



Building on the Foundations:

State of the Nation The 2008 National Survey

Muscular
Dystrophy
Campaign

Contents

What people have a right to expect:

“It is clearly unacceptable that there are still such large variations in care and that access to specialist diagnosis, treatment and on-going 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, Health Minister,
Muscular Dystrophy Adjourment
Debate, 14 May 2008**

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**Foreword, by Philip Butcher,
Chief Executive**

The State of the Nation

The evidence in this report is extremely important as it summarises the key findings of the largest ever survey conducted in the UK of people with muscular dystrophy and related conditions.

Many people continue to encounter poor care, inadequate support and a lack of service provision to enable them to successfully manage their condition. It is unacceptable that access to specialist care, expertise and support in the NHS is still being denied to many of the 60,000 people living with these progressive, muscle wasting conditions.

I have been dismayed by the number of patients and their families who are forced to go without treatments that prolong and improve their lives.

Their plight is made worse by a “postcode lottery” in the provision of essential services from local authorities. Many adults and children face significant delays in the provision of essential equipment and meet barriers to living independently.

Leading specialists agree that a care coordinator or key worker has a crucial role to play in coordinating the multiplicity of health and social care needs while providing valuable support and advice to individuals and families. Indeed, the importance of the care coordinator has been highlighted in many recent Government policy documents.

However, there are currently only 12 Regional Care Advisors/Key Workers in post across the UK of whom seven are reliant on charitable funding from the Muscular Dystrophy Campaign although three are now fully funded by the NHS. The NHS and the Muscular Dystrophy Campaign share the cost of the two remaining posts. **With an average case load of 1,000 patients, it is clear that some 50 additional key workers are urgently required, simply to provide a minimum level of support to each family.**

We are calling on Primary Care Trusts and Specialised Commissioning Groups, as well as Health Boards in the devolved countries, to work with the Muscular Dystrophy Campaign to secure additional posts of key workers like these. All patients should benefit from their vital support as the lead professional within a specialist multi-disciplinary team.

For some families access to specialist care can be a matter of life or death, and I urge all readers to join our fight for improved services and specialist care for all people living with neuromuscular conditions. We know the steps that need to be taken and this report underlines the urgency. The time for talking is over and action is needed now.

Action Needed

- Ensure that every person with muscular dystrophy or a related neuromuscular condition is supported by a care coordinator/key worker who would take a lead within the care team and provide support, information and a regular review of their care plan;
- Designate specialised neuromuscular services within the Department of Health’s Specialised Services Definition Set so that Specialised Commissioning Groups (SCGs) strategically plan for these services across England;¹
- Call on each Specialised Commissioning Group in England, as well as the responsible bodies in Scotland, Wales and Northern Ireland, to follow the lead of the South West SCG and carry out a comprehensive review of the provision of specialist services for people with these conditions living in their region;
- Support The South West Specialised Commissioning Group to implement the proposals from their review into specialist services for people affected by neuromuscular conditions, from April 2009;²
- Build on the foundations of those successful services already in place across the UK and share best practice;
- Call on the National Institute for Health and Clinical Excellence and the Scottish Intercollegiate Guidelines Network to develop guidelines for the management of neuromuscular conditions and tackle current inequities in access to diagnosis, treatment and ongoing care;
- Local health and social care commissioners to work in partnership with the charitable and private sector to establish ‘Neuromuscular Enterprise Centres’ across the UK; to replicate the successful model of the Neuromuscular Centre in Cheshire, which provides specialist physiotherapy, training and employment for people with neuromuscular conditions.

Introduction

This report contains the key findings from the largest ever survey in the UK of people living with muscular dystrophy and carers of people living with the condition.

The report provides a significant insight into all aspects of life with muscular dystrophy or a related condition. It includes information about the experiences of diagnosis, health and social care services, employment and education opportunities.

The report also contains responses from a number of Freedom of Information requests to all Hospital Trusts, Foundation Trusts, Primary Care Trusts as well as Local Authorities about the provision of services for people with these conditions.

There are more than 60 different types of muscular dystrophy and related neuromuscular conditions. It is estimated that around 60,000 people are affected by these conditions in the UK.

Many of these are low-incidence conditions and some are described as ultra orphan condition. They can be genetic or acquired and they can present in childhood or adult life.

A number of these disorders, such as Duchenne muscular dystrophy, are aggressive and cause progressive muscle wasting and weakness, orthopaedic deformity, cardiac and respiratory compromise and result in premature death.

Key Findings

Our nationwide survey of 4,000 people living with muscle disease has revealed vast disparities in service provision. Over 850 patients responded, and we can reveal:

- Three out of four patients and their families have no access to a key worker or care coordinator and lack support and information;
- Half of people with muscle disease have no access to a specialist neuromuscular consultant;
- 60% of patients rated their transition from childhood to adult services as either poor or very poor;
- Almost half of people with muscle disease fund their wheelchair out of their own pocket or thanks to a charity;
- Three out of four families believe that living with a neuromuscular condition has had a damaging impact on their income and finances;
- 50% of people with muscle disease of working age are not in employment;
- Three out of four carers lack any respite support.

Access to specialist health care

What the survey reveals:

- 80% of patients do not receive specialist care for their condition at a recognised specialist centre;
- Almost half said that their experience of the diagnosis process was either poor or very poor;
- Half of people with muscle disease have no access to a specialist neuromuscular consultant;
- Over half of families are not satisfied with the level of emotional support available to their families and to themselves.

