

The Thomas Report:

Access to Specialist Neuromuscular Care in Wales

Cross Party Group on Muscular Dystrophy

July 2010

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Contents

Foreword	1
About Ray Thomas	2
The Cross Party Group on Muscular Dystrophy	3
Executive Summary	4
Recommendations	5
Background to the Review	7
What is muscular dystrophy?	8
Muscular Dystrophy Campaign	8
Summary of evidence	
1) What constitutes specialist multi-disciplinary care?	9
2) Living with muscle disease	13
3) Importance of the role of the Care Co-ordinator	17
4) Commissioning, planning and delivery of specialist services	20
Appendix	
The Cross Party Group on Muscular Dystrophy Review	25
Witnesses	25
Terms of reference	26
Written evidence	27

Foreword



The evidence published in the Thomas Report emphasises the need for the Welsh Assembly Government and NHS Wales to take urgent action to address the significant gaps in the provision of specialist neuromuscular care highlighted by expert witnesses.

The evidence received painted the clear picture that existing specialist services have been reliant on the enthusiasm and expertise of individuals. However, the absence of a managed network has evidently resulted in a lack of vital access to specialist care for people living with neuromuscular conditions in Wales. As a GP, I am aware of many of the frustrations that patients and families face in trying to access the services that they are entitled to.

It quickly became apparent in the early stages of the Review that the absence of a care co-ordinator was one of the most crucial issues. Therefore, the Cross Party Group held a special session on the importance of the care-coordinator role for families living with muscle disease. Wales is currently the only country in the UK without a 'neuromuscular Care Advisor' so the recent announcement by the Welsh Assembly Government of two new neuromuscular Care Advisor posts in North and South Wales is very much welcomed.

The overwhelming impression conveyed by the evidence is that families feel completely and utterly abandoned by the failings of the NHS to adequately support their needs. I hope that the Care Advisor appointments will be made swiftly and that this signals the first step towards the development of a managed clinical network for neuromuscular services to deliver the specialist care that families deserve.

I would like to place on record my thanks to all those who have participated in the Review by giving oral evidence, submitting written evidence and attending the evidence sessions. I also want to thank my Assembly Member colleagues for their interest and contributions in supporting the work of this Review from November 2009 to June 2010. I also wish to thank the Muscular Dystrophy Campaign for its hard work and efficiency in providing the secretariat to the Review.

Finally, I would like to pay tribute to Ray Thomas, who has been tirelessly campaigning for improved neuromuscular services for more than 35 years for his sons, Robert and Leighton – who both had Becker muscular dystrophy – and people living with neuromuscular conditions across Wales. In March 2010, his son, Leighton, passed away and the Cross Party Group is proud to name this report the *Thomas Report* in recognition of the exemplary courage, commitment and determination shown by Ray and his family in the continued battle to see improvements to specialist neuromuscular care.

Dr Dai Lloyd, AM for South Wales West, Chair,
Cross Party Group on Muscular Dystrophy

About Ray Thomas



Ray Thomas is Chair of Muscular Dystrophy Campaign Wales and has been a tireless and committed campaigner for improved neuromuscular services across Wales for over 35 years following the diagnosis of his sons, Robert and Leighton, with Becker muscular dystrophy.

A fundraiser and campaigner, Ray has striven continuously to support the Muscular Dystrophy Campaign and fight to improve quality of life and life expectancy for everyone living with a neuromuscular condition.

Robert died at the age of 39 and, in March 2010, Leighton also passed away. For years Ray saw his sons denied the vital, specialist care which could have drastically improved their quality of life. Leighton was forced to spend the last 11 years of his life living solely in his wheelchair, not able even to sleep in a bed because of his lack of specialised physiotherapy support when it was needed.

Ray has played an influential role in the charity's work in Wales and has been a powerful voice as the Cross Party Group on Muscular Dystrophy's Review has developed.

In respect of Ray's lifetime of campaigning for better access to medical care for people in Wales with a neuromuscular condition, the final report of the Review is to be named the *Thomas Report*.

Ray's campaigning work will be his sons' legacy – that no one else with a neuromuscular condition should ever be denied essential medical and social care.

