



Get Moving 2013

**The case for effective
Wheelchair Services**

Muscular Dystrophy Campaign

November 2013

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Introduction

More than three years on from launch of the Muscular Dystrophy Campaign's 'Get Moving – the case for effective Wheelchair Services' report, new findings reveal that there are still substantial gaps in specialist wheelchair provision for people with muscular dystrophy and related neuromuscular conditions. Improvements are urgently required, at both a national and a local level.

This new report illustrates the key findings from the Muscular Dystrophy Campaign's 2013 *Patient Survey* and is supplemented by powerful case studies highlighting severe delays and barriers to effective wheelchair provision.

Sulaiman Khan, a powered wheelchair user from London, is 28 years old and has congenital muscular dystrophy. Sulaiman was restricted to his bed for 26 days in July when his wheelchair stopped working. He said:

“Being in bed for the best part of a month really took its toll on my body and my mental health – I can honestly say it was one of the lowest points of my life. Owing to my condition, I have severe scoliosis of the spine and without the right support I am in constant pain. These wheelchairs are a necessity, not a luxury – without it I am hugely dependent on other people. I lead an active lifestyle. It is important to me. Having to essentially put my life on hold was frustrating, and made me feel useless. July was a complete disaster, cancelling all plans, campaigning, voluntary work – even much anticipated birthday celebrations. I struggled to find support with maintenance locally and in the end I had to go to Portsmouth to get my chair fixed.”

Summary of key findings

- **Almost half of respondents that use a wheelchair did not receive full NHS funding for its cost;**
- **Over one-third of respondents have to fund the upkeep of their wheelchair themselves;**
- **Approximately one-third of patients waited more than six months after requesting an appointment from the NHS to receiving the wheelchair.**
- Assessment processes for appropriate wheelchair provision have been described as insufficient, too general, and unstructured and not taking into account the varying needs of individuals, from different age groups and lifestyles.
- A lack of knowledge and poor communication by many wheelchair service providers of specialist requirements are significant factor in delays to providing the required wheelchair or enabling the necessary maintenance to be undertaken.
- Delay in providing the appropriate wheelchair can result in a detrimental impact on the quality of life for people with muscle-wasting conditions and increases the possibility of unplanned emergency admissions to hospital.
- Funding limitations of services mean that the voucher or funding provided is often insufficient and people with muscle-wasting conditions are being forced to resort to alternative sources to top up the funding or fully pay for their purchase.
- There is a lack of clarity over who is responsible for funding wheelchair repairs once an individual has self funded their equipment. Wheelchair maintenance was highlighted as problematic with long waiting lists for repairs and charities often being relied upon for help.
- Generic manual wheelchairs were often provided for people with muscle-wasting conditions. Inadequate seating can exacerbate scoliosis and contractures, and this highlights the crucial importance of customising powered wheelchairs for many people with muscle-wasting conditions. It is clear that the NHS needs to take more account of the complex postural needs.

An effective wheelchair service not only has significant benefits to the health of people living with muscle-wasting conditions but would also lead to NHS cost savings by contributing to a reduction in unplanned emergency admissions to hospital. A joint report by The Treasury and Department for Education and Skills in 2007 noted that 'early provision of equipment or wheelchairs...may prevent the development of pressure sores, contractures or skeletal deformity.' The report acknowledged that funding for the equipment can reduce the cost to the NHS in the long run, minimising the need for potentially expensive operations and medical treatments.

Calls to Action

The Muscular Dystrophy Campaign is calling for the following actions to take place:

1. Clinical Commissioning Groups need to ensure assessments are based on a full understanding to the needs of the individual, taking into account elements such as age, the rate of progression of the muscle wasting condition, severity of the condition and lifestyle of the individual
2. The Department of Health should establish a national target for waiting times for wheelchairs at a maximum of 18 weeks from initial referral to delivery of the chair to minimise the impact of deterioration of an individual's condition during the period following assessment.
3. Clinical Commissioning Groups need to ensure better access to information and advice and improve their communication of how to access wheelchair services.
4. The Department of Health should increase the budget for access to powered wheelchairs within each Clinical Commissioning Group, as well as promoting better understanding of the benefits a powered wheelchair can bring to people with muscle-wasting conditions, which can in turn lead to cost savings by helping to prevent unplanned emergency admissions to hospital.
5. Clinical Commissioning Groups should pay for the cost of maintaining all wheelchairs, including those that have been modified or privately funded and maintenance of these wheelchairs needs be carried out quickly and efficiently. The current system requires clarification regarding eligibility for NHS-funded for people who purchase chairs privately.
6. NHS England and the Clinical Reference Group (CRG) for Complex Disability Equipment should ensure the effective implementation of the service specification of *Complex Disability Equipment: Specialised Wheelchair and Seating Services*.