What the Freedom of Information responses reveal:

- Two out of three PCTs in England are failing to support a muscle clinic for either adults or children meaning that many patients do not receive specialist multi-disciplinary care;
- Almost three out of four Local Health Boards in Wales fail to support a muscle clinic for either adults or children;
- One in three Scottish Health Boards do not offer home ventilation as a service to adults and children.

Muscular dystrophy and related disorders are complex conditions which require accurate diagnosis by a specialist in these conditions, regular assessment and ongoing specialist care.

Leading specialists would recommend specialist multidisciplinary care as the best model for delivering effective care for individuals with these conditions. This model has been shown to prolong life and improve the quality of life of patients with muscular dystrophy and related neuromuscular conditions.

The Department of Health's National Service Framework for Long Term Conditions, 2005 suggests that *"the care planning process needs an integrated multidisciplinary team of people who have the appropriate training, expertise and skills and who are able to cross-refer to provide coordinated care."*

Also, *"as part of the process of diagnosis, people need information about their condition and an opportunity to talk through the implications for them."*³

According to patients and their families, these standards are not being met:

"I have to wear silicone ankle supports to walk safely. I have been told the NHS will not fund these so I will have to pay approximately £1,500."

"I was told by a local neurologist that treatment would be of no benefit because there is no treatment. I phoned another neurology department only to be told they have no-one interested in muscle disease."

"There has been very little coordinated medical support. Each consultant we see is in isolation to other specialists."

"When my son was dying, the local paramedics did not know how to help him. I knew he was in serious trouble and the ambulance people had severe difficulty in dealing with his muscular dystrophy."

"Having moved homes within the last two years, I have seen the difference in getting excellent all-round care and ongoing help and advice, to virtually nothing."

“There are patches of excellence but on the whole the system is utterly chaotic or non-existent.”

NHS-funded Muscular Dystrophy Care Advisors are a key priority for the charity

Consultant Neurologist at the Institute of Neurology, Professor Mike Hanna, said:

“It is simply unacceptable that life expectancy for conditions such as Duchenne muscular dystrophy can be halved, after diagnosis, depending on your postcode.”

“Specialist care is essential in extending life expectancy and yet it is not available for many patients. Too often specialist care is vulnerable and heavily dependent on a handful of leading clinicians with a research interest in this field, rather than embedded in a properly resourced, long term service.”

There are a number of reasons why the provision of services is patchy and variable. The development of services for patients with muscular dystrophy and related neuromuscular conditions has been heavily dependent on the research interests of individuals who have developed a clinical interest in these conditions. However, there is no strategy in place for succession planning, leaving the services fragile and vulnerable in view of their heavy dependence on the lead clinicians who in time may move on or retire.

People face severe deficits, differences in provision in different localities and the absence of a clear pathway both for service development and the accessing of existing resources.

What the Muscular Dystrophy Campaign wants:

- Specialised Commissioning Groups in England and devolved Governments to urgently review the provision of services in their area and ensure that all people have access to specialist diagnosis, treatment and care wherever they live.
- Every person with muscular dystrophy or a related neuromuscular condition to be offered a care coordinator (key worker) who would take a lead within the care team and provide support, information and a regular review of their care plan.
- The Department of Health to designate neuromuscular conditions on the Specialised Services National Definition Set so that Specialised Commissioning Groups (SCGs) strategically plan for these services across England.
- The devolved governments to ensure that all patients are able to access specialist diagnostic services and specialist multi-disciplinary services even if these are based elsewhere in the UK to ensure adequate care and diagnosis for these complex diseases.
- The National Institute for Health and Clinical Excellence and the Scottish Intercollegiate Guidelines Network to develop guidelines for the management of neuromuscular conditions and tackle current inequities in access to diagnosis, treatment and ongoing care.

What the survey reveals:

- Three out of four patients and their families have no access to a key worker or care co-ordinator.
- 60% of families are unsatisfied with the amount and clarity of information available to them.

As early as 2005 the Department of Health recognised that:

*“Some people with more complex needs requiring skilled multi-disciplinary input from a number of different agencies **will need an identified person who co-ordinates care.** This role includes developing a comprehensive care plan involving a range of agencies and may involve arranging access to appropriate health and social services”*

(National Service Framework for Long-term Conditions).

Earlier this year, Ivan Lewis MP, Health Minister, reaffirmed this vision:

*“people want continuity of care, care co-ordination and **a lead professional who takes responsibility for examining all the family’s needs**”*

(Muscular Dystrophy Adjournment Debate, 14 May 2008).

Lord Darzi’s final report, *High Quality Care for All* finally set out how the Government intends to provide this more personalised level of care for people with long-term conditions. He said,

*“Over the next two years, every one of the 15 million people with one or more long-term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed **with a named lead professional from among the team of staff who help manage their care.**”⁴*

The Muscular Dystrophy Campaign wishes to see this approach adopted universally with the care co-ordinator as the named lead professional. A lead professional (care coordinator/key worker) has a crucial role to play in ensuring individuals, both children and adults with complex conditions, receive a holistic and personalised package of care as well as ensuring regular and timely assessments. The care advisor is often the first point of contact for families with rare illnesses after they have received a diagnosis and they would take the lead within the care team to coordinate health and social care needs.

