Muscular Dystrophy Campaign

Invest to Save:

Improving services and reducing costs in Scotland

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I am pleased to welcome this briefing, which puts forward the case for investing in preventative services for people with neuromuscular conditions in Scotland. I pay tribute to the excellent work of the Scottish Muscle Network. However, despite this, services remain patchy across Scotland 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 lead to increased costs. Following on from last year's *Mackie Report* and the service review carried out by the Scottish Muscle Network, I therefore call on the Scottish Government and NHS Scotland to take note of these findings and work to improve patient care for everyone with a neuromuscular condition in Scotland.

Jackie Baillie MSP
(Chair, Cross Party Group on Muscular Dystrophy)

Investing in preventative care for people with neuromuscular conditions, like my two grandsons who have Duchenne muscular dystrophy, would not only help to reduce costs to the NHS in Scotland but could also help people avoid the distressing experience of an emergency admission to hospital. I urge everyone reading this briefing to take that message on board and do all they can to help improve the lives of patients and their families in Scotland.

Eileen McCallum

Endorsed by the Muscular Dystrophy Campaign's Scottish Council.

campaigns@muscular-dystrophy.org

Why invest?

There is increasing evidence to suggest that investing in a broad range of health and social care services for a person with muscle-wasting disease, before their health reaches crisis point, can save money in the longer term.

Specialist multi-disciplinary care has been developed by the Scottish Muscle Network and leading clinicians as the best model for delivering effective care for neuromuscular conditions, given that they are complex, multi-system diseases. Specialised services also need specialised 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 Scotland when doctors and physiotherapists move on. With around 6,000 patients in Scotland with neuromuscular conditions, providing the right services at the right time becomes even more important.

The cost of unplanned emergency admissions

In Scotland, we estimate that the cost of unplanned emergency admissions could be as high as **£6,829,731** and as much as **£81,527,633** across the whole of the UK .[1]

The Scottish Government has recently confirmed that one of its key Health and Wellbeing priorities in 2011-2012 is to "protect the most vulnerable people in our society through early intervention and by promoting equality"[2]. With the costs of emergency hospital admissions for patients with neuromuscular conditions being so high, **the evidence is clear: investing in neuromuscular services could not only reduce spending on unplanned admissions in Scotland but also improve patient outcomes.**

Robbie Warner
(Chair of the Muscular Dystrophy Campaign's Scottish Council), from Dumbarton:

"Earlier intervention does save money as it takes pressure off surgeons in emergency surgery.

"My son, Eoghan, was three when he was diagnosed with Duchenne muscular dystrophy. He underwent an operation for his developing scoliosis at an earlier stage than normal and it proved very successful. Not only was it a lesser operation, as it was performed early on in the diagnosis – it had as good as, if not better results than an operation performed later on – but he was taken off the breathing machine the day after the operation, which was unheard of. He was also discharged after five days in hospital, when the average at that time was 10 – 11 days."

[1] This figure has been calculated using NHS data which takes the average number of emergency admissions per patient (0.3949), and average cost per emergency admission (£2,890.18).
[2] http://www.scotland.gov.uk/Publications/2010/11/17091127/9

We estimate that **investment in preventative services could result in savings of approximately £31 million** across the whole of the UK, with relatively small investment. We estimate that an investment of only **£4.6 million** across the UK could go a long way to preventing unplanned hospital admissions.[3]

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 in the US 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.[4]

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 chair can actually reduce the cost to the NHS in the long run, decreasing the need for potentially expensive operations and costly inpatient episodes. However, access to these services can be limited. Clinicians interviewed as part of the Scottish Muscle Network's service review of 2010 described some difficulties experienced by service users in accessing services, particularly physiotherapy and wheelchair services.[5]

