

**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



Hydrotherapy in the UK

The urgent need for increased access



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About Muscular Dystrophy UK

Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions.

- ▶ We support high-quality research to find effective treatments and cures, and leading the drive to get faster access to emerging treatments for UK families.
- ▶ We ensure everyone has the specialist NHS care and support they need, with the right help at the right time, wherever they live.
- ▶ We provide a range of services and opportunities to help individuals and their families live as independently as possible.

What are muscle-wasting conditions?

There are about 60 types of muscle-wasting conditions. These conditions cause muscles to weaken and waste over time, leading to increasing disability. The conditions may affect not only the muscles in the limbs, but also those of the heart and lungs, sometimes significantly shortening life-expectancy.

Many of the conditions are low-incidence, rare conditions, with some regarded as very rare or ultra-orphan. Muscle-wasting conditions can be genetic or acquired and, with few exceptions, there are currently no effective treatments or cures available.

Clinical trials for some muscle-wasting conditions are now underway and it is hoped that these may lead to the introduction of new treatments that can slow or arrest the progression of these often devastating conditions.

Foreword

For many people who are, like me, living with a muscle-wasting condition, hydrotherapy can be essential in maintaining the best quality of life for the longest time possible.

In some countries, hydrotherapy is seen as a vital part of conventional medicine and patients are reimbursed by the health insurance companies in some of these regions, at least in part (e.g. Germany). However, in the UK, hydrotherapy is not seen as a routine service for managing a long-term mobility problem, meaning disabled people and their families find it extremely difficult to access this service. In fact, one peer said that they knew about hydrotherapy for horses and asked whether people could have it too.

Where NHS-funded hydrotherapy is available it is often restricted to patients whose improvements can be demonstrably measured. A patient with a broken leg can be documented as referred, treated and then discharged or 'cured'. I know this from first-hand experience when I broke my leg in 2007. I was given hydrotherapy for the leg, not for my muscle-wasting condition, because those like me with muscle-wasting conditions fail to meet the 'cured' criteria.

Hydrotherapy and other water-based activities are vital health and social activities for families. They promote mobility, build confidence, and provide important sporting opportunities for disabled people. But, just as important, is the feeling of wellbeing when one is immersed in warm water. It is a relaxing time, even if one is exercising quite hard.

I urge anyone reading this to join me and Muscular Dystrophy UK in calling on hospital trusts and local authorities to improve the availability of hydrotherapy services to ensure the best quality of life for disabled people.

Baroness Celia Thomas of Winchester MBE



Executive summary

For people with muscle-wasting conditions, hydrotherapy has been outlined by many as an excellent treatment. Many health professionals believe it improves or maintains mobility, strength and flexibility and is a good form of aerobic exercise for cardiopulmonary fitness¹.

However, access to hydrotherapy is a key barrier faced by people with muscle-wasting conditions. Many people are not able to benefit from the positive effects hydrotherapy could have on their health.

Muscular Dystrophy UK has conducted research into the provision of hydrotherapy treatment in the UK for people with muscle-wasting conditions. Our research has found that animal owners have a much higher chance of accessing a hydrotherapy pool for their animals, than people with muscle-wasting conditions do. In the UK currently, there are 362 pools (appendix 1) available for animals and 179 pools available for people.

David Jones' son, Carson (7), has Duchenne muscular dystrophy

Carson and his family lives in Rhyl. After their local hydrotherapy pool at Glan Clwyd Hospital closed in 2014, Carson began suffering from cramps – these had previously been relieved by hydrotherapy. This forced the family to fundraise so they could buy a small inflatable spa that Carson could use at home. Mimicking hydrotherapy in this way was the only option they had to relieve Carson of his cramps and pains.

David said:

“Carson has been struggling since the closure of the pool at our local hospital; the warm waters allowed him to relax and helped loosen his tightening muscles.

“We want to improve his quality of life. Hydrotherapy gives him the chance to rest as he is in a wheelchair all day.”

Patient survey findings

Muscular Dystrophy UK undertook a survey of people's experiences of accessing and receiving hydrotherapy treatment.

Nearly 500 people living with muscle-wasting conditions responded to our nationwide survey. Results revealed that for many people, hydrotherapy reduced pain, increased mobility and improved quality of life, however many people struggled to access the treatment at all.

