Health and Social care Committee

Access to medical technologies in Wales
MT ToR 34 Multiple Sclerosis Society Cymru

The Cross-Party Group for Neurological Conditions is committed to improving services for people living with a neurological condition and for their carers.

English or Welsh copies of this report can be found on the Wales Neurological Alliance website: **www.walesneurologicalalliance.org.uk**

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The Cross-Party Group for Neurological Conditions

The Cross Party Group for Neurological Conditions was established in 2009 and is chaired by Mark Isherwood AM and is made up of a cross party group of Assembly Members and voluntary sector organisations. The group aims to raise awareness about neurological conditions and raise concerns of people living with neurological conditions. The secretariat of the group is provided by the Wales Neurological Alliance.

Acknowledgements

The Cross Party Group for Neurological Conditions wishes to thank the Wales Neurological Alliance for its administrative support in gathering written evidence and producing this Report.

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With a special thanks to the Chartered Society of Physiotherapists and all of the individual physiotherapists who assisted in the development of this report.

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Executive Summary

Over 100,000 people are affected by a neurological condition in Wales. There are a large number of neurological conditions, which include conditions that emerge from a traumatic incident (Acquired Brain Injury for example), conditions that can be lived with for decades (Multiple Sclerosis – MS), conditions where there is a high prevalence (Parkinson's Disease – 1:500) and rarer conditions with a lower prevalence (Wilson's Disease – 1:30,000).

For the majority of neurological conditions physiotherapy can offer the prospect of slowing the progression of a progressive condition (Motor Neurone Disease for example) or offer the prospect of rehabilitation and a return of function (Stroke or Head Injury for example).

Physiotherapy services cover a range of specialities from neonatal care right through to palliative end of life care. Physiotherapy uses physical modalities, exercise, moving and handling to assess, treat and enable people to manage their condition. It can make a major difference to quality of someone lives and is cost effective in comparison with drug costs. Yet too many people are either not able to access services or are receiving only short term rehabilitation.

As a result of this we are making 11 recommendations, summarised below. These recommendations are designed to ensure that examples of best practice become normal practice.

Recommendation 1: We recommend that Health Boards expand self referral so that anyone can self-refer to local physiotherapy services (page 15)

Recommendation 2: We recommend that Hywel Dda Health Board establish regular neurological multi-disciplinary teams across West Wales so that service users can access physiotherapy and other support (page 16)

Recommendation 3: We recommend an expansion in the number of clinical specialist neuro-physiotherapy roles so that every Health Board has a specialist neuro-physiotherapist for Multiple Sclerosis, Parkinson's Disease, neuro muscular disease, spinal cord injury

and other specialist neuro-physiotherapists to provide support for rarer conditions such as Huntingdon's Chorea (page 18)

Recommendation 4: We recommend that Health Boards organise specific neurological skills rehabilitation courses for generic physiotherapists (page 20)

Recommendation 5: We recommend that the Health and Social Care Committee consider whether the All Wales Medicines Strategy Group should appraise equipment and technology and recommend whether they are cost effective as part of the upcoming inquiry in access to medical technology (page 24)

Recommendation 6: We recommend that the Welsh Government should consider expanding the role of the All Wales Medicines Strategy Group should appraise equipment and technology and recommend whether they are cost effective page 24)

Recommendation 7: We recommend that the Welsh Government commissions a review of hydrotherapy provision across Wales to ensure those people with neurological conditions who might benefit from hydrotherapy are able to access it, both as an inpatient and an outpatient (page 25)

Recommendation 8: We recommend the Welsh Government work with health boards to fund an expansion of telemedicine and telecare technology across the NHS (page 26)

Recommendation 9: We recommend that Heads of Therapies ensure that validated outcome measures are used to ensure that physiotherapy for people living with neurological conditions is not time limited (page 30)

Recommendation 10: We recommend that the National Exercise Referral Scheme be expanded into all neurological conditions to support those individuals who are able to self manage their condition (page 33)

Recommendation 11: We recommend that Health Boards review their specialist physiotherapy facilities such as hydrotherapy pools to determine whether they could be opened up for community use (page 33)

Physiotherapy and neurological conditions

What is physiotherapy?

1.1 Physiotherapists help people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice. They maintain health for people of all ages, helping patients to manage pain and prevent disease.

1.2 The profession helps to encourage development and facilitate recovery, enabling people to stay in work while helping them to remain independent for as long as possible.

1.3 Physiotherapy takes a 'whole person' approach to health and wellbeing, which includes the patient's general lifestyle. At the core is the patient's involvement in their own care, through education, awareness, empowerment and participation in their treatment. Physiotherapy helps with back pain or sudden injury, managing long-term medical condition such as ataxia, and in preparing for childbirth or a sporting event.

Physiotherapy and neurological conditions

1.4 Physiotherapy provides a unique contribution to the management of people with a variety of neurological conditions through improvement and maintenance of functional abilities and management of the long term symptoms.

1.5 Physiotherapists can provide specific rehabilitation programmes, facilitate self management and co-ordinate care. For people with more complex needs physiotherapy should where possible be delivered within a multi-disciplinary specialist team/service where regular evaluation and assessment can be provided.

1.6 In Multiple Sclerosis for example, there is evidence that multidisciplinary rehabilitation can improve levels of activity and participation levels of people with MS[1]. Physiotherapy intervention and advice early after diagnosis can reduce disability, maximise potential for independence, improve employment sustainability and

[1] Khan F, Turner-Strokes L, Ng L, et al. (2008) 'Multidisciplinary rehabilitation for adults with multiple sclerosis', *Cochrane Database of Systematic Reviews*. Chichester, John Wiley & Sons Ltd. URL: http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD006036/frame.html

reduce the impact that the disease has on health and quality of life factors.

1.7 There is a strong body of evidence demonstrating that exercise used as part of a rehabilitation programme can increase activity and improve wellbeing of people with MS[2] and other neurological conditions. In addition there is an emerging body of evidence to say that physiotherapists, as part of a specialist neurorehabilitative service, have a key role in managing specific symptoms of MS including pain, spasticity and the prevention of secondary complications such as contracture. Results from randomised controlled clinical trials of exercise programmes in MS have demonstrated benefits in muscle strength, cardiovascular fitness, aerobic thresholds and activity levels and functional improvements, such as walking ability.

1.8 Physiotherapy is seen as a cost effective treatment of people who have had a stroke. There is wide consensus based on the National Clinical Guidance for Stroke[3] about the beneficial impact of physiotherapy on the physical effect of stroke. Physiotherapists have a critical role to play in supporting stroke survivors during their hospital stay and when they leave hospital.

1.9 When stroke survivors receive rehabilitation at home or in the community rather than in hospital, early supported discharge has been shown to be a cost effective service when combined with stroke unit care. Early supported discharge can reduce long term dependency and admission to institutional care as well as releasing hospital beds by reducing length of stay. ESD has been shown to be most successful where there is a co-ordinated stroke multi-disciplinary, multi-agency team delivering the service.

1.10 Many stroke survivors report a very real sense of both personal and physical loss. Physiotherapists and other allied health professionals are ideally placed to support individuals in working towards re-enablement and recovery.

What do people living with neurological conditions think about physiotherapy services?

[2] Turner AP, Kivlahan DR, Haselkorn JK. (2009) 'Exercise and quality of life among people with multiple sclerosis: looking beyond physical functioning to mental health and participation in life', *Arch Phys Med Rehabil,* Mar;90(3):420-8

[3] Royal College of Physicians Intercollegiate Stroke Working Party (2008). *National Clincial Guidelines for Stroke*, 3rd edition. London. URL: http://bookshoprcplondon.ac.uk/details.aspx?e=250

1.11 Research for this report demonstrated that overwhelmingly people living with neurological conditions believe that physiotherapy has a positive impact on their condition.

