



**Invest to Save:**

Improving services and  
reducing costs in Wales

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## Invest to Save:

# Improving services and reducing costs in Wales

I am pleased to welcome this briefing, which puts forward the case for investing in preventative services for people with muscular dystrophy and related neuromuscular conditions in Wales. Following the Cross Party Group for Muscular Dystrophy's inquiry into service provision in Wales and subsequent publication of the *Thomas Report*, there has been significant progress in Wales with the appointment of three neuromuscular care advisors. However, despite this, services remain patchy across Wales and many people are simply not getting the services they need. Not only does this lead to poorer patient outcomes but, in many cases, may also lead to increased costs. I therefore call on the Welsh Assembly Government and NHS Wales to take note of these findings and to work to improve patient care for everyone in Wales with a neuromuscular condition.

Bethan Jenkins AM  
(Chair, Cross Party Group on Muscular Dystrophy)

Sadly, two of my sons who had Becker muscular dystrophy have now passed away but I am continuing to fight for better services in Wales because it is so important that other families can get the preventative services they need to give them the best quality of life possible.

Ray Thomas  
(Neath)

My son, Alex, is only two and doesn't need a great deal of support yet. At the moment, we go to Great Ormond Street Hospital in London once a year to see his specialists but I am fighting for similar high quality care to be available locally to make sure that Alex and other patients in Wales don't have to fight to get the right services at the right time.

Jeanette George  
(Cardiff)

**This report has been endorsed by the following neuromuscular specialists in Wales:**

Dr Jane Fenton-May  
Sarah Harris  
Dr Gareth Llewelyn  
Dr Mark Rogers  
Rachel Salmon

## Why invest?

There is increasing evidence to suggest that investing in a broad range of health and social care services for people with muscular dystrophy and related neuromuscular conditions, before their health reaches crisis point, can save money in the longer term.

Specialist multi-disciplinary care has been developed by leading clinicians as the best model for delivering effective services for neuromuscular conditions, given that they are complex, multi-system diseases. Specialised services also need specialised staff and equipment: expert physiotherapy, orthotics, early cardiac monitoring and intervention and corticosteroids have been shown to improve muscle function and maintain independent mobility. It is also important to put succession plans in place to ensure the continuity of specialised services in Wales when doctors and physiotherapists move on. With around 3,500 patients in Wales with neuromuscular conditions, providing the right services at the right time becomes even more important.

## The cost of unplanned emergency admissions

We estimate that the cost of unplanned emergency admissions in Wales could be as high as **£3,917,052** and as much as **£81,527,633** across the whole of the UK <sup>1</sup>.

NHS Wales has made significant progress since the publication of the *Thomas Report* in 2010, including welcome investment in three neuromuscular care advisor roles: two covering south and mid-Wales and one covering north Wales. The NHS has also invested in specialist paediatric and transitional physiotherapy posts, and has recognised that there are a number of areas which should be prioritised for development. This includes work to identify unplanned emergency admissions, which, the NHS recognises, can often result in significant additional care requirements.

With the high costs of emergency hospital admissions for patients with neuromuscular conditions, **the evidence is clear: investing in neuromuscular services could not**

**only reduce spending on unplanned admissions in Wales but could also improve patient outcomes.**

We estimate that a relatively small investment in preventative services could result in savings of approximately **£31 million** across the whole of the UK. An investment of just **£4.6 million** across the UK could go a long way towards preventing unplanned hospital admissions <sup>2</sup>.



<sup>1</sup> This figure has been calculated using the NHS data which takes the average number of emergency admissions per patient (0.3949), and average cost per emergency admission (£2,890.18).

<sup>2</sup> In a recent Parliamentary debate on neuromuscular services in the North West of England, the Minister for Care Services, Paul Burstow MP, said, "The number of people admitted for non-invasive, elective care, shows that there are many preventable costs in the system. That amounts to just under £5 million in the north-west alone. Those costs could be avoided and the money could be spent better." Westminster Hall Debate (9 February 2011), *Neuromuscular Care (North West)*. Available at: [www.bit.ly/rzoapU](http://www.bit.ly/rzoapU). The estimate of £4.6 million is based on the investment of £400,000 made into services in the West Midlands.