The Cross Party Group on Muscular Dystrophy

The Cross Party Group on Muscular Dystrophy is chaired by Dr Dai Lloyd AM and is made up of a cross party group of Assembly Members. It aims to raise awareness of muscular dystrophy and related neuromuscular conditions among Assembly Members. The secretariat of the group is provided by the Muscular Dystrophy Campaign.

Acknowledgements

The Cross Party Group (CPG) on Muscular Dystrophy wishes to thank the Muscular Dystrophy Campaign for its administrative support in the organising and staging of evidence sessions, gathering written evidence, and producing this Report.

The Cross Party Group's Assembly Members are:

Dr Dai Lloyd AM (Plaid Cymru, South Wales West) (Chair)

Lorraine Barrett AM (Labour, Cardiff South and Penarth)

Peter Black AM (Liberal Democrat, South Wales West)

Eleanor Burnham AM (Liberal Democrat, North Wales)

Jeff Cuthbert AM (Labour, Caerphilly)

Andrew RT Davies AM (Conservative, South Wales Central)

Nerys Evans AM (Plaid Cymru, Mid and West Wales)

Lesley Griffiths AM (Labour, Wrexham)

Bethan Jenkins AM (Plaid Cymru, South Wales West)

Gareth Jones AM (Plaid Cymru, Aberconwy)

Helen Mary Jones AM (Plaid Cymru, Llanelli)

Val Lloyd AM (Labour, Swansea East)

Jonathan Morgan AM (Conservative, Cardiff North)

Jenny Randerson AM (Liberal Democrat, Cardiff Central)

Janet Ryder AM (Plaid Cymru, North Wales)

A full note of the witnesses who gave oral evidence to the Review is attached in the Appendix together with a note of the written evidence submissions.

Executive Summary

The Cross Party Group (CPG) on Muscular Dystrophy in the Welsh Assembly launched its Review into access to specialist neuromuscular care in Wales in November 2009.

Patients in Wales affected by neuromuscular conditions currently have an alarming shortage of specialist services to support them from diagnosis and throughout their lives. This lack of specialist support has a severely detrimental affect on those patients both in terms of the quality and longevity of life.

Despite the Welsh Assembly Government announcing two neuromuscular Care Advisors and Specialist Nurse posts in North and South Wales, additional Care Advisor posts are needed across the country to avoid patients in Wales remaining the poorer cousins of those with the same conditions in the rest of the UK.

Leading clinical experts agree that specialist neuromuscular services and multi-disciplinary specialist care in Wales must be urgently brought inline with services in the UK.

The CPG and the Muscular Dystrophy Campaign are calling on the Welsh Assembly Government to act on the following recommendations.

Recommendations

1. The Welsh Assembly Government and all NHS organisations in Wales define and fully recognise neuromuscular services as specialist services.
2. The Welsh Health Specialist Services Committee plays a central role in planning these specialist services across Wales. Neuromuscular specialists, in conjunction with the Health Boards and patient groups, would develop suitable pathways and protocols. Regular review and audit processes would be facilitated.
3. The Welsh Assembly Government sets up a Managed Clinical Network using existing expertise to ensure gaps in service provision are filled immediately and that the recommendations of the Neurosciences review are implemented.
4. The Welsh Assembly Government implements a structured long-term succession planning system for key neuromuscular posts to address the alarmingly inadequate provision that currently exists.
5. The Chief Executive of Cardiff and Vale University Health Board, as the nominated Chief Executive lead for muscular dystrophy in Wales, facilitates a series of discussions with patient representatives, clinicians and the Muscular Dystrophy Campaign to ensure services are improved as soon as possible.
6. The Welsh Assembly Government continues to look into the possibility of creating more neuromuscular Care Advisor and Specialist Nurse posts in Wales to work alongside the two posts announced in April 2010.
7. New Care Advisors learn from experienced Care Advisors already in post throughout the UK.
8. The Welsh Assembly Government ensures adequate care and support is in place for the newborn-screening service in Cardiff.
9. The Cardiff and Vale NHS Trust ensures the long-term stability of the sleep-study service in Cardiff.
10. Specialist paediatric and adult neuromuscular physiotherapists are appointed to educate and train community physiotherapists.
11. A multi-disciplinary team is set up to conduct internal reviews of different areas of neuromuscular care provision to ensure the transition from paediatric to adult services is smooth and that any gaps in service provision are filled.
12. Health Boards in Wales ensure that adequate training in neuromuscular conditions is undertaken by all relevant staff at all levels of care.
13. That comparison studies are conducted by the Welsh Assembly with other parts of the UK to ensure equality of access to specialist neuromuscular care.
14. The Duchenne muscular dystrophy standards of care guidelines are made widely available to those commissioning, planning and delivering services so that high quality standards of care are achieved in a multi-disciplinary approach for all neuromuscular conditions. As new guidelines emerge for other neuromuscular conditions, these should also be made widely available so that commissioning, planning and delivery of these services can also be improved.
15. Welsh Assembly Government officials and organisations in the NHS in Wales are made accountable for the decisions made in service provision.

