested if medical evidence from their consultant is provided to prove that they have a severely disabling neuromuscular condition.

Recommendation 3: DLA should be continued as a separate benefit, paid to help cover some of the extra costs of living with a disability. The criteria should remain distinct to those of out of work benefits such as ESA.

Recommendation 4: The proposal to remove DLA Mobility Component from people living in residential care should be scrapped.

2. Housing

Many families affected by disability struggle to find accessible and affordable housing, and often battle for years for home adaptations. Most traditional homes are inaccessible and inappropriate for powered wheelchair users, and people with mobility difficulties.

> One family from Norfolk have a 10-year-old son with Duchenne muscular dystrophy. They say:
>
> *"There is a £200,000 difference between the cost of our current house and the adapted home we are moving into soon"*

Recommendation 5: We support the adoption of the Lifetime Homes standard for all new housing developments to help to ensure that people with disabilities have a wider choice of affordable and accessible housing.

Disabled Facilities Grant

People with neuromuscular conditions often face bills of tens of thousands of pounds to pay for essential adaptations to their home to make them accessible for mobility difficulties, or for wheelchair users. The Disabled Facilities Grant is available in England, Wales and Northern Ireland to help pay for these adaptations (with Housing Grants available in Scotland).

In 2005 the means test for the DFG was abolished for disabled children; however, this still applies for adults applying for support. The current test does not take into account an accurate picture of a family's outgoings, and can leave people with disabilities in severe financial difficulties struggling to fund this essential work.

In addition, households with a family member affected by a neuromuscular condition often find that the maximum amount of grant a local council is required to pay (£25,000 in Northern Ireland, £30,000 in England and £36,000 in Wales) often does not meet the total cost of the work assessed as necessary. This can leave families being required to take out loans or re-mortgage their properties to meet the full cost of the work being undertaken.

> “Since I was diagnosed we have spent about £20,000 on essential things”

Recommendation 6: The ceiling on the Disabled Facilities Grants should be substantially increased or removed altogether. The current maximum grant level does not meet the cost of the complex adaptations required by many people with neuromuscular conditions; forcing families to make up the shortfall themselves.

Recommendation 7: The means test should be removed for disabled adults making essential adaptations to their homes through the Disabled Facilities Grant.

Carolyn Bean from Middlesbrough lives with her partner who is affected by spinal muscular atrophy. She says:

“We are not allowed a door opener unless we pay the £2,000 ourselves so when I am out my partner cannot leave the house, even if there is a fire!”

Michelle Young from Sutton Coldfield has spinal muscular atrophy. She says:

“Last year my bathroom ceiling hoist broke the council refused to replace it saying I could use a commode. It was awful. My mum and Dad had to pay for new hoist.”

Jeff Johnson from Nottingham has FSH muscular dystrophy. He says:

“Because I work I can’t get any help – and any support I can get I have to pay for myself.”

Nancy Jordan from Suffolk is affected by a rare and progressive adult-onset neuromuscular condition. She was told by her local council that she would have to take out a loan for over £100,000 to pay for her home adaptations.

Alun Watson from Bedfordshire is affected by limb girdle muscular dystrophy and says:

“I can only manage to work three days a week normally, but as I still earn, I do not qualify for funding. As I still work, I am not able to receive any funding; therefore I have to pay for everything myself – such as my wet room and stair lift.”

Charles Gibbs from Cardiff is affected by limb girdle muscular dystrophy and says:

“I fail the means test because of my wife’s income. Since I was diagnosed we have spent about £20,000 on essential things like a stair lift and bathroom conversion.”

Joanne Robinson from Cardiff has a teenage son with Duchenne muscular dystrophy. She says:

“We have had a nightmare with home adaptations. This will be the fourth time that we have had major work done. I feel if the parents’ views were taken into account the first time then this wouldn’t happen. What these people don’t seem to grasp is the children grow up and as they grow they need bigger chairs and equipment, if that was taken into account the first time then we wouldn’t have the stress of the house being knocked around more than once, I feel going through it four times is unacceptable.”

Recommendation 8: Local Authorities should take progressive conditions into account when planning home adaptations to make best use of limited funds, and to avoid costly repeated adaptations as a condition progresses.

