

P-04-532 Improving Specialised Neuromuscular Services in Wales – Correspondence from Petitioner to Clerking Team

Welsh Neuromuscular Network - The development of neuromuscular services in Wales

Summary

Patients with neuromuscular condition have specialist and complex care needs. They typically require support from a number of sectors and are vulnerable in terms of their health and risk of falling between services. Evidence confirms lack of / inequity of access to services, treatments and support. This is compounded by sub-optimal understanding across services regarding patient and family needs, even at the most basic levels.

The Muscular Dystrophy Campaign has presented a strong case that investment in neuromuscular services would improve outcomes and experiences whilst also realising savings across the wider health economy.

Background

It is estimated that there are 3,400 people affected by neuromuscular conditions in a Wales. These are typically life threatening, complex multi system disorders. Effective care requires input from health, social services and third sector providers coordinated by specialist multidisciplinary teams. With the exception of a small number of acquired conditions, there are no known effective treatments or cures.

A number of reviews of Welsh Neuromuscular services have consistently highlighted a shortfall in service provision. One outcome was the establishment of the Welsh Neuromuscular Network (WNMN) in 2011.

The WNMN consists of interested clinicians and service user representatives from across Wales supported by the Planning Directorate of Aneurin Bevan Health Board. It operates to a discrete terms of reference and has no funded posts.

The WNMN has reviewed and evaluated existing services. The details of this are presented in the "Vision document of the Wales Neuromuscular Network". This briefing provides an executive summary.

Patient experience

Sadly, there a many stories from patients and family members that highlight:

- Lack of access to specialist neuromuscular clinicians including medical, nursing, physiotherapy and psychology staff;

- Delay in diagnosis and management leading to premature health deterioration and death e.g. Lung infections, heart failure and extended hospital stay;
- High hospital admission rates and extended lengths of stay due to absence of support pre and post exacerbation / deterioration;
- Inequity of access to physiotherapy and hydrotherapy which are evidenced to improve quality of life and prevent / delay deterioration;
- Inequitable access to even basic equipment such as adaptable armchairs. In one instance a neuromuscular patient was bed bound for two years due to lack of funding for a chair (costing £300-£400);
- A dramatic difference between child and adult services with further degradation in access to all neuromuscular services once leaving paediatrics.

Key actions and work

The WNMNs vision document confirms the following priorities:

- Improved and equitable access to specialist neuromuscular multidisciplinary teams for patients, families and professionals
- Education, training and support for social, primary and secondary care services to facilitate earlier referral and management across care pathways
- Equitable access to basic and specialist equipment
- Equitable access to available therapies including immunosuppressive agents

Priority investment

The requirements are predominantly specialist workforce. These appointments will provide a critical mass around which other changes and improvements can be built upon.

Recommendation

The WNMN is recommending the following priority developments:

- 1. Increase in Family Care Advisors and support.** These posts act as patient and family advocates and navigate them through health, social and voluntary care services to ensure optimum treatment and experience.

Benefit: This would provide a level of 1 wte Family Care advisor for every 1000 neuromuscular patients. Administrative support would reduce FCA time being absorbed by general administration

- 2. Specialist adult neuromuscular physiotherapists.** Wales currently has no specialist neuromuscular physiotherapists for adult patients.

Benefit: Such roles are critical in surveillance, early intervention and avoidance of admissions. The role would include undertaking

training, education and support for local non-specialist teams who may be required to manage NM patients.

3. Appointment of consultant in adult neuromuscular disease.

Wales has a disparity with other home nations with low and inequitable access to consultants specialising in neuromuscular disease.

Benefit: To provide leadership within the neuromuscular MDT with focus on education and support for partners, development and implementation of care pathways.

4. Increase in clinical psychology. There are currently no dedicated NM psychology services for adults or children in Wales. Access to generic services is variable and limited.

Benefit: This is a vital element of care and is required by both patients and their families in living with lifelong, disabling NM conditions. Psychology services are evidenced to improve engagement and compliance and thereby improving quality of life and reduction in avoidable contacts with care services.

5. An equipment budget to enable minor purchases and lease arrangements.

Total requirement for the above priorities is circa £480,000 per annum.

However the austere financial environment is well recognised by the WNMN. Current objectives are therefore to be focused on successes that can be achieved within existing budgets. These include removing duplication in patient contacts through more efficient provision of multi-disciplinary clinics and the training and education of wider health services to identify patients with neuromuscular disease and sign post them to specialist services.

Conclusion

Reviews have confirmed that neuromuscular services in Wales are dependent upon a small, dedicated but fragile group of professionals.

Service sustainability as well as immediate delivery remains at risk.

Priority investment would represent a disproportionate improvement in services and would result in tangible benefits to patients, families and staff.