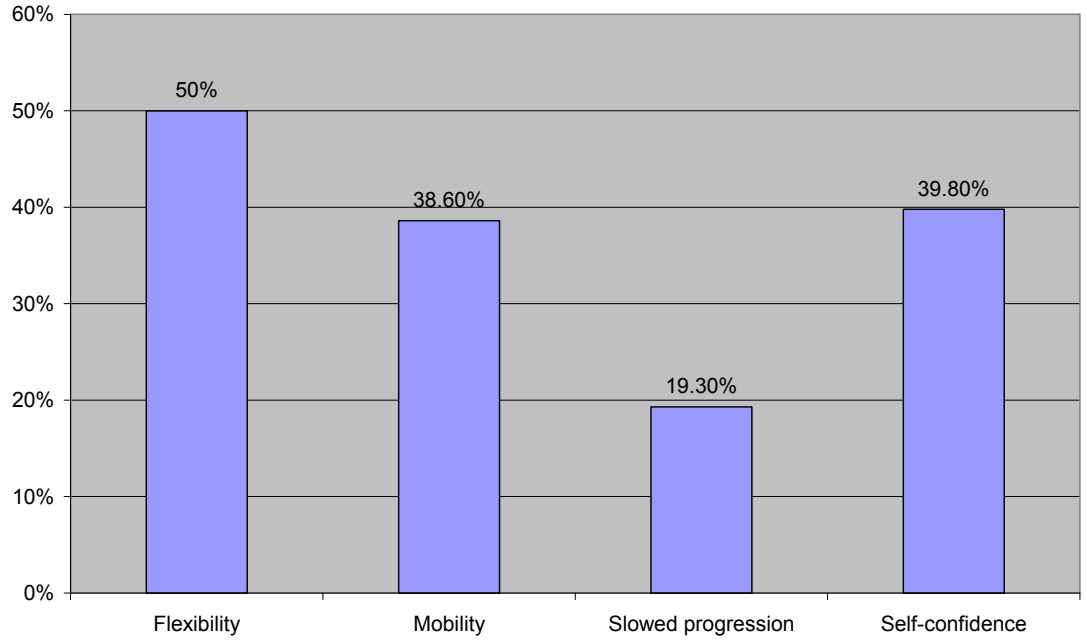


Figure 1

1.12 Service users were asked what they thought the benefits of the physiotherapy were and they selected a variety of responses. The most popular response with 50% of respondents was increased flexibility, but slowing progression was selected by almost 20%.

1.13 Many neurological conditions are progressive so for any delay in progression has real financial benefits to health and social services.

How easy is it to access physiotherapy services in Wales?

2.1 Physiotherapy services exist throughout Wales with staff delivering services in community hospitals, district general hospitals and tertiary centres.

2.2 According to Stats Wales there are 1,196 FTE physiotherapists employed across Wales, with less than 150 working with people living with neurological conditions. The number of specialist physiotherapists is low and is considered in the next section, but every member of staff should have some knowledge on neurological conditions from their training.

Are you currently receiving (or have you received) physiotherapy?

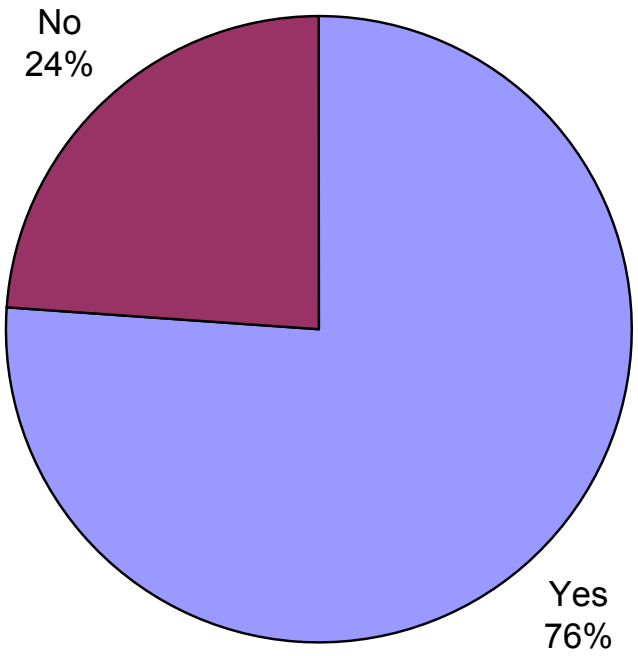


Figure 2

2.3 In response to the survey of people living with neurological conditions, 24% people indicated that they were no longer receiving physiotherapy nor had ever received physiotherapy.

2.4 Whilst it is positive that the majority of respondents were currently accessing physiotherapy, the size of the minority who were not remains a concern due to most of them living with Parkinson's Disease and Multiple Sclerosis, two conditions where

continued physiotherapy is an important factor in slowing the progression of the condition.

2.5 The research also identified that a sizable number of people were choosing to privately purchase physiotherapy services as individuals or as voluntary sector groups. 42% people of respondents indicated that they have purchased services privately either to supplement their existing programme or in place of regular physiotherapy services. Out of the cohort of individuals who were no longer being offered NHS physiotherapy or had never been referred to physiotherapy services, 33% were paying for private services indicating an unmet need.

2.6 Theoretically the process for referral to a physiotherapist is relatively straight forward with in patients being referred within 72 hours and out patients being referred within a maximum of 14 weeks. However there are some regional variations.

Health Board	**In patient wait for referral**	**Out patient wait for referral**
Abertawe Bro Morgannwg University Health Board	24 hours	14 weeks
Aneurin Bevan Health Board	72 hours	Between 2 weeks (urgent cases) and 14 weeks
Betsi Cadwaladr University Health Board	24 hours	14 weeks
Cardiff and Vale University Health Board	24 hours	4 weeks
Hywel Dda Health Board	72 hours	Between 2 weeks (urgent cases) and 14 weeks
Powys Health Board	72 hours	Between 6 and 8 weeks

- No reply was received from Cwm Taf Health Board following the letter in Appendix A

Figure 3

2.7 Although there are regional variations the data from Health Boards indicates that people with neurological conditions are being seen within the 26 week target that the NHS focusses on with many urgent cases being seen in hours rather than days.

Referral and Self-referral

2.8 If someone is admitted to an Emergency Unit following a sudden deterioration (if it is a progressive condition) or a traumatic event (if it is brain injury or a stroke, then as an in patient, they are typically referred to physiotherapy services if it is appropriate. The challenge in this case is whether the course of treatment will be timed and this is topic is covered later in the document.

2.9 However for those people seeking an out patient referral the process is not as straight forward. A GP can refer someone to a physiotherapist, but in many cases they prefer to leave decisions about a neurological condition to the individual's neurologist or specialist nurse. Depending on the condition and the Health Board it can be difficult to see the specialist team and even then they might not recommend the individual for physiotherapy.

Case study: Helen

Helen, 52, was diagnosed with Parkinson's disease in 2009. When diagnosed with the condition, Helen was simply told to conduct her own research on the internet. She eventually found physiotherapy via another charity, as symptoms were making her working life increasingly difficult.

Helen paid for physiotherapy at the centre, which was provided on a one-to-one basis for 8 weeks. However, when this course ended and was followed up by an eight week group course, Helen found that she was unable to attend as it clashed with work.

