



Building on the Foundations:

# **Invest to Save**

Improving services  
and reducing costs

May 2011



*"It is clearly unacceptable that there are still such large variations in care and that access to specialist diagnosis, treatment and ongoing care services can far too often still depend on where people happen to live."*

*"It is important that we are clear about what people have a right to expect – access to health professionals with an understanding of their medical condition and individual needs; timely access to the appropriate specialist neurological services and equipment; information on their condition, communicated in a more sensitive and understanding way; and close involvement for carers and families."*

**Ivan Lewis MP, former Health Minister,  
Muscular Dystrophy Adjourment Debate,  
14 May 2008**

*"What is the Government's assessment of specialist neuromuscular services?' For large parts of the country, I am afraid that the answer is clearly 'not good enough', and perhaps 'poor' in some parts. We know that there are historic weaknesses [in the provision of neuromuscular services], which noble Lords have drawn attention to during today's debate. The urgency for change is all the greater because these failures have a massive impact on the lives of people with these conditions."*

**Earl Howe, Parliamentary Under Secretary of State (Department of Health), Health: Neuromuscular Services Question for Short Debate, 31 March 2011**

**As these quotations show, neuromuscular services remain patchy and inadequate despite changing governments.**

### **This report has been endorsed by the following neuromuscular clinicians:**

**Professor Martin Bobrow**, Emeritus Professor of Medical Genetics, University of Cambridge

**Dr Charlotte Brierley**, Consultant Neurologist, Addenbrooke's Hospital and West Suffolk Hospital (Bury St Edmunds)

**Professor Katie Bushby**, Action Research Professor in Neuromuscular Genetics, University of Newcastle upon Tyne

**Dr Anne-Marie Childs**, Consultant Paediatric Neurologist, The General Infirmary at Leeds

**Dr Gabriel Chow**, Consultant Paediatric Neurologist, Nottingham

**Dr Michael Davies**, Consultant Chest Physician, Papworth Hospital NHS Foundation Trust

**Professor Lionel Ginsberg**, Professor of Clinical Neurology, University College London Consultant Neurologist and Clinical Director of Neurosciences, Royal Free Hospital

**Dr Nicholas Hart**, NIHR Clinical Research Consultant, The Lane Fox Respiratory Unit

**Dr David Hilton-Jones**, Clinical Director; Muscular Dystrophy Campaign Muscle & Nerve Centre and Clinical Director; Myasthenia Gravis Association Myasthenia Centre, Oxford

**Dr Anirban Majumdar**, Consultant Paediatric Neurologist, Frenchay Hospital, Bristol

**Professor Francesco Muntoni**, Professor of Paediatric Neurology, Head of the Dubowitz Neuromuscular Centre

**Dr David Nicholl**, Consultant Neurologist/ Honorary Senior Clinical Lecturer in Neurology, Birmingham City Hospital

**Dr Ros Quinlivan**, Consultant in Neuromuscular Disorders, Great Ormond Street Hospital and The National Hospital for Neurology and Neurosurgery

**Jennie E Sheehan**, Clinical Specialist Paediatric Physiotherapist (Neuromuscular Disorders), Evelina Children's Hospital

**Dr Stefan Spinty**, Consultant Paediatric Neurologist and Neuromuscular Lead Clinician, Alder Hey Hospital

**Professor Volker Straub**, The Harold Macmillan Chair of Medicine, University of Newcastle upon Tyne

**Dr John Winer**, Consultant Neurologist/Honorary Senior Lecturer Department of Clinical Neurosciences, University Hospital Birmingham

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## Forewords



**Lord Walton of Detchant,  
Kt TD MA MD DSc FRCP  
Fmed Sci**

I am delighted to welcome this report, which puts forward a compelling case for investing in preventative services for people with neuromuscular conditions. Services for patients with neuromuscular conditions are patchy across the country and many people are simply not getting the services they need. Not only does this lead to poorer patient outcomes but, in many cases, these deficiencies actually increase costs.

As this report shows, relatively small investments in treatments such as non-invasive ventilation can help to prevent unplanned emergency admissions to hospital. Such admissions are extremely costly and, by investing earlier, the savings can be substantial.

I have a long standing personal interest in this field since I began research into neuromuscular disease, and in particular into the muscular dystrophies, in the early 1950s, and established a major research centre in Newcastle upon Tyne. Subsequently, for many years I directed the neuromuscular service centre and its research arm in Newcastle before I moved to Oxford in 1989 as Warden of Green College. I am delighted that in both of those cities outstanding work on neuromuscular disease – not only in research but also in patient care - has continued to burgeon over the years.

This report sets out a very powerful case for investing a little to save a lot. I urge policy makers, parliamentarians and professionals to take note of its findings and to do all they can to improve patient care for people – both children and adults - living with neuromuscular conditions. Given the changes that the NHS is currently undergoing, and the difficult current financial situation, decision-makers cannot afford to ignore this report and its recommendations.



**Dr Ros Quinlivan FRCPCH  
FRCP MD, Consultant in  
Neuromuscular Disorders,  
Great Ormond Street  
Hospital and the National  
Hospital for Neurology  
and Neurosurgery**

I welcome the progress that has been made in improving neuromuscular services over the past few years. All of the regions across England have recognised that there is a need to review the services that are available to patients with neuromuscular conditions and this has resulted in welcome investment in the South West and West Midlands.

I am particularly pleased to note the £60,000 that has been allocated to fund an audit of unplanned emergency admissions for patients with neuromuscular conditions in London and the South East. From my experience working as the Lead Clinician at a specialist neuromuscular centre at The Robert Jones and Agnes Hunt Hospital I believe that access to the right specialist care at the right time can help to prevent such emergency admissions.

This report begins to bring together the existing evidence demonstrating how investment in specialist services can both save money and lead to improved patient outcomes. I urge decision-makers to take both this evidence, and the data from the audit of unplanned admissions due out later in the year, into account when planning their services for patients with neuromuscular conditions.