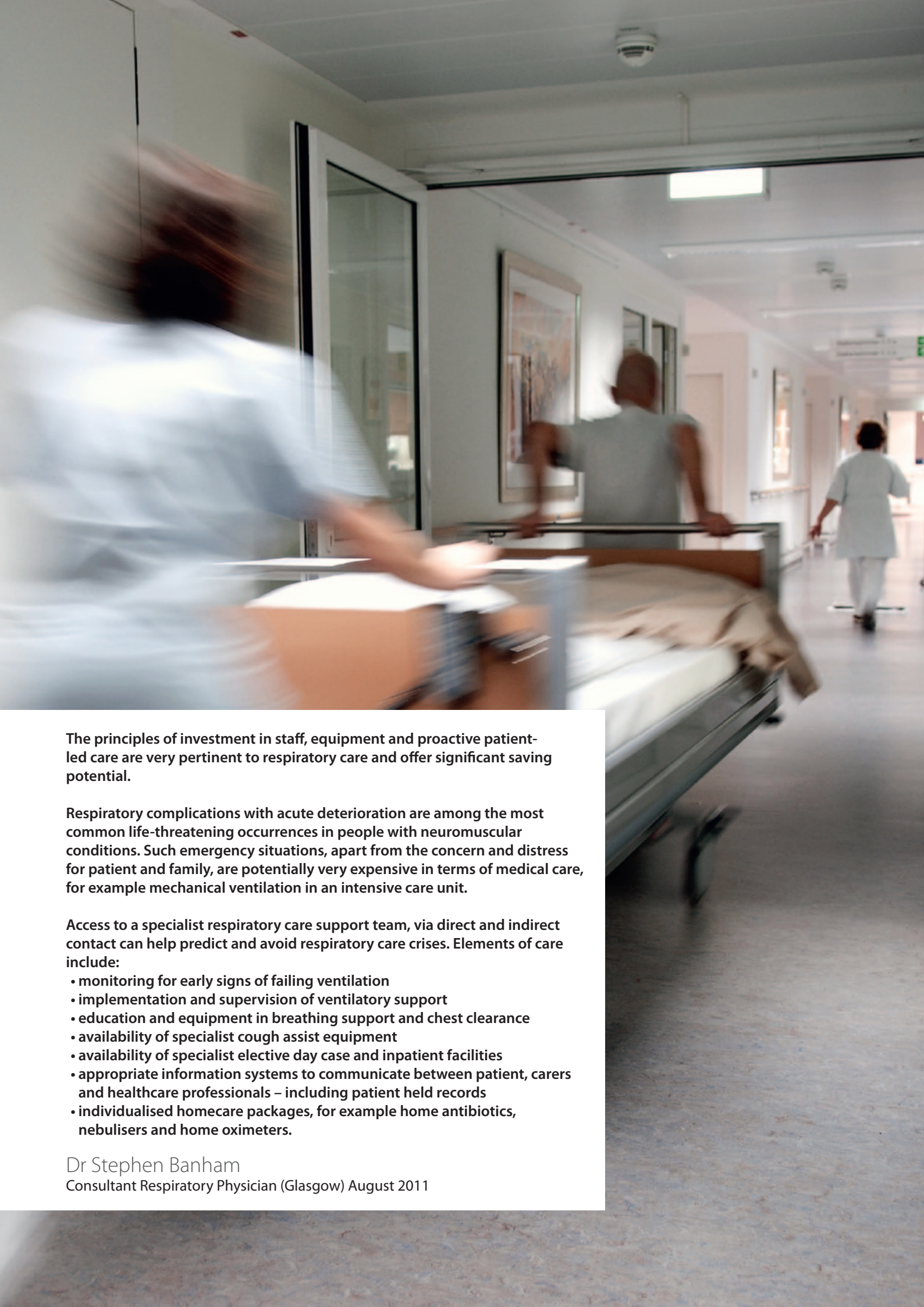
Provision of specialist equipment, such as cough assist machines (which helps a person clear lung secretions by giving a deep breath in followed by a suck out, helping patients to cough), can also help to provide vital support. However, we are concerned that access to such machines can be patchy. [6]

[3] In a recent Parliamentary debate on neuromuscular services in the North West of England, the Minister for Care Services, Paul Burstow, 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: http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110209/halltext/110209h0001.htm#11020958000001. The estimate of £4.6 million is based on the investment of £400,000 made into services in the West Midlands.

[4] 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.

[5] Health Services for People with a Neuromuscular Condition, Report by Craigforth (2010)

[6] *The Mackie Report*. Available to download from: http://www.muscular-dystrophy.org/assets/0001/9335/Mackie_Report.pdf



The principles of investment in staff, equipment and proactive patient-led care are very pertinent to respiratory care and offer significant saving potential.

Respiratory complications with acute deterioration are among the most common life-threatening occurrences in people with neuromuscular conditions. Such emergency situations, apart from the concern and distress for patient and family, are potentially very expensive in terms of medical care, for example mechanical ventilation in an intensive care unit.