The Service Specification for *Complex Disability Equipment: Specialised Wheelchair and Seating Services*, adopted in October 2013, sets out its aims of the service:

“The aim of a Specialised Wheelchair service is to maintain independence and improve the quality of life for people living with a disability and for their carers through timely access to specialised assessment, provision and maintenance of equipment. The service should respond to changes in people's health conditions through regular review and deliver a service that patients perceive to be a good experience.”

Extract from the Service Specification on *Interdependencies with other services*:

“Local wheelchair services to ensure a seamless pathway of care for patients and will offer advice and support to local wheelchair providers. These local services will be commissioned through their Clinical Commissioning Group (CCG) and close liaison will be required with local commissioners to ensure any local development or service redesign considers the implications for the complete patient pathway.”

Challenges of wheelchair services

1. Wheelchair provision problems

While in some instances the wheelchair itself was considered adequate, in others the seating or other elements of the equipment were not.

Wheelchairs were described as being too general and basic and not specialised enough for the needs of the particular condition, which might be for the chair to tilt or rise and not distribute weight correctly. By the time the appropriate seating is put in the place, the posture of people with muscle-wasting conditions has often deteriorated.

NHS wheelchair services generally do not get a high level of experience of working with clients with very complex needs so they often find it harder to develop those very specialist skills.

Some wheelchairs are also suitable only for short periods of time and not for all-day-long usage and replacements were issued without re-assessment and re-fitting to ensure suitability. Respondents to the survey felt generally that the wheelchairs provided by the NHS were unsuitable and they were forced into buying their own wheelchairs, often at great expense.

The following comments were made in the survey responses:

'My son's wheelchair is adequate but seating is not - he aches and you cannot get the best that you want for his comfort, just the cheapest!' – Parent, Surrey

'NHS provides wheelchairs for basic needs that are not suitable for all-day-long use and do not meet needs' – Young man with Duchenne muscular dystrophy, Lancashire

'My wheelchair is a manual push one. I am unable to use it by myself' – Anonymous (50), East of England

'It's a bit squeaky, and it's the Red Cross or Salvation Army that deal with it all.' – Anonymous (50s), Northampton

2. Detrimental effect of long delays in receiving a wheelchair

Having the right wheelchair at the right time is vital to the ongoing health and well-being of people with muscular dystrophy and neuromuscular conditions. For children with the most severe muscle-wasting conditions, the rapid rate of progression of their condition – combined with their growth – leads to a constant change of needs. Early provision of wheelchairs with tilt-in-space and recline facilities are thought to relieve the impact of scoliosis, while supportive seating can also prevent the development of contractures in the hip, knee, ankle and foot.

One respondent claimed that it took nearly five years to get the wheelchair they required for their specific needs and this was only after several consultations with different services. Other views expressed on this issue were:

'I have been waiting to see them again – it has been about seven weeks and still haven't seen anyone' – Anonymous man (64), Becker muscular dystrophy from Peterborough

'I haven't been seen by them for three years plus, haven't been asked or questioned about how I am coping with my chair' – Anonymous (20), the West Midlands

'I waited for eight months for a new wheelchair after my previous one had been scrapped. Had to make do with one that was too small, not enough power of battery life for someone my size, hence it broke down or ran out of power many times' – Martyn Blenkarn from Lancashire

'I am on the waiting list to obtain a voucher because my current chair needs replacing and they cannot provide me with a chair which meets my needs. This has been going on for about two years' – Katy Etherington from the East of England

3. Cost limitations of the service and the need for self-funding

When people with muscle-wasting conditions are unable to get the equipment they need they are put in the position of having to approach a charity, fund the equipment themselves or not receive any equipment at all.

NHS funding is inadequate to meet the complex needs of many clients – their basic wheelchair may only cost £8000 but by the time you have added special seating support, specialist control systems and bespoke modifications and adaptations, that figure can easily quadruple.

