

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

Rhwydwaith Niwrogyhyrol Cymru – y dyfodol

Vision document of the Wales Neuromuscular network (WNMN)

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Introduction

This document sets out a vision for a clinical network for the management of neuromuscular (NM) conditions in Wales. Clinical networks enable a more coordinated approach to service provision based on agreed service models and standards and based on known patient pathways. They usually comprise health professionals from a range of national health service (NHS) organisations working in a co-ordinated manner across institutional and local boundaries in order to ensure equitable provision of high quality and clinically effective services.

Why do Neuromuscular (NM) conditions require a networked approach to their management?

NM conditions are often life-threatening, complex, multi-system disorders whose effective management requires specialist multi-disciplinary care. The nature of these conditions is such that some patients present acutely with life-threatening consequences, some patients present indolently and are slowly progressive and others lie in between. As a consequence, appropriate management must focus on both acute and chronic care of these patients in order to effectively address their needs. The development and use of complex immunosuppressive agents both in the acute and chronic setting has been a further development in the treatment of NM conditions.

The development of specialist care for children and young people has led to a growing population of adults who, in earlier times, would not have survived, but who now require continuing, high quality anticipatory care and support to ensure they enjoy the best possible quality of life, regardless of its length. NM conditions are best considered as long term medical conditions that affect all ages and as such services need to be developed both in paediatric and adult services as well as in the transition phase between.

The management of NM conditions requires a multi-disciplinary team (MDT) approach – often involving a wide range of different medical and associated disciplines (physiotherapy/ occupational therapy/orthotics/ medical appliance/ wheel chair service/ dietetics/ respiratory services/cardiology services /palliative care) and also social and education services. Noting that the management of such conditions involves a great number of professionals across Wales, a networked approach to organisation of care is necessary.

In Wales we have the expertise to diagnose, manage and monitor the vast majority of NM conditions and we also benefit from access to UK national specialist centres who are able to provide diagnostic support, which is often research related, into very rare conditions. These services are accessed on a 'named patient basis'.

Other areas in the UK have established NM networks such as the Scottish Muscle network (established 1998) and the South-West NM network (established October 2009). All of these networks function across the child/adult divide as well as across Health Board and professional boundaries.

Prevalence of NM conditions in Wales

It is estimated that 1000/million population are affected by a muscle wasting NM condition, ie 60,000 in the UK and 3400 in Walesⁱ. The prevalence of Charcot Marie Tooth disease is 40/100,000 (23,600 UK) (1200 Wales)ⁱⁱ, of Muscular Dystrophy 50/ 100,000 (30,000 UK) (1500 Wales)ⁱⁱⁱ, of Motor Neurone disease 7/100,000 (4000 UK) (210 Wales)^{iv} and of Myasthenia Gravis 30/ 100,000 (10-30,000 UK) (900 Wales)^v.

Background to NM network

The all Wales neuroscience review (Steers review, September 2008)^{vi} looked at the provision of adult neuroscience services across Wales at that time. It made the following recommendations:

- That there was a need to increase the workforce delivering all aspects of care to people with acute and long term neurological conditions, including NM disorders
- That NM services should be provided on a 'networked' basis and include the development of care pathways from initial diagnosis to end of life care
- That networks need to work with paediatric services to ensure transition of care from child to adulthood is addressed appropriately
- That networks should be planned and provided on an equitable basis across Wales, working to agreed evidence-based care pathways.

The Walton Report (August 2009) entitled 'Access to specialist NM care'^{vii} looked at NM care in the UK. It made the following recommendations

- Lack of Workforce Planning for specialist NM clinicians must be addressed as a priority. These services must be protected and strategically developed with succession planning.

- A named transition co-ordinator should be in place for each young person with a NM condition who is moving from paediatric to adult services.
- There is both paucity and weakness of adult NM services in many parts of the country. In particular the report authors were alarmed to hear of the decline in services in Wales over the last 10 years. Fear of a further decline in services in the following 2 years was also noted unless urgent action was taken.

As a result of this criticism, in July 2010 The Thomas report was commissioned - 'Access to Specialist NM care in Wales' ^{viii}. This found similar problems in Wales to those set out in the Walton Report and made recommendations including the development of a Managed Clinical Network with a Chief Executive lead from one of the Health Boards as well administrative support. The report also made recommendations relating to additional posts required to support NM services in Wales.

Current Clinical NM Network

Since 2011 a clinical NM network has been established. To date this has been formed by professionals with a specialist interest in NM conditions but with no administrative support. Following The Thomas Report, two further NM care advisors have been appointed in Wales. Two part time specialist paediatric NM physiotherapists were also appointed, but no progress has been made with the recommendation relating to the equivalent adult physiotherapy post, chest physiotherapy, psychology support, occupational therapy or specialist Consultant roles. A Steering Group comprising key professionals has been established in order to identify priorities for the network as a whole.

In the context of funding and support challenges for the NM network, this document sets out to establish an overview of current services across the network, the network aims, concerns regarding service gaps and challenges and the network future services vision.

Aims of the Welsh NM network

The following aims have been agreed:

- Assess current NM services and highlight identified shortfalls. Plan and develop NM services, including service configuration, care and treatment pathways (supported by referral policies and processes) and service specifications (incorporating published Standards of Care and appropriate quality measurements)
- To reflect on the experiences of NM patients and their carers. Raise standards of care and support for people with a NM condition – to enhance the patient experience in a way that is meaningful to users of the service.

- Ensure an equitable and accessible service for patients and their families across Wales, based on agreed patient pathways.
- Act as a reference group and resource across Wales – support ongoing NM training and education for both professionals and patients and their carers.
- To operate differently – incorporating a MDT approach (often wider than the NHS) with patient perspective as the focus of all we do.

Current NM resources (see appendix 1)

A priority of the NM network was to fully map current service provision. One of the greatest challenges clinicians and care advisors face when managing patients with NM conditions is being aware of the most appropriate referral patterns for that area. The management of these conditions requires a multi-disciplinary team approach. Mapping of current service provision will allow the most appropriate referral route to be met in each area with the aim of enabling patients to be managed as locally as possible.

Audits of interest to NM network

Clinical audit has been recognised as an effective mechanism for improving the quality of care patients receive and will act as a crucial component of the drive to improve quality for the NM network as a whole. A number of audits have been undertaken by network professionals and summaries are provided below:

- A collaborative audit of admissions in adults with NM disease – C & V UHB and ABUHB^x. This has shown
 1. 33% of all unplanned admissions are avoidable
 2. The mean duration for an unplanned admission was 10.3 days
 3. Avoidable unplanned NM admissions accounted for 164.8 bed days in 2011
 4. 63% of patients admitted with an avoidable admission had a confirmed NM condition, only 19% were known to local NM services pre admission
 5. A demonstrated lack of emergency care planning as documented in the case notes of patients with NM conditions

Based on similar audit showing that 42% of all admissions in pts were avoidable and 4.5% potentially avoidable^x.