Helen felt that she would have benefited more if she were able to arrange sessions to suit her own routine, and feels that more physiotherapists with neurological knowledge and experience are needed. She was also later frustrated when informed by charities that newly diagnosed Parkinson's patients need to access physiotherapy and speech therapy, as this advice was not given to her when she was diagnosed at a hospital.

2.10 A recent innovation to simplify the process of referring out-patients to physiotherapy services has been through self referral. Abertawe Bro Morgannwg University Health Board has been at the

forefront of the drive to expand self referral to a wide range of conditions.

2.11 The Health Board established Physio Direct, a telephone triage self referral service where patients can ring and speak to a qualified physiotherapist. This service is open between 9am and 12 mid day Monday – Friday (excluding Bank Holidays) The physiotherapist will ask a series of questions to find out what the problem is and then either, give exercises and advice over the phone or arrange an appointment to attend the physiotherapy department for further treatment.

2.12 Local physiotherapists have also established a walk-in assessment clinic allowing individuals to have a face to face assessment service.

A quick guide to self-referral

Self-referral is popular with patients. It is a patient-centered approach that increases ease of use, convenience, portability, patient influence, choice, engagement and involvement in care, and promotes self-management. The pilots in other parts of the UK showed that people who self-refer to physiotherapy take fewer days off work and are about half as likely to be off work for one month, compared with those referred to physiotherapy by a GP.

Self-referral to physiotherapy is efficient for other healthcare providers too, reducing costs, time and resources. Patients often see a GP several times before being referred to physiotherapy, by which time their condition may be more longstanding and difficult to resolve.

Where trialed, self-referral has not led to an increase in demand for physiotherapy, apart from in physiotherapy services that have a history of under-referral. A proportion of people who would normally have seen their GP first simply opt for a more direct route to solve their problem.

2.13 In May 2012 the Health Board confirmed that in the short time it has been operation the clinic has resulted in a reduction in

waiting lists and an increase in the number of patients seen.[4] This specific service is for musculoskeletal physiotherapy, but it is model that has been expanded to neurological conditions in Scotland and could improve the lives of service users.

Recommendation 1: We recommend that Health Boards expand self referral so that everyone can self refer to local physiotherapy services

Multi-disciplinary Team Clinics

2.14 Across Wales there are emerging examples of best practice to bring together physiotherapists together with occupational therapists, speech and language therapists and other clinicians into conditions-specific or neurological clinics.

2.15 The research collected for this report indicated that only 11% of people are travelling over 10 miles to see a physiotherapist and only 2% are travelling over 25 miles. These figures are a reflection of the success of multi-disciplinary team (MDT) clinics, particularly in Powys, which have cut down travel times considerably.

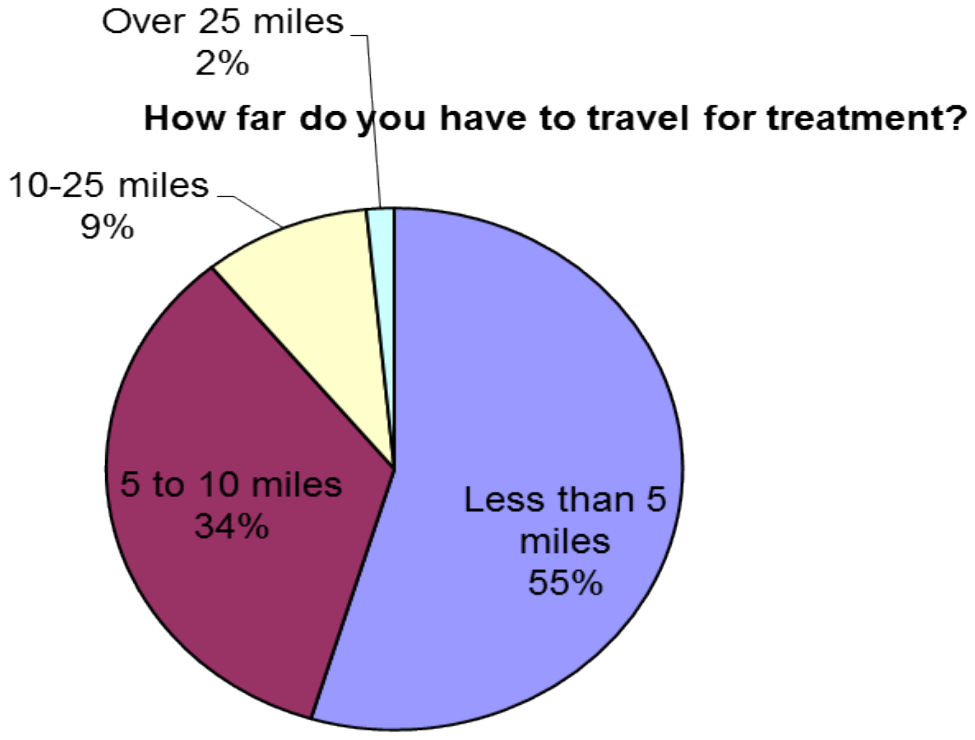


Figure 4

[4] http://www.csp.org.uk/news/2012/05/18/waiting-times-cut-first-welsh-walk-clinic

2.16 In recent years Powys Health Board has established monthly neurology multi-disciplinary team clinics in each of the 3 localities. These clinics have dramatically improved the patient experience and reduced the number of long drives out of county to see specialist physiotherapists at tertiary centres.

2.17 With all of the professionals meeting in one location an individual is able to receive a full "service" with their condition being monitored and possible future referrals being made for additional treatment or to other therapists who are not at the MDT. Once someone has been initialled referred to the MDT and the therapists have their medical records, they are able to make subsequent self-referrals.

How multi-disciplinary teams have improved services for Motor Neurone Disease

Three multi-disciplinary teams (MDTs) have been established across North Wales to improve planning and coordination of services for people living with Motor Neurone Disease. These MDTs meet monthly in the East, West and Central areas of the Betsi Cadwaladr University Health Board area and involve a range of Health and Social Care Professionals.

The MDTs have demonstrated benefits for both people living with Motor Neurone Disease and the professionals providing care services for such a complex progressive degenerative disease. The Motor Neurone Disease MDTs will now be supported by a newly established North Wales Disease Specific Advisory Group led by Dr Andy Fowell, Consultant in Palliative Medicine. The group will ensure consistent and equitable service development across North Wales for people living with MND through shared learning and developing local expertise.

It is anticipated that the Disease Specific Advisory Group will serve as a model for the development of further groups reporting to the North Wales Neuroscience Network.

Recommendation 2: We recommend that Hywel Dda Health Board establish regular neurological multi-disciplinary teams across West Wales so that service users can access physiotherapy and other support

Generic vs. specialist physiotherapy

3.1 Neurological conditions are complex, varied and in many cases extremely rare. Over recent years the specialist roles have developed within neurosciences to reflect that whilst some services can be provided by neurologists, service users can benefit from specialist therapists.

3.2 The Mid and South Wales Neuroscience review developed the following pathway dividing people living with neurological conditions into three distinctive levels.[5]

Figure 5

3.3 Many people with neurological conditions will move through the different levels as their condition evolves. Certain conditions such as Motor Neurone Disease would be focussed on Level 3 throughout the patient pathway, whilst conditions where there are periods of stabilisation or remission might start at Level 3, but then have periods where Level 2 is more appropriate.

3.4 In some Health Boards people living with neurological conditions can access specialist neuro-physiotherapists, whilst in others there are concerns that the existing physiotherapists do not have the knowledge and expertise about the conditions.