Local Housing Allowance

We welcome the decision to allow people with a severe disability an extra room to allow for an overnight carer. This is overdue, and essential for independent living.

We further welcome the decision to remove people with a disability from the single room rate (which allows single people up to the age of 35 only enough funding for a room in a shared house). This is not appropriate for people with severe disabilities, and we urge the Government to continue this exception.

However, families with disabilities in receipt of the Local Housing Allowance (LHA) may still face living in overcrowded accommodation, or be forced to make up the shortfall from other benefits – reducing spending on other essentials, such as heating and food – as the level of allowance paid may not reflect the extra space needed for medical equipment or would expect a severely disabled child to share a room with a non-disabled child, despite the impact this could have on their health and schooling. The LHA may also not take into account the availability of accessible housing in a particular neighbourhood or town, which could drive up rents.

Some local authorities have advised disabled claimants to rent a larger property which meets their needs, and then claim for a Discretionary Housing Payment (DHP). This system has several fatal flaws – notably, you cannot claim for a DHP until you have moved into the relevant property. This means that a claimant who requires a larger property than the LHA will provide for would have to sign a lease and move into a property before they know if they will be able to afford the rent. This could leave the claimant in rent arrears and in breach of the lease they have taken out, with the potential of eviction and homelessness. In addition, local authorities have a limited DHP budget – even if your claim is valid, you may not receive a payment as too many other people have claimed. Furthermore, even if your claim is successful, the payment can be withdrawn at any point, denying the claimant security of tenure and risking the problems of rent arrears and potential eviction as outlined above.

Recommendation 9: Local councils should have the power to offer Discretionary Housing Payments to people with disabilities before they take up a tenancy, to reflect the restricted choice people with a disability face in finding an accessible home.

Recommendation 10: Families with severely disabled children should be allowed sufficient provision for that child to have a room of their own. A child who requires frequent attention in the night, or has considerable medical equipment, requires their own room to avoid disturbing their siblings, and to allow for harmonious family life.

Heating your home

For people with neuromuscular conditions, heating their home is essential for their muscles and mobility. Indeed, many patients are advised by their specialist consultant that even during the night, they must keep their heating at a minimum level.

Despite needing this support, people under the age of 60 with severe disabilities are not eligible for the Winter Fuel Allowance – the annual payment made to help people pay for their heating in the winter. Instead, this is only paid to people over 60, even if they are in full health and in employment.

A survey by the charity Papworth Trust earlier this year found that 90 percent of the public believed that Winter Fuel Allowance should be extended to severely disabled people.[2]

While there would be a cost to increasing the eligibility for Winter Fuel Allowance, we believe that we have a moral duty not to let people with a severe disability freeze due to the high cost of energy.

Recommendation 11: Eligibility for the Winter Fuel Allowance should be extended for people on Disability Living Allowance higher rate for care or mobility.

"My mum just gets the measly £50 a week Carer's Allowance which is pathetic because she looks after me night and day."

Mr Hardy from Suffolk has limb girdle muscular dystrophy. He says:

"I feel the cold sitting in a wheelchair all day. The recent winter weather conditions meant I had to keep the heating on all day, despite using blankets, extra clothes layers – that restrict my movement – just to keep my body warm. I feel government should allocate a heating grant for people like me, not just the elderly."

Margaret Mateer from Northern Ireland has a teenage daughter with spinal muscular atrophy. She says:

"Our heating bill is so much higher - heating has to be used all days on very cold days and even in summer."

Allison Hayhurst is affected by myotonic dystrophy and also has a teenage son affected by the condition. She says:

"The cost of keeping the house warm is really high, my last gas bill was £1,005 and I am now struggling to raise £148 every month to pay it I only have three items on gas, my cooker, my heating and my hot water."

Juliet Chapman from Brierley Hill is affected by FSH muscular dystrophy. She says:

"My muscles tend to cease up or stiffen when I get cold, so the temperature of my house affects my mobility, but I do have to worry about the bill."

3. Electricity bills

Severe disability can require a wide range of electric equipment, such as powered wheelchairs, ceiling hoists, through-floor lifts, and ventilators, all of which can cause a dramatic increase in household electricity bills, which many families struggle to meet.