- Ongoing audit of intravenous immunoglobulin (IVIg) use in the treatment of immune mediated NM conditions – an awareness of current IVIg use is critical to assess whether alternative therapies could be considered for some patients. Any reduction in IVIg use would have significant cost savings

- Audit on the clinical usefulness of peripheral nerve biopsies^{xi} – has shown
 1. 79% nerve biopsies conducted added usefully to the process of reaching a clinical NM diagnosis for the patient
 2. made recommendations – double muscle/ nerve biopsy suggested for all and made recommendations about when/ when not to request a biopsy
 3. overall provided agreed guidance about how to investigate patients with a potential NM diagnosis

- Audit based on the guidelines for management of Duchenne muscular dystrophy are planned for 2013-14. Standards of care for DMD - Lancet Neurology, 2010, 9, 77-93 & 177-189) Bushby K et al.

Financial/ Economic case

Investing in services for people with NM conditions in order to proactively manage their care not only delivers the services these patients are entitled to but can also reduce NHS costs, particularly in relation to avoiding unnecessary hospital admission . Indeed, we cannot afford not to invest in services that will support this vulnerable group of patients.

The recent audit on unplanned NM admissions showed that 33% of all unplanned admissions are avoidable and the reasons for these admissions are multifactorial. In the majority of cases it demonstrated that a lack of access to initial NM diagnosis and lack of surveillance and monitoring of the NM condition were major contributory factors.

Investing in early intervention and emergency care planning helps reduce unplanned hospital admissions, improve outcomes for patients and reduce costs for those commissioning services^{xii}. The mean duration for an unplanned admission was 10.3 days. Avoidable unplanned NM admissions accounted for 164.8 bed days in this audit period. Unplanned admissions are extremely costly and avoidable and admission to a specialist ward can cost the NHS up to £1,925 per day^{xiii}.

Identified service gaps and challenges across current NM network services

Impact of emergency hospital admission. Not only are unplanned admissions costly, they also have a negative impact on a patient’s health, jeopardise their rehabilitation prospects and consequent independence. The MDC’s report ‘Health care not health risk’ based on the MDC’s 2011 hospital

survey revealed the ways in which poor quality care whilst in hospital have a devastating impact on the health of patients with NM conditions^{xiv}. They looked at various aspects of inpatient care and were able to show how these had affected patients;

- access to vital facilities whilst and inpatient – hoists etc. They found that a third of patients who required a profiling bed were not able to use one in hospital.
‘When I ask for a hoist I feel like I’m causing trouble and they don’t want to know’. It is important to consider that access to this type of facility is critical for patients with a wide range of long term and mobility conditions and not specific for those suffering with NM conditions.
- being looked after by health professionals who did not understand their rare condition. 27% of patients rated their experience of hospital as poor or very poor in terms of being given poor advice that was not appropriate for their condition.
‘I was treated by people who did not understand my condition and as a consequence my treatment resulted in my permanent need for a wheelchair. I broke my leg and guidelines for people with muscular dystrophy are that prolonged immobilisation should be avoided. In my case I was placed in a full leg cast for 12 weeks’
- inadequate support on leaving hospital alongside poor coordination of care resulting in lengthy hospital stays. 12% were not given the right care and support for a timely discharge from hospital.
- inadequate preventative care – 2 in 5 patients admitted to hospital as an emergency admission felt that this could have been prevented if they had received timely specialist care.

NM family care advisors (FCA) provide support in terms of both health and social care for paediatric and adult patients with NM conditions. However, it must be recognised that the care advisors have been tasked with establishing a new service in a very complex care environment. Challenges remain in ensuring that the Care Advisors are adequately supported in their peripatetic roles as part of improvements to NM services.

The care advisors are clear on the demonstrable benefits they provide to their patients – mainly from patient case studies and feedback. The 3 post holders are aware of the need to work together in developing their roles. This includes looking at the most appropriate approach to the documentation of their case load – factoring in travel time/ complexity of cases / numbers of affected family members etc. Overall a ‘case study’/ ‘individual stories’ approach has been suggested as a possible mechanism by which the care advisors can demonstrate the benefits to patients as a result of care advisor support.

The role of the care advisors is still subject to ongoing development recognising current limited capacity. Development of protocols for service provision will form part of the service improvement aims of the network. The care advisors have emphasised the need for emergency planning for patients with NM conditions. Ideally all patients should be issued with an advance emergency care plan to allow case appropriate agreed care to be given at times of clinical deterioration.

Transition. This is the process of transferring from paediatric to adult services. It requires the paediatric services to identify required adult services and arrange transfer. It involves all services including physiotherapy, orthotics, speech and language therapy services. Where gaps are identified it is the responsibility of paediatric services to search for next best services. Transition clinics involving paediatric and adult service representatives should be established so that young people can have a comprehensive and well managed transfer. Where numbers are insufficient to justify such a clinic, a named individual in paediatrics needs to manage transition on an individual basis. Good engagement with adult services is essential in maintaining optimal healthcare for young adults and the point of transition is often where young people are lost to follow up with significant consequences.

Specialist physiotherapy involvement. Throughout Wales patients with NM conditions have very different experiences of physiotherapy involvement. As a network we believe a more equitable delivery of physiotherapy with agreed care pathways would be beneficial. It has been noted that the expectation of patients and their families appears to be high and in some cases unrealistic. Agreed care pathways and minimum requirements of assessment may allow a more equitable delivery of service and help address patients expectations. In view of the rarity of some of NM conditions, general physiotherapists may feel uncomfortable in providing support for such patients. This has been raised as a problem especially in North Wales.

Currently there are no specialist NM physiotherapists for adults in Wales. The involvement of NM physiotherapists into clinics where adult patients are regularly seen is essential. The situation for children and young adults differs in that a specialised NM physiotherapist is available in such clinics in South Wales. In north wales there is no specialist NM physiotherapists in either child or adult clinics, a situation we feel needs to be addressed. We hope to create links between specialised NM physiotherapists and the community based physiotherapists as appropriate.

Respiratory Care. Respiratory disorders are recognised as the leading cause of mortality in NM disease^{xv}. Respiratory muscle weakness is a very common feature to most NM conditions and is often inevitable in the later stages of such conditions. However, treatment including ventilation, has been shown to improve both quality and length of life^{xvi}. An All Wales pathway for the management of respiratory problems (ventilation cough and others) in NM problems has been produced^{xvii}. Nevertheless there is variable provision of specialist nurses/physiotherapists who can enable patients to be safely managed at home and access to important equipment such as cough assist devices is patchy across Wales.

WHSSC fund invasive ventilation but not non invasive ventilation. In Hywel Dda they have developed an innovative way of dealing with a geographically dispersed population via a virtual respiratory network. Non invasive ventilation occurs in all hospitals and all health boards have teams dealing with patients requiring non invasive ventilation in the community. It can be difficult to get them to take on NM patients as these services are all under resourced.

NM patient experience – ‘...due to the lack of specialized consultants my breathing inadequacy was not noticed, resulting in a heart strain leading to water retention, giving me in the end heart failure. Had there been specialist monitoring of my condition - realising my chest muscles were weak, a Bi-pap ventilator could have been placed in use to assist breathing before I ended up with heart failure’

Cardiac care is reasonably well organized with most areas having systems in place for routine monitoring. It has been recognised, largely due to pressure on services and the way they are structured, that some adults with NM disease are not receiving the necessary monitoring of their condition that is required.