Costings data calculated as part of the Cross Party Group's Inquiry outlined the minimal investment required for service improvement in Wales.<sup>3</sup>

Posts required	£s recurring	Achieved?
1.5 WTE Consultants (inc. secretarial support) specialising in neuromuscular conditions	£195,000	✗
3 WTE Care advisors/specialist nurse (band 7 – mid range)	£129,036	✓
1 WTE Specialist physiotherapist (band 7 – mid range)	£43,012	Part-achieved
0.5 WTE Psychologist (mid grade band 8a)	£25,533	✗
0.5 WTE Occupational therapist (band 7 – mid range)	£21,506	✗
1 Network manager (band 7 – mid range)	£43,012	✗
0.5 WTE Administrator (band 5 – mid range)	£14,591	✗
<b>Total investment required (full year cost)</b>	<b>£471,690</b>	

Hospital admissions are extremely costly and often avoidable. For example, admission to a specialist ward can **cost the NHS up to £1,925 per day**. Research has found that the provision of interventions at home can help prevent hospital admissions for patients with neuromuscular conditions. Between October 2006 and September 2008, 39 patients who were part of a study, received respiratory support (for example, mechanically assisted coughing) on call at home. As a direct result of these preventative interventions at home, over 30 hospital admissions were prevented<sup>4</sup>.

### Investing to save

Investing in a wide range of preventative services can contribute to these cost savings and improved outcomes. For example, getting the right wheelchair at the right time can prevent the development of pressure sores, contractures or skeletal deformity in patients with neuromuscular conditions. The provision of the appropriate wheelchair can actually reduce the cost to the NHS, decreasing the need for potentially expensive operations and costly inpatient episodes. However, as the *Thomas Report* demonstrated, access to these services can be limited.

Provision of specialist equipment, such as cough assist machines (which helps a person clear lung secretions by giving a deep breath in followed by a suck out, helping patients to

cough), can also help to provide vital support. However, we are concerned that access to such machines can be patchy.<sup>5</sup>

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

A survey of clients who attend the Neuromuscular Centre in Cheshire, the only dedicated centre in the United Kingdom that 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. 100 percent of respondents believed that access to specialist physiotherapy had kept them out of hospital. All respondents also agreed that they felt better for having access to such physiotherapy and 82 percent of respondents believed this helped them to stay in paid employment.<sup>6</sup>

<sup>3</sup> *The Thomas Report* (2010) [www.muscular-dystrophy.org/assets/0001/7692/Thomas\\_Report.pdf](http://www.muscular-dystrophy.org/assets/0001/7692/Thomas_Report.pdf)

<sup>4</sup> Vitacca, M., Paneroni, M., Trainini, D., Bianchi, L., Assoni, G., Saleri, M., Gilè, S., Winck, J. C., and Gonçalves, M. R., (2010) At Home and on Demand Mechanical Cough Assistance Program for Patients With Amyotrophic Lateral Sclerosis, *American Journal of Physical Medicine and Rehabilitation*, Vol. 89, No. 5, May 2010, pp. 401 – 406.

<sup>5</sup> *The Thomas Report*

<sup>6</sup> NeuroMuscular Centre (2009), *Social Accounts 2008-09*



### Henry Langen

Henry is from Narberth and has facioscapulohumeral muscular dystrophy (FSH). He cites a number of instances when his care has been more costly than it should have been because of a failure to provide the right services at the right time.

Despite an admission to hospital with heart failure a decade earlier and ongoing health issues since then, Henry's need for respiratory care wasn't recognised until he was admitted to hospital in 2008. It was only at the insistence of the physiotherapist and respiratory nurses that Henry was put on non-invasive ventilation (NIV) to enable him to breathe normally at night. Since being discharged from hospital, Henry has continued with nightly NIV sessions and now enjoys a fit and active life. He has had no subsequent admissions, and said:

“The psychological and physiological damage that I have endured by not having the correct facilities and treatment – plus counselling – has most certainly cost the NHS dearly, through many unnecessary hospital admissions, leaving me with a permanent heart condition and the associated massive ongoing costs that could have been prevented.”

However, access to specialist physiotherapy in Wales is limited; many patients do not receive continuous, specialist physiotherapy or indeed any physiotherapy at all<sup>7</sup>. The situation has improved since the publication of the *Thomas Report*, with ring-fenced funding now agreed for paediatric physiotherapists. However, there are still significant gaps in physiotherapy provision for adults in Wales.

There are too few specialist clinicians in Wales to provide the services that patients need. In addition, succession planning for key posts is also of concern. Without this planning, posts are likely to remain vacant and services could suffer as a consequence. Evidence from the *Thomas Report* highlighted this issue:

### The role of care co-ordination and the neuromuscular care advisor

Neuromuscular care advisors play a vital role in improving patient care by taking responsibility for co-ordinating the specialist care they receive. Having a care advisor in post can also save money, for example by saving consultants' time (such as by reducing administrative tasks), reducing GPs' time, signposting patients to local services and liaising with other service providers.

We are delighted that NHS Wales has responded to the *Thomas Report* by employing much-needed neuromuscular care advisors in Wales.

