



Building on the Foundations:

State of the Nation The 2010 National Survey

August 2010

**Muscular
Dystrophy**
Campaign 

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Foreword

Our 2010 national survey clearly shows that vulnerable families living with devastating muscle-wasting conditions are not getting the specialist health care and support they desperately need.

Many of these conditions are life limiting, which is why it is so important that action is taken by the NHS without delay. The 70,000 babies, children and adults living with muscle disease and related conditions across the UK deserve a high-quality, specialised neuromuscular service.

The need for action to improve the lives of people living with muscle disease was highlighted in August 2009 with the publication of *The Walton Report*, following an in-depth inquiry conducted by the All Party Parliamentary Group for Muscular Dystrophy in Westminster. It is worrying that, one year on from this report most of the 17 important recommendations are yet to be implemented.

We estimate that across the UK the NHS is spending more than £81 million per year on unplanned emergency admissions for people with muscle disease. Huge sums can be saved by investing a fraction of this amount in specialist care – which clinicians agree keeps people out of hospital. As NHS commissioners consider how to reduce costs, this is an important consideration to take into account.

As proposals set out in the recent NHS White Paper¹ are considered, it is important that the Government does not allow paralysis in service development to take place. The needs of vulnerable patients and their families clearly continue during this period of organisational changes.

The Muscular Dystrophy Campaign calls on NHS commissioners responsible for specialised services to work with our charity, as well as their local 'Muscle Groups', to ensure a national neuromuscular service is established to provide specialist healthcare for all people living with muscular dystrophy or a related condition.

**Robert Meadowcroft,
Acting Chief Executive,
Muscular Dystrophy Campaign**

Progress since the last survey in August 2008

Some significant progress has been made over the past two years. It is vital that we build on this progress to develop a specialised, national neuromuscular service.

- Neuromuscular services are now recognised by the Department of Health as a specialist service on the NHS 'National Definition Set'ⁱⁱ – something we have long called for.
- Many of the Muscular Dystrophy Care Advisors – crucial key workers who provide patients and their families with information and support – are now being funded by the NHS.
- Plans are also underway to recruit new Care Advisors in those parts of the UK previously denied this level of support. Patients in Hull and Sheffield will soon benefit from new Care Advisors and commitments have been made to start recruiting for these vital posts in Oxford, Southampton and Wales.
- The NHS Specialised Commissioning Groups (SCGs) – the ten English bodies responsible for commissioning specialist, neuromuscular services – have been making headway in reviewing local services and planning service developments. At the time of writing, reviews are complete in two regions and underway in seven other regions.ⁱⁱⁱ
- The NHS South West SCG is investing an additional £1million into specialist neuromuscular services, to fund five new Muscular Dystrophy Care Advisors, as well as new neuromuscular consultants. In the West Midlands an additional investment of £400,000 was agreed, which will fund three new Care Advisors and two much needed consultants to serve local patients.
- Significant progress is being made in Scotland, where a review is currently underway led by the Scottish Muscle Network; as well as an Inquiry by the Cross Party Group on Muscular Dystrophy in the Scottish Parliament.

- In Wales, patients will this year benefit from the support of NHS-funded Care Advisors in response to the publication of *The Thomas Report*^{iv} and sustained pressure from local patients and families.

It is essential that the reviews underway in the remaining regions lead to additional investment in these essential services which have been overlooked for far too long.

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

The Muscular Dystrophy Campaign is calling for the establishment of a national neuromuscular service to ensure that patients and their families living with muscular dystrophy or a related condition have access to specialist care and support, wherever they live in the UK.

This can be funded through savings made in the huge costs of unplanned emergency admissions, estimated at £81 million per annum across the UK.^v

To improve patient services NHS commissioners need to:

- Ensure that every person with muscular dystrophy or a related neuromuscular condition is supported by a specialist, multi-disciplinary team of health professionals; accessible within their local region;
- Ensure that every person with muscular dystrophy or a related neuromuscular condition is supported by a Muscular Dystrophy Care Advisor who would take a lead within the care team and provide support, information and a regular review of their care plan;
- Recognise that huge amounts of money are being wasted unnecessarily on unplanned emergency admissions for people with muscular dystrophy and related neuromuscular conditions – money that could be saved by investing in specialist care, which helps to keep people out of hospital;
- Implement the new internationally agreed standards of care for Duchenne muscular dystrophy, as well as those for Spinal Muscular Atrophy;