Clinical psychology and counselling involvement. Psychological support is a vital element of the care required by patients and their families often living with lifelong, disabling NM conditions. It is recognised that there are ‘key times’ such as; Diagnosis, genetic counselling, becoming wheelchair dependent, transition and when end of life approaches where psychological support is required.

Currently there is no dedicated NM psychology service for adults or children in Wales. Some areas have better access to generic services than others. In Cardiff over the last 12 months a limited provision of clinical psychological services has been made available to patients attending the transitional care clinic in Rookwood.

Psychological problems often present indirectly to health care services and inclusion of psychological expertise in the multidisciplinary team will ensure that identification and treatment of such problems, so potentially reducing unplanned hospital admission. Psychological expertise is therefore a key component of providing quality services and managing costs. The Muscular dystrophy campaign (MDC) recognises the value of psychological expertise and in a patient survey they report that half of all respondents were not satisfied with the level of emotional support available to their families and to themselves^{xviii}.

NM patient experience - ‘Support on the onset is vital especially in later adult cases, without it there is a large tendency... to think I could not care less attitude...I am going to die.. lack of knowledge about the disease...enable easy access to aids i.e. wheelchairs, home adaptation etc, the stress due to lack of knowledge is immense. Mentoring is essential during the onset period when the patient is not aware how deep the water is’.

‘The ignorance of the establishment continually wanting proof of your incapacity is another topic that dangerously tips the balance of sanity. The patient is already in a traumatic state dealing with the life threatening condition, we must avoid “Incidents of double trauma” which this personal independence payments (PIP) reassessment is causing’.

NM conditions are long term medical conditions. There is evidence available that demonstrates the increased risk of psychological and mental health difficulties in people with long term medical conditions^{xix xx xxi}, as well as for their families and carers^{xxii}. There is also some more specific research on NM disorders that demonstrates the relevance of psychosocial factors to healthy coping and

adjustment and the risk of psychological/mental health issues in sufferers and their families^{xxiii xxiv xxv}
xxvi .

As well as affecting NM conditions generally, studies have shown specific psychological problems associated with muscular dystrophy. The incidence of autistic spectrum disorders, attention deficit hyperactivity disorders and obsessive compulsive disorders is higher in males affected by Duchenne muscular dystrophy^{xxvii}. In addition behavioural changes have been shown to be an adverse side effect of treatment with corticosteroids – which is used to prolong ambulation and preserve muscle strength and respiratory function^{xxviii}. Early input from a clinical psychologist may help parents develop strategies with which to manage these behavioural difficulties and thus prevent the need to withdraw steroid treatment.

Psychological expertise in NM conditions should include:

- Direct clinical work with patients and their families - psychological assessment, problem formulation, psychological intervention/treatment and reviews.
- Consultancy, supervision of other professionals using psychological approaches, and team support.
- Leadership, development and management of organised systems of psychological care within NM services
- Service improvement and development projects
- Research and audit skills
- Teaching and training on the psychological aspects of NM disorders.

As a network we believe a more equitable service is required across Wales. A Health and Care Professions Council (HCPC) Registered Practitioner Psychologist is required. This Practitioner Psychologist would be a clinical (or counselling) psychologist with experience of applying psychology in medical settings.

NM rehabilitation. Currently adult NM rehabilitation clinics are able to provide help to maintain independence or in adapting to changes that affect social and domestic life. These include a number of services including physiotherapy, access to communication and controls, occupational therapy, speech and language therapy, wheelchair services and orthotics.

Orthotic Services. Maintaining mobility is a significant challenge for patients with NM conditions and access to local orthotic services is essential to enhance ability and support independence.

Each health board in Wales provides an orthotic service, supplying a diverse range of both stock and made to measure orthotic products and footwear to suit individual clinical need. Most orthotic services in Wales are now managed in-house but a few health boards still outsource their service to commercial contractors.

Regardless of how the service is commissioned there is a significant degree of collaboration between all of the Welsh orthotic services to ensure parity of care and service provision.

Patients can normally be referred to their local orthotist led clinical service by letter or application form where provided and the service is available for both adults and children. In addition, stock orthotic products are generally available for in-patients and for busy out-patient clinics where a more rapid solution is required.

Whereas most, if not all orthotists, have experience of treating patients with NM problems there is a perceived need to develop specialist orthotists to work alongside the multidisciplinary team to ensure the best outcomes are achieved. The orthotic needs of NM patients can be quite complex and require adequate time and expertise to address effectively. NM patients often become orthotic patients for life and it is recognised that a mutual understanding of their needs built up over time produces the best results.

Patient needs. It has been raised that patients with a NM condition require a named individual who is able to provide advice and support at critical times during the disease process. Within the network it is the family care advisors who are best placed to provide this function however with large caseloads this may not always be possible. The care advisors provide an advocacy role for patients. This is also provided free of charge from the MDC who have produced an advocacy pack which provides information on access to Personal Independence Payments (PIPs), Employment Support Allowance as well as housing and care packages. The care advisors have significant concerns regarding the introduction to the newer PIP system as described in Appendix 2.

Self care and Complementary services.

Patients and families/ carers are aware of the importance of 'self-care' such as stretching exercises, posture and good diet to maintain the best quality of life for patients. Encouragement and support in these types of activities is important and best delivered by a specialist NM network. Patients need to be both empowered to make decisions about appropriate care for themselves (by participating in emergency care planning) and to engage in self-care exercise.

Currently there are drop-in sessions available twice yearly for families affected by NM conditions to share experiences and receive support from others in a similar position^{xxix}. Currently these are run in Cardiff but we hope these could be relayed across Wales in a similar format.

Many patients with NM conditions find hydrotherapy and other water-based activity beneficial however at the current time in the UK it is seen as a complimentary therapy and access/ provision is very variable. The MDC encourage patients who have been able to access such services to work in collaboration with them so that others may be able to benefit from these. A list of availability of hydrotherapy services in Wales is shown in Appendix 3.

Visions for the future of the Wales NM network

Advances have been made in recent years to improve care delivery to patients with NM conditions for example the development of NM care advisors and specialist paediatric/ transition NM physiotherapists. However gaps in service provision still need to be addressed.

Future service developments proposed by the network include:

- **Developing Care advisor roles.**

These posts should be full time with administrative support. This would allow care advisors to provide a more equitable service across the wide range of NM conditions, across their geographical area and would allow further development of care pathways, emergency care planning for individuals and protocols for service provision.

Predominant support is to patients with muscular dystrophy and to a lesser degree to some with hereditary neuropathy. At the current time the care advisors are unable to offer support to patients within the wider range of NM conditions that the network covers (for example inflammatory neuropathy or myasthenia gravis). It is suggested that these patients would also benefit from their support.

Currently the majority of patients with a NM condition are not known to NM services. The audit on unplanned NM admissions also showed that whilst 63% of patients admitted with an avoidable admission had a confirmed NM condition, only 19% were known to local NM services pre admission. Even after an unplanned admission, only 53% had follow up arranged with NM services.

The muscular dystrophy campaign estimate a ratio of 1 Whole time equivalent (WTE) care advisor to 1000 patients with a NM condition^{xxx} (estimated 3400 in Wales would suggest at least 3 fulltime equivalents are needed). The Thomas report calculate that the cost of 3 WTE care advisors would be £129,036 per annum^{xxxi} (2009 cost). In Wales in view of the wide geographical distribution of patients it may be argued that additional posts are needed. Currently we have 3 care advisors working in total 87.5 hours a week. We require another 25.5 hours a week to be provided to meet the recommendations calculated by the Thomas report.