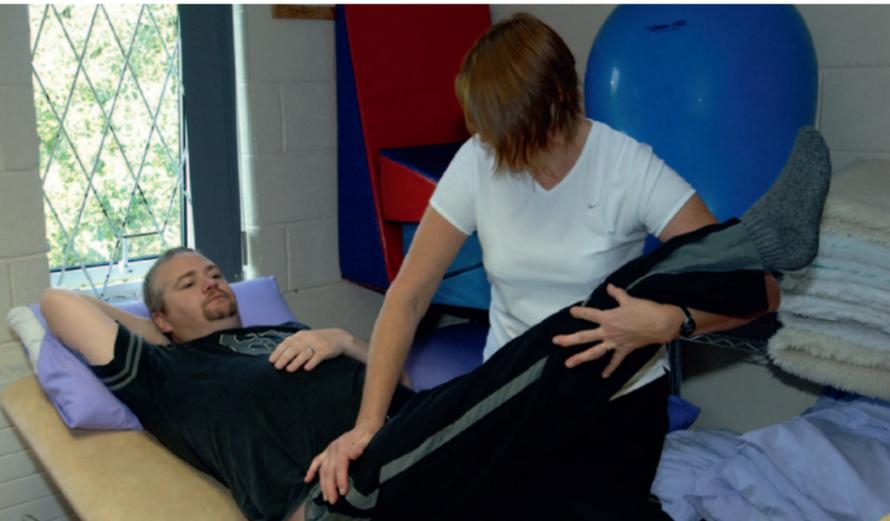
“The service that Jane [Fenton-May], Angus Clarke and I provide within medical genetics, would be a total of 0.5 Whole Time Equivalent (WTE) [i.e. 0.5 full-time posts]. If you were to add Cathy [White], Jon Walters and Louise [Hartley], that might increase to 1.25 WTE. That may be an over-estimate between us of the time and care we provide. You haven't got the physios and the clinical nurse specialists. If you look at North East England, including professors and doctors, it is 4.5 WTE and there are two clinical nurse specialists. Adding up the package for them it is 7.5 WTE, for Glasgow it is 7 WTE and for South West England it is 8 WTE. There is such a huge disparity.”

**Dr Mark Rogers**

“I am very concerned and unhappy with the non-existence of physiotherapy, a social worker, a muscle specialist (vital for Duchenne muscular dystrophy), occupational therapy, orthopaedics, a psychologist or the Speech and Language Therapy team. It's non-existent so the quality is non-existent as well.”

**Ian Griffiths (who has Duchenne muscular dystrophy)**

Since the publication of the *Thomas Report*, Dr Fenton-May has retired, therefore further reducing the neuromuscular specialist time available to patients in Wales.



<sup>7</sup> Muscular Dystrophy Campaign (2008), *Focus on Physio*. Available to download from: [www.muscular-dystrophy.org/assets/0000/6276/Access\\_to\\_physio\\_report.pdf](http://www.muscular-dystrophy.org/assets/0000/6276/Access_to_physio_report.pdf)

## Recommendations

Following on from the recommendations in the *Thomas Report*, it is vital that the new Welsh Assembly Government and NHS Wales continue to make positive improvements in service provision for both children and adults across the whole of Wales. It is vital that they invest to prevent unplanned emergency admissions to hospital.

We recommend that the investment is used in line with the following:

- succession planning is prioritised to ensure there is adequate consultant time available to meet the needs of patients in Wales, including ensuring training of specialist neuromuscular clinicians
- more neuromuscular care advisor time is funded in Wales so that there are at least three full-time posts, rather than the current part-time posts, serving the whole of the country so all those with a neuromuscular condition who require the services of a care advisor have access to one
- specialised services – for example specialist physiotherapy – for patients with neuromuscular conditions are available to all patients across the country and, in particular, the gaps in adult physiotherapy provision are filled
- specialised wheelchair services are available to all patients regardless of where they live
- the Welsh Assembly Government should work with clinicians in Wales to commission an audit of unplanned emergency admissions to hospital
- managed clinical networks are fully established, with a physical hub in each region, to provide specialist knowledge and services in both North and South Wales
- vital equipment, such as cough assist machines, is provided to patients where evidence shows this may help them avoid a hospital admission.

Support our campaign to improve specialist service provision for people, in Wales, with muscular dystrophy and related neuromuscular conditions. You can do this by sending a copy of our report to your Assembly Members and Health Board. If you'd like to send the report by email, or would like more information on the campaign, please contact us at [campaigns@muscular-dystrophy.org](mailto:campaigns@muscular-dystrophy.org)