



Building on the Foundations:

Focus on Physio

May 2008

Muscular
Dystrophy
Campaign

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Foreword



**Foreword by Baroness
Celia Thomas of Winchester**

The following report shows that patients with chronic, progressive conditions are being denied ongoing physiotherapy on the NHS.

For many people who are, like me, living with a neuromuscular condition, physiotherapy, coupled with individually designed exercise programmes, is essential in maintaining the best quality of life, for the longest time possible.

However, physiotherapy is often restricted to patients whose improvement can be demonstrably measured by physiotherapists so that outcomes match goals set at the outset of treatment.

A patient with a broken leg can be documented as referred, treated and then discharged or 'cured'. Patients with neuromuscular conditions, whose ongoing physiotherapy can boost mobility, independence and improve quality of life, fail to meet these criteria.

The situation is particularly difficult for young adults making the transition to adult services – their physiotherapy is often immediately withdrawn as soon as they turn 18.

There are also many patients who have no choice but to pay for their physiotherapy privately, including hydrotherapy and specialist massage.

I urge anyone reading this report to join me and the Muscular Dystrophy Campaign in calling on the Government to recognise the specialist nature of neuromuscular services and improve access to ongoing therapies as a matter of urgency.

Executive Summary

Overview

This report by the Muscular Dystrophy Campaign draws on the views and experience of leading physiotherapists, patients and their families to set out a number of serious concerns regarding the provision of physiotherapy on the NHS for people with neuromuscular conditions.

We will show that many patients with neuromuscular conditions in the UK do not receive the specialist physiotherapy necessary to treat their condition. This is severely impacting their quality of life, mobility, independence and in some cases has resulted in the rapid deterioration of their condition. It is recognised that early and ongoing intervention of physiotherapy can help reduce hospital admissions.

The report contains responses from a patient survey, a Freedom of Information request to all acute Trusts, Foundations Trusts and Primary Care Trusts about the provision of physiotherapy, as well as information from the latest research papers on the effects of physiotherapy for patients with neuromuscular conditions (Appendix 3).

There are more than 60 different types of muscular dystrophy and related neuromuscular conditions. Over 1,000 children and adults for every 1 million of the population are affected by muscle wasting neuromuscular conditions in the UK.

Neuromuscular conditions can be genetic or acquired. A number of these conditions, 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. Others cause life-long disability. Some neuromuscular disorders can present in childhood or young adult life. Others are late onset conditions in adulthood. There is currently no known cure.

However, physiotherapy maintains the best quality of life for the longest time possible for many patients with neuromuscular conditions.

Key Findings

- Many patients with neuromuscular conditions do not receive continuous, specialist physiotherapy or any physiotherapy at all - local provision is particularly poor in some areas;
- current referral practices, particularly for adults with neuromuscular conditions, seem arbitrary and show considerable variation for patients;
- adults with neuromuscular conditions face particular difficulties, principally young adults making the transition from paediatric to adult care;
- where there are specialist physiotherapy services many are vulnerable as they rely on charitable sector funding;
- many physiotherapists are being prevented from attending training courses in neuromuscular conditions, despite the NHS's commitment to Continuing Professional Development (CPD);
- there is a lack of guidelines and standards of care for people with neuromuscular conditions;

“Physiotherapy has a vital role to play in the treatment and management of these conditions throughout every stage of the condition”.

Journal of the Association of Paediatric Chartered Physiotherapists March 2000

Action Needed:

We are calling on the Government, local authorities, the devolved Governments and the NHS to:

- Ensure that children and adults with a neuromuscular condition be offered and have access to ongoing and timely physiotherapy, including hydrotherapy, when they need it;
- Press Specialised Commissioning Groups, acute trusts and local health boards to provide more physiotherapists with support and training in muscular dystrophy and related conditions as part of their Continuing Professional Development;
- Better understand the positive impact physiotherapy has on the health and wellbeing of people with neuromuscular conditions;
- Ensure that a multidisciplinary service is in place for the care of patients with neuromuscular conditions;
- Ensure Specialised Commissioning Groups follow the lead of the South West and establish neuromuscular working groups to undertake reviews of local services. This would include a gap analysis of physio services for patients with neuromuscular conditions;

What is physiotherapy and why is it important?

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

Physiotherapy is the physical treatment and management of a condition which enables people with neuromuscular conditions to reach their maximum physical potential by maintaining mobility, independence and improving quality of life (Appendix 4).

Physiotherapists have an essential role to play in assessing muscle function, strength and changes over time as well as providers of treatment, advice and support. Their assessment and evaluation skills will become even more important as new treatments are developed.