[5] NHS Wales (2011) 'Adult rehabilitation and supportive care', p. 11 in 'Mid and South Wales Neurosciences Review Final report,' Cardiff

What is the definition of a specialist neuro-physiotherapist?

3.5 The Chartered Society of Physiotherapy defines a specialist as a physiotherapist who works at an advanced clinical level within a specific clinical field. Clinical specialists will work as advanced practitioners – a term which is familiar in Wales where a framework for advanced practice has been developed by the National Leadership and Innovation Agency for Healthcare.

3.6 The clinical specialist role relies on a network of physiotherapists in in-patients, out-patients and the community who will see people with MS and may need expert input. A key part of the role involves education, advice and support to others, including patients and their carers, the MS team, other professionals and students. Other parts of the role include working in clinics seeing newly diagnosed patients or those in relapse and requiring symptom management.

3.7 Neuro-physiotherapists tend to focus on individuals with more complex problems and there is often a need for a range of different agencies to come together to provide the treatment programme in a timely and appropriate manner. A great deal of time can be spent enabling this.

3.8 According to Stats Wales there are 1,196 FTE physiotherapists employed across Wales with many of them working with people living with neurological conditions, but only xx specialist neuro-physiotherapists.

3.9 However identifying exactly how many work with people living with neurological conditions can be difficult as the figures would include a small number of specialists neurophysiotherapists at Band 6 or 7 and a larger number of generic physiotherapists who would be less specialist.

Health Board	No. of physiotherapists working for the LHB	No. of physiotherapists working mainly with neurological conditions
Abertawe Bro Morgannwg University Health Board	188	17.5 staff involved in neurorehabilitation
Aneurin Bevan Health Board	201 WTE	22 with a specialist knowledge of neurosciences
Betsi Cadwaladr University Health Board	253	13 with a specialist knowledge of neurosciences
Cardiff and Vale University Health Board	253 WTE	38 WTE working in neurosciences
Hywel Dda Health Board	148	31 mainly dedicated to neurology
Powys Health Board	33 WTE	1 Consultant Therapist and 3 WTE with neuroscience background

- No reply was received from Cwm Taf Health Board following the letter in Appendix A

Figure 6

3.10 In evidence given to the Cross-Party Group for Neurological Conditions, the MS specialist neuro-physiotherapist for South East Wales, Rhian O'Halloran stated that one of their greatest challenges was managing expectations due to their low numbers.

> "It is not possible to provide on-going services to everyone and it is important with long term conditions management to develop a long term management approach, providing home exercise programmes, review medication for home management and pain management, use of splinting and directing people to classes relevant to them."

3.11 Someone with a neurological condition is more likely to come into contact with a non-specialist physiotherapist, so it is important

that there are enough specialist neuro-physiotherapists to provide training and support to their peers.

Recommendation 3: We recommend an expansion in the number of clinical specialist neuro-physiotherapy roles so that every Health Board has a specialist neuro-physiotherapist for multiple sclerosis, parkinson's disease, neuro muscular disease (NMD), spinal cord injury and other specialist neuro-physiotherapists to provide support for rarer conditions such as Huntingdon's Chorea.

What can be done to improve the knowledge of generic physiotherapists?

3.12 Research showed that there are positive examples of best practice across Wales where a limited number of specialist neuro-physiotherapists are sharing their skills.

3.13 In Hywel Dda Health Board a neurological clinical practice group meets monthly to review individual cases by bringing together generalist and specialist practitioners, whilst a locality network community service brings together staff to provide intervention, education and training for generalist practitioners.

3.14 In Powys the Health Board has been developing creative solutions to compensate for the vast geography and the low number of specialists in different conditions.

3.15 In evidence to the Cross-Party Group for Neurological Conditions Michelle Price, the Consultant Therapist in Stroke and Neuro Rehabilitation, Powys Teaching Health Board, outlined her model of the "specialist generalist" where through training and multi-disciplinary team working generic physiotherapists could acquire further skills and knowledge of neurological conditions.

3.16 The development of MDTs was referred to in section 2, but other developments include organising specific neurological skills rehabilitation courses for generic physiotherapists, Bobath courses for paediatric physiotherapy, and investments in technology such as telemedicine and functional electrical stimulation (FES).

3.17 Across Wales the physiotherapy community has set up a national group, the Association of Chartered Physiotherapists in

Neurology (ACPIN), to bring together individuals who have an interest in neuro-physiotherapy and who wanted to develop a portfolio of training to other physiotherapists with an interest in (further) specialising in neuro-physiotherapy.

3.18 Over the proceeding 18 months ACPIN has organised a pusher syndrome course (June 2011), an upper limb rehabilitation workshops (December 2011), an evidence based neuro-rehabilitation workshop (February 2011) and has attended conferences. The association aims to make neuro-physiotherapy training more accessible to physiotherapists working in Wales and is developing web based training through WebEx.

Conclusions

3.19 Education and training is improving the service user experience and reducing examples of bad practice where physiotherapists have little knowledge of the condition. Research undertaken for this inquiry showed that only 17% people thought that their physiotherapist "had limited knowledge" of their condition, whilst the majority had some knowledge or were a specialist in the condition.

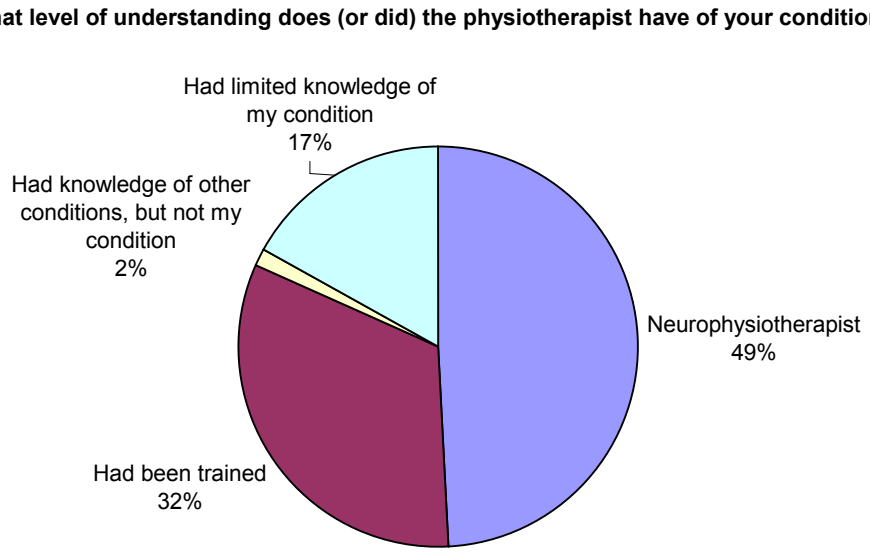


Figure 7

3.20 However there are too few neuro-physiotherapists and examples of poor understanding of neurological conditions still exist.

Case study: William

William, 75, was suffering from MS, and had initially had therapy from a community physiotherapist, who taught him a range of exercises, explaining the importance of standing up daily to improve his bladder problems and deal with his condition.

However, when William went into hospital for respite care, it was very difficult to get physiotherapy. On a general ward, William felt that members of staff did not properly understand MS as a condition, and the importance of him moving regularly. William gradually lost morale and his mobility after being kept in bed for so long.

William was still fully aware of the importance of exercising and standing, however short-term memory problems and the varying routine of a hospital environment lowered his spirits and powers of assertion.

When William was ready to be discharged, NHS staff would not release him until a care package was organised, which took a long time to arrange – this increased the financial cost of his care, which would have been greatly diminished had William received the necessary physiotherapy when first admitted. Consequently, William returned home in a wheelchair, because he was not reminded to do his exercises, integral to successful management of the condition.