- **Appointment of specialist paediatric/ transition NM physiotherapists for N Wales**

Currently there are no NM physiotherapists for paediatric or adult care in N Wales. Some who attend paediatric clinics in Alder Hey Children's Hospital have access once or twice yearly to the NM physiotherapist linked with their clinics, this is not provided locally.

- **Appointment of specialist adult NM physiotherapists**

Currently there are no specialist NM physiotherapists for adults in Wales. As a network we feel that the involvement of physiotherapy into clinics where NM patients are regularly seen would be of benefit.

- **Appointment of specialist adult NM clinicians**

In the audit of unplanned admissions for NM conditions a significant proportion of the potentially avoidable unplanned admissions were due to poor surveillance and a lack of monitoring of the underlying NM condition. The Thomas report supports the employment of an additional 1.5 WTE consultants specialising in NM conditions (with secretarial support), with an approximate cost of £195,000 per annum (2009 cost). The addition of further specialist clinicians would also increase the amount of support available to the care advisors.

The clinicians working in Wales should have the NM components of their day to day work recognised in their job plans. The network has established that the amount of consultant led clinical care that is currently formally dedicated to NM conditions is approximately 10 sessions a week. While it may appear that a significant number of consultants are involved in the care of such patients, it is important to realise that the number of whole time equivalent (WTE) sessions that are currently dedicated to NM care in Wales is very small. See appendix 4.

The solution for North Wales is dependant on what contracts are made with the current English providers. Increased support for patients on immunosuppressive regimes will also be needed. A consistent approach regarding treatment decisions and the ability to endorse decisions made by NM network would be of benefit.

In the recent National Patient Survey by the MDC more than a quarter of patients responded to have spent more than 12 months to see a specialist consultant even after they had been diagnosed with a NM condition. Of those seeing a consultant, a quarter of responders see the specialist less than once a year^{xxxii}.

The newly developed 'Service specification for Neurosciences' developed by NHS England gives a framework for the provision of NM services and states that patients to be reviewed by a specialist MDT including NM consultant at least every six months, or if rapidly progressive every three months^{xxxiii}.

NHS Wales will launch its Neurological Conditions Delivery Plan in October 2013

- **Joined-up clinics**

We aim to provide more opportunities for a 'one stop shop' adult NM clinics in Wales - incorporating a specialist adult NM clinician, adult NM physiotherapist, NMCA and links with respiratory and cardiac monitoring. This has been newly established in ABMU. A similar clinic would be useful in Cardiff.

In the audit of unplanned admissions for NM conditions a significant proportion of the potentially avoidable unplanned admissions were due to poor surveillance and lack of monitoring of the underlying NM condition. This type of clinic offers the varied needs of these complex patients to be considered by members of the NM multidisciplinary team. It is hoped that over time some of the routine monitoring of patients could be taken on by the physiotherapist and care advisor so freeing up the clinician.

NM carers perspective – ‘When it comes to accessing medical care in North Wales there appears to be no advice on where we go and who to see. We attend Gobowen for all the Muscular dystrophy stuff. However, we have separate appointments to be seen by Dr. Willis and her team, ORLAU and spinal....For cardiac care we go to see Dr Chickermane in Birmingham Childrens Hospital....For respiratory care we go to Wrexham....For wheel chair services we attend Wrexham and for anything else we go to the Maelor, apart from dentistry who we see in Mold but get the impression they want us to go elsewhere. All the above makes a list of 7 clinics we need to attend in 5 hospitals’.

NM Patient perspective – ‘I was greatly encouraged... as far as I am concerned I know that when I have my annual appointment later this year that it will be a "one stop shop" with the neurologist, physio, family care adviser all in the same place (hopefully).

- **Provision of clinical psychology**

The provision of clinical psychology is a key component to provide quality services and to manage the costs of the care of patients with NM conditions. Whilst there are no definite recommendations for the psychology workforce in NM conditions, the Thomas report suggested the employment of 0.5 WTE Psychologist (mid grade band 8a) with an approximate cost of £25,533 per annum (2009 costs).

In Wales, in view of the wide geographical distribution of patients it should be argued that additional posts are needed. We view the recommendations made by the Thomas report an absolute minimum. In other areas of physical healthcare (such as renal medicine, HIV/AIDS and oncology) recommendations have been made using formulas such as 0.5 WTE psychological cover per medical consultant.

A comparison may be made with services that have been established in Wales for Cystic Fibrosis – a chronic condition, which may be seen to mimic some genetic NM disorders quite closely. This has a psychology post for paediatric services (8a 0.5 WTE); a more senior post for transitional/adult services (8b 0.6 WTE) and a post for adult services (8a 0.5 WTE), providing a total of 1.6 WTE for a population of about 400 patients.

The West Midlands specialised commissioning group suggested a 2 WTE psychology support for a population of 5500 NM patients. If this were applied to the Welsh NM population (3400) we

estimate approximately 1.2 WTE psychology posts would be appropriate. Splitting these posts into 2/3 part-time posts would allow best geographic coverage of Wales.

- **Provision of shared electronic health records together with support from a data manager**

The development of a network crossing organisation and disciplinary boundaries requires shared access to health records ideally in electronic form so that records can be viewed from sites across NHS Wales. Current health records are located within individual organisations and access to these records is generally not possible from other sites. Lack of access to shared systems prevents an integrated team-based approach to the care of patients. Shared electronic records record the narrative history of patients' problems and stories but also form a vital part of monitoring outcomes for patients with neuromuscular disease. As such, a successful NM network will be dependent on the development and maintenance of a database accessible across Wales together with administrative support from a data manager.

- **Provision of administrative support and a NM network manager**

To be able to achieve the NM network aims of providing strategic direction, to raise standards of care and to act as a reference/ resource for other professionals across Wales, the network requires administrative support and management. The Thomas report suggest the employment of 1 WTE Network manager (band 7-mid range) with an approximate cost of £43,012 per annum (2009 cost) and 0.5 WTE administrator (band 5-mid range) with an approximate cost of £14,591 per annum (2009 cost).

- **NM educational programme**

Providing specialist education and support for health care professionals who support patients in the community is a vital part of keeping patients out of hospital and maintaining optimal health. Upskilling where necessary is as important as providing clear signposting for professionals in seeking advice and support when required. Encouraging and empowering patients to manage their own complex health needs is also part of this equation. As a network we aim to establish an education programme focusing on the management on NM conditions to achieve this. Plans for the education programme are outlined in appendix 4.

- **Improvement in inpatient care/ emergency care**

A well organised and funded clinical NM network can provide a 'joined-up', patient-centred co-ordinated service. This has been shown to be able to assist in enabling a better quality of inpatient service as well as preventing some hospital admissions in the first place^{xxxiv}. The care advisor role is central to this process as well as support from specialist clinicians. All patients with a NM diagnosis should have a documented emergency care plan which specifies a clear point of access for the emergency care. This should include telephone access for the patient to a known NM specialist team for times of worsening health^{xxxv}.