# Executive Summary

## Overview

This report by the Muscular Dystrophy Campaign brings together the views of clinicians, researchers and patients and their families, to set out the case for investing in specialist services for people with neuromuscular conditions. We show that investing a little now could save a significant amount in the long term, while making much needed improvements to patient care.

Many patients do not receive the specialist, preventative services that they need. Services like specialist physiotherapy and non-invasive ventilation can not only improve patient outcomes but can also be vital in preventing unplanned, and extremely costly, emergency admissions to hospital.

This report contains responses from a patient survey, evidence from patients who have received specialist care, information from clinicians and evidence from the latest research papers on the savings potential of preventative services.

We argue that health services cannot afford not to invest; the cost of doing nothing is far greater.

## Key Findings

- Specialist, multi-disciplinary services have been established by clinicians as the most effective way of delivering effective care for patients with complex neuromuscular conditions.
- Investment in such specialist services could result in savings of approximately £25 million in England alone<sup>1</sup>.
- Getting the right wheelchair at the right time can also prevent costs to the NHS in the longer term; without timely provision of an appropriate wheelchair, patients can develop pressure sores or skeletal deformity and require costly inpatient provision later on.
- Specialist physiotherapy also plays a vital role in identifying where problems may develop in the future and taking action to prevent deterioration, again helping to avoid costly inpatient episodes.
- Neuromuscular care advisors have an important role in co-ordinating the specialist care patients with neuromuscular conditions need, for example through saving consultants' and GPs' time and signposting patients to local services.
- Access to specialist respiratory services and support are essential for preventing unplanned emergency admissions to hospital.

## Our recommendations

- We recommend the findings of the forthcoming audit of unplanned emergency admissions due to be carried out by the London Specialised Commissioning Group are fully taken on board by NHS commissioners, in particular the National Commissioning Board, when they are published in late 2011.
- It is vital that the Specialised Commissioning Group reviews completed or underway in each region of England now translate into investment in specialist neuromuscular services.
- As part of this investment, it is essential that more neuromuscular care advisor posts are funded so that all patients and families have access to this vital support.
- With the establishment of the National Commissioning Board, which will take on responsibility for commissioning specialised services from 2013, we also recommend that regional structures are put in place to ensure specialised commissioning can continue on a regional level.
- It is essential that specialised services for patients with neuromuscular conditions, for example specialist physiotherapy and wheelchair services, are available to all patients regardless of where they live.
- It is also important that equipment is provided to patients where evidence shows this may help them avoid a hospital admission.
- Finally, we would welcome the production of NICE-accredited evidence into the standards of care for neuromuscular patients.

## 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 and without multi-disciplinary care, most patients experience a reduction in quality of life and, for some conditions, shortened life expectancy.

## Why invest?

There is increasing evidence to suggest that investing in a broad range of health and social care services before a person with muscle disease reaches crisis point can save money in the longer term. Research has indicated the value, both financially and in terms of improved patient outcomes.

Specialist multi-disciplinary care has been developed by leading clinicians as the best model for delivering effective care for neuromuscular conditions, given that they are complex, multi-system diseases. Specialised services also need specialised personnel: the provision of expert physiotherapy, orthotics, early cardiac monitoring and intervention and corticosteroids has been shown to improve muscle function and maintain independent mobility. It is also vital to put succession plans in place to ensure the continuity of specialised services as staff such as doctors and physiotherapists move on.

**Dr Ros Quinlivan, a leading consultant in neuromuscular disorders, has outlined the effects of neuromuscular conditions and how they need to be managed:**

*“Neuromuscular conditions are rare and include: muscular dystrophies, metabolic myopathies, congenital myopathies, inflammatory myopathies, spinal muscular atrophies and peripheral neuropathies. Many of these conditions affect only skeletal muscle and thus cannot be considered to be neurological disorders, in fact skeletal muscle can be considered to be the largest organ in the body. Most neuromuscular disorders are genetic in origin and affect families, but the inflammatory myopathies are acquired and require specific treatment. Affected patients range from new-born infants to elderly people. The effect of many of these conditions is on the skeleton causing skeletal deformities due to muscle contractures and on the heart and lungs causing respiratory or cardiac failure which can significantly limit life-expectancy.*

*“The physical management of these disorders is quite distinct compared with conditions affecting either the nervous system or the*

*musculo-skeletal system (bone and joints). Proximal and axial muscle weakness causes specific functional difficulties not seen in patients attending clinics in other specialist areas. The progressive nature of these conditions means that an anticipatory multi-disciplinary approach to care with experienced clinicians specialising in neuromuscular disorders is essential for best outcomes.”*

**In a recent Parliamentary debate on neuromuscular services in the North West of England, the Minister for Care Services, Paul Burstow MP, said:**

*“There is a real sense of urgency for change, not least because of the simple fact that we know about the huge personal and family costs of this condition and how it impacts upon people’s lives. Unless care is properly co-ordinated and well-conducted, NHS resources will be wasted. They will be invested in the wrong places and will not deliver good outcomes. That cannot be acceptable in our modern health care system. Several colleagues alluded to the costs. The figure of £13.6 million was mentioned as the overall cost of unplanned hospital admissions for those with neuromuscular conditions in the North West.*

*“...the number of people admitted for non-invasive, elective care, shows that there are many preventable costs in the system. That amounts to just under £5 million in the North West alone. Those costs could be avoided and the money could be spent better. That has to be a key message. It is not just about spending more; it is also about spending better in our system. We need to ensure that we consider the economic case for investing wisely in services that can, in fact, provide a better quality of life. We must also ensure that we avoid unnecessary admissions in the first place.”<sup>2</sup>*

Based on the figures outlined by the Minister, **investment in preventative services could therefore result in savings of approximately £25 million in England** and approximately £31 million across the whole of the UK, with relatively small investment. Based on the investment of £400,000 made into services in the West Midlands, we estimate that an investment of only £4.6 million across the UK could go a long way to preventing unplanned hospital admissions.

