

**Muscular  
Dystrophy UK**

Fighting muscle-wasting conditions



# Breaking point

The crisis in accessible housing  
and adaptations

September 2015



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## Foreword

"In January of 2012, I made a firm decision. It had been on my list for a while, but I still remember the exact moment I decided to move out of my parents' house. Like all young adults, I wanted my own space, but what I wanted most of all was a house without stairs.

"As a lifelong wheelchair user with spinal muscular atrophy, getting up and down the stairs had always been a challenge. As I got older, and taller, it got more difficult, to the point where I thought 'one of these days I'll end up injuring myself.'

"Having spent years doing voluntary work whilst looking for paid employment, the only option available to me was to add my name to the local social housing list.

"Though I accepted the first suitable property available, I was sat on that list for more than 2 years. During this time, as Murphy's Law predicted, I sustained an injury to my right shoulder. I remember going to my voluntary work the next day and explaining that I couldn't type as I'd injured my shoulder going upstairs. My boss replied 'What on Earth were you trying to do that for?', highlighting the apparent ridiculousness of the whole situation.

"It gets far more ridiculous than that. Across the country, there are huge numbers of people waiting for accessible houses that simply don't exist. Phrases involving 'needles' and 'haystacks' spring to mind, but seem very inadequate. Though housing providers have legal obligations to consider the needs of local people with disabilities, there seems to be no consistently used method to accurately assess the number of accessible homes the community needs. There are also no figures showing just how much it costs the NHS to treat people injured by accidents due to inaccessible housing, nor the short or long term social care costs that result from this.

"I consider myself lucky to have found my little bungalow in just over two years; I have heard of people waiting several times this long. Though I still can't move my right shoulder in certain directions, it could have been much worse.

"The right to independent living was a gift from the disability rights movement of the last century. For everyone to have the freedom to exercise this right, there needs to be accessible housing available.

"I can't imagine living in a house with stairs now, and wouldn't do it again if you paid me."

**Fleur Perry is 25 years old and has spinal muscular atrophy (SMA). She is currently living in Wiltshire.**

## **Why is accessible housing so important for people with muscle-wasting conditions?**

Muscular dystrophy and related neuromuscular conditions (muscle-wasting conditions) are progressive by nature. This means that those affected by muscle-wasting conditions will have changing needs throughout their lives and are often faced by periods of rapid deterioration.

As people's conditions deteriorate, this progressive muscle weakness means that their ability to be able to mobilise or carry out daily activities can be affected.

This means that many people may need access to specialist equipment and significant adaptations to their home to make sure that it is still safe and accessible.

For example, as their condition progresses, many people may require a powered wheelchair or need other specialist equipment such as hoists to help them transfer from a wheelchair to the bed. This can make it necessary for significant adaptations to be carried out to their home before they can access equipment. In other cases, a stair-lift, which is considered a major adaptation, may be required to allow the individual to still be able to use the upstairs rooms in their house. Others will require further adaptations, such as a wet room or an extension.

## **Executive summary: the crisis in accessible housing**

Accessible housing and adaptations are vital in allowing individuals and families affected by muscle-wasting conditions the best possible quality of life and levels of independence at home.

However, following an extensive survey of people affected by muscle-wasting conditions, carried out between July and September 2015, and Freedom of Information requests to local councils, this report uncovers a crisis in accessible housing, which is having a devastating effect on people's lives.

Our alarming findings reveal that families are falling into serious financial hardship after exhausting their savings to fund vital housing adaptations, because Disabled Facilities Grants from their local council simply cannot cover the costs.

Other individuals and families affected by progressive and often life-shortening muscle-wasting conditions are ending up trapped in homes that can no longer meet their mobility needs. Some are confined to downstairs rooms because they can no longer get up the stairs; others, who are wheelchair users, are unable to use their

wheelchairs indoors, or have no turning space, which can often mean limiting access to their own bathrooms and bedrooms.