In addition we feel that the 'patient passport' scheme may be a simple communication tool that could be utilised by NM patients who may be vulnerable in mainstream emergency services that do not understand rare NM conditions. It allows the normal everyday needs of a person to be documented, their wishes, emergency plan, as well as information as to their specific condition. This may enable mainstream services to deliver better patient centred care to NM patients.

Appendix 1

3 NM family care advisors – specialising in the support of paediatric and adult patients with NM conditions throughout Wales

- SE Wales - Rachel Salmon (C&V – Sept 2010 onwards, 25 hrs/wk)
- SW Wales - Sarah Harris (ABMU - June 2011 onwards, 30 hrs until Feb 2013, then 25 hrs)
- N Wales - Sam Power (October 2011 onwards, 37.5 hrs)

NM physiotherapists

- SE Wales (Bethan Parsons- June 2011 18.75 hrs) – paediatric care
- SW Wales (Kate Greenfield – June 2011 18.75 Hrs) - paediatric care
- All Wales paediatric palliative care/transitional physiotherapist for Wales (Sarah Clements – appointed 2011 37.5 Hrs) – ages 16-24
- North Wales - no dedicated NM physiotherapist for community consultant paediatricians – no NM physiotherapist for adult services.

Genetic services

- Clinical genetics clinics in DGHs

Peripheral nerve clinics

Adult

- Cardiff – Dr Gareth Llewelyn (adult neurology)
- Swansea – Dr Nigel Hinds and others (adult neurology)

Paediatric

- Swansea - Dr Cathy White, Kate Greenfield, Sarah Harris
- Neath - Dr Cathy White, Kate Greenfield, Sarah Harris
- Hywel Dda – Wthybush clinic Dr Cathy White, Kate Greenfield, Sarah Harris

Muscle/ NM clinics

Adult

- Cardiff – Dr Jon Walters (adult neurology) and Rachel Salmon,
- Cardiff – Dr Mark Rogers, Prof Angus Clarke (clinical genetics), Rachel Salmon - plans underway to involve an adult physiotherapist with an interest in NM conditions
- Newport – Dr Gareth Llewelyn
- Swansea – Dr Marguerite Hill (adult neurology, myasthenia interest)
- Swansea – Dr Jon Walters , Sarah Harris, respiratory technician Simon Hilldrup, and adult neuro-physiotherapist Richard Pawsey

Paediatric

- Cardiff – Dr Louise Hartley, Bethan Parsons and Rachel Salmon
- Penarth Ysgol Erw'r Delyn transitioning clinics_ - Dr Louise Hartley, Rachel Salmon, Bethan Parsons, OT Eithne Wood, School Nurse , Respiratory Nurses
- Swansea – Dr Cathy White, Kate Greenfield, Sarah Harris with ALAC wheelchair services, Transition physio and OT invited to non ambulant clinics.
- Royal Glamorgan Hospital (Cwm Taf)– both teams for problem solving, discussion and local provision
- Aberdare (Cwm Taf)- Dr Louise Hartley, Bethan Parsons and Rachel Salmon
- Serennu Childrens Centre (ABHB) - Dr Louise Hartley, Bethan Parsons and Rachel Salmon
- Wthybush Hospital (Hywel Dda)- Dr Cathy White, Kate Greenfield, Sarah Harris

- North Wales:-
- Central: Colwyn Bay Hospital : Dr Val Klimach (lead consultant paediatrician for NM care) as part of NM paediatric clinic with Sam Power (NMCA). Tertiary NM specialist services held at Alder Hey Children's Hospital, Liverpool run by Dr Stefan Spinty

Dr Val Klimach resp consultant and local MDT and Sam Power

East : Dr B Harrington, Dr Praveen Jauhari (lead paediatrician for Wrexham & Flintshire), Dr Sathymoory (pending)

West:: Dr Janet Horn (lead paediatrician for Gwynedd), Sam Power and MDT members locally (pending)

Transition and young adult rehabilitation clinics

- Cardiff – covers ABUHB, CTHB and CVUHB) Dr Gareth Llewelyn, Dr Louise Hartley (peripheral neuropathy/neuromuscular)
- Cardiff - Dr Jenny Thomas (rehabilitation), Dr Victoria Lidstone and Sarah Clements and Rachel Salmon
- Swansea- Covers ABMU and Hywel Dda Transition patients. Dr Cathy White (paediatric neurology), Sarah Harris, Sarah Clements and Dr David Abankwa (neuro rehabilitation) Lynette Thacker (pall care CNS). Clinics began in April 2013
- Cardiff - for dystrophy patients - Dr Simon Barry (respiratory), Dr Zaheer Yousef (cardiology) and Dr Victoria Lidstone (transition/ palliative care)
- Swansea - Adult Muscle Clinic where patients have access to the Consultant, Dr Walters, Sarah Harris (NMCA), Richard Pawsey (Adult Physio), Lung Function suite and ECG monitoring. This clinic has now been running for 4 sessions.
- North Wales: Glan Clwyd clinics: Dr Val Klimach, Sam Power, OT, Physio

Respiratory

- Cardiff- for NM patients – Dr Simon Barry and Dr Mark Rogers
- Swansea - Dr Jon Walters , Sarah Harris, respiratory technician Simon Hilldrup, and adult neuro physiotherapist Richard.
- North Wales

Central and East – Dr Nick Duffy, Dr Liz Brohan and Laura Bryant (specialist respiratory nurse) at Wrexham Maelor Hospital.

West – Mike Wild and Julia Roberts (specialist respiratory nurse – adult pts) at Ysbyty Gwynedd.

Clinical Psychology

- Cardiff- Dr Richard Cuddihy (consultant clinical psychologist, ALAS Cardiff and Vale UHB). This is a very limited service development initiative which is currently accessed via Dr Jenny Thomas's adult/ transitional clinics at ALAS. There are no dedicated NM sessions at the present time.
- North Wales, - no dedicated sessions at present

Adult NM rehabilitation clinic

- Cardiff- Dr Jenny Thomas
- Swansea – Dr David Abankwa
- North wales - no clinics at present

Patient Support Groups

South East Wales - Implementation of twice monthly support groups for patients and families affected by NM conditions. Held at Rookwood Hospital Cardiff. Focusing on increasing awareness, signposting to relevant services, sharing information, information from guest speakers and peer support.

South Wales Motor Neurone Disease (MND) Care Network

South Wales MND Care Network was established in 2011/2012 with joint funding via the NHS and a grant from the Motor Neurone Disease Association (MNDA). It seeks to make systematic improvements in care for MND patients, improve equity of access and also reduce the chronic inequities in care provision across South Wales in line with the MND Association Standards of Care. These include:

- Rapid and accurate diagnosis,
- Sensitive communication of diagnosis with appropriate emotional/psychological support
- Holistic approach to assessment, regular monitoring and review
- Provision of information to patients' carers and professionals involved in providing care
- Provision of services proactively, with flexibility and speed in response with timely access to services. A key worker approach and communication between agencies.