Hospital admissions are extremely costly and often avoidable; for example, admission to a specialist ward can cost the **NHS up to £1,925 per day**. Research has found that the provision of interventions at home can help prevent hospital admissions for patients with neuromuscular conditions. Between October 2006 and September 2008, 39 patients were part of a study and received respiratory support (for example, mechanically assisted coughing) on call at home. Over 30 hospital admissions were prevented, as illustrated in Table 1 below.<sup>3</sup>

It is not only through investing in healthcare that savings can be made. Recent studies have demonstrated that investment in social care services can also lead to savings for both the NHS and local authorities. Research found that re-ablement services appeared to be good value for money and produced better outcomes for patients, particularly those with non-progressive conditions. The researchers concluded that *“home care re-ablement is almost certainly cost-effective because of improved outcomes for users.”*

Re-ablement services focus on helping individuals to develop confidence and learn, or re-learn, self-care skills so they are able to increase their independence and rely less on longer-term support services. Provision of re-ablement was found to be cost effective for increases in health-related quality of life outcomes: at a ‘willingness to fund’ threshold of £30,000 for each increase, the researchers found a 99 percent probability of cost-effectiveness against both health and social care costs. If a threshold of £20,000 was used, the cost-effectiveness was 98 percent.<sup>4</sup>

There is also evidence that NHS costs through unplanned admissions, for example, can also be reduced through spending on social care. Without this kind of preventative service, costs to the NHS will increase due to emergency admissions, delayed discharges and longer waits for treatment<sup>5</sup>. The King’s Fund argue that *“growing numbers of people with long-term health conditions often have a mixture of needs that require an integrated response so that they can live as independently as possible without recourse to inappropriate admissions to hospital or long-term care”*<sup>6</sup>.

**As this report demonstrates, investing in services for people with neuromuscular conditions not only delivers the services these patients are entitled to but also saves the NHS money. Investing in early intervention helps reduce unplanned emergency hospital admissions, improve outcomes for patients and reduce costs for those commissioning services.**

**Table 1 - Outcomes of home care visits<sup>3</sup>**

	Total Patients Having Home Visits (n = 27)	Patients With Home Visits Only (n = 15)	Patients With Home Visits Plus MI-E <sup>a</sup>	TIV Users Having Home Visits and Provision of MI-E (n=9)	NIV Users Having Home Visits and MIE (n=3)
Total respiratory exacerbations, <i>n</i>	67	20	47	40	7
Home visits without MI-E delivery, <i>n</i>	13	4	9	9	0
Home visits plus provision of MI-E, <i>n</i>	21	0	21	18	3
Patients hospitalized, <i>n</i>	18	8	10	7	3
Total hospitalizations, <i>n</i>	33	16	17	13	4
Avoided hospitalizations, <i>n</i>	34/67 (51%)	4/20 (22%)	30/47 (64%)	27/40 (67%)	3/7 (42%)

Avoided hospitalizations are defined by the domiciliary need for continuous ventilatory support and correction of a persistent decrease in baseline oxyhemoglobin saturation by assisted coughing. / <sup>a</sup>only the TIV and NIV users required home visits plus MI-E, all of which resulted in correction of SpO<sub>2</sub> baseline by some combination of adjusting ventilator use and assisted coughing. / TIV, tracheostomy intermittent positive pressure ventilation; NIV noninvasive intermittent positive pressure ventilation; I-E, mechanical insufflation-exsufflation.



## The cost of unplanned emergency admissions

The table below outlines the estimated spending on unplanned emergency admissions across the UK for people with a neuromuscular condition. Using the NHS data from the West Midlands, which takes the average number of emergency admissions per patient (0.3949), and average cost per emergency admission (£2,890.18) we can estimate the UK total as 28,208 emergency admissions, at a total cost of £81,527,633.

Region/Country	Number of people with a neuromuscular condition	Number of emergency admissions	Cost of emergency admissions
Scotland	5984	2363	£6,829,731
Wales	3432	1355	£3,917,052
Northern Ireland	1992	787	£2,273,534
North East	3101	1225	£3,539,271
North West	8141	3215	£9,291,584
Yorkshire and Humber	6076	2399	£6,934,734
East Midlands	5122	2023	£5,845,903
South Central	4769	1883	£5,443,013
South West	6064	2395	£6,921,038
South East Coast	5008	1978	£5,715,791
East of England	6628	2617	£7,564,749
London	8880	3507	£10,135,029
West Midlands	6235	2462	£7,116,206
<b>Total</b>	<b>71432</b>	<b>28208</b>	<b>£81,527,633</b>

### The value of investment

Both the South West and the West Midlands Specialised Commissioning Groups (SCGs) have agreed significant investment into neuromuscular services in recent years, in recognition of both the gaps in services and the savings that can be made from this investment. The investment has been made by top-slicing Primary Care Trusts' (PCTs) budgets to invest in a regional service. An initial investment of £400,000 was agreed for the first phase of implementation in the West Midlands. (See Appendix I for further details.)

**The evidence is clear: investing in neuromuscular services could not only reduce spending on unplanned admissions but also improve patient outcomes.**

The Muscular Dystrophy Campaign recently conducted a survey to assess patients' experiences of the standard of care on offer in their local hospital – and how access to multi-disciplinary care could have prevented them being admitted to hospital in the first place<sup>7</sup>.

Our survey found that:

- 37 percent of respondents had between one and three admissions to hospital over the past two years: over half of these admissions were unplanned emergency admissions
- these emergency admissions totalled 803 bed days, including one admission of 70 days
- 32 percent of those who were admitted to hospital did not feel they were provided with adequate support on discharge, for example through specialist wheelchair provision
- 39 percent of those who were admitted to hospital as an emergency admission felt that this could have been prevented if they had received timely specialist care.