NHS commissioners also need to:

- Give full commitment to an urgent review of South Central SCG as promised by NHS Directors in the House of Commons earlier this year;^{vi}
- Undertake an urgent review of neuromuscular services in London and Northern Ireland – the only areas in the UK where they have so far refused to do so;

- Ensure that the current reviews being undertaken by NHS SCGs in England result in investment in specialist neuromuscular services;
- Support commissioners from the South West and West Midlands regions to fully implement the proposals from their reviews into specialist services for people affected by neuromuscular conditions;
- Encourage all SCGs to follow the lead of the South West and Scotland, who have developed a Managed Clinical Network as their preferred model of care;
- Ensure local health and social care commissioners follow the lead of the South East Coast SCG and agree to carry out a feasibility study to establish a network of 'NeuroMuscular Enterprise Centres' across the UK. They will replicate the successful model of the NeuroMuscular Centre in Cheshire, which provides ongoing, specialist physiotherapy for people with neuromuscular conditions; and reduces costs to the NHS by keeping people out of hospital through the provision of specialist care.

The Government must:

- Ensure that future NHS reform does not delay the current, vital work being undertaken by the majority of the SCGs;
- Ensure that adequate resource is allocated to fulfill the commitment that all services on the Department of Health's National Definition Set are to be commissioned via the proposed National Commissioning Board;
- Encourage NICE and SIGN to develop guidelines or a quality standard for the management of neuromuscular conditions and tackle current inequities in access to diagnosis, treatment and ongoing care.

Key findings

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

- Patients and their families can wait several decades for a correct diagnosis.
- Many people have had children who are also affected; when diagnosis or delays in diagnosis prevented the timely provision of genetic counselling.
- Devastating diagnosis can be delivered in a cold and unsympathetic manner.
- Almost 50 percent of patients do not receive a correct and prompt diagnosis.
- Over half of people with muscle disease feel their GPs do not have a good understanding of muscular dystrophy.
- One in four patients does not see a specialist neuromuscular consultant.
- Over 95 percent of people with muscle disease are denied access to NHS hydrotherapy – cited as the only effective treatment by many patients.
- Four out of five patients do not receive ongoing NHS physiotherapy to prevent contractures and help reduce falls; it also helps to improve posture and breathing.
- Four out of five patients and their families still do not have access to a Muscular Dystrophy Care Advisor.
- Children with devastating muscle-wasting conditions can wait up to four years for their essential wheelchair.

“I had another child because I was told I was not affected.”

1. Information, support and diagnosis:

What the survey reveals:

- A number of people have been misdiagnosed and told that it is safe to have children – only to pass on the neuromuscular condition to their children.
- One in five patients are not offered a follow up appointment after diagnosis.
- Almost 50 percent of patients do not receive a correct and prompt diagnosis.
- Of those who did not receive a correct and prompt diagnosis; almost 30 percent were forced to wait over five years.
- People can wait decades for a correct diagnosis; with one patient having waited 68 years, which reflects the rarity of some conditions.

What people have said:

Deborah Hurst from Liverpool is affected by facioscapulohumeral (FSH) muscular dystrophy, but was not diagnosed until she was in her late 30s (she is now 47). Her two daughters were born before her correct diagnosis was made, and one of her daughters has inherited the condition (now aged 25). She says:

“I have two daughters and I knew one was affected but the doctor told me I was fussing and silly. When I finally got them tested he congratulated me on my actions which I was very mad about as my daughter took her diagnosis very badly at the time and ‘congratulations’ wasn’t what we wanted to hear.”

Ms L from Whitehaven is affected by Bethlem myopathy but was not correctly diagnosed until the age of 37 – when she gave birth to her daughter **who is also affected by the condition**. She says:

“For years they thought I had arthritis. I am a very bad walker, I’m slow and weak, I can’t lift well I struggle with physical things. But they didn’t diagnose me with Bethlem myopathy until my daughter was born, they realised something wasn’t right in the hospital, and sent us to Professor Bushby at Newcastle.”