<p>The Joseph Patrick Trust (JPT), the welfare fund within the Muscular Dystrophy Campaign, provides grants towards the costs of specialist equipment such as powered wheelchairs, adapted computers and electric beds, for children and adults. The Muscular Dystrophy Campaign has awarded more than 6,000 grants, totaling more than £6million, towards specialist equipment such as powered wheelchairs. In the last 25 years, the to children and adults, helping more than 5,000 children and adults with muscular dystrophy and related neuromuscular conditions to purchase specialist mobility equipment not available on the NHS.</p>

People with specific and complex needs are potentially vulnerable to exploitation from private providers who could take advantage of this group of people.

Vouchers that are supplied to meet the costs of wheelchairs are often not sufficient and mean that the individual has to make up the full cost of the wheelchair themselves. The equipment that is needed to go with the wheelchair is often an expensive add-on and can be a hidden cost on top of the initial pay-out. Respondents were often left feeling that the service was run on the grounds of cost rather than the health needs of the individual and that wheelchairs are often bought as a bulk buy rather than for specific needs.

Young people with muscle-wasting conditions also commented that a teenager's requirements for a wheelchair may be different from those of a younger child or adult and that this should be taken into account.

Comments included:

'My first powerchair was part funded by NHS - I was told I must return it before getting any help funding a new chair. I therefore had to fund the entire cost/upkeep of my new chair so I could keep the old one as a spare, which is essential'. Anonymous (40s), Cambridgeshire

'There was not a great deal of variety of pushchair / wheelchairs available which made us purchase a specialist off road one which suited our lives better.' Parents of a six-year-old, Cumbria

'We receive an £800 wheelchair voucher every five years and my son's wheelchair cost just over £3000. He needs a very light wheelchair to be able to self-propel and extras like foldaway handles for when he gets tired. We have never been offered a suitable wheelchair through Wheelchair Services since my son started to self propel at the age of seven. He had an electric wheelchair from Wheelchair Services when he was three years old which was suitable for him for a couple of years: his next electric wheelchair was provided by the Whizz-Kidz charity as he needed something other than a basic chair.' Parent of an 18-year-old from Cumbria

4. Inadequate assessment process

Many respondents commented that they had never been assessed for wheelchair needs and some said that assessments were carried out without looking at the individual's needs at school or work and home.

Occupational Therapist graduates can have completed their training and still have a poor understanding of muscular dystrophy and related neuromuscular conditions, which can lead to an inadequate assessment for wheelchair seating and posture management.

Patient assessments for wheelchair provision are often based on a strict and inflexible interpretation of clinical need rather than on essential elements of the individual's life – such as independent living, their social development and educational attainment – with teenagers being assessed in the same way as older people and younger children. Appointments were described as being long with no structure and people with muscle-wasting conditions and their families not knowing what to expect. Some respondents' experiences included:

'They are very slow. The technician who saw my son did not know anything about muscular dystrophy. I had to tell him about the disease and how it affects my son.' Justine McAlister from Sussex, whose six-year-old son has Ullrich congenital muscular dystrophy

'They need to change the 'DVLA' ruling. My daughter had controlled epilepsy, meds gave her hepatitis, absence seizures came back for a short while....wheelchair services rejected application for chair' – Carrie Higginson, Lancashire, whose 15-year-old daughter has congenital muscular dystrophy

5. Increasing access to powered wheelchairs

Often only manual wheelchairs were offered by Wheelchair Services, with vouchers not offered for powered wheelchairs. Charitable organisations like the Muscular Dystrophy Campaign – through the Joseph Patrick Trust – and Whizz-Kidz were relied upon for powered wheelchairs when the NHS criteria were not met. Respondents felt that the system was a postcode lottery when waiting for a powered wheelchair.

Powered wheelchairs are essential for people with a muscle-wasting condition, especially those who don't have an able bodied carer to assist them and would prefer the independence of a powered wheelchair.

One area of concern is the increase of powered wheelchairs purchased independently and secondhand from internet sites such as eBay, without the full assessments and checks having been done. One respondent complained of having developed pressure points as a result of this which could be detrimental to their health. Family members also complained of health issues such as hernias as a result of having to lift manual wheelchairs.

'Now use an electric as am not strong enough to wheel myself (upper body/arm strength). Self funded, and NHS will not help with upkeep as my house is not suitable for it to be used indoors.' Anonymous (50s), the South Central region

'They were able to provide a manual chair but I do not have sufficient strength to self propel so rely on a carer. I enquired about a powered chair but as I can still walk a little and only required it for outside I was told no.' Anonymous (40s), the South Central region

6. Maintenance problems

Delays frequently occur in carrying out wheelchair repairs which has led to discomfort and inconvenience for many people across the country with muscle-wasting conditions.