“We have no key worker, no social worker no physios and no OTs – you feel completely abandoned as a family.”

Kathy, from Oxfordshire, has limb girdle muscular dystrophy. Jane Stein is her MDC Care Advisor. She said:

“When I was first diagnosed I was sent away with little knowledge about how my condition would affect my life. I got in touch with the Muscular Dystrophy Campaign who put me in touch with Jane and that was 10 years ago!

“Jane’s always been there, with help, advice, tissues and tea. She’s the one person I can talk to about any aspect of my life and she really understands the nature of my condition. She has guided and supported me every step of the way.

“The everyday support she has provided has made the world of difference. When my husband and I made the decision to have children Jane let us know about genetic counselling. I also don’t think I would have been able to remain at work had it not been for Jane. She came to my workplace to discuss with them ways of working.

“There’s no doubt in my mind that I would have been completely lost without the Muscular Dystrophy Campaign’s Care Advisor and that’s why I wanted to share my story with you.

“They give so much of their time, energy, friendship and care, yet I know they are rushed off their feet. And I know that there are even more people struggling to cope with muscular dystrophy who could benefit from their wonderful care and support too.”

Both the Department for Education and Skills and the Department of Health support this model. They said:

“Parents of severely disabled children or those with high levels of need require a single point of contact with services and an effective, trusted and informed named person (a ‘key worker’ or Care Manager) to help them obtain the services they require.

Studies of key workers consistently report positive effects on relationships with services, fewer unmet needs and greater family well-being”.

However, their report, *Every Child Matters* also revealed that “less than a third of families with severely disabled children have a key worker.”⁵

“As a parent with a child with a neuromuscular condition I find one of the most frustrating things is that I am, if you like, the ‘manager’ of the entire care regime. If I count all the people I have to deal with because of my daughter’s condition in one year, it probably reaches 30-40. Why can’t children or adults with recognised complex care needs have a coordinator who does all of this?”

“I deal with 40 different people a year because of my daughter’s condition. Why can’t children or adults with recognised complex care needs have a care coordinator who does all of this?”

What has been the role of the Muscular Dystrophy Campaign?

The Muscular Dystrophy Campaign has made huge efforts and placed considerable investment in developing and maintaining the existing team of Regional Care Advisors (RCA). The RCAs are greatly valued and appreciated by individuals and families who receive their advice, guidance and support.

There are currently 11 RCAs in post (plus one vacant post) of whom seven are fully funded by the Muscular Dystrophy Campaign and **three are now fully funded by the NHS**. This leaves two posts where the costs of the post are shared between the NHS and the Muscular Dystrophy Campaign.

Additional posts are needed to ensure that all individuals and families can access the service. A key worker with a potential caseload of 1,000 individuals and families would be quite stretched to provide the necessary level of support but this caseload is thought to be sustainable. With a UK prevalence of some 60,000 people living with a neuromuscular condition, a minimum of 60 RCAs are needed to provide the necessary coverage, without taking into account their geographic distribution and other factors.

It is very encouraging that the South West Neuromuscular Working Group – set up by the South West Specialised Commissioning Group to address the deficiencies in services in the South West highlighted in our *‘Building on the Foundations’* report – has reviewed the evidence and has proposed inter alia four posts of Neuromuscular Care Co-ordinators to be established to serve the South West population.

The Muscular Dystrophy Campaign wants:

- the NHS to implement the proposals in Lord Darzi’s recent report, *High Quality Care for All*, and ensure that all people with long-term conditions, are offered a named lead professional (care advisor/key worker) to manage their care;
- a minimum of 60 care advisors to be employed across the United Kingdom by the NHS and local authorities to fulfill this vision and ensure that all people with muscular dystrophy and related conditions receive adequate care and support;
- these key worker posts to be embedded within the care structure provided by the NHS and local authorities.

Physiotherapy

What the survey reveals:

- Half of patients do not see a physiotherapist;
- Over half of patients felt that they do not receive enough physiotherapy;
- Specialist physiotherapy services are vulnerable where they rely on charitable sector funding.

What the Freedom of Information request reveals:⁶

- Three out of four of NHS Trusts do not provide ongoing physiotherapy for patients with muscular dystrophy and related conditions;
- Half of NHS Trusts do not provide children with a physiotherapist with specific training in muscular dystrophy and related neuromuscular conditions;
- Two out of three NHS Trusts do not have physiotherapists available to adults with specific training in muscular dystrophy and related neuromuscular conditions.

The effective role of therapies as apart of a holistic approach to care for patients with muscular dystrophy and related neuromuscular conditions is increasingly recognised by healthcare professionals. It is accepted that all patients with these conditions will at some point during the course of their condition require access to ongoing and timely therapies.

The Chartered Society of Physiotherapy agrees. They said:

“Physiotherapy has a vital role to play throughout every stage in the treatment and management of the 60,000 people with neuromuscular conditions in the UK. Without it, mobility and independence can suffer and in some cases their condition can rapidly deteriorate. It is recognised that early and ongoing intervention of physiotherapy can also help reduce unplanned hospital admissions.”

The majority of tertiary centres for neuromuscular conditions in England provide regular specialist physiotherapy reviews, assessment, advice and management to patients and importantly they liaise with community physiotherapists to ensure that physiotherapy can be provided locally.