**Tracey (not her real name) has a son with Duchenne muscular dystrophy. Despite being admitted to hospital with pneumonia, he was not assessed to start treatment at home. With such treatment, his hospital admission could have been prevented. She told us:**

*"My son's first chest infection was pneumonia; in hindsight other professionals should have known he needed to start night time ventilation. Even after antibiotics and a 10-day stay in hospital, my son did not have assessments to determine his home ventilation needs. We should have been given instructions on chest physiotherapy*

*and we should have had antibiotics at home to start treatment early. The hospital took several days to diagnose his chest infection believing it was a heart condition."*

Patients and their families also reported having to provide treatment themselves to prevent emergency hospital admissions. Sheila (*not her real name*) has a son with spinal muscular atrophy and she told us: *"There is a dire shortage of respiratory physiotherapy - I do it at home myself - it's what keeps us out of the hospital in the winter."*

Without appropriate and timely treatment, patients' needs can worsen leading to more expensive treatment in the long term.

**Lindsay has Charcot-Marie-Tooth disease and was unable to get the treatment she needed to prevent deterioration in her knee. This eventually led to her being unable to walk for anything more than a few seconds, having previously been much more mobile and able to walk for around ten minutes. She told us:**

*"I had chronic arthritis in my left knee and this was made unbearable as no-one would treat me until I had had my operation. This led to me being unable to walk without searing pain, so I walked less and less. This ended up, over a six-month period, with me being unable to walk across a room and three years on I can now only walk for ninety seconds at a time. If I had been treated within one to two months, the whole backlog of pain and deterioration of my health could have been prevented. I am now on morphine and have gone from being able to stand and walk for ten minutes to someone who is not far from being in a wheel chair. The services I have used since June 2008 have been vast and this could all have been avoided if someone had just listened to me and given me a course of steroid injections at the time."*

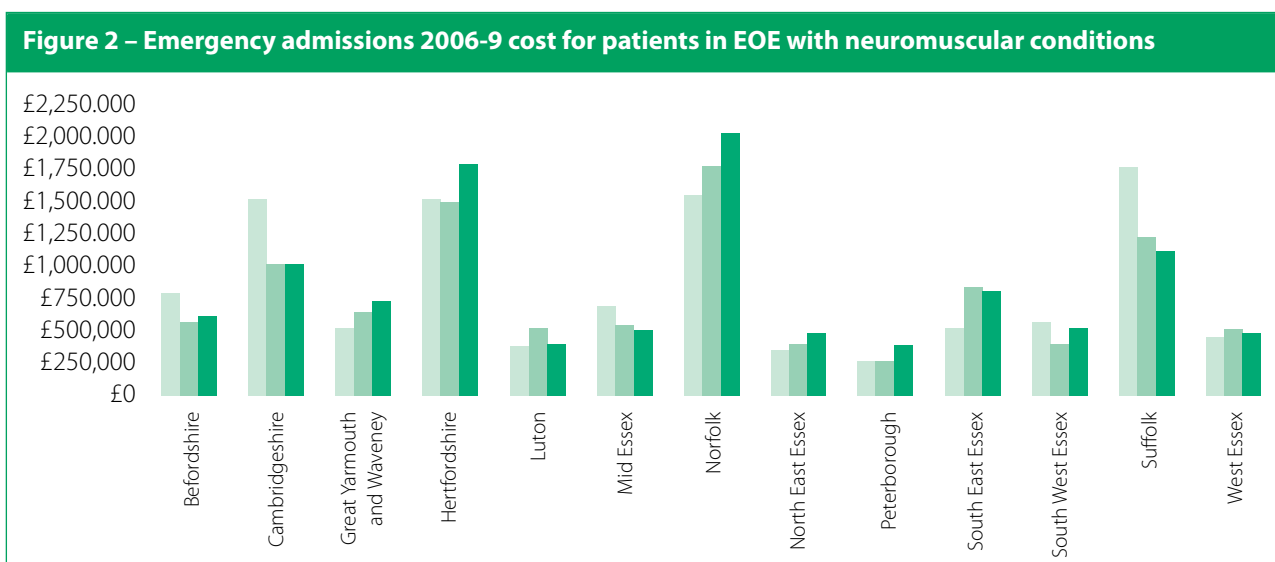
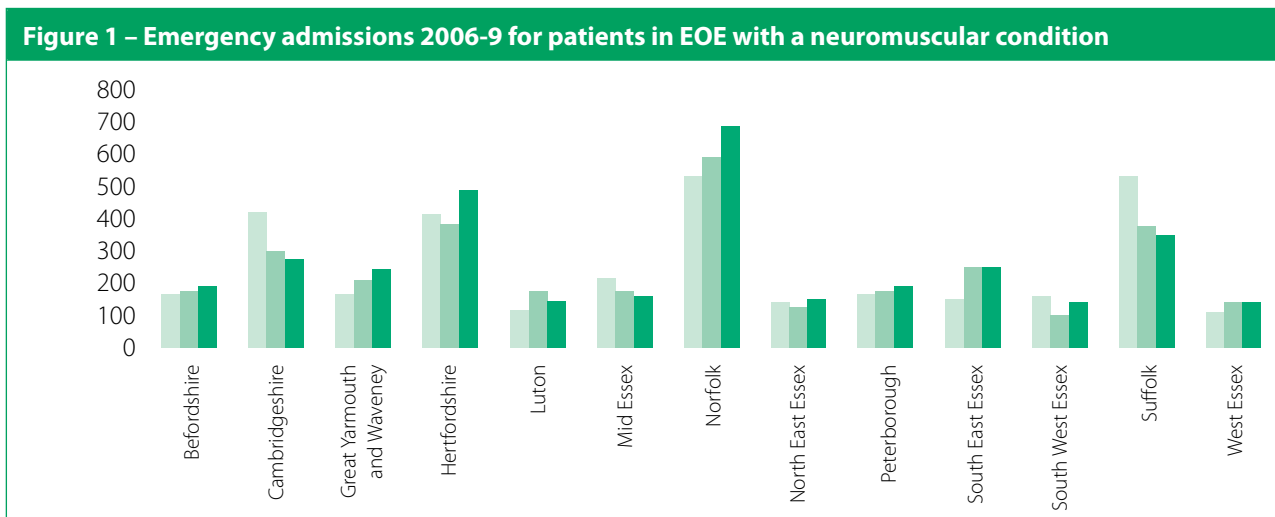
## Investing to save

There are a number of examples across England that indicate how investment in specialist, preventative services for patients with neuromuscular conditions can save money in the longer term and contribute to improved patient outcomes.