If William had received respite care away from hospital, he would have received more specialist attention and would have been reminded to carry out his exercises where needed.

Recommendation 4: We recommend that Health Boards organise specific neurological skills rehabilitation courses for generic physiotherapists

Access to equipment

4.1 The research for this inquiry has shown that access to physiotherapists who understand neurological conditions is important and is key concern for service users. However the role of equipment and technology in physiotherapy is increasingly becoming important both for self management and for equipment supervised by professionals.

4.2 The classic image of physiotherapy is one of manual therapy, where physical manipulation is used to move limbs to increase flexibility. Physiotherapists analyse the movement, examining how muscles, tendons and joints move.

4.3 Whilst this traditional model can be useful for neurological conditions, this method is predominantly used for musculoskeletal physiotherapy, whilst treatments for neurological conditions tend to be more reliant on equipment.

4.4 Service users can benefit from using sports equipment and aids when exercising, and some of these may be suggested by a physiotherapist. For example, exercise bikes and rowing machines can offer quite strenuous exercise in a controlled environment – which could be useful if vision, coordination or balance problems make these kind of activities difficult outdoors. A standing frame can be an aid to weight-bearing exercise and weights strapped around the wrists or ankles might help strengthen arms or legs.

4.5 Aids and equipment can also help compensate for difficulties with balance, muscle weakness or other symptoms. For example trekking poles and walking sticks can help keep balance when walking. If someone has more strength in their arms than their legs, a hand-cycle might be an option, a bicycle powered by pedals for the hands instead of the feet.

4.6 There is currently little guidance on the funding of equipment for physiotherapy and this can make it difficult to access appropriate support to improve the quality of life for the service users. Whilst the upfront costs of the equipment might seem high in comparison with the long term costs of medicines they can in fact be very good value for money.

4.7 In a case study presented by a physiotherapist to the Cross-Party Group a piece of equipment was required for a service users but at £6,000 it was said to be too expensive when compared to medication. However, the equipment if used for 10-years would have cost £3.85 a stand (3 minutes x 3/week) and if used for 5-years £7.70 a stand. This cost should be offset against the cost of care delivered if the patient deteriorates or it they need staff to support them in access to physical exercise.

4.8 The challenge is that it is far more likely to find a medicine that has been appraised for its cost effectiveness than a piece of equipment, leading physiotherapists and GPs to negotiate on a case by case basis to use equipment regarded as expensive.

How is equipment appraised?

4.9 Across the UK the National Institute for Health and Clinical Excellence (NICE) can issue guidance on the safety and suitability of procedures to the NHS in each of the 4 jurisdictions called an "interventional procedures."

4.10 An interventional procedure is defined as a procedure used for diagnosis or for treatment that involves:

- making a cut or a hole to gain access to the inside of a patient's body
- gaining access to a body cavity
- using electromagnetic radiation (which includes X-rays, lasers, gamma-rays and ultraviolet light) - for example, using a laser to treat eye problems.

4.11 NICE interventional procedures guidance covers the safety of the procedure, whether it works well enough for routine use and whether special arrangements are needed for patient consent. Interventional procedures do not consider the cost effectiveness of a device or piece of equipment and the ultimate decision remains with the Health Board.

4.12 This guidance covers some of the equipment used by physiotherapists, but not all. However both NICE and the All Wales Medicines Strategy Group (AWMSG) have a far greater role in issuing guidance on which drugs should be provided by the NHS.

4.13 Both organisations make their decisions based on both the clinical and cost effectiveness of the drug, and if approved patients are legally entitled to be prescribed the treatment – so long as they meet the eligibility criteria.

4.14 The result is that whilst Health Boards have an obligation to prescribe approved drugs, when they are deciding whether to approve the use of a piece of technology, the guidance that exists is advisory and in many cases does not exist.

Functional Electrical Stimulation

4.15 Functional Electrical Stimulation (FES) is a technique that uses low levels of electrical current to stimulate nerves. This can help to move parts of the body that have been affected by upper motor neurone lesions that can result from conditions such as stroke, cerebral palsy, multiple sclerosis or spinal cord injury but may occur in other conditions.

4.16 The technique involves attaching electrodes (similar to self-adhesive patches) to the surface of the skin. These transmit small electrical impulses to stimulate the nerves and activate the muscles. The most common problem treated by FES is called dropped foot.

4.17 The technique is relatively cheap, costing approximately £1,000 per year to use and can prevent expensive trips to Emergency Units due to falls.

4.18 NICE published interventional guidance in 2009 confirming the safety and efficacy of the procedure but a postcode lottery has existing across Wales with some health boards funding the treatment routinely whilst others restricting supply.

4.19 In 2010/11 192 people were benefiting from FES across Wales, but Health Boards in Mid and South Wales are currently waiting the outcome of a review by Cardiff and Vale University Health Board into the effectiveness of the service to determine how the service could be funded in the future.[6] Most service users require FES for a number of years and the Health Boards have not currently allocated funding for the growth in patient demand. This

[6] NHS Wales (2011) 'Adult rehabilitation and supportive care', p. 33 in 'Mid and South Wales Neurosciences Review Final report,' Cardiff

resulted in the service being closed to new patients in Cardiff and Vale University Health Board in 2011.

4.20 The absence of Wales-wide guidance on the cost effectiveness of equipment means that even when a treatment has NICE Interventional Procedure guidance, there is not guarantee it can be accessed.

Recommendation 5: We recommend that Health and Social Care Committee consider whether the All Wales Medicines Strategies Group should appraise equipment and technology and recommend whether they are cost effective as part of the upcoming inquiry in access to medical technology

Recommendation 6: We recommend that the Welsh Government should consider expanding the role of the All Wales Medicines Strategies Group should appraise equipment and technology and recommend whether they are cost effective

Botox

4.21 Botulinum toxin (botox) injections are used to treat a wide variety of medical problems, including Stroke, traumatic brain injury and motor neurone disease, where injections treat tightened muscles.

4.22 The injections are not a substitute to physiotherapy but allow physiotherapists to increase the range of move, reduce muscle tightness, spasm and pain over a period of 3-4 months. Intensive physiotherapy treatment before and after the injections is essential to achieve the best possible range of movement and functional outcome. After the injections, hands-on treatment may include muscle mobilisations, massage, manual stretches and practice of functional movement patterns. Research shows that muscles respond well to stretching over a prolonged period of time.

4.23 The treatment is not cheap – a botox treatment designed for combating over active bladder symptoms costs approximately £1,000 including the cost of the physiotherapists time, but it is cheaper than other medical intervention.

Hydrotherapy

4.24 The inquiry revealed that there is a shortage of hydrotherapy services in parts of Wales, whilst some existing facilities are not up to a modern standard.

4.25 Hydrotherapy is the use of water to increase flexibility and where possible slow the progress of disability. Hydrotherapy differs from swimming because it involves special exercises that are carried out in a warm-water pool. The water temperature is usually 33–36ºC, which is warmer than a typical swimming pool.

4.26 The treatment can be used for a range of neurological conditions and is one of many tools that physiotherapists can use but the costs of maintaining the pools are expensive, so access is not universal.

Recommendation 7: We recommend that the Welsh Government commissions a review of hydrotherapy provision across Wales to ensure those people with neurological conditions who might benefit from hydrotherapy are able to access it, both as an inpatient and an outpatient.

Telemedicine

4.27 One of the most exciting technological challenges for physiotherapy and in Wales, as with many other therapies is the potential for telemedicine to bring together specialist neuro-physiotherapists at a tertiary centre in Cardiff, Swansea or the Walton Centre and allowing them to examine a service user in a community hospital or even in their homes.