“My daughter, who like me has muscular dystrophy, has been waiting over a year for an appointment with a physiotherapist.”

The Neuromuscular Centre (NMC) in Cheshire, a charitable organisation and part of the Muscular Dystrophy Campaign, is the only centre in the UK which provides the unique combination of on-going physiotherapy, employment and training support for young people affected by muscular dystrophy and related conditions.

The NMC Social Accounts reveals the positive impact benefits of specialist physiotherapy for its clients.⁷ Indeed, when surveyed, all respondents agreed that they felt better for having physiotherapy.

One person attending the NMC said:

“Its not only the physical benefit, but the ability to share experiences with other patients, for example, Access to Work schemes, suitable wheelchairs and holiday accommodation

“I feel very lucky as I live relatively close to the NMC. Some people make long journeys to use the facilities there and they all seem to go away with positive experiences. They wouldn't need to do this if there were suitable services nationwide. These services should include physiotherapy, as well as being a 'knowledge centre' where experiences can be shared and learnt from.”

What the research reveals:

Research by Hill and Phillips in 2006, of service provision for adults with chronic neuromuscular conditions in UK, found that access to physiotherapy was inconsistent.⁸ In their study, clinicians commented that patients in their care were disadvantaged in terms of access to experienced therapists because of inadequate provision in their area.

Only seven out of 20 clinics (35 per cent) had a physiotherapist with an interest in muscle disease. Follow-up was also variable; physiotherapists only offered long-term review of patients in seven clinics, five of which had a specialist muscle physiotherapist; intermittent review in 16 clinics and only short-term treatment in seven.

“When I had it physiotherapy it was wonderful – it helped the pain, but it was too far to travel in the car.”

A retired physiotherapist who has congenital myopathy said:

“In my local area there is no physiotherapy for people such as myself with a long term disability. The benefits I feel from receiving physiotherapy are invaluable and I would like to have it more regularly. Unfortunately, as I pay for it myself I can only go as often as I can afford to.

“Luckily for me, I was a physiotherapist and therefore understand the importance of regular exercises under the supervision of a physiotherapist, but for most patients it's not the situation. We must ensure that the NHS takes note of this report and increases the currently poor service offered to patients.”

“I received physio when I was at school but as soon as I turned 16 and left school my physio was withdrawn immediately.”

It is clear there are a number of reasons why the provision of physiotherapy services, and in particular specialist physiotherapy services for adults, is poor and patchy across the United Kingdom.

- Patients, particularly adults, are generally limited to 6-8 sessions of physiotherapy as the NHS does not recognise the progressive nature of these conditions and the need for ongoing support.
- Physiotherapy is often restricted to patients where an improvement can be demonstrably measured. Due to the progressive nature of muscle disease, patients with muscular dystrophy fail to meet these criteria and are refused ongoing NHS physiotherapy. They are then forced to pay for these services privately or go without.
- Local provision is particularly variable and is made difficult by the sheer case load of physiotherapists in the community. A physiotherapist commented, “Many paediatric physiotherapists in the community have a caseload of 80-100+ children and cannot hope to offer adequate support”.

The situation for clinical specialist physiotherapists is equally challenging as there simply are not enough physiotherapists with specialist knowledge of muscular dystrophy and related conditions. In Scotland, for example, there is only one specialist physiotherapist involved in the care of neuromuscular disorders and this service is limited to the West of Scotland. The Clinical Specialist Physiotherapist aims to undertake annual assessments of the Duchenne population but realistically these sessions are around every 14-24 months due to the increased caseload which currently is in excess of 200 patients.

What the Muscular Dystrophy Campaign wants:

- Specialised Commissioning Groups, Hospital Trusts, PCTs and Local Health Boards to provide more specialist physiotherapists who have an in-depth understanding of muscular dystrophy and related neuromuscular conditions and can provide advice to community physiotherapists;
- NHS Trusts, PCTs and Health Boards to recognise the positive impact physiotherapy has on the health and wellbeing of people with neuromuscular conditions and to end the 6-8 week rule;
- NHS Trusts, PCTs and Health Boards to provide financial support to enable physiotherapists to access specific training in neuromuscular conditions;
- Local health and social care commissioners to work in partnership with the charitable and private sector to establish Neuromuscular Enterprise Schemes across the UK; to replicate the successful model of the Neuromuscular Centre in Cheshire.

“Radical change needs to happen. Children’s lives are being ruined and cut unnecessarily short due to where they live. In this day and age this is a crime”

The need for Continuing Professional Development

Patients require access to a specialist multi-disciplinary network or centre of health professionals and therapists who can provide expert assessment, treatment, advice and diagnosis of their condition. This team should be underpinned by adequate local support from community health professionals and therapists.

However, local health professionals and community therapists, for example community physiotherapists, do not always have the expertise and knowledge about the complexity and progressive nature of these conditions and this can result in incorrect advice and information. To meet the different and complex needs of these patients, there is a burning need to transform the local healthcare workforce through professional development and training.

Two Muscular Dystrophy Campaign initiatives, the Physiotherapy Network and the Occupational Therapy Network have been set up to improve the professional training and knowledge of physiotherapists and occupational therapists.