This is to be achieved through:

- Improved support and co-ordination of services

- Promotion of effective integrated working between sectors
- Development of multidisciplinary teams
- Introduction of Integrated care pathways

Collaborative working between neurology and palliative care services is a central feature to the MND network, allowing for sharing of expertise. This builds on the established links between key professionals from a variety of relevant specialties and help forge new links across primary, secondary and tertiary care, across health and social care and across community and hospital settings. Whilst the care of MND patients may be managed by a specific clinical network we are able to work together in the Welsh NM network, where we identify very similar patient needs.

A Steering group comprising of key professionals and managers from all local health boards has worked towards identifying priorities and the network team is now in post. The MND network has two hubs, with bases in Swansea for South West Wales and in Cardiff for South East Wales and the team comprises

- Ruth Glew, Network Lead and Care coordinator for South West Wales
- Katie Hancock, Care coordinator for South East Wales (0.8WTE)
- Sara Mallams Network Occupational Therapist (0.2WTE).

The service will be audited in lines with the MNDA standards of care, and opportunities will be sought for patients to be involved in research

Motor Neurone Disease clinics:

- Cardiff - Dr Ken Dawson (adult neurology), Dr Andrea Lowman, Katie Hancock, Care Co-ordinator and additional Specialist nurse)
- ABUHB – Dr K Dawson and Katie Hancock
- Cwm Taf HB – Dr Mark Wardle (adult neurology), Katie Hancock - clinic in development
- ABMU HB – Swansea – Dr Savvas Hadjikoutis (adult neurology) Ruth Glew, Care Network lead coordinator
Bridgend – Dr Jon Walters (adult neurology), Ruth Glew - clinic in development
- Hywel Dda – Carmarthen – Dr Nigel Hinds / Dr Claire Hirst (adult neurology), Ruth Glew - clinic in development

Programmed investigation unit (PIU)

The PIU is based in University Hospital of Wales Cardiff and is led by Sister Lynette Herrity (specialist nurse) and Natalie Ryan (nurse). The unit admits patients with NM conditions from C&V and ABHB for planned short term inpatient care – particularly inflammatory neuropathy, myasthenia gravis and metabolic myopathies. It is able to

- provide intravenous immunoglobulin and intravenous cyclophosphamide therapy

- provide plasma exchange safely and efficiently, so providing an alternative to intravenous immunoglobulin use in the acute setting to treat acute inflammatory neuropathy.

ABMU and Hywel Dda patients would be admitted at Morriston Hospital, Swansea for similar treatments.

Wheelchair Service

The Artificial Limb and Appliance Service (ALAS) aims to offer a consistent and equitable service to people in Wales who have a permanent or long-term impairment. It is provided by a unique collaboration between three NHS Trusts and is commissioned via Welsh health specialised services committee (WHSSC). The three ALAS centres (ALAC's) are situated in Cardiff, Swansea and Wrexham, working together to provide an All-Wales service.

Orthotic Service Contacts

ABMU (Swansea)	Jane Neathey
ABMU (Bridgend)	Martin Wright
ABUHB	Lance Reed
Betsi Cadwaladr UHB	Stuart Harmes
Cardiff & Vale UHB	Paul Mason
Cwm Taf Health Board	Bryan Watters
Hywel Dda Health Board	Mike Mulroy
Powys Teaching Health Board	Karen Meyrick

Appendix 2

Welsh Neuromuscular network response to introduction of Personal Independence Payments (PIPs)

Following a discussion about the introduction of PIPs in the March 6th 2013 cross-party NM meeting in Cardiff, the Welsh NM network wished to express its concerns regarding the introduction of such benefits. Whilst accepting that a review of the Disability Living allowance (DLA) is welcomed, PIPs must continue to allow people with NM conditions to meet these extra costs and enable them to live the lives they want to.

With the Government aiming for a “reduction target” of 20% in DLA payments, as set out in the Budget Report in June 2010, we are concerned that some people’s needs may not be recognised, meaning some may miss out on the vital support they need to live an independent life.

We support the work of the muscular dystrophy campaign (MDC) who continue to be very active in campaigning the government to consider the complex needs arising from their NM condition.

As a network we feel it necessary to emphasise a few points;

- The first part of the assessment focuses on activities vital to daily living such as feeding, toileting and dressing. The second part focuses on mobility. None assess the needs of the individual for access to education, work or involvement in local community.
- In our experience as a clinical network, we are well aware that people with NM conditions tend to be very focused on the positive and their ability to do things. We feel this attitude may hinder people getting the care they need.
- We believe the assessment (with the possibility of losing a benefit) by an independent healthcare professional that has limited/ no knowledge of NM conditions will be distressing for people. Most cases require a supporting document outlining the specifics of the condition to support the applications.
- We are very aware of the psychological stress that is associated with having a lifelong likely progressive disabling condition and are very concerned that the process of having to justify their genuine need for benefits will compound this stress.
- Since the changes and pilot schemes have been underway the family care advisors have been inundated with telephone calls and requests for advice from patients and their families. They have been able to advise families in to how to fill in the documentation appropriately the first time to avoid the refusal and then appeal process. This involves support in how to word the documentation effectively to ensure that safety, efficacy and risk factors are included and stressed upon how their NM condition affects then especially when completing the mobility component. The care advisors are only aware of the families who contact them directly. We are concerned for the large numbers of patients who are completing these applications without appropriate support and advice, then being declined and giving up.

Appendix 3

Access to hydrotherapy for NM patients – the picture across Wales

The purpose of this appendix is to act as a 'signposting' tool for interested patients, families and carers. The information reflects the collated position as at June 2013.

Aneurin Bevan Health Board

The physiotherapy departments do not control access to all of the pools that NHS care is provided from. Most of them are controlled by education/charities. This does sometimes lead the service to be very cautious with recommending any non-NHS managed pools to patients in continuing with their rehabilitation as there have been concerns about safety systems and processes in the past. As a result, patients make the decision on further access themselves.

The only other element to consider in relation to the above information is the fact that the neuromuscular patients have to be independent with washing and dressing in order to access most of the non-NHS pools or pay more to have their carer attend with them. This, and the fact that it would take up another space for a client, precludes them from attending the Health Board self management sessions.

Cardiff and Vale University Health Board

Children and Young Peoples Physiotherapy Services (CYPPS)

Recreational swimming / exercise:

Within Cardiff and the Vale, information is provided to patients and their families as to where and how, they can access a swimming pool for recreational activity / exercise. The Families First Directory of services is available at all Children's Centres and Special Schools, and for children and young people, a Disability Sports Directory is also available from Disability Sport Wales. (www.disability-sport-wales.org.uk) (www.cardiff.gov.uk/sport)

Access to hydrotherapy via education:

Within Cardiff and the Vale, the pool at Ty Gwyn School provides access to hydrotherapy for pupils with additional needs on the Western Learning Campus in Ely. There is also limited access for other Cardiff pupils by arrangement with the Head Teacher. The new sensory pool which is planned for the Penarth Learning Community and is due to open in 2015, will provide access to hydrotherapy for all children and young people with additional needs in the Vale area.

Access to NHS hydrotherapy pools:

There is currently limited access to hydrotherapy for paediatric inpatients at the University Hospital of Wales (UHW); however the new hydrotherapy pool planned for the Children's Hospital for Wales, which will open in 2015, will provide NHS access to hydrotherapy for all children and young people within Cardiff and the Vale.