Background to the Review

The Cross Party Group Review into Access to Specialist Neuromuscular Care in Wales, chaired by Dr Dai Lloyd AM, aims to improve services to ensure that all people living with muscle disease in Wales have access to the multi-disciplinary care, support and advice that they are entitled to.

The Review heard the views of people in Wales who are affected by muscular dystrophy and related neuromuscular conditions, and those clinicians and health professionals who have a direct interest in the provision of services for this group of patients. The Review also sought the perspective of those people who are responsible for the commissioning of these services and for workforce planning in the NHS.

The Muscular Dystrophy Campaign's *Building on the Foundations in Wales* report of February 2008 was welcomed by the First Minister, who was made aware of the problems and the need for a review. The report highlighted distinct differences in the quality of service provision for people with neuromuscular conditions across Wales.

The All Wales Recommendations of the Neurosciences Review published in September 2008 included the need for a Managed Clinical Network and nurse specialists for neuromuscular conditions. Groups were subsequently set up to determine how the recommendations should be implemented in each region.

In October 2008 Health Minister Edwina Hart AM attended a Muscular Dystrophy Campaign Conference in Swansea citing the charity's *Building on the Foundations in Wales* campaign and the need for improved services for people living with neuromuscular conditions. Addressing attendees at the conference, the Health Minister said, "things will get better in a year – that's a promise".

One year after the publication of the Neurosciences Review, access to many essential services had been greatly reduced; some services have such little clinical support that they are in real danger of becoming unsustainable.

A further meeting was held between Health Minister Edwina Hart AM, her officials, patient and clinician representatives and the Muscular Dystrophy Campaign, where it was disclosed that services had actually been getting worse, not better, since the Minister's promise.

However, there are at last encouraging signs that the decline in neuromuscular services in Wales may be halted and service developments will be embedded within the NHS. Firm action is now needed to implement the fifteen recommendations in this report to ensure all people living with muscle disease in Wales have the same access to specialist services as others in the UK.

What is muscular dystrophy?

There are more than 60 different types of muscular dystrophy and related neuromuscular conditions. It is accepted that, for every million people in the UK, just over 1,000 children and adults are affected by muscle-wasting neuromuscular diseases. It is therefore estimated that some 3,400 people are affected by a neuromuscular condition in Wales.

Many neuromuscular conditions are low-incidence, orphan conditions, with some regarded as very rare and ultra orphan. Neuromuscular conditions can be genetic or acquired and, with the exception of a couple of acquired conditions, there are currently no known effective treatments or cures.

Clinical trials in some forms of muscular dystrophy are now under way and it is hoped that these will lead to the introduction of new treatments that can slow or arrest the progressive nature of these often devastating conditions. There is a pressing need to develop the clinical trials infrastructure with additional trial centres in the UK to enable more patients to participate in them and, in turn, help to hasten the development and introduction of new treatments.

Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign is the leading UK charity focusing on neuromuscular conditions and is dedicated to improving the lives of all people affected by these conditions. Founded in 1959, the Muscular Dystrophy Campaign funds vital research, provides and supports care services and also gives information, advice and direct help to individuals living with these conditions.