Mr A from the West Midlands was misdiagnosed with consequences for his family:

“Thirty years ago I was diagnosed with a glycogen storage disorder (phosphofructokinase deficiency) and due to a shoulder problem was re-examined in 2004/5.

“I was then rediagnosed with FSH muscular dystrophy, which was a shock, since the other condition would not have affected my two girls. They have now had tests and sadly they both have FSH.”

Jane and Mark Field from Droitwich have a 12-year-old son Murray with Duchenne muscular dystrophy. Jane and Mark fought for over two years to get the correct diagnosis for Murray after he was misdiagnosed by their GP and two community paediatricians with ADHD and dyspraxia and prescribed with Ritalin. This had catastrophic implications for Murray: due to the misdiagnosis and subsequent delay in referral to a specialised centre he missed the ‘window of opportunity’ to benefit from steroid therapy and became wheelchair dependent from the age of nine years.

“Every day for eight years I kept wondering what was wrong and I didn’t like having to wait so long between seeing people who could possibly help me.”

Ms Harvey from Essex has two sons affected by Duchenne muscular dystrophy. As there is a history of the condition in her family both sons were tested at birth for the condition. However, in both instances the diagnosis of this severe and life-limiting condition was delivered by letter. Ms Harvey says:

“This was a shock as I felt I should have been told in person.”

John Burke from Wales, whose three-year-old son has Duchenne muscular dystrophy, said:

“Wales is a world leader in new born screening for Duchenne muscular dystrophy. However the level of post diagnosis care leaves me dumbfounded at its level of cruelty.”

Mrs P from Colchester first visited her GP with symptoms in 2002. She was then referred to an orthopaedic surgeon in 2003, and saw a number of different consultants who were unable to diagnose her. In 2005 Mrs P visited Dr De Silva at Romford who suspected some form of distal myopathy and sent her for further tests in the summer of 2008. It wasn’t until December 2008 that Mrs P was finally diagnosed with myofibrillar myopathy. She says:

“Every day for eight years I kept wondering what was wrong and I didn’t like having to wait so long between seeing people who could possibly help me.”

One mum in Wales, whose son is now seven years old, said:

“I had another child because I was told I was not affected.”

Recommendations

- All people going through the diagnosis process should be treated sensitively, with access to genetic counselling where appropriate.
- People should be able to receive a prompt diagnosis; where possible, with access to the appropriate muscle biopsies and further checks.
- Additional follow-up care and support must be offered to those patients affected by Duchenne muscular dystrophy in Wales – the only part of the UK offering new-born screening for this particular condition.

"I always have to explain my dystrophy every time I visit the doctor."

2. GPs and health professionals

What the survey reveals:

- Over half of people with muscle disease feel GPs do not have a good understanding of muscular dystrophy.
- 70 percent of patients do not believe that health professionals have a good understanding of muscular dystrophy.

What people have said:

Mrs H from Lancashire has a son affected by a neuromuscular condition. She says that in her experience GPs do not understand the condition:

"My GP is very good but says 'we have about two hours of tutorial on muscular dystrophy in the whole medical training'. So therefore they have no in-depth knowledge."

Olive Armstrong from County Durham is affected by FSH muscular dystrophy. She says that GPs do not understand her neuromuscular condition as a result she says:

"I try to keep away from my GP as much as I can!"

Ms P from Newcastle is affected by myotonic dystrophy. She says that her GP does not understand her condition:

"I always have to explain my dystrophy every time I visit the doctor."

Mrs C from Birmingham is affected by FSH muscular dystrophy and has found a lack of understanding about her condition from her GP:

"It has taken many years for him to have begun to show some empathy. As my condition has progressed he has become more aware of difficulties. However, last year an unexplained symptom was passed off as being perhaps 'breakdown of the muscle'; it was a deep vein thrombosis!"

One Welsh patient said:

"My GP told me he had never looked after anyone with Duchenne muscular dystrophy nor did he know anything about the condition. This did not fill me with anything other than dread."

Recommendations

NHS commissioners must:

- Ensure planning for specialist services for these rare and very rare conditions is not the responsibility of GPs; and remains within the proposed National Commissioning Board;
- Ensure that the proposed GP consortia have appropriate knowledge of neuromuscular conditions by increasing training to GPs so that they can recognise the symptoms in their surgeries and make appropriate referrals to specialists;
- Strengthen links between quaternary, tertiary, secondary and primary care; underlining the importance of a Managed Clinical Network.