The Network organisers run a number of conferences each year to provide support and learning for physiotherapists across the UK. The conferences are largely funded by the Muscular Dystrophy Campaign. Despite the charitable support and subsidised fees, a number of therapists are still prevented from attending on cost grounds.

In 1999 the Department of Health set out its commitment to Continuing Professional Development to ensure the delivery of high quality NHS services. However, despite the fact that the majority of community therapists are unable to offer advice based on evidence or experience and particularly for adults with these conditions, some therapists are being prevented from attending training courses by their local Trust.

Transition from childhood to adulthood

What our survey reveals:

- 60% of people with muscle disease rated their transition from childhood to adult services as either poor or very poor.
- Essential services, such as physiotherapy, are often immediately withdrawn between the ages of 16-18.
- Obstacles to a smooth transition include a lack of communication between those working in health, social care and education services.
- Families often experience multiple assessments and a lack of forward planning.

What the research reveals:

Hill and Phillips (2006) found that only 42% of muscle clinics in the UK requiring transfer from paediatric to adult care had a service in place to do so. This excludes clinics where no transfer arrangements were required, because both children and adults were seen in one clinic, or the same team ran both clinics.

They concluded **“the provision of specialist clinics to facilitate transfer of care from paediatric to adult services is generally poor”**.

There is also considerable published data which recognises the importance and benefits of a dedicated key worker or co-ordinator for young people with long-term conditions.⁹

Between 2003-2007, the Big Lottery-funded non-cancer palliative care programme employed **‘outreach’ workers** to identify, and help meet the needs of, people with long-term disabling conditions that are not included in ‘chronic disease management’ programmes or part of a managed clinical network.

One of the ‘outreach’ workers worked specifically with adolescents and young adults (and their families) with muscular dystrophies and congenital ataxias.

The posts were very successful in securing services and ‘benefits’, in providing information and advocacy, and in directing clients to other sources of help. This was particularly important for the many individuals who had ‘fallen through the net’ during the transition from child to adult services.

“The lives of many people were transformed from being virtually housebound or even bed-bound to being able to live a reasonably active and rewarding life both in and outside the home.”

Dr John Womersley, Manager of Big Lottery-funded non-cancer palliative care programme 2003-2007

Despite conclusive evidence supporting the benefits of this model, this post is no longer in place as Local Health Boards were not forthcoming in providing much needed long-term funding and support.

“My lads are gone but I wanted to tell my story so that care can be improved. The condition gets worse as they grow older, so why should the care stop?”

In Dundee, a pilot project is currently engaged in providing a care coordination process for young people reaching transition. The organisation advises:

A lead person will be chosen by the young person & parent/carer to be their link between all actively involved services/agencies. The lead person will ensure relevant information is shared between involved professionals and the young person is central to all planning.

At present, funding for this pilot is only assured to March 2009. However, it is anticipated that the care co-ordination process will be adopted if the pilot illustrates the advantages of this system.

Young people with Duchenne muscular dystrophy will be amongst the client groups to be considered for inclusion. As we have not yet received all nominations for inclusion in the pilot, we cannot confirm (at this time) whether any young people with this condition will be part of the pilot study.

The Royal College of Nursing (2004) recognises that **“the successful and seamless transfer of adolescents is one of the greatest challenges facing both paediatric and adult services.”**¹⁰

The National Service Framework for Children and Young People (2004) also recognises that **“disabled young people need high quality, multi-agency support to allow them to have choice and control over life decisions, and to be aware of what opportunities are open to them and the range of support they may need to access.”**¹¹

Increasing numbers of young people with complex conditions are reaching transition and living longer because of improvements in therapies and medical care.

Moving to adult-oriented healthcare services can be a very stressful time for individuals, their families and carers, particularly given that the complexity of their care increases.

Young people will also be making the same transition to adulthood as their able bodied peers. For example, they will be moving from school to training/employment, financial dependence, leaving the family home, beginning sexual relationships, coupledness, marriage and parenthood.

Despite the significance of this period for people with these progressive neuromuscular conditions, there is no dedicated key worker to support their transition to adulthood and there is a lack of facilities for adolescents to support any preparation for transition to adult services.

“We had excellent services in paediatrics but when reaching adult services, everything stopped.”

Three mothers said:

“The change over to adult services is appalling. We spent years building up trust and confidence in all the doctors, physiotherapist and occupational therapist and then suddenly it all stops. Everything is now fragmented and we are going to three different hospitals and nobody is looking at his health overall.”

“The transition from childhood to adult services was sadly lacking in fact non-existent. If it hadn't been for the local consultants I doubt we could have gone very far and the boys would have died earlier. I can't praise their help enough.”

“I think services are only going to get worse for my teenage son.”

What the Muscular Dystrophy Campaign wants:

- Local authorities and Health Boards to work in partnership to ensure that a care coordination process is in place for every young person moving from child to adult services.
- Each care coordination team to offer the young person a lead professional from within the team to actively support the coordination of services.
- Directors of adult social services in partnership with directors of children's social services to implement the recommendations from 'Growing Up Matters' (2007)¹² and undertake joint appraisals of local arrangements and commissioning strategies to assess their progress in successful transition planning.

Finance, Employment and Training

Our survey has revealed:

- Half of people with muscle disease rate the support they receive to live independently either as poor or very poor;
- 75% of families believe that living with a neuromuscular condition has affected their income and related standard of living;
- Half of people with muscle disease of working age (21-60) are not in employment.