The Muscular Dystrophy Campaign has set up a Wales Muscle Group which works closely with the Cross Party Group to campaign for better neuromuscular services in Wales.

The charity also campaigns and works with Parliamentarians across the UK to ensure all people living with neuromuscular conditions have access to high quality health and social care services.

Section 1

Evidence Summary

What constitutes a specialist neuromuscular service?

Oral evidence was provided by:

Dr Jane Fenton-May – Associate Specialist in Medical Genetics, Cardiff (retired May 2010)

Dr Louise Hartley – Consultant Paediatric Neurologist, Cardiff

Dr Gareth Llewelyn – Consultant Neurologist, Newport

Dr Mark Rogers – Consultant Clinical Geneticist, Cardiff

Dr Cathy White – Consultant Paediatric Neurologist, Swansea

1. Listening to detailed evidence from experts in the neuromuscular field, we were left in no doubt that urgent action is required to make improvements to neuromuscular services in Wales which were described as at best patchy, at worst non-existent. Dr Cathy White emphasised:

“The service is extremely vulnerable because were it not for Dr Louise Hartley or myself running clinics there would be no service. The same applies to the specialist physio I have. If my Trust decides that they would not let her do this, there would be no physio service. She provides information to us and feeds back to other local physios.”
2. We recognised the essential nature of services that are currently provided for patients with neuromuscular conditions. Dr Mark Rogers highlighted the pressures that health professionals currently face:

“One reason things were stronger ten years ago is that we were more autonomous, we weren’t reliant on a budget, and there was a simple referral system based on need, not whether anybody could pay for the service or where they lived. One of the weaknesses of the current system is that things have got compartmentalised so much into budgets. I’m not saying it was a good system back then and I recognise why we need to have budgets, but the reason it was better then is because things weren’t being squeezed.”

3. We heard of the need to create and sustain the vital posts of specialist neuromuscular physiotherapist and clinical nurse specialist, both in relation to service provision and training capabilities. Dr Louise Hartley told us:

“I do a lot of outreach clinics in order to meet all the physios who look after all the kids – we really do need specialist neuromuscular physios, both to see the children and adults, but also to train and teach all the physios out in the community who are going to be looking after most of the children.”
4. Evidence received throughout the Review demonstrated clearly the urgent need for crucial care co-ordinator posts, which are key to providing advice and support for families with muscle disease, and which we believe should be funded by and embedded in the NHS. Wales is currently the only country in the UK without a neuromuscular Care Advisor. Therefore, we are encouraged by the agreement of the Welsh Assembly Government to create two new care co-ordinator posts in North and South Wales and hope that these appointments are made swiftly. Dr White explained the significant gap in service provision that currently exists:

“All we can provide is a medical and physio input – the other thing we lack is the more generic role of the care co-ordinator who, being a key worker, is someone people can get hold of relatively easily, who can signpost them to various services, who can help them fight with wheelchair services or social services etc. I think that is a huge need.”
5. We were alarmed to discover the lack of sufficient support in place for post-diagnosis patients and families. Dr Jane Fenton-May highlighted the paucity of the service:

“I think if we had some of the other services in place for the support of the paediatric patients particularly, then hopefully that would support the newborn screening families, because the nurse specialist or the care co-ordinator would have that role.”
6. We were also concerned to learn of the neglect that the follow-up patients often experienced. Dr Gareth Llewelyn explained how this happens:

“What happens is that the follow-up patients get forgotten about because there are no targets set in terms of follow-up patient care. So if your manager has new patients that need to be seen those that need follow-up care get pushed to the back of the queue.”
7. Evidence gathered by the Review strongly pointed to the necessity to increase the number of health professionals interested in specialising in neuromuscular conditions. Dr Fenton-May told us:

“What is important is to have clinicians who have got an interest in neuromuscular conditions. Ideally if you can get people from different branches of practice in the same room, that’s very helpful.”