"I am in dire need of local respiratory support but there is nothing available in the area"

3. Specialist care and support

Clinicians agree that the best management of a neuromuscular condition requires a multi-disciplinary approach, with the input of specialists in many different areas, and that there must be a health professional that coordinates these efforts.

What the survey reveals:

- One in four patients do not see a specialist neuromuscular consultant.
- Of those that do; ten percent only see their consultant every two years or even less frequently.
- Families with children affected by the condition are forced to travel long distances in order to access essential specialist care.

What people have said:

Hannah-Lou Blackall from Kings Lynn is 24 and affected by congenital myopathy. She is a powered wheelchair user who as a result of her condition requires 24-hour care. However Hannah-Lou does not receive any specialist care:

"No one is interested in who to refer to me, so since eighteen I have had no consultant."

Tracey Anne Pilato from Stoke-on-Trent is affected by FSH muscular dystrophy and receives specialist neuromuscular care. She says:

"Dr Quinlivan [specialist neuromuscular consultant] sorted out my respiratory and cardiac care. It was like a weight being lifted, having a consultant who knew about muscular dystrophy and was able to point me in the right direction regarding other specialist consultants."

Mrs R from Suffolk has a two-year-old son affected by Duchenne muscular dystrophy. The family go to Great Ormond Street to see a specialist consultant and are happy with the care they receive but Mrs R says:

"My only wish is that we didn't have to travel two hours to London to see a specialist consultant."

Mr McNulty from Luton is affected by FSH muscular dystrophy but does not receive any specialist care after being discharged back to the care of his GP. His local hospital has told him that it can do nothing else for him. Mr McNulty is worried about his respiratory care and would like a consultant to monitor this.

Jon Hastie from Worthing is 29 years old and is affected by Duchenne muscular dystrophy. He says:

"I am in dire need of local respiratory support but there is nothing available in the area. I was referred to the specialist MS respiratory nurse but she has been unable to help me secure access to proper home suction which I need doing for chest infections."

One Dad from Wales said:

"We need more neuromuscular qualified specialists in Wales. The situation is desperate."

“NHS should be trying to keep people well not just looking after them when they are ill.”

Clinicians believe that implementing the Duchenne Standards of Care will improve patients with all neuromuscular conditions. One of the country's leading neuromuscular specialists, Dr Ros Quinlivan, said:

“Clinicians agree that if you can get it right for Duchenne, then you can get it right for all of the neuromuscular conditions.”

“This is why it is so important that the Duchenne Standards of Care are implemented across the UK. The benefits would be felt by all patients with a neuromuscular condition – not just those with Duchenne.”

Recommendations

- Recognise that specialist care not only extends lives, improves health and quality of life, but also saves the NHS money by keeping people out of hospital and reducing unplanned emergency admissions.
- Ensure that every person with muscular dystrophy or a related neuromuscular condition is supported by a specialist, multi-disciplinary team of health professionals; accessible within their local region.
- Specialist teams need to work within a Managed Clinical Network; as developed in the South West and Scotland.
- Respiratory and cardiac health professionals with an interest in neuromuscular conditions should be recognised as specialist, and a central part of the multi-disciplinary team.
- The Department of Health must consider the need for professional development, particularly around expanding the number of Muscular Dystrophy Care Advisors and specialist neuromuscular nurses.
- NHS commissioners must implement those proposals published in the *Lancet* – the internationally agreed Duchenne Standards of Care – as well as the SMA standards of care, as a benchmark for best practice.

4. Physiotherapy and hydrotherapy

What the survey reveals:

- Four out of five patients do not receive ongoing NHS physiotherapy.
- Over 95 percent of people with muscle disease are denied access to NHS hydrotherapy – often the only effective treatment for patients.
- Many patients are forced to fundraise themselves for this essential service.
- Often physiotherapy and hydrotherapy is withdrawn from the ages of 16-18 when young people leave school and paediatric care for adult services.