It is shown that physiotherapy can:

- Improve sleep quality, reduce pain and promote comfort;
- minimise the development of contractures and deformities through a programme of stretches and, where appropriate, exercises;
- maintain muscle ability over the long term;
- anticipate and minimise any secondary physical complications;
- delay age at which the client becomes wheelchair reliant;

- delay age of onset of scoliosis ;¹
- prevent surgery for tenotomies;
- reduce the likeliness of hospital admissions for chest infections;
- help to identify (in those conditions that require it) optimum time for intervention with non-invasive positive pressure ventilation (NIPPV) which will minimise emergency HDU and ITU admissions;

The role of a specially trained physiotherapist is vital to ensure the correct treatment for patients with neuromuscular conditions. A physiotherapist will not only ensure the above, but will also:

- develop individually designed exercise programmes;
- identify and prescribe aids and equipment (orthoses, callipers, wheelchairs and standing frames, for example);
- advise on moving and handling issues thus preventing potential fractures due to inappropriate handling;
- monitor respiratory function and advise on techniques to assist with breathing exercises and methods of clearing secretions.

High intensity physiotherapy input may be required at times, for example, following an acute event such as a fracture, chest infection, following surgery to regain function or to prevent deterioration.

How should physiotherapy be delivered?

Patients with neuromuscular conditions require access to a locally delivered multi-disciplinary network of care. Care should be delivered by local health professionals and therapists, with supervision from specialist clinicians and experts in neuromuscular conditions.

It is evident that by providing the correct specialist training and support, day-to-day physiotherapy can be delivered by a local community physiotherapy team as part of a network of care.

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

Unfortunately, services vary widely across the country and this model is not currently available to all patients, particularly adults. The following evidence outlines the key findings in this report and the current problems facing physiotherapy services for patients with neuromuscular services in the UK.

The Clinical Specialist Paediatric Physiotherapist at the Evelina Children's Hospital, in London, said:

"As a regional Clinical Specialist in addition to twice weekly neuromuscular clinics here, some of which are physiotherapy – only clinics, I do regional clinics with our paediatric neurology consultants. We travel to Chailey Heritage (Sussex) Medway and Maidstone to see neuromuscular patients closer to their homes. We aim to see the patients with their local paediatrician and local physiotherapists. This is really helpful for communication between teams, but is also important for teaching local teams who have less experience of neuromuscular conditions. It is obviously beneficial to families.

We also visit Valence school, a residential school for disabled children in Kent four times a year, where there are several pupils with neuromuscular conditions and we see them at school with their parents, carers and physiotherapist. This is welcomed by all concerned as communication is good and the pupils only miss 1 or 2 lessons within their school day."

Evidence – the need for action

1. Many patients with neuromuscular conditions receive limited specialist physiotherapy or no physiotherapy at all – local provision is particularly poor in some areas

The NHS does not provide ongoing physiotherapy for the management of chronic progressive, long term conditions. Indeed, only patients able to demonstrate an improvement in their condition or ailment receive the physiotherapy they need.

The evolution of services for patients with neuromuscular conditions in the UK has been inconsistent and heavily dependent on the commitment of dedicated healthcare professionals who have developed a clinical interest in neuromuscular conditions. Consequently, services for patients with neuromuscular conditions between each region of England vary considerably.

As the following testimony illustrates, local provision is particularly variable:

The Clinical Specialist Paediatric Physiotherapist at the Evelina Children's Hospital and provides outreach services locally, said:

"Local provision is very variable. In one area that we cover, children in mainstream school are only seen by their local physiotherapist once a year. This is actually less often than they are seen by us for expert review and is clearly not sufficient.

Better services should be provided in the community, with all patients having a local physiotherapist as well as access to a regional specialist centre."

The provision of local services is made difficult by the sheer caseload 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 following case study further illustrates the huge importance of specialist physiotherapy for children and the difficulties families experience in receiving this vital input:

A parent living in the South West of England talking about her daughter's experience, said:

"When my daughter was small, we had frequent physiotherapy. She is now 9 years old and we receive virtually none. I believe that a lack of specialist physiotherapy was a major factor to my daughter's unusually rapid development of scoliosis as it was left untreated. We eventually saw a specialist at the Hammersmith in London but by that time it was too late. My daughter has appalling scoliosis and is too fragile for surgery. Physiotherapy is just not seen as important."

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. 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 7 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 7 centres, five of which had a specialist

“I believe that a lack of specialist physiotherapy was a major factor to my daughter’s unusually rapid development of scoliosis as it was left untreated. Physiotherapy is just not seen as important.”

A parent living in the South West of England spoke about her daughter’s experience

muscle physiotherapist; intermittent review in 16 centres and only short term treatment in 7.²

The following case study illustrates the difficulties adult patients’ experience in receiving physiotherapy.