One mum of a teenager with spinal muscular atrophy from the South West said:

"I had my bathroom changed to a wet room and was advised to have an electric shower to give constant water temperature for my son. It was so expensive I've had to have it taken out as I couldn't afford the electric to run it. My direct debits went from £67 a month to £125 and I just couldn't afford to pay it."

Tracey Franklin from Brough has a 13year-old son with Duchenne muscular dystrophy. She says:

"He has so much electrical equipment; wheelchair-tracking hoist, ventilator, nebuliser, bed, which all need charging every night and I cannot get any reduction on my electric bill."

Dawn Blakemore has a daughter with Emery-Dreifuss muscular dystrophy, and says:

"We have higher electricity bills because Amy needs her BIPAP (ventilator) machine on all night."

One family from London reported that their electricity bill went up 400 percent when their teenage son, who has Duchenne muscular dystrophy, had to start using non-invasive ventilation.

However, there are some examples of good practice. The British Gas Essentials Combined tariff is available to people earning less than £15,000 per year, and in receipt of Disability Living Allowance. The tariff is on average 16 percent cheaper than the standard tariffs. The npower Spreading Warmth tariff is available to households where one member has a disability, and the household income is less than £13,500. It offers annual savings to their standard prices on average of over 20 percent. Our experience is that families are rarely made aware of the support they might be entitled to, and miss out on much-needed help.

Recommendation 12: Energy companies to increase their provision of social tariffs for people on low incomes and who incur higher electricity and heating bills because of their disability. These tariffs should be promoted and publicised to ensure that people with severe disabilities are taking up the support.

4. The cost of caring

There are an estimated six million unpaid carers in the UK – and for many people caring for a family member or friend with a neuromuscular condition this is a full-time job. However, this is not reflected in the level of support carers receive – Carer's Allowance is paid at only £53.90. As you only are entitled to Carer's Allowance if you care for 35 hours or more a week. For the many people who care twenty four hours a day, they receive just 32p an hour.

> Vivek Gohill, 19 from Leicester, has Duchenne muscular dystrophy. He says:
>
> *"My mum just gets the measly £50 a week Carer's Allowance which is pathetic because she looks after me night and day."*

Furthermore, you are ineligible to receive Carer's Allowance if you are in employment and earn more than £100 a week (after income tax has been deducted). This denies many carers the chance to support their family, and where carers are able to carry out some paid work, acts as a disincentive for carers to seek out well-paid work.

We believe that the work of carers, and the costs they save the NHS should be reflected through an increase in Carer's Allowance to an equivalent level of Employment and Support Allowance or Incapacity Benefit. As carers are prevented from working full-time, or in well-paid employment due to the earnings limit, they should receive the same income as people who are unable to work due to a disability. This would increase Carer's Allowance to the level of Employment and Support Allowance: £91.40-£96.85 per week.

Recommendation 13: Carer's Allowance to be increased to an equivalent level of Employment and Support Allowance/Incapacity Benefit

Recommendation 14: The earnings premium for Carer's Allowance should be disregarded to allow carers the chance to escape poverty.

“I depend on my 88-year-old mother for 99 percent of my care.”

5. The Disability Premium

Many people with disabilities find that they have to pay extra for many everyday objects and day to day activities than non-disabled people.

- **Transport –** travelling by public transport is often impossible for people with disabilities, due to non-accessible buses, tubes and train stations. This means that many wheelchair users, and those with disabilities, rely on taxis (and often larger wheelchair accessible vehicles which are more expensive), or on lifts from family/friends in wheelchair accessible vehicles.

Brandon Fick is 20 and lives in Derbyshire. He has Duchenne muscular dystrophy, and says:

“Public transport is not possible due to the size of my wheelchair, so for all my social outings, private taxi is required.”

- **Holidays –** People with disabilities often find that accessible holiday accommodation is limited and that they have to pay more for the extra space for a powered wheelchair, or essential equipment. Research by *Trailblazers* has also shown people with disabilities often cannot take advantage of last-minute deals to save money when booking holidays, as this will not meet their accessibility needs. Furthermore, 80 percent of young disabled people feel that being a tourist is more expensive for them than it is for their non-disabled peers.[3]

Joanne Ashton from Liverpool has a six-year-old son who is affected by Duchenne muscular dystrophy. She says:

“We have noticed that we take more care and pay more for holidays as we must be sure of suitable accommodation for Liam – we took him to Eurocamp last year and had to find a site that was suitable for disabled access and the caravan we ordered was bigger than we would have required therefore we paid the extra for comfort.”