Research reveals:

- In England and Wales 16 year olds are twice as likely to be out of work, education or training as their non-disabled peers. (DfES, Youth Cohort Study: The Activities and Experiences of 16 Year Olds: England and Wales 2004);
- In Scotland, disabled people are twice as likely to have no recognised qualification as their non-disabled counterparts. (Labour Force Survey 2003)
- Forty per cent of people of working age who are out of work are disabled.

Sir Bert Massie, Disability Rights Campaigner and former Chair of the Disability Rights Commission, said,

“It is completely unacceptable that people living with muscle disease are facing undue hardship as a result of their condition. Employers must learn to be more flexible in their approach to disabled employees. The inflexible culture within social care structures must also change, to grant people living with muscle disease the right to independent living”.

In order to lead as independent lives as possible, people living with muscular dystrophy and related neuromuscular conditions must be provided with access to appropriate employment, training, higher and further education.

There is currently only one dedicated service meeting these needs in the United Kingdom, the **Neuromuscular Centre (NMC) in Cheshire**, which provides the unique combination of on-going physiotherapy, employment and training support for young people affected by muscular dystrophy and related conditions. The NMC also offers distance learning and remote support for a growing number of clients.

The Muscular Dystrophy Campaign is currently planning a new social enterprise centre in the North East of England – **Muscle Enterprise North East**. The centre will provide ongoing, specialist therapies for adults, particularly physiotherapy as well as training, business support services and direct employment for people with muscular dystrophy and related neuromuscular conditions. It will also provide home-based courses and extended outreach to supported training opportunities with local colleges and universities. Local partnerships are already being built between the NHS, Newcastle College, and the voluntary and private sector to take this initiative forward.

“Before my son was on night time ventilation our gas and electricity bills were about £60 every month. Now that’s shot up to £220 per month.”

Access to such dedicated employment advice and support is essential to ensure disabled people are able to lead fully independent and fulfilling lives.

“I did try to get a part time job working from home – I went to Job Centre for help and they wanted me to walk upstairs for the interview.” [Something the respondent’s muscle disease prohibits]

“I was part-time employed until very recently – made redundant. I have always worked. I’m now feeling extremely stressed and wondering if I will ever be able to find work again, particularly in view of being my daughter’s main carer.”

“I get a lot of grief from my employer because of my condition. I have worked for the NHS for the past 30 years. The work at times can be strenuous but my employer doesn’t understand the effect that this has on my muscles.”

Many families are struggling with the additional costs of caring for their loved ones:

“My son is 22 and at home all of the time. He is on night time ventilation. Because of his age and because he is not at school or college he is classed as a non-dependent adult!

“We are really struggling to pay the electricity bills because we have to use ventilation through the night.

“Before he was on night time ventilation our gas and electricity bills came to about £60 every month. Now that’s shot up to £220 per month. Although the power company has offered us an economy rate, it’s actually made virtually no difference whatsoever.”

What the Muscular Dystrophy Campaign wants:

- Local authorities to work in partnership with the NHS, private companies, education facilities and disability organisations to carry out feasibility studies for regional Muscle Enterprises in every region of England, Scotland, Wales and Northern Ireland. The model could be based on the very successful social enterprise centre based in Cheshire, England, but adapted to regional needs;
- Job Centres to ensure that Disability Employment Advisers (DEAs) are sufficiently supported and trained to understand the impact of neuromuscular conditions.

Wheelchairs, community equipment and support from Local Authorities

What our survey reveals:

- Almost half of people with muscle disease fund their wheelchair out of their own pocket or thanks to a charity;
- Half of patients have experienced delays or difficulties in receiving the appropriate chair;
- One in three rated the service received for assistance in the upkeep of their chair as either poor or very poor;
- Over half of families have experienced delays and difficulties in receiving appropriate home adaptations;
- 40% of families have experienced delays in receiving an appointment with their occupational therapist – the key worker most likely to assess their needs;
- One in four rates the service received from their social worker as either poor or very poor.

Staff Shortages at one London PCT

It has been brought to the Muscular Dystrophy Campaign’s attention that accessing information regarding wheelchairs is not as straightforward as it should be.

One PCT’s Wheelchair Service, which deals with patients’ wheelchairs in North London, is an example of this alarming lack of information available to the public.

For over one week during August 2008 there was a message on the answer phone that calls could not be answered due to ‘severe staff shortages’. The Muscular Dystrophy Campaign is deeply concerned at the shortage in the number of staff addressing patients’ urgent concerns.

Provision of the correct wheelchair and seating system is likely to be one of the most critical factors in helping to alleviate dependency and the sense of isolation for people with muscular dystrophy and related neuromuscular conditions.

These conditions can often be extremely debilitating and many users become dependent on others for all activities of daily living. Mobility is one of the few areas in which with appropriate provision, people can be fully independent and this should always be the goal.

The correct wheelchair can enhance learning and concentration, reduce fatigue, and prevent social isolation, thereby reducing the likelihood of depression. It can also greatly reduce the strain on carers.

Michelle, from Yorkshire, commenting on the new wheelchair for her son, 10-year-old Harry who has Duchenne muscular dystrophy said:

“I knew this chair would enhance Harry’s life but I didn’t expect it to be such a major life changer, I cannot describe what this chair has done for Harry – he is happy, much more confident and back to the Harry who disappeared a long time ago, the naughty cheeky funny Harry.