Jill Brown, a retired physio from Wiltshire who has congenital myopathy, said:

“In my local area there is no physiotherapy for people such as myself with a long term disability. I have to pay for private physio as I know how much it benefits me.”

Furthermore, there is usually no strategy in place for succession planning, leaving the services fragile and vulnerable in view of their heavy dependence on the lead clinicians and health professionals (including physiotherapists) with a special interest in neuromuscular conditions.

Hydrotherapy

Hydrotherapy can be a highly effective form of therapeutic exercise for people with muscle weakness and patient experience illustrates it as an effective way of controlling pain and increasing mobility.

Despite its benefits, it is a very difficult therapy to access. It is a rare resource within the NHS and some hospitals have chosen not to include hydrotherapy provision in their rebuilding programmes because of the costs involved.

Hydrotherapy is not available in all trusts and where it does exist it is always over subscribed so people are frequently limited to 6-8 sessions and then discharged and usually cannot be referred again for 6 months to a year. The waiting list for hydrotherapy is often very long, likely to be several months.

Most patients find that in Council run Leisure centres the water temperature is too cold. However, private Leisure Clubs often keep their pools at a pleasantly warm temperature but membership fees are costly and pool access not always disabled friendly.

The following case study illustrates the barriers patients experience in accessing hydrotherapy.

A 28 year old patient who has Congenital Muscular Dystrophy, said:

“I am very disappointed that I have been unable to get hydrotherapy. I attended special school until I was 13 years old and I had hydro and physio each week. Once you reach 18 years old it’s like you get forgotten about. I have tried to get hydrotherapy organised but you need a carer plus someone else with a first aid certificate. As you can imagine this is not always possible. I really feel that we should not have to fight so hard to get hydrotherapy and physiotherapy. Once we reach adulthood we should automatically get referred to a physiotherapist and not get referred out of the system.”

“My children see an excellent physio at the Hammersmith hospital. It is a shame that we have to travel so far on trains and buses with two children to see these physios. It’s a long day although worthwhile as we get a lot of input and help.”

Emma, from Essex, a mother whose two sons have Duchenne Muscular Dystrophy

2. Current referral practices, particularly for adults with neuromuscular conditions, seem arbitrary and show considerable variation for patients

For adults, referral to physiotherapy in general is mixed and often very limited. Many patients only have access to blocks of therapy, i.e. 6-8 sessions, on a yearly basis; others have no access at all except in acute situations or for chest physiotherapy when required. Indeed, some patients are referred by their GP, others from their Consultant Neurologist and some have to make a self-referral.³

The following examples illustrate the difficulties adults have in receiving a referral to ongoing and timely physiotherapy:

Steve is 34 and lives in Weston-Super-Mare. He has Becker Muscular Dystrophy. In his own words:

“Muscular Dystrophy is a progressive disease that will always necessitate access to physiotherapy. However, there is a severe lack of understanding about my condition and ongoing physiotherapy is not available to me. I am restricted to a few weeks at a time as I have to go backwards and forwards to a GP to be re-referred again and again. Whenever I get discharged I always ask – does this mean I am cured?? The reality is that the system does not work for people like me with a long-term condition.

We require ongoing and timely physiotherapy from a physiotherapist with an understanding of our condition. I know that my condition has deteriorated because of the lack of therapy.”

Sheila has FSH and lives in Leicester. She is the head of the FSH support group and said:

“Many people’s experience is that they are told there is nothing that can be done for their condition, so they are not referred to physiotherapy or any kind of specialist help.

Some of our members decide to seek physiotherapy, perhaps through talking to other members, or hearing talks at events. When they try to get a referral to a physiotherapist there are various barriers. My local hospital has a computer system that automatically discharges patients after six months, so when I see the physiotherapist I then have to make an appointment for five months and 3 weeks.”

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

Jennifer Gallacher, from Middlesbrough who has SMA

3. Transition and challenges reaching adulthood

Increasing numbers of young people with neuromuscular conditions are reaching transition and living into adulthood due to improvements in therapies and medical care. For therapists who look after adults it is highly likely that there will be more patients with neuromuscular conditions due to improved longevity.⁴

It is crucial the health and social services respond to this change and provide adequate support and therapies to the emerging population of young people and adults.

Current service provision is not meeting this demand and the following problems have been identified:

- Once young people reach 16-19 years of age there is no standardised physiotherapy service available;
- Some young adults are discharged from satisfactory paediatric services with no follow up. This is very often a time when interventions are required for respiratory and cardiac complications of the condition;
- For respiratory physiotherapy there is very little expertise locally;
- Adults with an acute chest infection or who require acute rapid intervention, for example following a fracture, may not be seen quickly enough or for long enough to ensure that they regain their ability.
- Patients often experience difficulty receiving long term physiotherapy following a fracture and might consequently lose ambulation with disastrous implications for the patient and family.