Due to a lack of available housing and long waiting lists, these individuals are unable to move home and can wait years before they get the support they need.

## Key findings

### Key findings from our survey and Freedom of Information Requests include:

- ▶ Well over a third of individuals and families faced debt and serious financial hardship when trying to fund vital adaptations for their homes, often being forced into tens of thousands of pounds worth of debt or using up life-savings in the process.
- ▶ 70% of people are in properties that do not meet their mobility needs
- ▶ Local councils have hundreds of people waiting to be re-housed in accessible accommodation, with zero houses available
- ▶ Individuals are going without vital adaptations because they are unable to afford the costs, in some cases leaving them unable to use the bath or shower.
- ▶ Some parents have to carry their children upstairs due to their property being inaccessible
- ▶ Over a third of local councils provide no additional financial help with the costs of adaptations
- ▶ Some local councils have “minimum residency” periods of 5 years and over, during which time individuals and families with muscle-wasting conditions can face periods of rapid deterioration without the right support – a serious threat to their health and well-being.

## What needs to happen?

“Our property has 18 steps to lead to our front door. My sons cannot walk up or down stairs. I have to carry both of them at the same time up/down the stairs. I don’t drive, so am mainly house bound because of safety and the pain when I lift them is getting too much. It is very hard to cope.”

Amy Rollinson has two sons with Duchenne muscular dystrophy

### To fix the crisis in affordable adaptations and accessible housing, Muscular Dystrophy UK is calling for:

- 1. The Department for Communities and Local Government (DCLG) and local authorities to act immediately to increase the building of accessible properties.** Local authorities’ responses to our Freedom of Information (FOI) requests painted a shocking picture, with demand for wheelchair accessible properties dramatically outstripping supply. For example, one local council (Harlow Council) has 166 people on their waiting list needing wheelchair accessible housing, and 0 available properties. The crisis in accessible properties has reached crisis point and is continuing to spiral out of control. The DCLG must support local authorities to implement ambitious housing targets in their ‘local plans’, with new developments built on greenbelt land if necessary. At least 10% of all properties within new developments should be wheelchair accessible, and all new houses should be built to ‘Lifetime Home’ standards (the model for building accessible and adaptable homes).
- 2. The Government to increase the statutory maximum grant available for Disabled Facilities Grants (DFGs), and ensure that this figure moves up in line with inflation.** The maximum DFG grant was last raised in 2008, from £25,000 to £30,000 . This means that whilst the costs of adaptations have gone up during that time, the money available from councils to fund them has stayed the same. Consequently, people with muscle-wasting conditions are having to use up their life savings to fund the work, are facing financial hardship or are having to go without vital adaptations altogether.
- 3. Local authorities to make more use of ‘discretionary payments’ for DFGs, and for all local authorities to have a policy to consider requests for these payments.** Through the Better Care Fund, there is currently £220million per year available across England to be given to local housing authorities to cover the costs of DFGs . Evidence from our survey and FOI requests show that this is simply not enough to provide the support that people with muscle-wasting conditions need to adapt their homes. Local authorities have the power to top up a DFG through a ‘discretionary payment’. However, in reality, very few of these requests are approved

and discretionary funding is notoriously difficult to access. Our Freedom of Information requests revealed that well over a third of local authorities had awarded no discretionary payments for DFGs, and many had a policy not to offer discretionary payments at all.

**4. Local authorities to apply criteria on 'minimum residency periods' with greater flexibility.** Some local authorities have criteria that must be met before an individual or family can go on their housing register. This might require them to demonstrate family links to the area, or have lived in the area for a period of time. We understand that this can be necessary to protect demand on resources. However, in some cases this criteria can be applied far too inflexibly and can have devastating affects on people with muscle-wasting conditions. For example, Hillingdon Borough Council has a policy that a family must have lived in the borough for at least 10 years. The change in physical abilities in someone with a condition such as Duchenne muscular dystrophy during this time would be huge. We know of families across the country who have been affected by policies such as this, and left stuck in housing they can't afford to, or are unable to, adapt.