Figure 1 below illustrates the rate of unplanned emergency admissions for patients with neuromuscular conditions across the East of England region from 2006 – 2009. There is marked rise in the number of emergency admissions in Norfolk, compared to a similarly marked decrease in emergency admissions in Cambridgeshire and Suffolk.

This coincided with changes to the service in Cambridgeshire and Suffolk which meant that the muscle clinic consultant was much more able to co-ordinate the care patients received. As a result, they weren't discharged back to their GP but instead continued to receive specialist care, for example through respiratory services. This means that preventative measures, such as sleep studies to assess their ventilation needs, were carried out earlier and may explain the decrease in earlier admissions. Elective admissions for the same period were also examined and there was no increase in the number of admissions during this period. Figure 2 below illustrates the costs associated with these emergency admissions and shows the costs in Norfolk rising by almost £500,000, while in Cambridge they decrease by the same amount.<sup>8</sup>

■ 2006/07 ■ 2007/08 ■ 2008/09



Dr Ros Quinlivan looked back on the patients she had seen in her role leading the specialist neuromuscular clinics at the Robert Jones and Agnes Hunt Hospital in Oswestry and Birmingham Children's Hospital from April 2009 to March 2010. In her analysis of 700 child and adult patients she saw during that period, only eight were admitted to hospital for emergency care. Of these eight admissions, only four were related to their underlying neuromuscular conditions. Although the figures here are much smaller than those in an area such as Norfolk, the exceptionally low rate of unplanned emergency admissions to hospital indicates that investing in specialist neuromuscular care can have a significant positive impact.

### Specialist wheelchair services

Getting the right wheelchair at the right time can prevent the development of pressure sores, contractures or skeletal deformity in patients with neuromuscular conditions. The provision of an appropriate chair can actually reduce the cost to the NHS in the long run, decreasing the need for potentially expensive operations and costly inpatient stays.

However, we carried out research in 2010 and found that:

- children in England with neuromuscular conditions are forced to wait an average of 20 weeks to receive a powered wheelchair from the NHS. In 15 PCTs the average wait is longer than six months and, shockingly, **in two PCTs, the average wait is more than a year.** We have also heard of cases where a child has had to wait so long for a wheelchair that they've outgrown it by the time it finally arrives
- adults in England with neuromuscular conditions wait an average of 20 weeks to receive a powered wheelchair from the NHS. However, this masks a shocking postcode lottery. For example, adults in Bolton wait between two and a half and 12 weeks compared to those living in Cumbria who are forced to wait an average of 60 weeks<sup>9</sup>.

### Karen lives in Essex and has Duchenne muscular dystrophy. She said:

*"Even though I can't walk and I need to be in my wheelchair all the time, wheelchair services told me that because I still had a small amount of power in my arms I couldn't have an electric wheelchair. I think pushing the wheelchair has made my arms worse. I've been told I would be on the waiting list for 18 months for another wheelchair assessment. I ended up having to buy my own powered wheelchair and had to borrow money from my parents to pay for it."*

**Phillippa is chair of the Duchenne Family Support Group (DFSG) and has a son, Dan, with Duchenne muscular dystrophy. She had to battle for Dan to get the wheelchair he needed: at one point they were told they would have to wait a year for a new wheelchair due to lack of funding. Not only did Phillippa and Dan argue that this was completely unacceptable for a young person who relies on his wheelchair to get around and to maintain some sort of independence, but also in many cases this can cause additional medical problems. Phillippa said:**

*"If a boy has the start of scoliosis – spine curvature which happens to all boys with Duchenne muscular dystrophy – and then he has to sit in an unsuitable wheelchair, this can cause the scoliosis to worsen. This can result in major orthopaedic surgery and, in some cases, complications in the surgery due to the problems caused by the wrong wheelchair. This can all be avoided and made easier with correct postural seating and adequate wheelchair provision."*

**It is clear that the right wheelchair at the right time can not only save money but also improve patient outcomes.**

## Specialist physiotherapy

Specialist physiotherapy is vital for people with neuromuscular conditions. A physiotherapist plays an important role in minimising the development of contractures and deformities; anticipating and minimising any secondary physical complications; identifying and prescribing aids and equipment; advising on moving and handling issues; monitoring respiratory function and advising on techniques to assist with breathing exercises and methods of clearing secretions; and optimising function and positively managing deterioration. They can therefore be key in helping prevent unplanned hospital admissions.

The Neuromuscular Centre in Cheshire is the only dedicated centre in the United Kingdom which provides ongoing physiotherapy for young people (from 16 years old) and adults affected by a neuromuscular condition. A survey of its clients revealed the benefits of physiotherapy for its patients: 100 percent of respondents believed that access to specialist physiotherapy kept them out of hospital. All respondents also agreed that they felt better for access to such physiotherapy and 82 percent of respondents believed this helped them to stay in paid employment.<sup>10</sup>

Without access to specialist physiotherapy at the right time, care can end up costing more and patients can experience poorer outcomes:

**A young woman with a full-time job was admitted to hospital having fallen and fractured her femur, which was successfully operated on. However she could not go home because she was not allowed to weight-bear for six weeks and she was unable to stand and balance on one leg. Eight weeks later she was still in hospital. The ward physiotherapists were too busy to take her to the gym more than once a week or to take her to the hydrotherapy pool. She is now waiting for a rehabilitation bed in another hospital to become available that she can begin her rehabilitation. In the meantime she sits all day in her bed or chair.<sup>11</sup>**

Specialist respiratory care, such as that provided by the Lane Fox Respiratory Unit at Guys and St. Thomas' NHS Foundation Trust, are a vital aspect of the multi-disciplinary care that neuromuscular patients need and can be instrumental in saving money. Techniques such as non-invasive ventilation (NIV), both in the acute and stable state, are routinely carried out by only a few specialised centres, such as the Lane Fox Respiratory Unit. Specialist centres such as this also link up with other units across the country and help to drive up standards of care.