Nurinda Bhoji, from Kent whose son has Duchenne Muscular Dystrophy:

“When my son was at school he received physio at least once a week. Since he turned 18 it has been non existent. As soon as you reach adult services you are lost”

Young people accessing further education can face particular problems, because additional support is often required at this stage.

Moving to adult services has become a right of passage for young people and many specialist centres have introduced the concept of “transition clinics”. They recognise that there is sufficient adult population and a real need for services to be developed in this area. Paediatric physiotherapists are developing transition processes in order to ensure the young person is fully prepared and able to accept responsibility of their condition to ensure they can access the appropriate service at the correct time. However, it is well documented that adult services on the whole tend to be less well staffed and locally delivered services are poor.⁵

The case study on the next page illustrates the difficulties adults experience in receiving rapid physiotherapy intervention following a fracture:

“It is vital that health and social services acknowledge the importance of access to ongoing physiotherapy for patients with muscle disease”

Rosie Paver, Head of Physiotherapy at the NMC

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 6 weeks and she was not able to stand and balance on one leg. 8 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 so that she can begin her rehabilitation. In the meantime she sits all day in her bed or chair.

4. The Neuromuscular Centre (NMC) in Cheshire

The Neuromuscular Centre (NMC) in Cheshire is a charitable organisation founded in 1990 and it is now part of the Muscular Dystrophy Campaign group. Its beginnings go back nearly 20 years when anger at the lack of adult provision for people with muscular dystrophy led to its creation. A core objective of the NMC is to provide ongoing physiotherapy for adults with neuromuscular conditions.

A survey of clients who attend the Neuromuscular Centre (NMC) in Cheshire, 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, revealed the benefits of physiotherapy for its patients. Indeed, 100% of respondents agreed that they felt better for having physiotherapy.⁶

Heather has been receiving physiotherapy at the NMC for eight years. She attends one or two sessions a week. In her own words:

“If I hadn’t started attending the NMC I don’t think I would ever have accepted my condition. I used to feel inadequate and downtrodden, embarrassed about having to use a manual chair. But meeting other people who were in the same boat as me was a revelation – I could see how they were getting on with their lives. I’ve made lots of friends and I’m close to the physios too – I confide in them in a way I wouldn’t with other people. They don’t just provide physiotherapy; they also provide me with emotional support. The NMC has given me my confidence back. It’s given me everything really.”

“I’ve been waiting over a year for an appointment with a physio. Ongoing physio just isn’t available, as you are restricted to a few weeks at a time. I have to go backwards and forwards to a GP to be re-referred again and again.

Steve, from Westen-Super-Mare who has Becker Muscular Dystrophy



The NMC achieves this core objective to provide physiotherapy in a caring and responsive environment by:

- Delivering appropriate specialist physiotherapy and hydrotherapy treatments;
- Assessing new patients referred to the service to identify the aims of treatment;
- Planning an individual’s treatment programme;
- Annually re-assessing patient’s physical and social needs;
- Responding to enquiries and questions received by phone, email, post or in person;
- Offering training to the families and carers of patients to increase awareness of the condition and help with ongoing care and Home Exercise;
- Supporting physiotherapy staff to maintain their skills and update their knowledge;
- Providing a professional, yet informal, environment for this service
- As far as is possible to secure full cost recovery for the service from PCT partners.

A major drive by NMC to find NHS funding support for physiotherapy has been increasingly successful and the NMC is nearly 90% of the way towards full cost recovery. However, a number of Primary Care Trusts are refusing to fund referrals to the centre.

The following case studies illustrate the difficulty patients experience in receiving funding from their PCT to pay for this vital service.

A patient who has CMT and receives physiotherapy every fortnight at the NMC, said:

“I was on a waiting list for 6 months to receive physiotherapy. I could not wait any longer and I am fortunate to now receive physiotherapy at the NMC. Although this has had a really positive impact on my life, my PCT will not pay the costs for this treatment which is really unfair.”

A 21 years old patient who has Becker Muscular Dystrophy and lives in Ripley Derbyshire, said:

“I really need regular physiotherapy from a physiotherapist knowledgeable of my condition to keep me mobile and stop my condition progressing so quickly. This is not available to me in my local area. I therefore travel to the excellent Neuromuscular Centre in Cheshire. However, this takes me nearly two hours to travel to the centre for therapy and, of course, the same time to get home and all at my own cost.”

“I have only ever had physio on the NHS for six weeks. I’m now forced to pay privately.”