What people have said:

Mr A from Cheshire has Charcot Marie Tooth disease and travels to the NeuroMuscular Centre in Winsford (only 15 miles from his home) for specialist physiotherapy and hydrotherapy. However his local PCT is unwilling to pay for this, despite not offering him any alternative physiotherapy or hydrotherapy provision.

Mark Perry from Stoke-on-Trent is affected by Becker muscular dystrophy. He says:

“I only seem to see specialists when I have a major problem. I can no longer walk and feel I would still be able to if I was given the right care (physio) as a preventative measure.”

Donald Sanders has to make a 260-mile round trip to the NeuroMuscular Centre in Winsford Cheshire for physiotherapy

Sheila Hawkins from Leicester is affected by FSH muscular dystrophy. She says:

“My local hospital does not provide ongoing physiotherapy so I have been discharged and re-referred countless times. I really cannot understand why the NHS cannot provide ongoing physio for a long-term condition: if I had a condition that required long-term medication, such as diabetes, I wouldn't be taken off it after six months. As I fall quite regularly and sometimes sustain injuries from falling I would really value easy access to someone who could assess and advise me.”

Rosemarie Lawy from Haringey PCT is affected by FSH muscular dystrophy and pays for her own physiotherapy, hydrotherapy and osteopath. She says:

“This has been crucial to keep me walking and also preventing chest infections. The NHS should be trying to keep people well not just looking after them when they are ill. Hydrotherapy and physio should be provided regularly for all patients and it would be cost effective in the long run.”

Donald Sanders from County Durham was diagnosed in 2008 with FSH muscular dystrophy at the age of 69, having waited ten years for a correct diagnosis. He was not able to receive specialist physiotherapy close to home, and so had to make a 260-mile round trip to the NeuroMuscular Centre in Winsford Cheshire for this physiotherapy.

Recommendations

NHS commissioners must:

- Ensure patients have access to ongoing physiotherapy and hydrotherapy, rather than in the current 'blocks' of treatment over six weeks; as these conditions are long term and progressive;
- Provide training for community physiotherapist from specialist, neuromuscular physiotherapists;
- Undertake feasibility studies across England, as well as the devolved countries, with the aim to develop a national network of NeuroMuscular Centres;
- Recognise data from the NeuroMuscular Centre in Cheshire, which shows that physiotherapy can keep people more independent and out hospital by reducing the likelihood of falls.

“Shirley, our Care Advisor, is fantastic – we only have to ask and she is there.”

5. Key workers:

What the survey reveals:

- Four out of five patients and their families do not have access to a Muscular Dystrophy Care Advisor.

A lead professional has a crucial role to play in ensuring adults and children receive a personalised package of care, as well as ensuring regular assessments. A Muscular Dystrophy Care Advisor is often the first point of contact for families with muscle disease after they have received a diagnosis and they can take the lead within the care team to coordinate health and social care needs.

The NHS now recognises their importance; with a growing number of Care Advisors now in post, but there is still a long way to go to ensure all patients can access their vital support.

What people have said:

Joanne Ashton has a five-year-old son Liam with Duchenne muscular dystrophy. Through the specialist neuromuscular service at Alder Hey Hospital, Joanne and her family have access to a specialist consultant, Dr Stefan Spinty and a full multidisciplinary service, including a Neuromuscular Care Advisor. Joanne says:

“Shirley, our Care Advisor, is fantastic - we only have to ask and she is there. Liam had his wish granted through the ‘Make a Wish Foundation’ because he was nominated by Shirley. So we are all impressed with the care advisors.”

Mr Bull from Aylesbury has Becker muscular dystrophy and says:

“The psychological support was a disaster when our family support officer post was lost. The work she did gave families lots of help.”

Elaine Sands from Stockport is affected by FSH muscular dystrophy. She does not receive any specialist care, but would value the support of a neuromuscular care advisor. She says:

“As I’m housebound, it would be nice to have someone give me physiotherapy, and also some kind of visitor who knows about my condition, as I live alone and I would appreciate being able to talk to someone who understands the disease.”

Recommendations

NHS Trusts and commissioners must:

- Employ a minimum of 70 care advisors across the UK to ensure all people living with muscle disease have access to the vital support and advice they provide;
- Recognise the cost benefit savings that the care advisors bring to the NHS; by saving clinician time and helping to reduce unplanned emergency admissions.