During an acute respiratory crisis, NIV has a much lower complication rate resulting in a reduction in intensive care and hospital length of stay compared to invasive ventilation, which can result in temporary tracheostomy formation. Such patients receiving NIV do not necessarily require admission to an intensive care unit, which costs over £2,000 per day. Furthermore, many neuromuscular patients can go on to access NIV at home after receiving support from specialists. The Lane Fox Respiratory Unit has a novel proactive programme, co-ordinated by a senior respiratory neuromuscular physiotherapist, of initiating NIV in the home prior to respiratory crisis and direct admission early in the respiratory crisis and this has resulted in an almost complete avoidance of the requirement for invasive ventilation and temporary tracheostomy formation.

A recent article in the *British Medical Journal* makes the case for specialist units who are able to co-ordinate the complex care package that patients who require home ventilation are likely to need, citing both reduced costs and improved outcomes:

*"Such patients [those who are dependent on ventilation] require assessment for home ventilation and often need an extensive care package that provides long-term medical, nursing, and physiotherapy support. Home ventilation and weaning units are best placed to co-ordinate this kind of care, although direct responsibility for the patient may switch to the community at hospital discharge. Such centres can also provide continuing support to patients at home, train carers, assess competency, and provide emergency support at times of crisis. In many parts of the United Kingdom, however, such units do not exist, and individual hospitals may have to arrange home care without adequate support for patients or appropriate assessment of the competency of carers. This places patients at risk.*

The complexity of care needed often results in delayed discharge, and this has an impact on limited critical care resources if such patients remain within the intensive care unit.<sup>12</sup>

**Nathan is a 25 year old man with Duchenne muscular dystrophy. Since 2003 he has had a number of admissions to hospital. In 2006 he had two admissions for lower respiratory tract infections. During one of these admissions Nathan had a gastrostomy inserted as he was unable to maintain his nutritional status. In both admissions he used a variety of cough assistance techniques including a lung volume recruitment bag (LVR bag), a manually assisted cough (MAC) and mechanical insufflator-exsufflator (a machine which helps a person clear secretions by giving a deep breath in followed by a suck out helping patients to cough) to help assist his cough. Nathan was then discharged home using a LVR bag and MAC performed by his parents to help his cough.**

**Nathan remained well until 2008 when he began to produce overwhelming amounts of frothy white secretions and the LVR bag and MAC were ineffective at assisting his cough. His parents asked if they could borrow a mechanical insufflator-exsufflator to see if this would help and prevent an admission to hospital. Nathan was now able to clear his secretions and managed some ventilator-free time and did not require a hospital admission. As Nathan was unable to clear his respiratory secretions with any other technique the PCT were asked to fund a device for home.**

**When Nathan and his parents were asked to look back on the major medical contributions to Nathan's life, they felt apart from non-invasive ventilation, the insertion of a**

**gastrostomy was a contributing factor to keeping him at home as it allowed him to receive fluids and medication when he was unwell in later years. Nathan and his parents also believe that without Nathan having access to a mechanical insufflator-exsufflator, he would have spent a significant amount of time in hospital over the last three years.**

**Dr Stefan Spinty (Consultant Paediatric Neurologist and Neuromuscular Lead Clinician, Alder Hey Hospital) spoke about his experience of using mechanical insufflator-exsufflator machines in treatment:**

*"Treating patients with neuromuscular conditions using a mechanical insufflator-exsufflator can be extremely cost-effective. We have found that, by using these machines, we can prevent admissions to intensive care or high dependency units. In fact, a mechanical insufflator-exsufflator pays for itself if it prevents just one two-to-three-day admission to a paediatric intensive care unit."*

The machine used at Alder Hey Hospital costs approximately £4,550 (plus VAT) and £150 (plus VAT) for the stand, equalling a total investment of £4,700 plus VAT. This compares to £2,500 - £2,700 for a 24-hour admission to intensive care.

### The Lane Fox Respiratory Unit<sup>13</sup>

The Lane Fox Respiratory Unit is a national referral centre for patients with respiratory failure, specialising in home mechanical ventilation and weaning from invasive mechanical ventilation.

The 14-bed unit provides inpatient assessment for patients with sleep disordered breathing, particularly from neuromuscular diseases. It is also a “safe haven” for these patients at times of acute respiratory illness, as they often have complex care needs.

It aims to provide expert care in a relaxed and friendly atmosphere, to encourage patient independence, maintain family and carer involvement and promote good health and wellbeing.

#### The unit:

- supports around 1,000 patients at home with both invasive and non-invasive ventilation
- supports over 700 people at home with a variety of breathing aids
- has an outreach ventilation weaning service to provide expert advice to intensive care units in the South of England. This service also provides care co-ordination for the ventilator-dependent patients in the community
- has an outreach transitional care service for the neuromuscular patients who are moving between paediatric and adult services
- provides 24-hour medical, nursing, physiotherapy and technical support
- holds four-weekly clinics for new referrals and to review patients' progress.