At present the UHB is unable to accept referrals for hydrotherapy for paediatric outpatients, however all patients referred are assessed by a specialist paediatric physiotherapist and will be provided with alternative treatment options for their conditions.

Adult Physiotherapy Services

Recreational swimming / exercise:

Discussion has been undertaken with the Local authority services in order to determine the suitability of using pools in leisure centres for adults with complex physical needs; the advice that has been received is that they are unable to provide the temperature and water environment required for hydrotherapy access.

Access to NHS hydrotherapy pools:

Rookwood Hospital- The pool at Rookwood is suitable for use by inpatient rehabilitation patients but has been risk assessed as unsuitable for paediatric outpatients and social / recreational use by adults with LD or physical impairment, due to the physical capacity of changing facilities within the unit which cannot afford privacy and dignity for clients.

UHW pool – The pool at the UHW has an above deck level installation and therefore has restricted access for patients with complex disability. It is currently fully committed to waiting list outpatient sessions; additional out of hours use by third sector partners has been agreed.

Hywel Dda Health Board

All children who have a significant level of disability due to neuromuscular disorders like Duchenne MD have access to ongoing, weekly hydrotherapy sessions at Glangwili hospital. These are ongoing and continue until they leave our service at age 19 years.

Children with neuromuscular conditions living in the Carmarthen and Llanelli area of Hywel Dda have access to the hydrotherapy pool at Glangwili general hospital two mornings a week. The paediatric physiotherapists also run an after school club on a Wednesday in the pool for patients who have attended formal hydrotherapy sessions and are able to continue their exercises independently or with the help of a carer. They are charged £1.50 a session.

Ammanford patients are also seen in Glangwili hydro pool and some who do not need the heat of the hydro pool are seen in the leisure centre at Ammanford supervised by a physiotherapist.

Withybush does not have a hydrotherapy pool and patients in Haverfordwest are seen in the leisure centre in the town. They also have limited access to Portfields Special Needs school hydrotherapy pool. There is a resident physiotherapist at the school employed by the council.

Bronglais Hospital in Aberystwyth does not have a pool and patients in that area have to travel to Carmarthen if needed. The same applies to Cardigan patients.

Betsi Cadwaladr University Health Board

No information available at this time

Abertawe Bro Morgannwg University Health Board

Swansea

For access in Swansea for the community paediatrics team there is a weekly hydrotherapy session in the hospital.

There is also Ysgol Crug Glas (a special school) providing pool time once a week (out of therapy time) and a contribution is needed from those who wish to access the pool. The pool can cater for up to 20 users at a time, it is used by pupils at the school, it is also rented out at a cost to groups like the Stroke association, mother and toddler groups and is used by other schools and day service users with profound physical and mental health needs.

Further information from the hospital based paediatrics physiotherapists on the availability of Singleton and Morriston hospital pools is being sought.

Bridgend

The physiotherapy department uses Heronsbridges's hydrotherapy pool (a local special school) for 3 blocks a year and sometimes an extra one in the summer holidays. The therapists put the children they would like to attend on the hydro waiting list and they are seen when a slot becomes available. The patients would not normally get more than 1 session a year. There is also the possibility of patients using the hydrotherapy pool at the Sandville self help centre in Ton Kenfig however users are asked to make a voluntary contribution.

Neath/Port Talbot

The physiotherapy department uses the hydrotherapy facilities at Ysgo-Maes-y-Coed (a special school) in Neath but in school time only. Ysgo-Maes-y-Coed is a Special Needs School situated in Neath. It is our understanding is that the pool is used every day for pupils and that it is not available during the day for other users.

Sessions are also booked at the Neath Port Talbot hospital hydrotherapy pool. This is used primarily for in house patients. There is no overhead hoist in place to assist wheelchair users in the changing area. It is a poorly designed pool, there are steps on the side, there is a hoist which can assist ambulant persons who are unable to climb the stairs.

The Pontardawe pool is used for both therapy and non-therapy sessions and can be accessed at any time. It is primarily used by children not suitable for adult NM patients as the pool is only one metre in depth, therefore one would have to be on ones knees to support an adult which is not appropriate.

Welsh patient experience

'I have had 4 sessions of hydrotherapy. This was about a year ago. Once I had had these sessions plus 2 physiotherapy sessions I had received "my quota" and that was that. I realise that all health authorities have limited budgets. However, my argument is that if I could receive regular, even if only occasional, hydro sessions, in the long run this could save the authority money as it would help me to manage my condition and help stop it deteriorating. It was suggested that a hydrotherapy pool in Swansea could be hired by a group of us with the same or similar conditions (we would have to pay obviously) but I can't see how this could work'.

'Up until the Summer of last year I was receiving post surgical rehabilitation at The Royal Glam in Llantrisant. This included week sessions of hydrotherapy. I joined a group of about 6 and we were basically allowed to do our own thing whilst under the supervision of a physiotherapist. Assistance was provided to access the pool using a pool-side powered chair. We were all hugely benefiting from the sessions which unfortunately stopped when the physiotherapist Megan McDonald retired! Personally and as a wheelchair dependent MD sufferer, I was able to undertake a rigorous and 'high-energy' work out performing exercised I devised myself. Admittedly, I was pretty 'limp' afterwards but felt so revitalized having pumped blood into parts of my body which maybe hadn't received a

good blood flow since the last session. Dressing afterwards was a challenge and I would have benefited much from having some assistance, but I managed nonetheless.

Since the facility of the hydro sessions have ended I have put on quite a bit of weight and the onset of my LGMD has accelerated.

With appropriate support I would very much like to resume hydro sessions whilst I still can however I understand that some services are already under review at RGH and I rather suspect that hydro would not feature as being very important.

I have kept in touch with other members of the group all of whom miss the weekly sessions very much. We are all of the opinion that it wasn't then and wouldn't be now necessary to have a 'life-guard' in attendance - we were all adults and were always on stand-by to help each other. That said, I realise that it would be essential to have an able bodied person in attendance and, personally, I would now need help to dress. But since the end of the sessions I don't get out so much and have lost the benefit of a weekly discipline from which I was really benefiting'.

Appendix 4

Wales NM network – NM work demonstrated in job plans by clinicians

Gareth Llewelyn – 0.75/wk (C & V)

Jon Walters – 0.5/wk (C &V), 0.17/wk (ABMU)

Nigel Hinds – no figures given

Marguerite Hill – 0.5/wk (ABMU)

Louise Hartley – 2.0/wk (C & V)

Cathy White – 0/wk (ABMU)

Victoria Lidstone – 3.5/wk

Mark Rogers – 2.5/wk

Total 9.92 sessions/wk total

Appendix 5

Plans for NM educational programme

- ‘meet the team’ session – opportunity for users of the Welsh NM network to meet individual team members for ‘question and answer’ session. Possibly linked to a X-party meeting in Cardiff. Other patient groups – hereditary neuropathy/ myasthenia – invited to attend.
- Respiratory involvement in NM disease – Professional session planned for October 2013. To be run in ABMU initially, with a view to be run elsewhere at a later stage. Primarily for respiratory physicians, respiratory nurses with an aim to increase awareness of NM conditions and how they can be managed successfully.
- Therapy for NM conditions – Professional session planned for October 2013. For all members of NM network. Aim to increase awareness of how NM conditions can be managed from specialist physiotherapist viewpoint. Hope to involve speakers from both adult/ paediatric specialist physiotherapy – both in terms of peripheral nerve and muscle physio from within UK
- General Practice session – Professional session. For GPs. Delivered by NM network with aim of making GPs aware of the different ways in patients with NM conditions may present clinically. To highlight situations in which early referral to NM specialist care is necessary. The mechanism by which this could be delivered is still undecided.

