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Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

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Mike Hedges AC/AM
Cadeirydd/ Chair

National Assembly for Wales
Petitions Committee

Petition P-04-532 Improving Specialised Neuromuscular Services in Wales

Dyddid/Date: 17th April, 201

Dear Mr Hedges

Abertawe Bro Morgannwg University Health Board has noted the recommendations within the Welsh Neuromuscular Network Vision Document for improving specialised neuromuscular services in Wales including the five priority developments outlined. We continue to develop our services to build sustainable long-term provision.

We follow the direction set in the Welsh Government's 'Together for Health, Neurological Conditions Delivery Plan, 2014-17. In line with this we update our delivery plan and review our milestones and actions annually. As the Neurological Conditions Delivery Plan is refreshed we will consider and align our local plans accordingly. As you would expect our local priorities would reflect our local populations needs assessment and also take into consideration of the needs of Hywel Dda as we provide regional services. Consideration is given to equity of access and prioritisation according to need to ensure we provide equitable services to utilise our finite resources in the most efficient and effective way we can.

The Physiotherapy Service of ABMU-HB currently provides a Physiotherapy Clinical Specialist in Neurosciences to attend the monthly Regional (ABMU & Hywel Dda) Adult Muscle clinics run by a Neurologist and the Family Care Advisor (FCA). This arrangement has been in place since 2013 and was implemented in response to a request from the FCA. No funding was identified for this role, it was achieved through reconfiguration of existing physiotherapy provision across neurosciences.

Individuals attending this clinic are given the choice of seeing the neurophysiotherapist or not, with approximately 60% of attendees wishing to. The majority of those who see the neurophysiotherapist will also do so during their annual reviews. Within clinic the neurophysiotherapist adopts co-production principles in terms of patient-centred assessment and decision-making. Individuals often ask advice about what is safe for them to do having previously been advised that there are no effective therapeutic interventions or even that exercising is unsafe and will accelerate their condition. Advice regarding the type and safety of general physical activity is given specific to their condition, alongside therapeutic interventions for postural management, pain, joint contracture and other impairments and activity limitations associated with their neuromuscular condition. Recent clinic developments include the inclusion of standardised assessment protocols including accurate muscle strength testing using a hand-held dynamometer. A standardised patient-reported outcome measure (ACTIVLIM) has also recently been implemented within clinic, although the clinic is cognisant to the joint plans of the All-Wales Stroke Implementation (SIG) and All-Wales Neurological Conditions (NCIG) groups to develop a PROM & PREM for individuals with long-term neurological conditions.

Conditions encountered within this clinic are:

FSH

Beckers

Inclusion Body Myositis

Duchenne Muscular Dystrophy

Limb Girdle Dystrophy

Spinal Muscle Atrophy

A developing role for this neurophysiotherapist is acting as an expert resource and providing support and advice to physiotherapy colleagues throughout ABMU & Hywel Dda Health Boards. This support currently ranges from remote advice giving via telephone or e-mail to joint consultations (often performed in the patient's home or local Therapy Dept. With the recent provision of an i-pad via the COPE Project it is anticipated that platforms such as Facetime and

Skype will offer an efficient range of support options. Currently adoption of the Neuro-inflammation Team's protocol for use of Facetime is being considered.

Alongside the FCA this neurophysiotherapist is contributing to a series of development events with the therapy teams of Hywel Dda Health Board. A full day workshop is planned for April, to identify the patient population across the Health Board and map the therapy service available.

This neurophysiotherapist also supported the development of a FCA-led Multidisciplinary clinic for individuals with Charcot Marie Tooth (CMT). The clinic runs monthly and is hosted within the Specialist Rehabilitation Centre at Morriston Hospital. The MDT comprises the FCA, a neurophysiotherapist, an orthotist and an individual with CMT. It is anticipated that the patient focus group that identified this need will reconvene in the near future and identify further service developments.

Individuals with neuromuscular conditions can often present with respiratory dysfunction, related to either weakness of the respiratory muscles or significant postural deficits such as scoliosis. Individuals may require ventilator support or cough augmentation. The neurophysiotherapist is currently involved with an ABMU Working Party looking at the Respiratory & Cardiac support for individuals with neuromuscular conditions. The provision of Non-invasive Ventilation is co-ordinated by a Consultant in Respiratory Medicine with a team of Clinical Nurse Specialists. Provision of cough augmentation is less well defined and supported, the Physiotherapy Service have submitted a case for a Neuro-ventilatory Physiotherapist and this business case is currently being refreshed in preparation for re-submission,

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The neurophysiotherapist is an active member of the Wales Neuromuscular Network, they attend and contribute to the Cross-Party Group for Neuromuscular Conditions.

To provide equipment that is deemed necessary Occupational Therapists would work with colleagues in the local authority to provide what is needed in an equitable manner. Although we do not have a specific budget for this client group there was some one off money allocated from Welsh Government in 2014, some of which was for cough assist machines which were purchased by ABMU Health Board on behalf of all Health Boards in Wales.

The rest of the money was allocated to each HB to be spent on specific equipment for neuromuscular patients. The co-ordination of the expenditure is via the Neuromuscular Care

Advisors. A decision was made by the Neuromuscular network that a portion of the funding could be utilised for on-going maintenance costs.

I hope this information is helpful.

Best regards,



Christine Morrell

Cyfarwyddwr, Gwyddorau Therapi ac Iechyd

Executive Director of Therapies and Health Science

cc. Alex Howells

Interim Chief Executive, Abertawe Bro Morgannwg University Health Board