*“There are approximately 140,000 admissions to intensive care units in England and Wales each year. A significant minority of the two to five percent of patients with continued dependence on mechanical ventilation, provided either by a tracheostomy or through non-invasive ventilation, continue to require this after they are discharged from intensive care. Without assessment for home ventilation and a specialist package of continuing support at home – such as that provided by the Lane Fox Respiratory Unit – patients are placed at risk and may well be subject to delayed discharge, which has a significant financial impact on limited critical care resources. A national commissioned strategy must be considered for these complex respiratory neuromuscular patients to reduce the variability in the delivery of clinical care with a clear target to improving patient outcome. This will have a combined result of enhancing quality of care and reducing cost.”*

**Dr Nicholas Hart (NIHR Clinical Research Consultant, the Lane Fox Respiratory Unit)**

**Jamie is 19 years old and has Duchenne muscular dystrophy. Since 2001, he has had a number of admissions to hospital. In February 2008, he was rushed into hospital while en route to school, unable to breathe. He was very ill and admitted to a high dependency children's ward where he was diagnosed with pneumonia. In June 2008, Jamie was again admitted to hospital with pneumonia. Following this admission, he was referred to the Lane Fox Respiratory Unit for an overnight stay to be established on to overnight ventilation and also introduced to the mechanical insufflator-exsufflator machine. It took Jamie some time to get used to using this but he is now comfortable using the machine at home and since he has been using it, he has not had any more recurrences of pneumonia.**

## Neuromuscular care advisors

**Michaela is from Northern Ireland and has spinal muscular atrophy. She told us how important her care advisor is to her:**

*"I regularly have chest infections so [my care advisor] researched equipment and found a machine to help me cough, even getting hold of one for me to try. That was in January last year and I haven't had a chest infection since. That kind of help keeps people out of hospital and saves NHS funds."*

Neuromuscular care advisors play a vital role in improving patient care by taking responsibility for co-ordinating the specialist care they receive. Having a care advisor in post can also save money, for example by saving consultants' time (such as by reducing administrative tasks), reducing GPs' time, by signposting patients to local services and liaising with other service providers. Dr Majumdar, Paediatric Neuromuscular Consultant at Frenchay Hospital in Bristol, estimated that the neuromuscular care advisor saved over 80 hours of consultant time per patient with Duchenne muscular dystrophy (see Appendix II).

### **The role of a neuromuscular care advisor**

Neuromuscular care advisors are key members of a neuromuscular specialist department and are responsible for specialist support for patients diagnosed with a neuromuscular condition in the outpatient setting. Some work with just children or adults, while others work with both.

They act as the patient's key worker and are responsible for supporting the delivery of consistent levels of care and service standards for all relevant patients with disabling and/or life limiting neuromuscular conditions in their Trust. They have a key role in assessing the patient's and

family's needs and making necessary interventions. These could be telephone advice, single visits, short-term interventions or regular assessments and reviews of ongoing complex issues. They support families and patients with neuromuscular conditions through signposting, liaising with local support teams, and developing care plans.

A care advisor also follows up with newly-diagnosed patients, for example through a home visit, to ensure families are given timely support. They organise and provide support and resources, helping patients and their families to adjust and adapt to a changed lifestyle in order to lead the fullest lives possible.

They also have a key role in communications and establishing local neuromuscular networks. A care advisor is the primary co-ordinator between GPs, health providers and medical consultants to ensure systems are in place to provide the most appropriate support for the patient and their families.

Joanne Ashton has a five-year-old son, Liam, who has 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 multi-disciplinary 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."*



## Recommendations

We welcome the significant progress that is being made in improving neuromuscular services across England. We are delighted that the NHS has recently taken groundbreaking steps towards a national neuromuscular service plan and agreed that neuromuscular services will be a priority in the annual work plan of each of the ten Specialised Commissioning Groups across England, covering key issues such as:

- specialist physiotherapy provision in the multi-disciplinary team
- access to specialist equipment
- an audit of unplanned emergency admissions for patients with neuromuscular conditions
- making sure there are well-equipped neuromuscular professionals across England
- a single service specification defining specialist neuromuscular services
- specialist trained neuromuscular transitional care co-ordinators.

In the context of this report, we particularly welcome the £60,000 investment in an audit of unplanned emergency admissions, which will be led by the London Specialised Commissioning Group. This work will be vital in establishing the reasons behind unplanned admissions and what can be done to prevent them and **we recommend that its findings are fully taken on board by NHS commissioners, in particular the National Commissioning Board, when they are published in late 2011.**

We also recognise the progress made by each Specialised Commissioning Group to date, with regional

reviews underway or completed in every region in England. **It is vital that these reviews now translate into investment in specialist neuromuscular services.** As part of this investment, it is essential that **more neuromuscular care advisor posts are funded.** We estimate that up to 60 care advisors are needed across England to meet the needs of the 60,000 patients with neuromuscular conditions; currently there are only 24 care advisors in post.

With the establishment of the National Commissioning Board, which will take on responsibility for commissioning specialised services from 2013, **we also recommend that regional structures are put in place to ensure specialised commissioning can continue on a regional level** to best meet the needs of the local population and invest in services which will save money in the longer term.

It is vital that specialised services for patients with neuromuscular conditions, for example **specialist physiotherapy and wheelchair services, are available to all patients regardless of where they live.** This is essential to both reducing the amount of money spent on unplanned emergency admissions and improving patient outcomes. **It is also important that vital equipment, such as mechanical insufflator-exsufflator machines, is provided to patients where evidence shows this may help them avoid a hospital admission.**

Finally, **we would welcome the production of NICE-accredited evidence into the standards of care for neuromuscular patients** to provide commissioners across the country with sufficient guidance to ensure they are investing in the most cost-effective services which deliver the best outcomes for patients with neuromuscular conditions.

Email us at [campaign@muscular-dystrophy.org](mailto:campaign@muscular-dystrophy.org) to support our campaign!