4.28 The UK Department of Health defines 'telecare' "as much about the philosophy of dignity and independence as it is about equipment and services. Equipment is provided to support the individual in their home and tailored to meet their needs. It can be as simple as the basic community alarm service, able to respond in an emergency and provide regular contact by telephone. It can include detectors or monitors such as motion or falls and fire and gas that trigger a warning to response centre."[7]

[7] UK Department of Health (2011) *'Whole system demonstrator programme'*, London

4.29 Some neurological conditions are already benefiting from telemedicine, but the technology remains in its infancy in Wales and has the potential to be expanded greatly. In December 2011 the Welsh Government invested £350,000 in telemedicine equipment to allow clinicians in community hospitals to diagnose stroke by liaising with consultants at a tertiary centre. The investment in portable, telemedicine units enabled consultants in a different location to give virtual assessments for stroke patients via a video camera and screen. The equipment also allowed health professionals to interview patients and relatives while simultaneously being able to see test results and scans to help them make a decision on treatment.[8]

4.30 In Section 3 the report sets out the challenge of a limited number of specialist neuro-physiotherapists being unable to see the vast majority of the service users on their case load due to the size of their caseload and rurality. As stated in that section training and the sharing of expertise is a positive way that community physiotherapists can be empowered to better understand a neurological condition. Telemedicine offers the opportunity for a small number of specialist neuro-physiotherapists to direct colleagues in a community hospital hundreds of miles and ensure that the most appropriate program of physiotherapy is developed.

4.31 The research showed that third sector organisations are working with Hywel Dda and Powys health boards to develop telemedicine services for neurology by attempting to connect professionals at Swansea and Shrewsbury to community hospitals in West Wales and Powys.

Recommendation 8: We recommend the Welsh Government work with health boards to fund an expansion of telemedicine and telecare technology across the NHS.

[8] http://wales.gov.uk/newsroom/healthandsocialcare/2010/101206telemedicine/?lang=en

Rehabilitation and self management

5.1 The classic image of physiotherapy is of a timed course of treatment where an individual regains the vast majority of their mobility when it concludes.

5.2 In musculoskeletal physiotherapy this tends to be the typical model with a timed course of physiotherapy of a number of weeks to tackle a broken leg or a dislocated shoulder. With a neurological condition an individual might need indefinite physiotherapy for the rest of their lives, with the treatment serving to delay progression rather than fix the problem.

5.3 The challenge for the physiotherapy community is to develop systems to ensure that individuals can continue to access appropriate levels of physiotherapy throughout the rest of their life. Accessing specialist neuro-physiotherapists if they fall into level 3 of the community model n Figure 5, accessing community physiotherapists with an understanding of neurological conditions if at level 2, and being able to access facilities in the community to manage their own condition if they would fall into level 1 of the model. People living with neurological conditions need to be able to self-refer back into the system when their needs change.

Case study: Helen

Helen, 52, was diagnosed with Parkinson's disease in 2009. When diagnosed with the condition, Helen was simply told to conduct her own research on the internet. She eventually found physiotherapy through a charity, as symptoms were making her working life increasingly difficult.

Helen paid for physiotherapy at the centre, which was provided on a one-to-one basis for 8 weeks. However, when this course ended and was followed up by an eight week group course, Helen found that she was unable to attend as it clashed with work.

Helen felt that she would have benefited more if she were able to arrange sessions to suit her own routine. She was also later frustrated when informed by charities that newly diagnosed Parkinson's patients need to access physiotherapy and speech therapy, as this advice was not given to her when she was diagnosed at a hospital.

5.4 Research undertaken for this inquiry has identified a series of best practice measures that specialist neuro-physiotherapists or generic community physiotherapists can use to monitor the progression of neurological condition and to determine whether the treatment is effective. The most common measures are Lindop Scale, Fatigue Measure, Berg Balance Scale and Goal Attainment Scale.

5.5 The Berg Balance Scale is one of the most commonly used tests of a person's static and dynamic balance abilities[9]. The test takes 15–20 minutes and comprises a set of 14 simple balance related tasks, ranging from standing up from a sitting position, to standing on one foot. The degree of success in achieving each task is given a score of zero (unable) to four (independent), and the final measure is the sum of all of the scores. If someone scores 0–20, they would typically require a wheelchair, 21-40 would be someone who could walk with assistance, whilst a score of 41-56 would indicate that someone could walk independently.

5.6 The Berg Balance Scale is flexible and can be used for most neurological conditions, but it is only one measure and is typically used with others that are condition specific. People living with Parkinson's Disease for example are monitored using a specific Lindop Parkinson's Assessment Scale. The assessment takes approximately 15 minutes and there are 9 questions scored on a 0-3 scale with 3 being the best score. There are 6 tasks for assessing gait mobility and 4 tasks for assessing mobility.

[9] Blum, Lisa; Korner-Bitensky, Nicol (2008). 'Usefulness of the Berg Balance Scale in Stroke Rehabilitation: A Systematic Review', *Physical Therapy* **88** (5): 559–566. doi:10.2522/ptj.20070205. http://ptjournal.apta.org/content/88/5/559.long.

An example task is:

Timed Unsupported Stand	
Starting position:	Standing in front of high plinth with hands resting on plinth. Patient takes hands off plinth when they have placed their feet apart and are ready to stand unaided. Therapist starts stop watch as soon as patient removes hands.
End position:	Patient places hands back on bed after one minute or before this if they feel unsteady. Therapist stops stopwatch when patient's hands are placed back on plinth.

5.7 Neurological conditions are lifelong and the research and there are recognised methods of monitoring the progress of physiotherapy as a condition progresses. Yet research for this inquiry revealed that a significant group of people (43%) have received courses of physiotherapy of less than 3 months and the majority of these felt that their treatment should have continued.

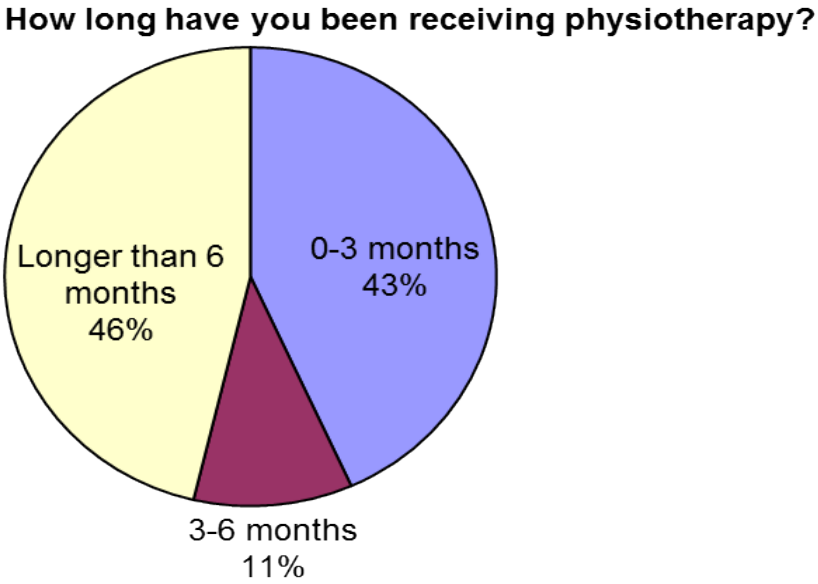


Figure 8

5.8 Best practice scales and measures exist within physiotherapy services across Wales, but there still appears to be a challenge to ensure that people living with neurological conditions can receive appropriate physiotherapy for as long as it is making a positive difference.