After using charitable funding for wheelchair and purchases, it is often unclear who should be responsible for maintenance and repairs.

Charities such as the Red Cross or Salvation Army were relied upon for maintenance in some survey responses. Repair services often have long waiting lists and time slots for repairs are often at inconvenient times that involve users having to take time off work. Battery power can be a problem with batteries running down quickly causing inconvenience for users. Wheels wear down easily and need frequent replacing and even small areas such as the Velcro on cushions need to be repaired on a regular basis.

7. Difficulties in contacting the service and the need for better information

Wheelchair Services were described as difficult to get hold of for basic repairs and as the delays increase, it is likely that some muscle-wasting conditions will deteriorate while waiting for wheelchairs to be mended.

People with muscle-wasting conditions have often had to look outside of their local area for information and for Wheelchair Services to carry out repairs which can mean extra travelling and significant expense.

Other respondents appeared not to know that there was an NHS Wheelchair Service or advice line and had never been given this information.

The need for local offices was summarised by Peter Edwards from Cambridge:

'They've recently closed their local office, thus making them less accessible. They are also very defensive, sometimes even seeming hostile, if approached!'

Respondents spoke of a lack of clarity in the information they receive, given leaving them unsure as to what is available for them. Rachel Murphy from Sussex commented that:

'I am not sure if they provide any other electric power chair than what I have already been given'

CASE STUDIES

Sulaiman Khan, 28, from London, who has congenital muscular dystrophy

Since I moved back to London from America in July 2006, the wheelchair services always want to provide me with a wheelchair that is completely unsuitable for my needs. The seating isn't right and is bad for my back – I have severe scoliosis and unsuitable seating will just make this worse. I had to really push to get the local Primary Care Trust (PCT) to fund a new specialist power wheelchair. It took them three years to authorise my current wheelchair. I need to be continually reassessed and they are not authorising it, which means that my condition is getting worse. The PCT no longer exists and now the Clinical Commissioning Group (CCG) has taken over, but they still keep referring me back to the wheelchair services who don't have the skill-set or time to deal with my complex wheelchair / seating needs.

On 27 June 2013 my wheelchair completely stopped working and I was in bed for 26 days. That was the second time that had happened with my wheelchair in a year!

I found another good specialist wheelchair / seating provider (TT Mobility) who fixed the problem and they can deal with complex postural needs, being able to provide both the seating and the wheelchair. They recently carried out the reassessment when I visited them because the current wheelchair or seating hasn't been readjusted in well over a year. They recommend I get a new wheelchair and seating and it will cost between £25,000 and £30,000 to do this; it may seem very expensive but that is about average to get specialist wheelchair / seating provision for disabled people with complex postural needs. I need to go to the local Clinical Commissioning Group to get them to fund this. I'm on continual health (funded by the NHS not Social Services), which means I have a continual health package because I have a long-term condition. I have two carers with me all the time (four carers in a 24 hour period, 365 days a year) and the inappropriate wheelchair is making their job difficult. I strongly believe that the wheelchair / seating should be covered by the care package as it needs to be continually re-assessed / re-adjusted every four months or so and the current situation is causing me a lot of pain.

The wheelchair dealer (Easy Mobility Limited) who originally provided the wheelchair from the manufacturer (Sunrise Medical) have been unprofessional and rude saying that it is my fault the wheelchair broke. I have been trying to call the local authority for a year to get them to fund the wheelchair servicing and seating readjustment, but nobody has answered or replied to my emails. Most likely, this is because of all the changes in local authorities and the fact that no-one really knows who I am when I tried calling my local authority since my previous contacts in the PCT just left without any proper handover or letting me know who the new contact will be.

As I mentioned in May 2012, the wheelchair dealer I deal with took away my wheelchair for 23 days and refused to return it until they were paid. My sister had to pay the wheelchair dealership £1,200 (as the local authority were taking a long time to release funds) to get the wheelchair back, and even after she had paid they wouldn't give the wheelchair back until after the bank holiday. The brakes had come off my wheelchair and I was almost hit by a car several times, as well the power completely cutting out and the electrics not working at all.

