



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Mr William Powell AC / AM
Chair
Petitions Committee
National Assembly for Wales

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Ein cyf / Our ref: GL/AM/1593/938

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Dyddiad / Date: 10 April 2014

Dear Mr Powell

RE: PETITION RECEIVED FROM THE MUSCULAR DYSTROPHY CAMPAIGN

Thank you for your e-mail dated 25 March 2014 regarding the petition received from the Muscular Dystrophy Campaign and asking for our views on the Petition.

The Welsh Neuromuscular Network has recommended a number of priority developments as highlighted below:

1. Increase in Family Care Advisors and Support

It is agreed that these posts can benefit patient and family by acting as advocates and can help patients and families through health, social and voluntary care services to ensure optimum treatment and experience as highlighted.

2. Specialist Adult Neuromuscular Physiotherapists

North Wales does not specifically have a Specialist Adult Neuromuscular Physiotherapist. We do, however, have Specialist Neurological Physiotherapists who have the appropriate training and skills to manage adults with neuromuscular conditions.

Our physiotherapy services support the role Neurological Physiotherapist to work with people with neuromuscular conditions, participating in further training specific to neuromuscular conditions, and continually improve the quality and efficiency of services provided.

Physiotherapy intervention for people with neuromuscular conditions involves developing a programme alongside the person with a neuromuscular condition, for example:

- to minimise the development of contractures and postural deformities through a programme of positioning, stretches and exercises;

- to anticipate and minimise any secondary physical complications through the above to include seating;
- to identify and prescribe aids and equipment, including positional equipment, and working with wheelchair services on seating equipment;
- to advise on moving and handling;
- to monitor respiratory function and advise on techniques to assist with breathing exercises and methods of clearing secretions.

The above therapeutic interventions could be carried out safely and effectively by neurologically trained Physiotherapists; which is a specialism within Physiotherapy. Depending on the clinical presentation, Physiotherapists with different specialisms have the most appropriate knowledge and skills to treat the person (for example, a Physiotherapist Specialist in respiratory care if the current problem is a chest infection).

It is important that there is a Specialist Neurological Physiotherapist with the awareness and knowledge of neuromuscular conditions involved in the care of people with neuromuscular conditions to ensure that these people receive maximally effective therapy. The Neuromuscular Specialist Physiotherapist would have a more in depth knowledge of those conditions, (such as muscular dystrophy), increased awareness and knowledge about the amount/intensity of exercise appropriate for these conditions. Treatment techniques are the same as other neurological conditions; stretches, positioning, exercise but knowledge of suitable intensity is an acquired skill. The evidence base is less than supportive currently to the profession in this remit, hence each case is considered individually and experience is invaluable.

Our Neurological Physiotherapists will hold the core principles of treatment, and if treating this group of patients they are professionally required to develop the necessary additional knowledge required of the condition. They would be supported by the organisation in this regard.

It would not be effective use of time to employ one Physiotherapist to treat adult neuromuscular conditions in North Wales given the low volumes and excessive travel time, however we would wholly support additional training/teaching/workshops for professionals working with people with this group of conditions to increase knowledge and skills to highlight any differences in therapeutic management to optimise the quality of the service provided, as suggested.

3. Appointment of Consultant in Adult Neuromuscular Disease

It is recognized that Consultants specialising in neuromuscular disease could provide leadership within multidisciplinary teams, focus on education and support for partners, and also lead the development and implementation of care pathways. We do however believe that further assessment would need to be undertaken to determine whether the



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appointment of a consultant in adult neuromuscular disease would be the best way forward in this regard.

4. Increase in Clinical Psychology

We recognise the valuable contribution made by Clinical Psychologists to the care provided to both adults and children with neuromuscular disease. We employ over a 100 qualified clinical psychologists in the Health Board with a range of expertise and are working hard to meet the needs of patients in a timely and appropriate way.

5. Equipment Budget

We note the recommendations from the Welsh Neuromuscular Network for the provision of designated equipment budget to enable minor purchases and care arrangements. We will continue to work with partners across health and social care to support patients in promptly accessing the vital equipment needed.

Once again, I would like to thank you for seeking the views of the Health Board on the Petition.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Geoff Lang'.

GEOFF LANG
ACTING CHIEF EXECUTIVE