“When we got back from Cambridge and built the chair up...he got in it and the first thing he did was go down to touch the grass...he said he couldn’t remember what it felt like.

“The next day he got his trucks and tractors out of the cupboard himself...took them outside and played with them on the grass... when I took that photo of him playing on the grass with the dog I got very emotional!”

“I had to buy my wheelchair from Argos, with no help.”

The Department of Health’s National Service Framework for Long Term Conditions, 2005 clearly states

People with long-term neurological conditions are to receive timely, appropriate assistive technology/ equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.

Rapidly progressing conditions can present a particular challenge for services that provide home adaptations and assistive technology/ equipment. Services need to anticipate, identify and regularly review the needs of people with rapidly changing conditions. Providing fast-track equipment can make sure that specialist equipment is prescribed and delivered promptly; maintained in full working order and exchanged flexibly as a person’s needs change.

In June 2006 the Government launched the **‘Transforming Community Equipment and Wheelchair Services Programme’** – saying that they aimed to develop a radical new model for delivery of community equipment and wheelchair services in England. It states *“Our over-riding principle is that any improvement or change must centre on the interests of the individual.”*¹³

Two years later and the ‘radical new model’ is yet to be published.

Many people with muscle disease and their families clearly feel let down:

“Shocking delays in regular appointments – no one seems to acknowledge a child will grow and thus the chair needs changing”

“You have to be careful with money because you have to buy equipment and special vehicles have to be purchased.”

“I have been trying since October 2007 to change my chair – it is now ten years old and falling apart. Wheelchair Services keep telling me that they are looking at other chairs for me and I can go and try them. Unfortunately, this never happens and they keep bringing out the same chair and I keep sending it back!”

“My disability has moved on since my last chair ten years ago. I need a different type and shape of chair now but no-one is listening – it’s soul destroying.”

“I got my wheelchair through people fundraising for me.”

“The funding for essential equipment was obtained by getting a re-mortgage on my house. Have been peniless since.”

On Community Equipment and aids to living independently, patients also felt frustrated:

“An occupational therapist wanted me to sleep downstairs and leave my daughters, aged 5 and 3 to sleep upstairs alone. I was forced to buy my own stairlift which cost £2,700.”

“I have had to save up to pay for necessary home adaptations.”

“We had to re-mortgage our home to cover the costs of the adaptations I needed. Before that I was sleeping in the living room on a chair.”

“I am on direct payments which in theory should work. But trying to explain my predicament has fallen on deaf ears.”

What the Muscular Dystrophy Campaign wants:

- Wheelchair Services to provide adequate resources and information are provided to wheelchair services so that people with these conditions receive appropriate and timely support and accurate advice.
- Publish the new model for the delivery of Wheelchair Services as a matter of urgency to improve service provision.
- Wheelchair Services to reduce delays in the provision of wheel-chairs and wheelchair assessments by implementing protocols for fast-track equipment for people with long-term conditions, in line with NSF 2005.
- The Scottish Government to establish a dedicated fund for housing adaptations for disabled people and their families and end means testing for families with disabled children who require aids in their home, in line with current policy in England and Wales.
- Social services departments and the NHS to provide greater flexibility and offer appointment times outside of school and working hours.

Lack of Support for Carers

“It has always been such a struggle, we as carers had to fight for everything.”

What our survey reveals:

- Three out of five carers of people with muscle disease have not received a carer’s assessment by their local authority, which is a statutory right.
- A number of people surveyed are caring for more than one disabled person within their immediate family, a result of the genetic nature of a number of these conditions.
- Over half of carers felt that their needs have not been met.
- Three out of four have no access to respite care, like a hospice or care home.

Caring for somebody with muscular dystrophy or a related neuromuscular condition is often a full time and demanding role and the demand on carers is particularly high. A number of people provide intensive 24 hour care for their loved ones.

We do not believe that families receive sufficient recognition for the additional costs of caring for a loved one. Carers often face costs that are not covered by Disability Living Allowance or Attendance Allowance (and in some cases disabled or older people cannot claim DLA or AA).

Commenting on the Government’s new carer’s strategy, **Carers at the heart of 21st-century families and communities**, Gordon Brown said:

“It recognises the increasingly important role that carers play in our society alongside the wide variety of caring roles and the diversity of those within these roles, and it acknowledges that carers need more help and support than has been available in the past.”¹⁴

What the Muscular Dystrophy Campaign wants:

- the Government to review the level of DLA to ensure that it provides appropriate contribution to the extra costs faced by disabled people;
- the Government to recognise that the rule that links one Carers Allowance claim to one Attendance Allowance/Disability Living Allowance claim provides no recognition for those carers who look after more than one disabled person;
- local authorities to improve the system for carers’ assessments so that all carers receive an assessment and the correct support and information they need;
- the Government to promote and proactively negotiate with local authorities, business and transport operators ‘concession cards’ for carers for travel, parking, leisure and other activities to help carers cope with the financial burden of caring.

“My partner is my carer and like me gets no help. We have to get through everything on our own.”

“My wife has not had a break in seven years – she’s working 24/7 to look after me.