Alan Dyer, from Somerset, who has Myotonic Dystrophy

5. Shortage of professional knowledge and expertise – the need for Continuing Professional Development

There is no doubt that medical advances have changed the natural history of neuromuscular conditions and this change has impacted on service provision within the NHS. In the last twenty years, for example, life expectancy for life limiting conditions like Duchenne Muscular Dystrophy (DMD) has increased.

Unfortunately, local community physiotherapists who treat adults do not always have the expertise and knowledge about people with neuromuscular conditions who in the past would not have survived into adulthood. There is therefore inadequate knowledge and experience to meet the needs of the emerging adult population.

A Muscular Dystrophy Campaign Initiative, the Physiotherapy Network has been set up to improve the shortage of professional training and knowledge of physiotherapists.

This Network runs a number of conferences each year to provide support and learning for physiotherapists across the UK. The conferences are funded by the Muscular Dystrophy Campaign with a small fee to be paid by each attendee. Despite the charitable support, a number of physiotherapists are still prevented from attending on most grounds.

In 1999 the Department of Health set out its commitment to Continuing Professional Development⁷ to ensure the delivery of high quality NHS services. However, despite the fact the majority of physiotherapists have little experience with inherited adult neuromuscular conditions and are unable to offer advice based on evidence or experience,⁸ some community physiotherapists are being prevented from attending training courses by their local Trust.

6. Lack of service standards and patient guidelines

Patients with neuromuscular conditions have no entitlement to specialist, ongoing physiotherapy.

However, progress is being made in developing agreement on standards of care for neuromuscular conditions through the TREAT-NMD initiative which is co-ordinated from the Newcastle centre (www.treat-nmd.eu).

Consensus has been agreed for a standard of care in Spinal Muscular Atrophy (SMA). This already provides a multidisciplinary approach to the management and care of patients with SMA. This Standard of Care cites the importance of chest physiotherapy for airway clearance and sets out recommendations for key interventions by physiotherapist, occupational therapists and orthopaedics on evaluation and treatment by functional levels.⁹

The Centre for Disease Control in the U.S. is currently coordinating a project – Care considerations for DMD. The project will draw up a comprehensive set of recommendations for standards of care in Duchenne Muscular Dystrophy. This will likely be complete in 2008. Treat-NMD, who contributed to the workshops, has produced a short version of their interim findings which can be found at www.treat-nmd.eu

In addition, a neuromuscular special interest group of the Association of Paediatric Chartered Physiotherapists was formed about three years ago. They aim to provide a national guideline on physiotherapy for patients with Duchenne Muscular Dystrophy.

International consensus for standard of care for all other neuromuscular conditions has not yet been realised.

“Developing the specialist physiotherapy service is much needed if we are to move away from the current postcode and specialist care lottery that currently exists.”

Clinical Specialist in Neuromuscular Disorders for the West of Scotland

The following is additional evidence from the devolved parts of the UK:

Physiotherapy Services in Scotland

Current provision

- Many patients in Scotland do not receive continuous, specialist physiotherapy or indeed any physiotherapy at all;
- There is currently only one Clinical Specialist Physiotherapist (CSPT) involved in the care of neuromuscular disorders in Scotland;
- This service is provided to the West of Scotland and is limited to children and young adults;
- Patients who live on the 95 inhabited islands of Scotland are often unable to access the local ferry or small aeroplanes to take them to the specialist muscle centre. Travelling can take in excess of 13 hours.
- Very few young adults have access to a local physiotherapist;
- There is no CSPT dedicated to the adult population and referrals have to be returned to the Lead Consultant creating an inequitable service.

It has been agreed that there is the need for a full time clinical specialist physiotherapist in the East of Scotland. Funding for this post has come from the Genetics Review and Scottish Government. However, this will still leave the North of Scotland and outer islands unaccounted for and the service will be limited to children and young adults.

Children and young adults – The CSPT is provided to the West of Scotland. She aims to undertake annual assessments of the DMD population but realistically these sessions are around every 14-24 months due to the increasing caseload which currently is in excess of 200 patients.

The CSPT undertakes specialist assessments both at clinic and in the community setting and inputs into the North Star database as well as undertaking teaching sessions to students, voluntary agencies and other professionals involved in the care of neuromuscular disorders.

Adults – There are no specialist physiotherapists dedicated adults with neuromuscular conditions living in Scotland. Referral to physiotherapy for adults is especially limited as they are only seen on request for an initial assessment and referral to a local physiotherapist. Furthermore, many adult patients only receive short bursts of therapy with no ongoing input. Those adults living in isolated areas have no access to physiotherapy at all.