## Appendix I

As part of their review into neuromuscular services, the West Midlands recommended the following investment “to ensure that service continuity ceases to be a risk and that service capacity can be enhanced to meet unmet demand.”<sup>14</sup>

<b>Total investment required (full year cost) (provisional figures requiring validation)</b>	<b>£s Recurring</b>
1 network manager (mid range band 7)	£43,012
1 administrator (mid range band 5)	£29,181
1 data input clerk (mid range band 3)	£20,872
Network non-pay support costs for clinical IT equipment and software for data base	£30,000 £10,000
Travel expenses/sundry	£20,000
Patient and carer involvement x 3 (1 for paediatric, adult and transition)	£15,000
Training and development	£20,000
2 WTE paediatric consultant specialising in neuromuscular conditions (including secretarial support), or equivalent sessions to attract part-time posts	£260,000
2 WTE adult consultants specialising in neuromuscular conditions (including secretarial support), or equivalent sessional time to attract part-time posts	£260,000
1 WTE consultant pathologist (including secretarial support)	£130,000
4.5 WTE care co-ordinators (mid range band 7 – including 0.5 WTE pick up of charitable funding for current post)	£193,554
3 WTE specialist physiotherapists (mid range band 7)	£129,036
2 WTE (in sessional time) psychologists (mid grade band 8a) including pick-up of Oswestry 0.5 in April 2011	£102,132
<b>Total investment required (full year cost)</b>	<b>£1,262,796</b>

An initial investment of £400,000 was agreed for the first phase of implementation.

Estimates of investment required to prevent neuromuscular services from collapse in Wales, and consequent costs of unplanned emergency admissions to hospital, were compiled by the Cross Party Group on Muscular Dystrophy<sup>15</sup>:

<b>Posts required</b>	<b>£s Recurring</b>
1.5 WTE consultants (including secretarial support) specialising in Neuromuscular conditions	£195,000
3 WTE care advisors (mid range band 7)	£129,036
1 WTE specialist physiotherapist (mid range band 7)	£43,012
0.5 WTE psychologist (mid range band 8a)	£25,533
0.5 WTE occupational therapist (mid range band 7)	£21,506
1 network manager (mid range band 7)	£43,012
0.5 WTE administrator (mid range band 5)	£14,591
<b>Total investment required (full year cost)</b>	<b>£471,690</b>

The North West has also recently completed their review and the NHS has recommended the following consolidation plan for phase one of service improvement:

<b>North West Neuromuscular Services Gap Analysis Proposed Phased Consolidation Plan Phase 1</b>		
<b>1</b>	<b>Consultants with neuromuscular commitment</b>	
	Paediatrics – consultant paediatric neurologist	i. 0.5 WTE Manchester Children’s Hospital ii. 0.5 WTE Alder Hey Children’s Hospital
<b>2</b>	<b>Neuromuscular physiotherapists</b>	
	Adult services	i. 0.5 - 1 WTE for Manchester service ii. 0.5 - 1 WTE for Walton service, Liverpool iii. 0.5 WTE for Preston service
	Paediatrics	0.5 WTE post to support Preston paediatric neuromuscular service
<b>3</b>	<b>Neuromuscular care advisors</b>	
	Model of working across paediatric and adult services	i. 1 WTE to support Manchester/Salford service (0.5 WTE for paediatric and adults services each) ii. 1 WTE to support Preston service (0.5 WTE for paediatric and adults each)

We estimate that this would cost less than £350,000 across the region.

In all three regions, the initial investment has been under £500,000 – a relatively small investment which could save significant amounts of money.

## Appendix II

<b>Name of NHS Trust: UHB/NBT Consultant: Majumdar 2007-2008</b>	<b>Estimated Consultant time saved (in hrs) by CA per DMD Patient</b>
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<b>Initial diagnosis of Duchenne muscular dystrophy (DMD):</b>	<b>Estimated consultant time saved (in hrs) by care advisor care advisor per -DMD Patient</b>
Informing parents/family of diagnosis	0.5
Explaining disease and prognosis to parents/family	0.5
Providing initial support to parents/family	1.0
Liaising with other organisations (e.g. Social Services) on behalf of parents and family	1.0
<b>Other activities at initial diagnosis (please specify):</b>	
Explanation of investigations	0.5
Genetic trials/counselling/biopsy/disability	0.5
Prognosis	0.5
<b>Estimated time saved at initial diagnosis</b>	<b>4.5 hours</b>

<b>Support during early years of Duchenne MD (i.e. until about 11 years of age and assume six clinic visits per year)</b>	
Providing ongoing information and support to parents/family	6.0
Assistance with patients provided by care advisor at outpatient clinic	2.0
Briefing of consultant by care advisor prior to outpatient clinics to ensure consultant fully aware of all relevant information (e.g. family circumstances)	2.0
Ensuring patients attend outpatient clinics when necessary	2.0
Liaising with other organisations (e.g. Social Services, education, housing) on behalf of parents/family (including aids and adaptations)	8.0
<b>Other activities during early years (please specify):</b>	
Discussion of physio/steroids	2.0
Discussion of genetics/carrier	2.0
Respiratory/cardiac/psychological involvement	2.0
<b>Estimated time saved during early years of Duchenne muscular dystrophy</b>	<b>26.0 hours</b>

**Name of NHS Trust: UHB/NBT**  
**Consultant: Majumdar 2007-2008**

**Estimated Consultant  
time saved (in hrs)  
by CA per DMD Patient**

<b>Support during later phases of Duchenne muscular dystrophy (i.e. from about 12 years of age)</b>	
Providing ongoing information and support to parents/family	12.0
Discussing surgical interventions with patient/family	6.0
Assistance with patients provided by care advisor at outpatient clinics	4.0
Briefing of consultant by care advisor prior to outpatient clinics to ensure consultant fully aware of all relevant information	2.0
Ensuring patients attend outpatient clinics when necessary	2.0
Liaising with other agencies ( organisations (e.g. Social Services, education, housing) on behalf of parents/family (including aids and adaptations)	12.0
Average number of inpatient admission per patient	
Direct assistance with patients/families provided by care advisor during inpatient stays	4.0
Estimate of any reduction in length of stay (in days ) per inpatient admission due to presence of care advisor	2.0
Transition care	4.0
Education	1.0
Palliative care	1.0
Bereavement support/counselling	
<b>Estimated time saved during later stages of Duchenne muscular dystrophy</b>	<b>50.0 hours</b>
<b>Total estimated time saved for each patient</b>	<b>80.5 hours</b>

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