- **Clothing –** many people with neuromuscular conditions find that special or altered clothes and shoes are required, for using a wheelchair or other mobility equipment or aids, such as knee ankle foot orthoses. Other people find they need to replace clothes and shoes more frequently due to falls.

Ms Thanki from London says:

“Off the peg clothes are not suitable, even if you get someone to alter them. Bulky clothes especially in the winter are too heavy. I have spent so much time, energy and money trying to find something suitable. My nephew [who has the same condition] needs new trousers and shoes as they get too badly damaged when he falls – my sister mends them but they are no good for work.”

Allison Hayhurst has myotonic dystrophy and also has a teenage son affected by the condition. She says:

“We struggle with the cost of nappies and wipes as my son is double incontinent. The local authority doesn’t recognise the need for more nappies, and we have to wash and dry bedding six times a week.”

6. Social care

People with neuromuscular conditions are keen to live independent lives, and play a full role in society. However, often they may need a little amount of support to do so – from small things, like help to wash and get dressed, or to help with tasks that they can no longer complete themselves, due to reduced physical mobility, such as changing light bulbs or a weekly shop.

Mr F from the South East has Becker muscular dystrophy and says:

"I depend on my 88 year old mother for 99 percent of my care."

All local authorities have to follow Department of Health guidance as set out in the Fair Access to Care Services (FACS) which outlines an Eligibility Framework for all Adult Social Care Services. The Eligibility Framework is graded into four bands: critical, substantial, moderate and low, which describe the seriousness of the risk to independence or other consequences if needs are not addressed.

However, most local councils currently restrict eligibility criteria for social care, to those assessed with "substantial or critical needs" – denying care to those assessed as having "moderate needs". Research by *Community Care* magazine found three-quarters of councils now meet critical or substantial care needs only and that this will rise to 80[percent by next year under plans to tighten thresholds by councils currently supporting people's moderate care needs.[4] This will mean that in 80 percent of councils, people with disabilities who are unable to carry out several personal care tasks, will receive no social care support at all.

Mr Jones from Sussex is a pensioner, and is affected by Becker muscular dystrophy. He pays for his own full-time carer at a cost of £25,000 per year.

Recommendation 15: All local authorities to provide social care to people with a severe disability due to a neuromuscular condition.

Even where a person is found eligible for social care, their income will then be assessed to judge the contribution they will have to pay towards their care.

John and Mary McAnulty from Luton are in their late 60s, and are both affected by neuromuscular conditions, but have been told by social services that they have to pay the full cost of the social care they receive: £13.50 an hour for 15 hours a week.

Steve Ledbrook from Weston Super Mare is affected by Becker muscular dystrophy. His only income is from his disability benefits, but he was informed that he would have to pay up to £51.37 per week to receive social care support.

The means-test acts as a perverse incentive for continuing in employment, and saving for the future. This may actually increase, rather than decrease benefit dependency. We are concerned that spending cuts for local councils will further reduce eligibility and increase the contributions people are to pay towards their own care.

By supporting people to live independent lives, health outcomes can be improved and depression and isolation reduced. People may be able to stay in their own homes for longer. Crucially, people with disabilities may be able to gain or retain employment, reducing dependency on out of work benefits, and increasing tax revenues.

Severely disabled children and adults may require continual supervision to prevent medical emergencies – such as the need for suction to clear airways. This does not fit easily into the criteria for social care support, but has a severe impact on family life – often preventing other members of the family from being in employment, or from being able to leave the home for essential chores or social activities.

"...all our friends have retired and have foreign holidays several times a year, whilst we exist on benefits."

7. Too old to be disabled?

Reaching the state pension age can have severe financial consequences for people with neuromuscular conditions. For those diagnosed late in life, they may not be able to claim Disability Living Allowance – the main disability benefit. In addition, carers face the loss of the only financial support they receive – Carer's Allowance – as you cannot claim this at the same time as receiving the state pension.

In addition, people with a neuromuscular condition, or who take years away from their career to care for a family member with a disability find that they are unable to build up savings to support themselves after retirement, or to buy a home.