“I don’t know what I would do without her, worth her weight in gold, shame the Government doesn’t think along the same lines.”

Conclusion

The Muscular Dystrophy Campaign urges all readers to support our Building on the Foundations campaign. If you would like to join us in seeking improved access to specialist care and support, please email your details to campaigns@muscular-dystrophy.org

References

- ¹ *Building on the Foundations* (December 2007): The Need for a Specialist Neuromuscular Service Across England: http://www.muscular-dystrophy.org/campaigns/building_on_foundations/index.html
- ² Following the publication of our report, the South West Specialised Commissioning Group carried out a review of the provision of specialist services for children and adults affected by muscular dystrophy and related neuromuscular conditions in the South West of England.

The draft review has identified the model of a managed clinical network as one element in their solution to ensuring that all people affected by a neuromuscular condition living in the South West can readily receive specialist care.
- ³ Department of Health’s National Service Framework for Long Term Conditions (March 2005) : <http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Long-termNeurologicalConditionsNSF/index.htm>
- ⁴ Department of Health’s High Quality Care for All (June 2008): http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
- ⁵ Every Child Matters, p. 28: <http://www.dcsf.gov.uk/consultations/downloadableDocs/EveryChildMattersNextSteps.pdf>
- ⁶ In April 2008 the Muscular Dystrophy Campaign submitted a Freedom of Information request to 173 NHS Trusts in England to identify the existence and standard of physiotherapy services for children and adults with neuromuscular conditions. 122 NHS Trusts responded. Focus on Physio (May 2008): http://www.muscular-dystrophy.org/news/over_100.html
- ⁷ Neuromuscular Centre Social Accounts (2006-07): http://www.nmcentre.com/Social_Accounts_Neuromuscular_Centre_2006-07.pdf
- ⁸ Hill, M E & Phillips, M F 2006: ‘Service provision for adults with long-term disability: A review of services for adults with chronic neuromuscular conditions in the United Kingdom’. *Neuromuscular Disorders*, 16, p. 107-112
- ⁹ Rearick, Ellen, Enhancing Success in Transition Service Coordinators – Use of Transformational Leadership, *Professional Case Management*, 12:5, pp. 283-287
- ¹⁰ Royal College of Nursing (2004): Adolescent transition care: Guidance for Nursing Staff: <http://www.rcn.org.uk/>
- ¹¹ Department of Health’s National Service Framework for Children and Young People (2004): http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Children/DH_4089111
- ¹² Commission for Social Care Inspectorate’s report ‘Growing Up Matters’, 2007, www.csci.org.uk/PDF/growing_up_matters.pdf
- ¹³ Department of Health’s Transforming Community Equipment (June 2006): <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Communityequipmentservices/index.htm>
- ¹⁴ Department of Health’s Carers at the Heart of the 21st century (June 2008): http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345

Details of the National Survey

- A survey was sent to 4,000 people across the UK between July and August 2008;
- 850 responses were received;
- The questions can be found at: http://www.muscular-dystrophy.org/campaigns/are_you_getting.html
- The results were analysed by an independent, external agency.

Breakdown of Regions

Northern Ireland (21)
Scotland (81)
North East (45)
North West (88)
Yorks/Humberside (49)
Wales (32)
West Midlands (68)
East Midlands (48)
East of England (42)
South West (85)
South East (185)
London (25)
No Location stated (81)

Appendices

Appendix 1

Models of planning and delivering specialist care for people affected by muscular dystrophy and related disorders

South West proposal – July 2008

The South West Specialised Commissioning Group has carried out a detailed review of the provision of specialist health care services for people with neuromuscular conditions (excluding Motor Neurone Disease).

A business plan for their proposals will be set out in September 2008 and we urge this to be implemented into their January 2009 Operating Plan to ensure that substantial improvements are made to quality of life and survival rates of patients with these conditions.

A managed clinical network model is proposed with two specialist centres providing specialised multi-disciplinary care and support to local clinics across the South West. One centre will be the overall lead centre for the whole of the South West and the second centre will support local services in another part of the South West, working closely with the lead centre.

Scottish Muscle Network

The Scottish Muscle Network (SMN) became formally recognised as a Managed Clinical Network in April 2007.

The SMN aims to improve patient care in terms of quality, access and appropriateness. The approach is particularly suitable for Scotland as it addresses the problems arising from the mix of rural, urban and island areas that exist across Scotland. The network also incorporates social with clinical aspects of care.

The SMN promotes access to local health, social, and educational professionals who are aware of their condition and its complications and who are provided with training and support offered by appropriate tertiary referral specialists.

The Scottish Muscle Network's main activities include

- Increasing communication between health, social and educational professionals and voluntary organisations across Scotland;
- Providing educational opportunities for professionals;
- Creating a consensus for standards of care;
- Providing patients with information about how the Health Service can help them;
- Setting up a variety of ways in which patients and their representatives can communicate their needs to the service deliverers.

The 'Hub-Spoke' Model

A number of centres in the United Kingdom follow a regionally based 'hub and spoke' model with a network of specialist regional centres providing care to patients at the hub while also giving clinical leadership, supervising and sharing care with local hospitals and primary care teams. The Newcastle Muscle Centre, for example, has for more than 15 years been providing "outreach" clinics to several sites across the Northern Region thereby providing specialist services closer to people's homes and allowing the better involvement of local staff.

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