**5. All local authorities to hold a register of accessible properties.** We were concerned that a number of local authorities who responded to our Freedom of Information requests had no disabled housing register, and no way of recording what properties they had available. It's essential that local authorities can quantify their accessible homes, and that they know where they are located.

"It has been a continuous fight over 20 years to be rehoused each time to meet Daniel's needs. In the end he has gone into independent living at a residential home, as the council would not re-house us anymore".

**Phillippa Farrant's son, Daniel, has Duchenne muscular dystrophy**

# The evidence

## Muscular Dystrophy UK survey and Freedom of Information Requests to local councils

Between July and August 2015, Muscular Dystrophy UK carried out a survey of people living with muscle-wasting conditions, to ask them about their experiences of securing accessible housing and carrying out adaptations to their home.

We also submitted Freedom of Information Requests to all local authorities in England, to find out what support was offered in their local area, and how many accessible homes they had currently available.

Our findings reveal an alarming lack of accessible housing in many parts of the country and the huge debt burden that people are being forced to take on to fund adaptations. They also lift a lid on the emotional strain this is placing on individuals and families, who already have to cope with the difficulties of living with a long term, and often life shortening, condition.

### Dealing with debt: the financial burden of adaptations

Of those who took our survey, well over one third had encountered financial difficulties in funding adaptations to their home.

For many of these individuals and families, the Disabled Facilities Grant (DFG) available from their local authority was simply not sufficient to cover the costs of the adaptation. Even families who qualified for the maximum £30,000 grant had to put forward additional money themselves. In some cases, the amount contributed by the family was nearly three the amount put forward by the council. For many of these families, this meant incurring huge personal debt, suffering long term financial hardship or relying on the generosity of wider family members to see them through.

### Alarming responses included:

- ▶ "Spent life savings"
- ▶ "When I retired I had a lump sum along with a monthly pension - this should have been our nest egg but gradually over time this has been eaten into to try and maintain a reasonable level of living and independence."
- ▶ " Needed a further £50000"
- ▶ "We had to move and re-mortgage."
- ▶ "Have now spent most of my savings & lost my safety net"

For some individuals, the costs were so prohibitively expensive that they have had to go without vital work altogether.





**John, who has Charcot-Marie-Tooth disease, lives in Cheshire with his wife. He has had to give up on carrying out some vital adaptations to his property, due to the high costs involved.**

John paid £16,000 of his own money to adapt his kitchen, as he didn't qualify for a DFG. He had also requested support from the council to install a wet room in his bathroom, but was told that he would have to pay the first £8,000 before the council could contribute.

Now, due to muscle wasting affecting his hands and arms, John can no longer transfer from his wheelchair, onto the side of the bath and then onto a battery operated bath seat. John discussed the matter with an Occupational Therapist. However, as there had been no changes to the qualifying parameters for a DFG, John would still have to fund a significant proportion of the adaptations himself.

John says: "I have quite simply exhausted my funds in adapting my home, and I cannot afford to put up a further £8,000. So for a year now I haven't been able to have a shower or bath and have to rely on my wife (who is also my carer) to wash me.

"This is really taking its toll but without support from the council and without sufficient personal finance, I'm unable to make the adaptations that I need."

### **Discretionary Payments**

DFGs provide a maximum of £30,000 towards the costs of adaptations. They are means tested for adults, and non means tested for children. As our survey results show, in many cases the amount available from councils only goes a small way towards covering the costs of the work. To help with further costs, local councils can provide what is known as a 'discretionary payment', over the £30,000.

However, our Freedom of Information requests revealed that well over a third of local authorities have awarded no discretionary payments for DFGs, and many had a policy not to offer discretionary payments at all.