Mr Ling has limb girdle muscular dystrophy and lives in Whitstable. He says:

"I had to give up work early, so was unable to build up a private pension. Now all our friends have retired and have foreign holidays several times a year, whilst we exist on benefits."

Disability Living Allowance

If you develop a disability after the age of 65, you are ineligible to make a new claim for the main benefit for dealing with the extra costs of living with a disability – Disability Living Allowance (both the Care and Mobility component). This is discriminatory because if your disability starts before the age of 65 and you make a new claim then, you are entitled to continue to receive DLA for the rest of your life.

While you may be entitled to claim a separate benefit, Attendance Allowance, this does not have a separate component for mobility – denying you the option of having a Motability adapted vehicle. This can restrict the independence of older disabled people, and prevent them from living a full and rewarding life.

People with late onset neuromuscular conditions, such as Inclusion Body Myositis, can often find themselves severely disabled, but unable to receive the financial support which is available to people who were diagnosed with the same condition earlier in life. This rule conflates severely disabling neuromuscular conditions with ageing, and fails to reflect the very severe financial burden of disability.

Auriol Ashley from Bristol was diagnosed with inclusion body myositis at 60, but was not made aware that she could claim DLA. She says:

"By the time I went to claim DLA it was too late, as I was over 65. DLA would cover the extra costs of my disability which are not met by Attendance Allowance."

Doug Sibley from Eastbourne is affected by FSH muscular dystrophy. He says that not being able to claim DLA is:

"Like kicking you when you're down. The rules do not consider the fact that you want to remain active."

Recommendation 16: We recommend that people over the age of 65 are eligible to make a new claim for Disability Living Allowance.

Reform of the overlapping benefits rule

For a couple where one member is affected by a neuromuscular condition is cared for by their husband, wife or partner, claiming the state pension can lead to severe financial difficulties. The Carer's Allowance of £53.90 a week is lost, even though the caring responsibilities do not change, and due to the progressive nature of neuromuscular conditions, often increase greatly.

Moira Findlay is the main carer for her husband Andrew who has FSH muscular dystrophy. However, when she turned 65, she lost her Carer's Allowance. Moira and Andrew say:

"The overlapping benefit rule in terms of the Carer's Allowance should be abolished. You have to contribute to receive a state pension so this should not be classed as a benefit and carers have to show they care for 35 hours minimum a week so, again, should not be classed as a benefit. The biggest impact with this allowance stopping is the devaluation of the carer and the work they are still doing."

Recommendation 17: We recommend that people claiming their state pension should also be eligible for Carer's Allowance.

References

1. Leonard Cheshire Disability *Poverty in the UK* (June 2008)

2. The Papworth Trust *Winter Fuel Payments Survey Results* (September 2010) http://www.papworth.org.uk/downloads/Winter_Fuel_Payments_Survey_Results.pdf

3. Trailblazers *All Inclusive?* (August 2010)

4 Community Care *Councils to deny social care support to all but most needy* (September 2010) http://www.communitycare.co.uk/Articles/2010/09/15/115321/councils-to-deny-social-care-support-to-all-but-most-needy.htm

Details of the survey

- A survey was sent to 2,000 people across the UK between April and June 2010;
- 635 responses were received;
- The questions can be found at: www.muscular-dystrophy.org/get_involved/campaigns/campaign_news/2026_2010_national_patient_survey_share_your_views

Breakdown of regions

Region	No of responses
East Midlands	47
East of England	75
London	41
North East	34
North West	75
Northern Ireland	23
Scotland	41
South Central	50
South East Coast	54
South West	74
Wales	25
West Midlands	58
Yorkshire and Humber	35
Anonymous	3
Total	**635**

To join the fight against muscle disease; and to get involved in your local campaigning Muscle Group, then please email **campaigns@muscular-dystrophy.org** or call **0207 803 4847.**

Muscular Dystrophy Campaign
61 Southwark Street
London SE1 0HL

020 7803 4800
0800 652 6352 (freephone)
info@muscular-dystrophy.org

Muscular Dystrophy Campaign
PO Box 14813
Bonnybridge
Scotland FK4 2YD

01324 810958
scotland@muscular-dystrophy.org

www.muscular-dystrophy.org

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445