¹Ciafaloni, E and Moxley, R (2008), Treatment Options for Duchenne Muscular Dystrophy, pp. 89



Key findings:

- ▶ families living with muscle-wasting conditions are being turned away from some hydrotherapy pools, being told they are only for use by people with broken bones
- ▶ families are being told if they use some hydrotherapy pools, they need to be able to show measurable change
- ▶ many hydrotherapy pools do not contain accessible changing rooms and hoists into the pool
- ▶ almost a third of respondents pay for their own hydrotherapy, with some families being forced to pay over £75 per visit to a hydrotherapy pool
- ▶ 30 percent find hydrotherapy pools too expensive to access
- ▶ more than three quarters of respondents are not able to access a hydrotherapy pool as often as they feel they need to, in order to improve their wellbeing
- ▶ nine out of 10 consider hydrotherapy to be a crucial part of managing their muscle-wasting condition, yet almost half say they are able to access hydrotherapy only very rarely
- ▶ more than two thirds of people struggle to find a suitable hydrotherapy pool to use
- ▶ almost 20 percent of respondents say they travel between 20 and 100 miles for hydrotherapy, with some being forced to travel over 100 miles to their nearest accessible hydrotherapy pool
- ▶ in some areas of the UK, there is only one hydrotherapy pool available for nearly 1,300 people living with muscle-wasting conditions
- ▶ in the UK currently, there are more than twice the number of hydrotherapy pools available for animals compared to those available for people.

These findings all reflect an unacceptable situation. Nine out of 10 people with muscle-wasting conditions, who have been able to access hydrotherapy treatment, have said that they find hydrotherapy to be crucial in managing their muscle-wasting condition.

We believe that all people living with muscle-wasting conditions should be able to enjoy the opportunity to access hydrotherapy, regardless of where in the country they live.

Calls to action

Muscular Dystrophy UK is calling on the organisations listed in this report to make sure people with muscle-wasting conditions can get the hydrotherapy treatment they need, and therefore improve their quality of life. This will require action by these organisations to remove the current barriers, including cost, travel and pool availability.

- 1. We call for a national review, led by the Department of Health in conjunction with the Department for Communities and Local Government, into the provision of hydrotherapy services for people affected by muscle-wasting conditions. The review should establish why they are not able to access the treatment and how changes can be made to enable them to access this form of healthcare.**
- 2. We call on all local authorities to make reasonable adjustments to ensure that their community swimming pools and changing rooms are accessible for people with muscle-wasting conditions to use.**
- 3. We call on the NHS to ensure that everyone with a muscle-wasting condition who requires hydrotherapy is referred for a course of it, so they can learn the exercises and continue doing them on their own in community-based hydrotherapy pools.**
- 4. We call on schools that have hydrotherapy pools to make them available to people outside of school hours.**
- 5. We call on organisations that have hydrotherapy pools available to people with muscle-wasting conditions to share details of their facilities with Muscular Dystrophy UK so we can add them to our online map of neuromuscular services.**

What is hydrotherapy?

Hydrotherapy is a therapy that involves the use of water for pain relief and treatment. It is different from swimming as it involves performing special exercises in a warm-water pool, and different from water aerobics as it focuses on controlled movements and muscle relaxation.

Hydrotherapy can be a highly effective form of therapeutic exercise for people with muscle-wasting conditions. Studies suggest that when patients with muscle-wasting conditions receive physiotherapy in association with hydrotherapy, they achieve measurable improvement in the quality of daily living. The main benefits include:

- ▶ a sense of freedom and a greater range of movements, which the weight of the water gives you
- ▶ muscle relaxation and alleviation of pain, which the increased temperature of the water allows
- ▶ greater range of movement and resistance provided by the water, which allows for exercises that can strengthen the muscles
- ▶ improved flexibility.



Benefits of hydrotherapy

Some people with muscle-wasting conditions have been told by health professionals that hydrotherapy would be of little benefit to them.

However, Muscular Dystrophy UK's survey found that many respondents who had had hydrotherapy found it had measurable benefits to their health:

- ▶ one in two say hydrotherapy reduces their pain
- ▶ more than three quarters say hydrotherapy increases their mobility
- ▶ more than a third says hydrotherapy improves their quality of life.

Anisa Kothia, from West Yorkshire, whose son has Duchenne muscular dystrophy:

“Hydrotherapy helps my son to relax his muscles and complete stretches. The water helps by bearing half of his weight, which he would not be able to do outside of a hydrotherapy pool.”

Anthony Platt, from Manchester, has limb girdle muscular dystrophy:

“Being able to access hydrotherapy provides great exercise and freedom from a wheelchair. Benefits that I have found have been increasing blood circulation and muscle tone.”