- ▶ We call for the Government to increase the statutory maximum grant available for Disabled Facilities Grants (DFGs), and ensure that this figure moves up in line with inflation.
- ▶ We call for local authorities to make more use of 'discretionary payments' for DFGs, and for all local authorities to have a policy to consider requests for these payments



## The Carr family's story

"My son Fraser is 15 and has Duchenne muscular dystrophy. He was diagnosed shortly before his 3rd birthday.

"When Fraser was diagnosed we relocated to a bungalow knowing that his needs would change. However, the bungalow still required some adaptations and an extension which needed to be put in place before Fraser became a full time wheelchair user.

"After very lengthy deliberations, and the intervention of the Ombudsman, the council eventually awarded us the maximum £30,000 Disabled Facilities Grant. The council had no policy which would have allowed us to apply for a discretionary payment even although the cost of the work needed was in excess of £100,000.

"The adaptations were extensive as we were not willing to settle for an inadequate scheme. At one point the council had suggested a "pod" type extension which did not even allow for a turning circle for a wheelchair! The £30,000 only covered part of the costs and we had to self fund the remainder to the tune of £70,000. We spent all of our savings and were left with £15,000 of credit card debt.

**"We spent all of our savings and were left with £15k of credit card debt"**

"We have two daughters at university and have not been able to financially support them so they have had to work part time while studying. We also feel that our son's opportunities have been limited because of financial restrictions. Holidays have been limited and very much on a budget; we could not manage the contribution for a larger ramped vehicle so can no longer go out as a family; we cannot upgrade Fraser's wheelchair from the basic NHS model supplied and we cannot make our garden accessible.

"We are grateful that we were able to achieve the necessary adaptations for our son while many families cannot. However, the battle for the right adaptations took around 8 years and it dominated our lives.

"At a time when we should have been enjoying family life and making memories we were stressed and anxious and for the most part terrified that we would not be able to provide for our child's needs. Our children were denied the care-free happy years which they deserved and given that Fraser's condition is life limiting this is particularly hard to bear."

**Julia Carr, Fraser's mum**

## The long wait for a home

Our survey and Freedom of Information (FOI) requests reveal a long wait for an accessible home, spiralling waiting lists and a complete lack of disabled and/or wheelchair friendly homes in local authority housing stock.

Following our FOI requests, we can reveal that amongst the local authorities who responded, there was an average of 45 applicants on the waiting list requiring an accessible property, with an average of 0 such properties available at the time.

This figure was far worse in some individual local authorities, with demand far outstripping availability, including;

- ▶ **Harlow Council**, where **166 people** need a wheelchair accessible property, with **0 properties** currently available
- ▶ **Blackburn with Darwen Borough Council**, where **155 people** need a wheelchair accessible property, with **0 properties** currently available
- ▶ **Blackpool Council**, where **258 people** need a wheelchair accessible property, with only **5 properties** currently available
- ▶ **Camden Council**, where **122 people** need a wheelchair accessible property, with **0 properties** currently available
- ▶ **Northumberland County Council** where **113 people** need a wheelchair accessible property with **0 properties** available

A number of other local authorities had waiting lists well into the hundreds, and a shocking lack of available properties in their local area.

The results of our FOIs are backed up by the experiences of the individuals and families who filled out our survey, many of whom are spending years waiting to be re-housed only to have to settle for a property that isn't properly accessible.

### **A huge 70% of respondents said they were allocated a property that did not meet their mobility needs.**

This is only storing up trouble for the future and places further strain on local authority resources, as it's likely these individuals and families will have to carry out further adaptations, or move house again.

#### **Comments include:**

- ▶ "The property was meant to be for a disabled person but it took almost 3 years to get some basic things fitted. There was a broken lift that was condemned and removed...the kitchen and bathroom were never adapted and left in ruin. I'm still fighting to get it done 8 years later."

- ▶ “The kitchen is not accessible nor is there a walk in bathroom, so I don’t use the bathroom.”