The CPST commented on current state physiotherapy provision in Scotland, in her own words:

“I often travel over 100 hundred miles to see patients in my care and a number of families travel these same distances to receive specialist care in Glasgow. If we had more specialist physiotherapy posts throughout Scotland we could deliver a more localised and ongoing service to families and provide much more support and training to local community physiotherapist. This would be better for patients and also be a lot more cost effective for service providers.”

“I’m pleased with the specialist service we receive in London. In Cardiff it’s a bit hit and miss. I worry about what happens if my son needs quick access to physiotherapy in Wales”

Lisa, from Cardiff whose son has Duchenne Muscular Dystrophy

Standards of care and guidelines

Many physiotherapists in Scotland have expressed a desire for a care pathway or indeed a clinical guideline, as keeping abreast of the changes in management and policy can be difficult. This is particularly relevant where a therapist is newly qualified or has a generic caseload with many different conditions to take account of.

To meet this need, a number of physiotherapists in Scotland with an interest in neuromuscular disorders created a comprehensive Duchenne Muscular Dystrophy Scottish Management Profile.

The profile has been written to assist physiotherapists, to offer effective intervention at the different stages of Duchenne Muscular Dystrophy. It aims to highlight current practice in this field and direct the reader to useful resources and references.

Scotland also benefits from a **Scottish Muscle Network** which aims to improve knowledge of the neuromuscular conditions and to improve communication between all those who are involved with neuromuscular conditions, including physiotherapists.

The objectives of the Network are to:

- improve care provided to all Scottish neuromuscular patients, ensuring they have access to local health, social and educational professionals;
- inform about the condition and ensure people are aware of what is offered wherever they live in Scotland;
- promote communication between health, social and educational professionals and voluntary organisations, providing them with educational opportunities;

- hold meetings for physiotherapists and other health professionals who have an interest in the management of the neuromuscular disorders in the community – this allows sharing of experience and for many professionals, leads to greater knowledge of neuromuscular disorders;
- establish ways in which patients and their representatives can communicate their needs to service deliverers.

Physiotherapy Services in Wales

- Many patients in Wales with neuromuscular conditions do not have access to physiotherapy as part of a multi-disciplinary management of care

Specialist neuromuscular physiotherapy is not available for patients at any adult muscle management clinic in Wales, other than through a single specialist respiratory physiotherapist who attends most of the bi-monthly neuromuscular ventilation clinics in Cardiff.

Physiotherapy intervention exists in some of the paediatric clinics in South Wales. However, these community physiotherapists are not specially trained nor do they have expertise in neuromuscular conditions. These services are reliant on the interest of the therapist and are not strategically planned as part of a holistic service.

The case studies on the next page illustrate the vulnerability and importance of these services:

“I found many parts Wales to be a desert for the treatment of patients with conditions like mine. Expecting disabled people and their families to travel long distances just to gain access to the clinical care they need is shocking.”

Steve from Colwyn Bay with Becker Muscular Dystrophy

Lynne’s son has Duchenne Muscular Dystrophy and attends a special school in Wales. In her own words:

“When my son was in mainstream school it was very difficult to access physio services. We therefore chose to send our son to a special school. However, the physiotherapy sessions in school have been reduced from 2 sessions a week to one session a week as the resident physiotherapist has retired and there appears to be no replacement.”

Anne is a community physiotherapist in South Wales. She has a few children in her care with neuromuscular conditions. In order to provide the best care that she can for her patients, Anne attended a specialist neuromuscular centre at the Hammersmith Hospital in England to learn about the physiotherapy sessions there and to receive guidance about best practice. Anne was very impressed by the care and expertise on offer at the Hammersmith and the difference made to quality of life. Anne wishes all patients with neuromuscular conditions had access to this level of support.

- Services exist across the border in England but some LHBs are reluctant to fund referrals and services are therefore dependent on charitable subsidy.

A specialist physiotherapy service and specialist muscle pathology services exists across the border in England at the Oswestry Neuromuscular Centre and neuromuscular physiotherapy services are provided at the NMC in Cheshire for adults. However, whether patients can access these services depends on the discretion of the Local Health Board to fund their referral and ongoing treatment.

Currently, eight patients from Wales travel to the NMC in Cheshire regularly to receive physiotherapy. They include five patients from Flintshire LHB. These five patients travel to the centre every two to three weeks for specialist physiotherapy.

However, Flintshire refuses to pay the NMC for the treatment, despite referring the patients indirectly for physiotherapy. Of these five patients, three were referred from Flintshire LHB to the Orthopaedic hospital in Oswestry where a consultant then referred them to the Neuromuscular Centre. One was referred from Flintshire to the Walton Centre for Life and then on to the Neuromuscular Centre, and one patient from Flintshire to the Wrexham Maelor Hospital, where a consultant referred them to the Neuromuscular Centre.