Max Huxham, from Sheffield, whose daughter Helena had Spinal Muscular Atrophy:

“Hydrotherapy pools are a fantastic facility for all children with mobility difficulties. The treatment provides a truly excellent play environment where considerable progress can be made in the neurological and physical empowerment for the child. Therapists can pursue a variety of strategies for the child that are not possible outside the pool.

“My daughter Helena who had Spinal Muscular Atrophy always looked forward to coming to the pool because she could be freed from the constraints of gravity and was able to “fly like an angel” with free movement of both her arms and legs in the water.

“She was able to play with her sister using toys and was able to have towing races around the pool. On occasions, her aunts were able to participate too making it possible for other members of the family to see Helena in a completely different light. I would recommend accessing a hydrotherapy pool to any parent with a child with a muscle-wasting condition.”

Availability of hydrotherapy services for people with muscle-wasting conditions vs. hydrotherapy for animals

Muscular Dystrophy UK has undertaken extensive research which has found that in the UK the provision of hydrotherapy is far greater for animals than it is for humans. In the UK, there are at least 362 hydrotherapy pools solely for the use of animals. This is compared to 179 pools² that Muscular Dystrophy UK knows of that are suitable for people with muscle-wasting conditions to use for hydrotherapy treatment.

This means that for every hydrotherapy pool available for a person with a muscle-wasting condition in the UK, there are more than two pools available for animals to use.

| Region | Hydrotherapy pools available for animals | Hydrotherapy pools available for people with muscle-wasting conditions |
|--------------------------|--|--|
| Scotland | 22 | 12 |
| North East | 17 | 12 |
| North West | 44 | 27 |
| Yorkshire and Humber | 27 | 26 |
| East Midlands | 27 | 4 |
| West Midlands | 30 | 9 |
| South East | 20 | 10 |
| London | 22 | 25 |
| South West | 60 | 12 |
| East of England | 35 | 14 |
| Thames Valley and Wessex | 35 | 17 |
| Wales | 13 | 7 |
| Northern Ireland | 10 | 5 |
| Total | 362 | 179 |

²http://hub.muscular-dystrophy.org/hub/near-you/?tax_category=21&gmw_address%5B0%5D&gmw_distance=500&gmw_units=imperial&gmw_form=1&gmw_per_page=5&gmw_lat&gmw_lng&gmw_px=pt&action=gmw_post

There are over 70,000 people in the UK living with a muscle-wasting condition. In the current situation, this means there is one hydrotherapy pool available for every 395 people with a muscle-wasting condition. By contrast, if the hydrotherapy pools solely for the use of animals were also to be made available to people, it would mean one hydrotherapy pool available for every 131 people with a muscle-wasting condition.

There is also unequal access to hydrotherapy pools across the UK. In the East Midlands there are 1,281 people with muscle-wasting conditions per hydrotherapy pool. Those who live in Yorkshire and Humber are better served – 234 people with muscle-wasting conditions per hydrotherapy pool.

| Region | Number of people with a muscle-wasting condition per animal hydrotherapy pool | Number of people with a muscle-wasting condition per hydrotherapy pool |
|---------------------------------|--|---|
| Scotland | 272 | 499 |
| North East | 182 | 258 |
| North West | 185 | 302 |
| Yorkshire and Humber | 225 | 234 |
| East Midlands | 189 | 1,281 |
| West Midlands | 208 | 693 |
| South East | 250 | 501 |
| London | 403 | 355 |
| South West | 101 | 505 |
| East of England | 189 | 473 |
| Thames Valley and Wessex | 136 | 281 |
| Wales | 264 | 490 |
| Northern Ireland | 199 | 399 |

Someone with a progressive muscle-wasting condition might need regular hydrotherapy to improve mobility and quality of life. However not all of the 179 hydrotherapy pools available to people in the UK can be accessed regularly, for many reasons, such as:

- ▶ many hydrotherapy pools are based in schools and are only open during school hours and terms
- ▶ privately-owned hydrotherapy pools can be expensive to access – often more than £75 for a half-hour session
- ▶ people have to travel long distances to get to a pool, and this is not sustainable
- ▶ hydrotherapy pools do not always have hoists, or accessible changing facilities.

Auzair Arshad (17) from Bristol has Duchenne muscular dystrophy. His brother, Khurm, relates their experience:

“When I first realised what the situation was, I thought it was an absolute joke. I had been looking on the internet for hydrotherapy pools and I was coming back with more and more results for animals but none for humans. I had to call round the pools to ask what they offered.