“There is no psychological support – I think that it would have helped me make more of my life.”

6. Psychological support

The impact of muscular dystrophy or a related condition can affect all aspects of daily life and the physical limitations may result in social isolation and reduced social activities. This may lead in turn to a higher risk of problems such as depression.

Being given the diagnosis can be a profound shock for many people who may experience a range of emotions. As the conditions progress, milestones as the condition progresses such as having to use a wheelchair or needing respiratory support can also give rise to feelings of loss and grief.

What the survey reveals:

- Over 70 percent of patients believe that they do not receive enough psychological support; which could lead to problems such as depression.

What people have said:

Mr P from Birmingham is affected by limb girdle muscular dystrophy and says:

“There is no psychological support – there have been many times when this would have been very welcome, and I think that it would have helped me make more of my life.”

One Dad from Wales said:

“There is no psychological support for families who are affected by Duchenne muscular dystrophy. There is little in the way of therapy support services in Wales.”

Recommendations

NHS commissioners must:

- Ensure that psychological support is offered to patients and their families, with a psychologist recognised as an important member of the specialist, multi-disciplinary team;
- Recognise that the emphasis in psychological support should be on prevention of problems and early intervention, as set out in the Duchenne Standards of Care document, but applicable to other neuromuscular conditions.

“I’ve not seen a consultant after transition at aged 18
– I am in need of medical support.”

7. Therapy services

What the survey reveals:

Over 55 percent of patients and their families are not receiving sufficient or ongoing support from therapy services, for example, Occupational Therapy and Speech and Language Therapy.

What people have said:

One patient from Yorkshire said:

“When I’ve asked about other services, I’ve been told that there’s ‘no point’, because there’s ‘no treatment’ available.”

Jeremy Barber from Bracknell is affected by Charcot Marie Tooth disease. He has experienced difficulties obtaining orthotics:

“Due to my postcode I cannot get silicone ankle foot orthotics on the NHS so I have had to purchase privately.”

Mrs Y from Saltash is married to a gentleman affected by myotonic dystrophy. She says:

“The speech therapy lady gave him some exercises and we never saw her again.”

Recommendations

NHS managers and commissioners must:

- Ensure that Occupational Therapists (OTs) join the Muscular Dystrophy Campaign’s OT Network, in order to continue professional development;
- Strengthen links between the multi-disciplinary team and speech and language therapy services.
- Strengthen links between physio and occupational therapists through professional networks.

8. Transition

What the survey reveals:

- Two thirds of patients were not happy with the transition from childhood to adult services.
- Many services, such as physiotherapy, are withdrawn during the transition period.
- Just when young people are thinking about getting jobs, going to university or living independently, they report that their care and support may be suddenly withdrawn or greatly reduced.

What people have said:

Lauren West is 18 and studying at university in Manchester. She is affected by spinal muscular atrophy, and says:

“I have found the transition quite hard as there is hardly any help or advice available. When I was under child services, I found all the specialists very helpful, but now I’m under adult services the help just seems to stop. Once I had my last appointment under children services, I was left to find a new hospital myself and my GP was also very unhelpful on helping finding me a new consultant.”

One 19-year-old patient from Yorkshire with Emery Dreifuss syndrome said:

“I’ve not seen a consultant after transition at aged eighteen – I am in need of medical support.”

“Wheelchair Services try to find you a chair that matches their budget rather than your need.”

Jennifer Gallacher from Middlesbrough is 27 and affected by spinal muscular atrophy. She received continuous physiotherapy while at school, but this stopped completely when she moved into adult services.

Tracy Franklin, a mum from Yorkshire, whose son Jack has Duchenne muscular dystrophy, said:

“Transition is a major worry of mine and I would like all the issues resolving before Jack turns sixteen. I am not willing to go through all the heartache and fighting for what Jack needs again.”