References

ⁱ All Party Parliamentary group for Muscular Dystrophy. Access to Specialist NeuroMuscular Care: TheWalton report. 2009

www.muscular-dystrophy.org/assets/000/9943/waltonreport.pdf

ⁱⁱ Neurological Alliance and ABN. Neuronumbers. 2003

www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

ⁱⁱⁱ Neurological Alliance and ABN. Neuronumbers. 2003

www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

^{iv} Neurological Alliance and ABN. Neuronumbers. 2003

www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

^v Neurological Alliance and ABN. Neuronumbers. 2003

www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

^{vi} Welsh Neuroscience Review group – led by James Steers. Reviewed current provision of adult neuroscience services, 2008

^{vii} Walton report - August 2009 – entitled ‘Access to specialist NM care’

www.muscular-dystrophy.org/assets/000/9943/waltonreport.pdf

^{viii} Thomas report – July 2010 – ‘Access to specialist NM care in Wales’. Cross party Group on Muscular Dystrophy

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- ^{ix} Marsh EA, Fung W, Llewelyn GJ. A collaborative audit of unplanned admissions in adults with Neuromuscular disease. 2012 – Unpublished to date.
- ^x Prof M Hanna. A Collaborative audit on Unplanned Admissions in Adults and Children with Neuromuscular Diseases. MRC Centre for Neuromuscular Diseases. Institute of Neurology, Queen Square. 2011
- ^{xi} Marsh EA, Vincent M, Llewelyn JG. Clinical Usefulness of Nerve Biopsies in Wales, 2011 – Unpublished to date.
- ^{xii} Invest to Save. Improving services and reducing costs. Muscular Dystrophy Campaign, May 2011
- ^{xiii} Muscular Dystrophy Campaign. Invest to Save. Improving services and reducing costs. 2011
- ^{xiv} Health care not health risk, based on the MDC's 2011 hospital survey
- ^{xv} Benditt JO. Management of pulmonary complications in neuromuscular disease. Physical medicine and rehabilitation clinics of north America, 1998; 9:1, 167-185
- ^{xvi} Bushby K, Bourke J, Bullock R et al. The multidisciplinary management of Duchenne muscular dystrophy. Current paediatrics. 2005, 15, 292-300
- ^{xvii} All Wales Guidelines for non-invasive ventilation in neuromuscular disease. Simon Barry, on behalf of Wales NIV group, 2011
- ^{xviii} State of the Nation. The 2008 National Survey. MDC 2008
- ^{xix} Naylor C, Parsonage M, McDaid D, Knapp M, Fossey M, Galea A (2012) Long-term conditions and mental health: The cost of co-morbidities. The Kings Fund. www.kingsfund.org.uk/publications/mental_health_ltc.html
- ^{xx} Cimpean D, Drake RE (2011) 'Treating co-morbid medical conditions and anxiety/depression', Epidemiology and Psychiatric Sciences, 20, 141–150.
- ^{xxi} Moussavi S, Chatterji S, Verdes E, Tandon A, Patel V, Ustun B (2007) 'Depression, chronic diseases, and decrements in health: results from the World Health Surveys', Lancet, 370; 9590; 851–58.
- ^{xxii} Cormac, I and Tihanyi P (2006) Meeting the mental and physical healthcare needs of carers. Advances in Psychiatric Treatment (2006) 12: 162-172
- ^{xxiii} Abi Daoud MS, Dooley JM, and Gordon KE (2004) Depression in parents of children with duchenne muscular dystrophy. Pediatric Neurology Volume 31 (1) Pages 16-19.
- ^{xxiv} Hendriksen JGM, Poysky J, Schrans DGM, Vles JSH (2009). Psychosocial adjustment in males with Duchenne muscular dystrophy. : Psychometric Properties and Clinical Utility of a Parent-report Questionnaire. Journal of Pediatric Psychology 34 (1), 69-78.
- ^{xxv} Poysky J, and Kinnett K. (2009) Facilitating family adjustment to a diagnosis of Duchenne muscular dystrophy: April 24–25, 2008, Miami, Florida. Neuromuscular Disorders Oct19 (10):733-8
- ^{xxvi} Fitzpatrick C., Barry C., Garvey C. (1986). Psychiatric Disorder Among Boys With Duchenne Muscular Dystrophy. Developmental Medicine & Child Neurology, 28 (5), pages 589–595

^{xxvii} Henriksen JGM, Vles JSH. Neuropsychiatric Disorders in Males with Duchenne Muscular Dystrophy: Frequency Rate of Attention-Deficity Hyperactivity Disorder (ADHD), Autism Spectrum Disorder, and Obsessive-Compulsive Disorder'. *Journal of Child Neurology* 2008 May;23(5):p. 477-81

^{xxviii} Manzur AJ, Kuntzer T, Pike M, Swan AV. Glucocorticoid corticosteroids for Duchenne muscular dystrophy (Cochrane review). *The Cochrane library* 2009, Issue 1

^{xxix} Adult NM Support Days, Rookwood Hospital. Rachel Salmon, NMCA

^{xxx} Invest to Save. Improving services and reducing costs. Muscular Dystrophy Campaign, May 2011

^{xxxi} Thomas report – July 2010 – ‘Access to specialist NM care in Wales’. Cross party Group on Muscular Dystrophy

^{xxxii} **The State of the Nation: National Patient Survey. MDC 2013.**

^{xxxiii} Service Specification for Neurosciences. NHS England June 2013 - produced by NHS commissioning board

^{xxxiv} State of the Nation. The 2013 national survey. MDC 2013.

^{xxxv} Prof M Hanna. A Collaborative audit on Unplanned Admissions in Adults and Children with Neuromuscular Diseases. MRC Centre for Neuromuscular Diseases. Institute of Neurology, Queen Square. 2011

Useful sources of support

- The MD Campaign – www.muscular-dystrophy.org - provision of educational sessions for families in the paediatric and adult setting – in SE and SW Wales – planning is underway to provide a similar support day for those in NWales
- Action Duchenne - www.actionduchenne.org
- Myotonic Support Group - www.myotonicdystrophysupportgroup.org
- MND association - www.mndassociation.org

Other useful references

Standards of better Health, Department of Health, 2004 (updated 2006) - 4132991
www.dh.gov.uk

National Service Framework for Long Term Neurological Conditions (march 2005) – 4105361
www.dh.gov.uk

Current care standards

Exist for;

- SMA - www.treat-nmd.eu/sma.care
- DMD – www.treat-nmd.eu/dmd.care & also Scottish muscle network
Standards of care for DMD - Lancet Neurology, 2010, 9, 77-93 & 177-189) Bushby K et al
- CMD
- MyD – produced by Scottish muscle network – upon Scottish intercollegiate guidelines network, www.sign.ac.uk