“A human can tell you the enormous benefits hydrotherapy brings to them, but an animal can’t. However, the animal seems to get a lot more care.

“We would have to pay for private hydrotherapy sessions, which would cost around £70 a time, because we would have to bring our own life guard and physiotherapist with us. Auzair would need to go once a week.

“When Auzair does not have any physiotherapy, it makes a massive difference to his sleep and his muscle relaxation. My parents and I do his physiotherapy in the evenings and we really noticed the difference in his muscle function after he stopped the hydrotherapy. People with muscle-wasting conditions who can still walk say they walk completely differently after a hydrotherapy session. Everyone swears to the benefits the treatment offers.”

Rosalind Webb, from Essex, has facioscapulohumeral muscular dystrophy (FSH):

“I would love the opportunity to access hydrotherapy treatment but my local pool at Broomfield Hospital was closed some years ago.

“This has meant that I am not able to access a hydrotherapy pool because the nearest one is in Sudbury in Suffolk, which is over an hour’s drive away. This is not possible for me due to my muscle-wasting condition.”

Dr Mustafa Haqqani, from Cheshire, has myotonic dystrophy:

“Hydrotherapy and physiotherapy are such vital ways to help people with muscle-wasting conditions. It is a shame that the hydrotherapy pools we can use are so few and far between.

“I used to travel over 100 miles every week to be able to access hydrotherapy, but as my condition continued deteriorate, I had to stop because it became too difficult to travel such a distance to access the pool I was using.”

Elizabeth Holt, from Gloucestershire, has a daughter who has spinal muscular atrophy (SMA):

“My daughter had access to hydrotherapy weekly during term-time at a school pool while she was in pre-school but now that she has moved to full-time education, there is no facility for her at school.

“I found a closer hydrotherapy pool that she could use,

but it was too expensive, at £50 per session. The pool [management] was not flexible with times of use as well as having no-one on the poolside to help."

Theresa Merry, from Oxfordshire, has two daughters who have congenital muscular dystrophy:

"The only way my daughters have been able to access hydrotherapy is to self-fund the treatment. This has cost us £75 per session and also means we can't afford to pay for a physiotherapy session, which would be also helpful and should be done in conjunction with hydrotherapy."

Vivek Gohil, from Leicestershire, has Duchenne muscular dystrophy

"There seems to be a lack of awareness about how important hydrotherapy is for people with muscle-wasting conditions.

"We have an ongoing need for hydrotherapy, which is not fulfilled by just being given a block of sessions for six weeks. This does not allow us to continue to maintain our condition because once our block of six sessions is over we struggle to be able to access hydrotherapy treatment anywhere else. This is due to community swimming pools not being the correct temperature and not having hoist facilities in changing rooms and to get in and out of the pool.

"The main issues I've faced when trying to access hydrotherapy is inaccessible changing facilities with no hoists, which means that I am able to access the pool but nothing else, which is useless to me.

"Hydrotherapy treatment seems to be catered for rehabilitation of patients after accidents rather than for people with muscle-wasting conditions who need access to this vital treatment to help us improve our mobility and reduce the pain that we feel in our muscles."

Summary

Access to hydrotherapy treatment can be vital for many people with for people with muscle-wasting conditions. It helps some to manage their condition and improve their quality of life by reducing pain and increasing mobility.

Being able to access this treatment should not depend on where a person happens to live, or the amount of money they have available to spend on hydrotherapy treatment.

Muscular Dystrophy UK is committed to working with families, healthcare professionals, the NHS and the Department of Health and equivalent bodies in the devolved countries to address the gaps in care that this report highlights.

Get involved

If you would like to share your story and get involved with our campaign and write to your local MP on hydrotherapy treatment, please get in touch with **Lloyd Tingley** on l.tingley@muscular dystrophyuk.org or call **020 7803 4804**.

If you have been affected by any of the issues raised in this report, or are struggling to access the healthcare you need, such as hydrotherapy, our care and support, and advocacy teams are here to help you. Please get in touch with them at info@muscular dystrophyuk.org or call **020 7803 4808**.

Appendix 1

Hydrotherapy pools for animals in the UK

Muscular Dystrophy UK undertook research (via Internet search engines and phone calls) to establish how many hydrotherapy pools there are in the UK for animals. This research was conducted by three members of Muscular Dystrophy UK staff over the period of a month. The final total that we found from our research was 362 pools. We believe, however, that there are more pools available for animals than this research found.