The essential clinical care these patients receive is funded by the NMC rather than these Health Boards in Wales. The NMC is a social enterprise and charitable organisation and relies on contributions from LHBs and PCTs for services they use, as well as its own fundraising efforts. Flintshire use services provided by the NMC at a total cost of £11,000 per annum. All other Local Health Boards using these services provided by the NMC fund their treatment and pay the NMC.

Conclusion

We have illustrated those gaps in service provision and the actions necessary to improve care for adults and children with neuromuscular conditions.

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, such as physiotherapy, please email your details to campaigns@muscular-dystrophy.org

Appendices

Appendix 1 – Importance of physiotherapy for all patients with a neuromuscular condition

For all neuromuscular conditions, the physiotherapist will help to:

- Minimise the development of contractures and deformities through a programme of stretches and, where appropriate, exercises
- Anticipate and minimise any secondary physical complications
- Identify and prescribe aids and equipment (orthoses, callipers, wheelchairs and standing frames, for example)
- Advise on moving and handling issues
- Monitor respiratory function and advise on techniques to assist with breathing exercises and methods of clearing secretions
- Optimise function and positively manage deterioration.

Patients, carers and families require access to a physiotherapist with specialist knowledge of neuromuscular conditions so that they can be given training on exercises recommended to be done regularly at home. A home physiotherapy regime would be based on:

- The needs of the patient
- The advice of your specialist physiotherapist
- The needs of the family (a practical routine to suit the family’s lifestyle).¹⁰

Appendix 2 – International evidence of the value of a multidisciplinary approach to the care of patients with neuromuscular conditions

A comparative cohort study was carried out with patients attending the Neuromuscular Centre Nijmegen in the Netherlands. Their findings and the reported problems regarding Occupational Therapy, Physiotherapy and Speech and Language Therapy for chronic conditions, support the value of an integrated multidisciplinary expert advice regarding appropriate allied health care for patients with neuromuscular conditions. Also the majority of patients rated the multidisciplinary assessments and advice positively.¹¹

Appendix 3

Survey of NHS Trusts, PCTs and Patients on Physiotherapy Services

Introduction

The purpose of the survey was to identify the existence and standard of physiotherapy services for children and adults with neuromuscular conditions.

Method

In April 2008, the Muscular Dystrophy Campaign contacted by email 173 NHS Trusts in England and under the Freedom of Information Act asked the following questions:

- Does your Trust have a system in place to ensure ongoing physiotherapy for patients with muscular dystrophy and related conditions where required?
- Does your trust have physiotherapists available to a) children and b) adults with specific training in muscular dystrophy and related neuromuscular conditions?
- Does your Trust provide financial support to physiotherapists who would like to attend training courses in muscular dystrophy and related conditions as part of their Continuing Professional Development?

NHS Trusts who responded

Out of the 122 NHS Trusts that have so far responded, the following picture has emerged:

- 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 have physiotherapists available to children 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;
- One in five NHS Trusts fail to provide financial support to physiotherapists to attend training courses in muscular dystrophy and related conditions as part of their Continuing Professional Development.

Method

In April 2008, the Muscular Dystrophy Campaign contacted by email 151 PCTs in England and under the Freedom of Information Act asked the following questions:

- Does your PCT have a system in place to ensure ongoing physiotherapy for patients with muscular dystrophy and related conditions where required?
- Does your PCT have physiotherapists available to a) children and b) adults with specific training in muscular dystrophy and related neuromuscular conditions?
- Does your PCT provide financial support to physiotherapists who would like to attend training courses in muscular dystrophy and related conditions as part of their Continuing Professional Development?

PCTs who responded

Out of the 75 PCTs that have so far responded, the following picture has emerged:

- Two out of three PCTs who responded do not provide ongoing physiotherapy for patients with muscular dystrophy and related conditions where required;
- More than half of PCTs who responded do not have physiotherapists available to children with specific training in muscular dystrophy and related neuromuscular conditions;
- One in five PCTs who responded do not have physiotherapists available to adults with specific training in muscular dystrophy and related neuromuscular conditions;
- One in five PCTs fail to provide financial support to physiotherapists to attend training courses in muscular dystrophy and related conditions as part of their Continuing Professional Development.

A survey of 90 patients living with neuromuscular conditions revealed:

- One in four patients do not receive ongoing physiotherapy;
- One in eight responses were from young adults whose ongoing physiotherapy has either stopped or been significantly reduced since leaving school in recent years;
- Half of patients who responded receive ongoing physiotherapy thanks to the charitable sector;

Appendix 4

Exercise therapy for patients with mitochondrial myopathies – Professor Doug Turnbull

Previous work has shown that exercise therapy may be beneficial in patients with mitochondrial disease.