Access to a specialist respiratory care support team, via direct and indirect contact can help predict and avoid respiratory care crises. Elements of care include:

- **monitoring for early signs of failing ventilation**
- **implementation and supervision of ventilatory support**
- **education and equipment in breathing support and chest clearance**
- **availability of specialist cough assist equipment**
- **availability of specialist elective day case and inpatient facilities**
- **appropriate information systems to communicate between patient, carers and healthcare professionals – including patient held records**
- **individualised homecare packages, for example home antibiotics, nebulisers and home oximeters.**

Dr Stephen Banham
Consultant Respiratory Physician (Glasgow) August 2011

Specialist physiotherapy is also vital for people with neuromuscular conditions, and can help significantly in preventing unplanned hospital admissions. A physiotherapist plays an important role in:

- minimising the development of contractures and deformities
- anticipating and minimising any secondary physical complications
- identifying and prescribing aids and equipment
- advising on moving and handling issues
- monitoring respiratory function and advising on techniques to assist with breathing exercises and methods of clearing secretions
- 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 access to such physiotherapy and 82 percent of respondents believed this helped them to stay in paid employment.[7]

However, access to specialist physiotherapy in Scotland is limited; many patients do not receive continuous, specialist physiotherapy or indeed any physiotherapy at all.[8] One of the professionals interviewed as part of the Scottish Muscle Network's service review said:

"When patients leave school, they leave a holistic paediatric service that includes physio, cardio, orthotics, speech and language, hydrotherapy, riding for disabled, neurology and genetics. They go to an adult service in which there is little specialist service provision. These patients have complex chronic conditions that require long-term management, not rehabilitation, they enter adult services often just as their condition becomes more complex and their needs become greater."

Health professional
Tayside

Care co-ordination and the role of 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.

The Scottish Muscle Network's service review identified the importance of care co-ordination in Scotland. The majority of professionals they interviewed highlighted the importance of greater co-ordination of services, including through increased numbers. Care co-ordination can be vital to the quality of service received.

"A lack of identified care co-ordinators to co-ordinate care and to support patients and their families can mean they get a patchy service."

Consultant Neurologist [9]

James, an adult patient in Ayrshire with Becker muscular dystrophy, was developing contractures at the ankles which made him liable to fall. It was not possible for him to get adult physiotherapy for this. He fell and broke his ankle. He was able to get physiotherapy while the ankle was healing but even though the physiotherapist recognised the need for continuing physiotherapy, he was discharged. As a result, his contractures have continued to worsen and he is now virtually unable to walk.

[7] NeuroMuscular Centre (2009), Social Accounts 2008-09
[8] Muscular Dystrophy Campaign (2008), Focus on Physio. Available to download from: http://www.muscular-dystrophy.org/assets/0000/6276/Access_to_physio_report.pdf
[9] Health Services for People with a Neuromuscular Condition, Report by Craigforth (2010)

Recommendations

Following on from the recommendations in the *Mackie Report* and the Scottish Muscle Network's service review, it is vital that the new Scottish Government implements the commitments made in March 2011 in response to these reports and invests to prevent unplanned emergency admissions to hospital.

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

- that more neuromuscular care advisor posts are funded and that all those with a neuromuscular condition who require the services of a care advisor have access to one, as recommended by the Scottish Muscle Network. We welcome the Scottish Government's commitment to increase the number of care advisors from two part-time posts to **three full-time posts** and urge them to fill these roles as soon as possible
- that specialised services for patients with neuromuscular conditions, for example specialist physiotherapy and wheelchair services, are available to all patients regardless of where they live
- that the Scottish Government should work with the Scottish Muscle Network to commission an audit of unplanned emergency admissions to hospital
- that vital equipment is provided to patients where evidence shows this may help them avoid a hospital admission.

Finally, we would welcome the production of SIGN guidelines into the standards of care for neuromuscular patients. These guidelines, produced by The Scottish Intercollegiate Guidelines Network (SIGN), are evidence-based clinical practice guidelines for the NHS in Scotland.

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Muscular Dystrophy Campaign
61 Southwark Street
London SE1 0HL
t: 020 7803 2865
e: campaigns@muscular-dystrophy.org
w: www.muscular-dystrophy.org

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