Recommendation 9: We recommend that Heads of Therapies ensure that validated outcome measures are used to ensure that physiotherapy for people living with neurological conditions is not time limited.

Self management

5.9 Whilst formal physiotherapy services may be necessary for someone living with a neurological condition if they fall into the category of level 2 or 3 of the pyramid shown in Figure 5, someone who falls into level 1, "Self managing with support of single health professionals", may be able to manage their needs their support in a non-medical setting through self management and exercise.

5.10 Every neurological condition is different, but health professionals would generally recommend the following types of exercise where possible:

- Strengthening exercises including lifting and moving small weights (or an elastic exercise band if tremor or spasm exist)
- Aerobic exercises such as cycling, running or rowing to exercise the heart and lungs
- Stretching to help keep muscles supple and relaxed
- Range of movement exercises to ensure that joints have as full a range of movement as possible
- Passive stretching where someone else moves the arms or legs to create a stretch
- Posture exercises to help keep feet, knees, pelvis, shoulders and head properly aligned[10]

5.11 The Welsh Government has been promoting formal exercise programmes since 2007 through the National Exercise Referral Scheme (NERS) that is primarily targeted at cardiac conditions, diabetes and other chronic conditions, although a Stroke service has been developed.

[10] MS Society, 'MS Essentials 21: Exercise and Physiotherapy', London, 2011, p5

5.12 The principle aims of the scheme are:

- To offer a high quality National Exercise Referral Scheme across Wales
- To increase the long term adherence in physical activity of clients.
- To improve physical and mental health of clients.
- To determine the effectiveness of the intervention in increasing activity levels and improving health.

5.13 The programme has not only brought physical benefits to service users (muscle strength, maintaining good posture etc), but also both psychological and social benefits. People who have benefited from NERS have given feedback including: "I feel less anxious and stressed", "My confidence and self-esteem are better", and "My wife says I look a lot happier" for psychological benefits. Comments given on the social benefits included "The sessions made me get out of the house and gave me a new interest" and "I made new friends and enjoyed the conversations we had."[11]

5.14 The psychological effects of a neurological condition and the isolation that any long term condition can bring are difficult to quantify, but if someone's psychological wellbeing is improved then they are more likely to maintain their own physical wellbeing.

5.15 In South East Wales research has identified that Aneurin Bevan Health Board has developed exercise support groups for mixed neurological conditions. These groups facilitate the formation of patient led self support groups and promotes self management in long term conditions.

Case study: Chepstow Yoga Group:

One of these groups developed into the Chepstow MS Yoga group. The group was established in 2006 in the Chepstow Community Hospital meeting once every Friday morning. The group has 12 members from across South East Wales and has been important in managing both the physical and psychological wellbeing of their members.

[11] National Exercise Referral Scheme website:
http://www.physicalactivityandnutritionwales.org.uk/page.cfm?orgid=740&pid=34474

"In some ways the coffee afterwards is the key bit," says Jackie from Chepstow. "It is when we all get together and talk that we can share any issues and give each other support. I've met people who have been uninterested in formal physiotherapy and don't want to see neurologists, who have benefited from the support of the group and the professionals the Yoga."

Another member of the group, Melissa says that she continues to impress her neurologist, who when he sees her is always surprised by how flexible she still is despite her MS due to her weekly yoga.

5.16 Another area where Health Boards can support service users is to open up hospital facilities to community patients. Section 4 explains the benefits of hydrotherapy to people living with neurological conditions. Whilst swimming can be beneficial as part of a self management programme, the heat of a specific hydrotherapy pool can still be useful.

5.17 The research shows that Cardiff and Vale University Health Board have been trialling the opening up of the specialist hydrotherapy services at Rookwood Hospital to community based service users. Use of this specialist facility could make a real difference in the community rehabilitation of people living with neurological conditions, without significantly increasing the running costs for the facility.

Recommendation 10: We recommend that the National Exercise Referral Scheme be expanded into all neurological conditions to support those individuals who are able to self manage their condition

Recommendation 11: We recommend that Health Boards review their specialist physiotherapy facilities such as hydrotherapy pools to determine whether they could be opened up for community use

Conclusion

It is the intention of this report to highlight examples of good practice within physiotherapy services and recommend reforms that could increase the number of people who can access these services. The report demonstrates the support for physiotherapy services from people living with neurological conditions and proposes 11 recommendations that seek to improve services.

Over 100,000 people are living with a neurological condition in Wales and most could benefit from physiotherapy or from self-managed exercise classes with the right support. There are networks of talented physiotherapists across Wales, who with right training, support from specialists, and by working through multi-disciplinary teams, they could make a positive impact to peoples lives.

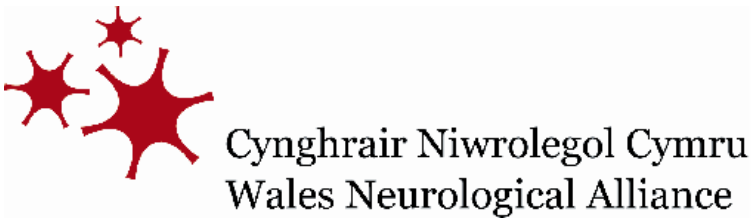
There are recommendations for health boards, the Welsh Government and for the Health and Social Care Committee. We would like the Welsh Government to consider the recommendations and ensure that the health boards implement the reforms.

Appendix

- Appendix A - Letter to Health Boards
  The following 6 out of 7 Health Boards responded to the survey

  Abertawe Bro Morgannwg University Health Board
  Aneurin Bevan Health Board
  Betsi Cadwaladr University Health Boad
  Cardiff and Vale University Health Board
  Hywel Dda Health Board
  Powys Health Board

- Appendix B - Copy of questionnaire sent to people living with neurological conditions – 88 responses



NAME
TITLE
HEALTH BOARD
ADDRESS1
ADDRESS2
ADDRESS3
February 2012

Dear NAME,

PHYSIOTHERAPY SERVICES FOR PEOPLE LIVING WITH NEUROLOGICAL CONDITIONS

We are writing to you on behalf of the Cross Party Group for Neurological Conditions based at the National Assembly for Wales.

This group is the successor to the Cross-Party Group for Neurosciences and was first established in 2009 by the Wales Neurological Alliance and Assembly Members to monitor the two reviews into neurosciences in Wales and to raise awareness about the treatment and management of neurological conditions.

Cross-Party Groups are a method of bringing the public sector, voluntary sector and professionals together with Assembly Members from all parties, to discuss issues of common interest.

An issue on this year's programme is an investigation of the physiotherapy services available for people with different neurological conditions and identifying possible improvements.

Physiotherapists operate across a range of specialities and physiotherapy is an important element to the treatment of most neurological conditions. For some conditions it is used to improve flexibility and mobility following the onset or a sudden deterioration in the condition. For many others it serves to slow down the disability, maintain flexibility and improve quality of life. We are interested in services that cover all neurological conditions, including stroke and neuromuscular disease and we will be interested also in spinal injury and neuropsychiatry if these are services in which physiotherapy is provided by your health board.

In light of this the Cross-Party Group would like to ask the following questions –

- In total how many physiotherapists does Cwm Taf Health Board employ?

- How many physiotherapists with a specialist knowledge and expertise in neuroscience does Cwm Taf Health Board employ?