Respondents also reported long waiting lists, and their devastation at being unable to find a suitable home:

- ▶ “In the whole time that I was on the list for an accessible property, only 1 which was wheelchair accessible and suitably adapted became available. I applied straight away and phoned every day to see if I had been successful as I was so desperate. When I was finally told it had been given to somebody else I was absolutely crushed.”
- ▶ “Tried for 19 months and eventually gave up and decided to go down the privately rented route due to the lack of accessible housing in my local authority. My living conditions at the time were just too dire and severe to stay on the housing list any longer and I just had to get out of there.”
- ▶ “We are still on the housing waiting list, and it could be years before we are re-housed. This is ridiculous: my son has Duchenne muscular dystrophy, and it’s not going to wait for him.”



**One respondent, Dr Chetna Patel, who has limb-girdle muscular dystrophy, had to spend time in residential care before she could find a suitable property.**

Chetna, who had to relocate from Aberdeen to Sheffield for a new job at the University of Sheffield, says:

“I first looked at various renting or buying options but nothing suitable to my physical needs were found. The accessible flats at the University were already occupied and they were not able to accommodate me. I approached and registered with the Sheffield City Council for housing and under these circumstances asked to be put on a priority list.

“I was desperate and needed to move and take up my post; a social worker came up with the solution of my staying in a residential home for the elderly. I had no other option and so accepted it. The home did its best but it was a battle to keep my motivation up as I lost much of my independent life whilst in there and it took a further 7 months before I was able to move into a place of my own. Unfortunately it didn’t end there. It took another further 3 months and numerous loans to make the place accessible for my needs. The lack of accessible housing and the lethargy of the council to respond unnecessarily hinders the mobility of people with disabilities. When you consider this against the contribution I make to education, the community and revenue (and I am just one example), it is social and economic madness to not address the lack of accessible housing.”

**We call for the Department for Communities and Local Government (DCLG) and local authorities to lead a revolution in the building of accessible homes. The crisis in accessible homes is spiralling out of control and the DCLG must support local authorities to implement ambitious housing targets in their 'local plans', with new developments built on greenbelt land if necessary. 10% of all houses within new developments should be wheelchair accessible, and all new houses should be built to 'Lifetime Home' standards (the model for building accessible and adaptable homes).**

### **Minimum residency period**

To help reduce demand on accessible housing, many local authorities have a minimum residency period in their housing policy. This means that someone applying to the council for housing must have lived in the area for a minimum period of time before they can go on a housing register.

**Our FOIs showed that this is an average of 16 months, however in many authorities where housing demand is greater, the minimum residency period is much higher.**

**For example, in Camden, Crawley and Slough the minimum residency period is 5 years, and in Hillingdon it is a lengthy 10 years.**

Muscular Dystrophy UK understands why these local authorities have such policies in place. However, we are concerned that these policies are often applied too inflexibly and do not take into account the needs of someone with a progressive muscle-wasting condition.

For example, a child with Duchenne muscular dystrophy could have been diagnosed and already be a full time wheelchair user within the period of time some local authorities have as their minimum residency period.

**Tara Cairns' 4 year old daughter has an undiagnosed type of myopathy:**

"I'm still in privately rented accommodation as we have been caught by the council's new clause that states you have to have been living in an area for 5 years continuously. I was born in the town we now live in and can trace my family back over 150 years. However, when I got married we moved to south London to be closer to my husband's work. When our daughter's condition became apparent, we moved to be closer to my family. We are currently in a property that we cannot adapt, and the council's OT department has stated it is not sufficient for our needs. However, the council are standing firm and we still have no support."

**We call on local authorities to apply criteria on 'minimum residency periods' with greater flexibility, so that people with muscle-wasting conditions are not unfairly penalised if they are applying to be re-housed following a recent diagnosis or an unforeseen change in circumstances.**

### **What is muscular dystrophy?**

There are about 60 forms of muscular dystrophy and related neuromuscular 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 neuromuscular conditions can be genetic or acquired and, with few exceptions, there are currently no effective treatments or cures available.

Clinical trials in some forms of muscular dystrophy and related neuromuscular condition 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.