The recommendations I would make are:

- *the wheelchair services need a complete overhaul for those with complex conditions*
- *more individualised wheelchairs and seating need to be provided rather than the basic chairs that are used across the board for people with all conditions, particularly complex postural needs*
- *the local authorities need to talk more with people with complex issues and look at the way their wheelchair services are contracted out – currently they use the same company to provide wheelchairs to people across all conditions*
- *local authorities need to be open to allow a third party to direct the way the service is run. They need to recognise that their skill-set cannot support those with complex postural needs and get specialist (possibly independent) wheelchair / seating providers to take over (recommending that to local authorities)*
- *most wheelchairs only last three to four years due to the nature of the complex conditions and this needs to be recognised and accepted by local authorities to provide funding*

Mike Moorwood, 30, from Woking who has Duchenne muscular dystrophy

It is not possible to get a wheelchair on the NHS that caters for my needs on the NHS – the basic wheelchairs provided are unsuitable and lead to you feeling stiff, uncomfortable and in pain. I had to go privately to get the right chair.

Electric wheelchairs started to be available on the NHS when I was 17 but they did not enable you to change your position. I was given a voucher of £4,000 towards the cost of buying a private chair and had to pay the rest myself, and I can't get repairs on the NHS. My parents and I have to pay for these. Even if you receive a wheelchair through a charity, you still have to pay for repairs yourself.

The NHS always used to say that they wouldn't pay for anything on a private chair although in my area they are now willing to pay for seating. The issue of funding is inconsistent – other areas are different to mine. There should be a policy across the board. If you've forked out for a wheelchair you can't afford to fork out for the seating as well.

I want to get a mini joystick so I can drive my chair without my arm hurting but as it's a private chair the local NHS won't pay for better controls.

I recommend that there should be a policy across the board to fit specialist seating and controls for private chairs.

Wheelchairs are overpriced like all mobility equipment. Prices are high and there isn't much incentive to reduce these. The Office of Fair Trading should investigate price fixing in the mobility equipment market.

Fi Anderson, 25, from Bury who has minicore myopathy

I have had to go private after waiting 18 months on the NHS waiting list only to be provided a chair I couldn't drive or stay sat up properly in. I ended up returning the chair they provided, only to be told I'd have to go through the whole 18-month process again in the hope they got my needs right the second time round. It forced me to fork out my mobility component when I'm already undergoing a full council house reconstruction and have a one-year-old daughter. I am very disappointed with the NHS wheelchair system - they are ok for the standard disabled person but if you have muscular dystrophy with postural issues, they fail you. I'd like to be involved with making the system better anyway I can!

Amritpal Kaur, 35, from Coventry, who has spinal muscular atrophy

In the first instance when I ended up in a wheelchair I had to pass many hurdles to get even a manual wheelchair as I was able to walk to a certain distance aided with crutches but when it came to a point when I couldn't walk it was a big struggle and I have never been supplied with a wheelchair from NHS Wheelchair Services which fully met my needs. I have had huge difficulties in getting the right cushion for my chair.

I was diagnosed with SMA at around the age of 12 and when I got married and came to a point when we decided we wanted to have our own child we and my family had to go through series of genetic tests which resulted in me being diagnosed with FSHD instead of SMA. This was shocking news for me and my family as I have already lived a decade of my life with SMA and was operated on due to the condition at the age of 17 which led me to being unable to walk and in a wheelchair.

The curvature in my spine has got worse recently as I have not had the correct type of chair. When I had a chair from the 'Access to Work' scheme I could elevate the chair and the company allowed me to keep the chair. Unfortunately I had an accident in that chair and it couldn't be repaired. I'm trying to look for grants as I can't afford to buy another chair and the NHS isn't helping me.

Independence is the main issue. If I'm going somewhere I don't always want a carer with me and a more complicated chair would really help me a lot. When I go shopping I can't reach up to get something and I can't reach things at home either. When I had a seat riser on the chair I could do some household chores. Now I'm completely dependent on my parents and husband.

Contact your MP to convey the findings of this report and the calls to action:

<http://findyourmp.parliament.uk/>

Your experiences are vital as we campaign for improvements – contact the Muscular Dystrophy Campaign on:

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campaigns@muscular-dystrophy.org

Additional information

Access to Specialist Neuromuscular Care: The Walton Report, All Party Parliamentary Group for Muscular Dystrophy, August 2009

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Wheel of Health – background information

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