- What is the physiotherapy staffing establishment in your Health Board dedicated to working in the field of neurosciences? Where possible, please provide a breakdown into the subdivisions:

  Stroke
  Neuromuscular
  Neurorehabilitation
  Neurosurgery
  Neurology
  Spinal
  Neuropsychiatry

- What is the process for referring to a ‘neurophysiotherapist ‘ (a physiotherapist with specialist expertise in neurosciences) in Cwm Taf Health Board? Please answer this from the inpatient and outpatient perspective

- How long would a patient typically have to wait from referral to see a ‘neurophysiotherapist ‘ in Cwm Taf Health Board? Please answer this from the inpatient and outpatient perspective

- With many neurological conditions physiotherapy might prevent further deterioration of the condition rather than improve mobility. What mechanisms are in place to monitor the success of physiotherapy for

someone living with a neurological condition and would a course of treatment be time limited?

- Does Cwm Taf Health Board follow the Map of Medicine Care Pathways for the following conditions:

    1. Muscular Dystrophy
    2. Multiple Sclerosis
    3. Motor Neurone Disease
    4. Epilepsy
    5. Chronic Fatigue Syndrome
    6. Fibromyalgia
    7. Post Polio
    8. Acquired Brain Injury
    9. Parkinson's Disease
    10. Chronic Conditions

- Does your Health Board use any other care pathways for neurological conditions (if so, which)?

- Does your Health Board have any examples of innovation/good practice within physiotherapy services in the speciality areas of neurosciences that you would be happy to share with the Cross Party Group?

Any further comments you may wish to make about physiotherapy services for people living with neurological conditions in Cwm Taf Health Board, including any potential future initiatives that may be undertaken in the local area, would also be appreciated.

We look forward to receiving your response.

Yours sincerely,

Mark.

Joseph Carter

Mark Isherwood AM
Chair of the Cross-Party Group for Neurosciences

Joseph Carter
Chair of the Wales Neurological Alliance

CROSS-PARTY GROUP FOR NEUROLOGICAL CONDITIONS – GRŴP TRAWS-BLEIDIOL AR GYFLYRAU NIWROLEGOL

The Wales Neurological Alliance is: Alzheimer's Society, **Association of Spina Bifida and Hydrocephalus,** Cerebra, **Charcot-Marie-Tooth United Kingdom,** Chartered Society of Physiotherapy, **Child Brain Injury Trust UK,** College of Occupational Therapists, **Dystonia Society,** Epilepsy Action, **Epilepsy Wales,** Genetic Alliance UK, **Guillain-Barré Syndrome Support Group,** Headway, **Huntington's Disease Association,** Motor Neurone Disease Association, **Muscular Dystrophy Campaign**, Myasthenia Gravis Association, **Myotonic Dystrophy Support Group,** MS Society Cymru, **Parkinson's UK,** Progressive Supranuclear Palsy Society, **Stroke Association,** Tourette's Syndrome Association, **Tuberous Sclerosis Association,** Welsh Association of ME & Chronic Fatigue Syndrome.

Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Physiotherapy Survey

Who are we?
The Wales Neurological Alliance (WNA) is a voice for the 100,000 people, their families and carers affected by neurological conditions who live in Wales. Our membership constitutes 25 organisations from the voluntary sector. Our aim is to improve the lives of those affected by neurological conditions by raising awareness of their needs for better health services.

What is the survey for?
The Wales Neurological Alliance is concerned that people living with a range of neurological conditions might not be able to access appropriate physiotherapy. We would like to find out about your experiences of trying to access physiotherapy, how effective it was, and how difficult it was to be referred.

1. Name: _____
2. Address: _____

   _____
3. Date of Birth: _____
4. What is your condition? _____
5. How long have you been diagnosed with your condition?

☐ 0-5 years ☐ 5-10 years ☐ 10-15 years ☐ 15 years or longer

6. In the last 12 months have you ever had contact with the following? (tick all that apply)

☐ Neurologist ☐ Physiotherapist ☐ Occupational Therapist ☐ Speech Therapist

☐ Specialist Nurse ☐ Continence Nurse

7. In the last 12 months have you had any contact with the following groups? (tick all that apply)

☐ A charity linked to your condition (if yes, please say which) _____

☐ A carers charity (if yes, please say which) _____

☐ The Wales Neurological Alliance ☐ A local neurological alliance

8. Are you currently receiving (or have you received) physiotherapy to help you manage your neurological condition?

☐ Yes ☐ No

(If yes, please could go to Q9, if no, please could you go to Q16)

9. How long have you been receiving physiotherapy (or if in the past – how long did you receive physiotherapy)?

☐ 0-3 months ☐ 3-6 months ☐ Longer than 6 months

10. If your course of physiotherapy has finished do you believe that it should have continued?

☐ Yes ☐ No ☐ Don't know

11. How beneficial do you think the treatment has been?

☐ Very beneficial ☐ Limited benefit ☐ Unsure ☐ Has not helped

12. What were the benefits of the physiotherapy? (tick all that apply)

☐ Increased flexibility ☐ Increased mobility

☐ Slowed progression of condition ☐ Improved self confidence

☐ Other (please specify) _____

13. How often do you (or did you) receive physiotherapy?

☐ Weekly ☐ Fortnightly ☐ Monthly ☐ Irregularly

14. What level of understanding does (or did) the physiotherapist have of your condition?

☐ I was treated by a physiotherapist 'neurophysiotherapist' (a physiotherapist with specialist knowledge and experience in neurosciences)

☐ The Physiotherapist had been trained with my condition

☐ The Physiotherapist had knowledge of other conditions, but not my condition

☐ The Physiotherapist had limited knowledge of neurological conditions

15. Approximately how far do you have to travel for treatment?

☐ Less than 5 miles ☐ 5 to 10 miles ☐ 10-25 miles ☐ Over 25 miles

16. If you do not receive Physiotherapy, do you believe that you would benefit from receiving physiotherapy?

☐ Yes ☐ No ☐ Don't know

17. Why are you not receiving physiotherapy? (tick all that apply)

☐ Have not discussed it with GP/neurologist/specialist nurses

☐ GP/neurologist/specialist nurses did not support referral

☐ The NHS could not offer any suitable physiotherapy locally

☐ The waiting list was too long ☐ I am currently waiting to receive physiotherapy

18. Have you ever paid for physiotherapy or used a service paid for by a charity?

☐ Yes ☐ No

19. Would you like to receive more information about the work of the WNA in your area?

☐ Yes ☐ No ☐ Don't know

For more information:

We would be pleased to meet and discuss any of the issues above with you in more detail or feel free to contact us for more information, please see details below.

The Wales Neurological Alliance is: Alzheimer's Society, **Association of Spina Bifida and Hydrocephalus,** Cerebra, **Charcot-Marie-Tooth United Kingdom,** Chartered Society of Physiotherapy, **Child Brain Injury Trust UK,** College of Occupational Therapists, **Dystonia Society,** Epilepsy Action, **Epilepsy Wales,** Genetic Alliance UK, **Guillain-Barré Syndrome Support Group,** Headway, **Huntington's Disease Association,** Motor Neurone Disease Association, **Muscular Dystrophy Campaign**, Myasthenia Gravis Association, **Myotonic Dystrophy Support Group,** MS Society Cymru, **Parkinson's UK,** Progressive Supranuclear Palsy Society, **Stroke Association,** Tourette's Syndrome Association, **Tuberous Sclerosis Association,** Welsh Association of ME & Chronic Fatigue Syndrome.

Wales Neurological Alliance: c/o Miss Gill Gleeson, Cerebra, 2nd Floor Offices, The Lyric Building, King St, Carmarthen SA31 1BD W: www.walesneurologicalalliance.co.uk T: 01267 244200 E: gill@cerebra.org