Recommendations

NHS Trusts, commissioners and social care managers must:

- Work closely in partnership to put a care co-ordination process in place for every young person moving from child to adult services;
- Ensure that each care coordination team offers the young person a lead professional from within the team to actively support the coordination of services;
- Ensure that essential services such as physiotherapy and hydrotherapy are not withdrawn after the transition to adult services;
- Ensure that health and social services provide transition support to all young people as set out in the National Service Framework for Children and Young People (2004).^{vii}

9. Specialist wheelchairs

What the survey reveals:

- One in ten patients have waited over a year and a half for their wheelchair, with one child forced to endure a four-year wait.
- Many families are forced to pay thousands of pounds for these essential pieces of equipment.
- Charitable funds are also used when NHS services fail to deliver wheelchairs and equipment.

What people have said:

One patient from Wales said:

“I have been waiting four years – and still not the right one to suit my condition. One was left on my doorstep a year ago and no one has asked me yet if it is suitable.”

One Scottish patient said:

“Wheelchair Services try to find you a chair that matches their budget rather than your need.”

Mr C from Merseyside is 35 and affected by Duchenne muscular dystrophy. He has had to fund his new wheelchair through charitable contributions and says:

“I am angry that my local wheelchair service does not provide vouchers when they do not have a suitable chair for me.”

“We’ve just had a four-year battle. I think Wheelchair Services are a disgrace.”

Deborah Hurst from Liverpool is affected by FSH muscular dystrophy and has been waiting for two-and-a-half years for a new wheelchair as her current chair is causing her considerable medical problems:

“I am still fighting for a wheelchair after two-and-a-half years. They don’t listen and the chair I have now is far too small causing all kinds of medical problems. I am in great pain constantly. I have a blood clot in my arm which I am being treated for at the moment, pins and needles in my lap and total numbness under my right leg where the chair is too small. They are aware of this and five months ago phoned me to say they will assess me again, I am still waiting.”

Danielle Hafeez from Gerrards Cross has a 14-year-old son Benjamin who is affected by Duchenne muscular dystrophy. Benjamin has been waiting four years for a new wheelchair. Mrs Hafeez says:

“We’ve just had a four-year battle. I think Wheelchair Services are a disgrace. My son has been in pain and discomfort. I have been so stressed it has bought me health issues too.”

Health Minister Paul Burstow MP was forced to accept widespread failings and inefficiencies in the commissioning and delivery of Wheelchair Services when replying to a House of Commons debate in June 2010.

Mr Burstow admitted to his shock on learning that over half of the Wheelchair Services’ budget goes on back office costs rather than paying for essential equipment:

“My jaw nearly hit the floor when I read that fifty-seven percent of wheelchair budgets currently go on back-office costs. Fifty-seven pence in every pound that the taxpayer puts into these services fails to reach the frontline at the moment. That is not acceptable; it is not a good way to use our taxpayer-funded resources for the Health Service.”

Recommendations

NHS Wheelchair Services, managers and commissioners must:

- Put in place targets for waiting times; set at a maximum of 18 weeks from initial referral to delivery of chair;
- Ensure that, in England, there is full implementation of Definition Number 5 of the NHS Specialised Services National Definition Set, which outlines standards for the assessment and provision of equipment for people with complex physical disabilities;
- Ensure Primary Care Trusts and health boards in the devolved countries pay for the cost of maintaining all wheelchairs, including those that have been modified or privately funded, and for maintenance to be carried out quickly and effectively.

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**.

References

- i. DH Equity and Excellence: *Liberating the NHS Health White Paper* (July 2010)
- ii. NSCG: *Specialised Services National Definitions Set* (3rd edition) 2010. Available: www.ncg.nhs.uk/index.php/key-documents/specialised-services-national-definitions-set/
- iii. Reviews of specialised neuromuscular services are currently underway in the following regions: North West, North East, East Midlands, East of England, Yorkshire and Humber and South East Coast regions, with a review also promised in the South Central region.
- iv. Cross Party Group on Muscular Dystrophy *The Thomas Report: Access to Specialist Neuromuscular Care in Wales* (July 2010)
- v. Clinical audit data from the specialist neuromuscular service at Oswestry and Birmingham suggests that a significant proportion of the estimated £81 million spent on unplanned emergency admissions for neuromuscular patients could be avoided through the provision of multi-disciplinary specialist care.
- vi. Evidence given to the All Party Parliamentary Group for Muscular Dystrophy: 9 March 2010
- vii. DFES/DH *National Service Framework for Children, Young People and Maternity Services* (2004)

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

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