Professor Doug Turnbull's study is looking at the long-term effect of this exercise to determine if the changes seen are long-lasting and result in a permanent improvement in amount of good versus bad mitochondrial DNA.

Prof Turnbull and his colleagues also wish to determine if combining both strength (using weights) training and resistance (exercise bike) training together results in a better improvement compared to resistance training alone. Most importantly this study should provide clear information about the type and degree of exercise that patients should take.

References

- ¹ Scoliosis is the lateral curvature of the spine in the coronal plane. Some authors have defined scoliosis as the lateral curvature of spine in the coronal plane with a Cobb angle measuring more than 10.
- ² Hill, M.E. and Phillips, M.F. Service provision for adults with long-term disability: A review of services for adults with chronic neuromuscular conditions in the UK, *Neuromuscular Disorders* 2006, 16, p. 109
- ³ Clemence, Mark L and Seamarka, David A. GP referral for physiotherapy to musculoskeletal conditions, *Family Practice*, 2003, 20:5, p. 581
- ⁴ Eagle M, Morrow M, Scott E 'The Changing role of the Paediatric Physiotherapist in the Emerging Population of adults with NMD', *Journal of the Association of Paediatric Chartered Physiotherapists* March 2007, p18-26
- ⁵ Eagle, M. Report on Muscular Dystrophy Campaign workshop: Exercise in neuromuscular disease Newcastle, January 2002, *Neuromuscular Disorders*, 2002, 12, p. 975-983
- ⁶ Neuromuscular Centre Social Accounts 2006-07, http://www.nmcentre.com/Social_Accounts_NeuroMuscular_Centre_2006-07.pdf
- ⁷ HSC 1999/154: Continuing professional development: Quality in the new, NHS http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH_4004315
- ⁸ Michelle Eagle, Report on Muscular Dystrophy Campaign workshop: Exercise in neuromuscular disease Newcastle, January 2002, *Neuromuscular Disorders* 2002, 12, p. 976
- ⁹ TREAT-NMD, Consensus statement for Standard of Care in Spinal Muscular Atrophy, http://www.treat-nmd.eu/assets/documents/SOC/SMA/precis/SOC_ENG.pdf
- ¹⁰ Physiotherapy Management for Duchenne Muscular Dystrophy, Muscular Dystrophy Campaign http://www.muscular-dystrophy.org/information_resources/publications/physiotherapy.html
- ¹¹ Cup, Edith H.C. Pieterse, Allan J. Knuijt, Simone. Hendricks, Henk T. Van Engelen, Baziel G.M. Oostendorp, Rob A.B and Gert-Jan Van Der Wilt. Referral of patients with neuromuscular diseases to occupational therapy, physical therapy and speech therapy: Usual practice versus multidisciplinary advice, *Disability and Rehabilitation*, May 2007, 29(9), p. 725

Bibliography

- Bushby, K. Bourke, J. Bullock, R. Eagle, M. Gibson, M, Quinby, J. The multidisciplinary management of Duchenne muscular dystrophy, *Current Paediatrics*, 2005, 15, p. 292-300
- Clemence, Mark L and Seamarka, David A. GP referral for physiotherapy to musculoskeletal conditions, *Family Practice*, 2003, 20:5, p. 578-582
- Cup, Edith H.C. Pieterse, Allan J. Knuijt, Simone. Hendricks, Henk T. Van Engelen, Baziel G.M. Oostendorp, Rob A.B and Gert-Jan Van Der Wilt. Referral of patients with neuromuscular disease to occupational therapy, physical therapy and speech therapy: Usual practice versus multidisciplinary advice, *Disability and Rehabilitation*, May 2007, 29(9), p. 717-726
- Delorme, Thierry. Boureau, François. Eymard, Bruon. Laforet, Pascal. Cottrel, Frédérique. Clinical study of chronic pain in hereditary myopathies, *European Journal of Pain*, 2004, 8, p. 55-61
- Eagle M, Morrow M and Scott E. The emerging population of adults with Neuromuscular Disorders, *Association of Physiotherapists in Neurology Journal Synapse Autumn/Winter* 2006, p18-24
- Eagle M, Morrow M and Scott E. The Changing role of the Paediatric Physiotherapist in the Emerging Population of adults with NMD, *Journal of the Association of Paediatric Chartered Physiotherapists* March 2007, p18-26
- Hill M.E. and Phillips M.F. Service provision for adults with long-term disability: A review of services for adults with chronic neuromuscular conditions in the UK, *Neuromuscular Disorders*, 2006, 16, p. 107-112
- Physiotherapy Management for Duchenne Muscular Dystrophy, Muscular Dystrophy Campaign http://www.muscular-dystrophy.org/information_resources/publications/physiotherapy.html

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