8. We were concerned to hear that luck played a greater part in the continuation of a clinic, as Dr Llewelyn informed us:

“We have to create a core, which we have, that will attract people who will want to come and do that work in Wales. We have done that to some degree with Mark Wiles leaving and then Jon Walters taking over his muscle clinic. We have been very lucky – it was more luck than planning though.”
9. We were shocked by the vulnerability of key posts and received the clear message that succession planning should be a top priority, with the need for juniors to be trained up to replace those who retire or leave their post. Dr Rogers explained to us:

“We need to plan to train up juniors as replacements. There are no plans at the moment as far as I am aware to replace Jane [Fenton-May] but even before considering who is retiring or leaving, we need to be looking at ways to attract other people who are interested in neuromuscular diseases.”
10. We discovered details of the ongoing uncertainty surrounding the sleep study service in Cardiff. Dr Hartley highlighted the need for proper service planning as she told us:

“From April [2010] and the new financial year, the promise is that there will be another appointment, a respiratory consultant, and a sustained service rather than just a stop-gap. They have now appointed definitively a successor to Dr Evans, who left the post, rather than the locum, with great sleep study qualifications.”
11. We received evidence regarding the staffing needs to provide a comprehensive multi-disciplinary service. Dr Hartley told us:

“To a large extent, there are more staff needed, there needs to be recognition of what the current staff are doing and make sure that they have got the time to do it. There is a lot more staffing that we’ve not covered; there’s also respiratory, cardiology and orthopaedics that need to be brought into it, and that might require a bit more staffing.”

12. We were alarmed by the lack of specialist service provision compared with the rest of the UK. Dr Rogers outlined for us the discrepancy in staffing allocation for neuromuscular services in Wales when compared to other parts of the UK:

“The service that Jane [Fenton-May], Angus Clarke and I provide within medical genetics; that would be a total of 0.5 Whole Time Equivalent (WTE) [i.e. 0.5 full-time posts]. If you were to add Cathy [White], Jon Walters and Louise [Hartley], that might increase to 1.25 WTE. That may be an over-estimate between us of the time and care we provide. You haven’t got the physios and the clinical nurse specialists. If you look at North East England, including professors and doctors, it is 4.5 WTE and there are two clinical nurse specialists. Adding up the package for them it is 7.5 WTE, for Glasgow it is 7 WTE and for South West England it is 8 WTE. There is such a huge disparity.”

13. We heard evidence in relation to the crucial need to establish a high quality, smooth transition from paediatric to adult services. Dr White explained:

“I think you do have to move on from a children’s service to an adult’s service. The core can be very similar. What we need to do is to get a good transition.”

Section 2

Evidence Summary

Living with muscle disease

Oral evidence was provided by:

Don Read – Penarth, husband and carer for Margaret Read

Margaret Read – Penarth, living with Charcot-Marie Tooth disease

Lynne Taylor – Cardiff, mother of young man with Duchenne muscular dystrophy

Ray Thomas – Neath, father and carer for two sons who lived with Becker muscular dystrophy

14. We received detailed and thorough accounts of patients' and families' experiences of the lack of access to organised and structured multi-disciplinary care.
15. Ray Thomas gave a detailed insight into the inadequate equipment available for his son over many years:

“I am a parent and carer of a son with Becker muscular dystrophy. Leighton is now 43 years old, has been a wheelchair user for 24 years, and has been a permanent 24/7 wheelchair user for 11 of those years, even having to sleep in his wheelchair because there isn't a bed available anywhere in the UK to suit his needs.”
16. We learned that the absence of a neuromuscular care co-ordinator had a huge impact on families living with muscle disease. Lynne Taylor highlighted the significance of the gap in the service:

“As a health professional myself, and as helpful as the paediatrician was, I wanted there to be someone who I could ask all sorts of questions, ideally a specialist and someone with experience.”
17. We discovered that many patients and families have encountered shortcomings in many parts of the service provision, and we therefore believe that the recognition and designation of neuromuscular services as specialist services will lay the foundations for a managed clinical network of services in Wales.
18. There is a completely unacceptable lack of vital support for many patients and families throughout diagnosis and once a diagnosis has been made. This is particularly notable after newborn screening for Duchenne muscular dystrophy. Lynne Taylor addressed the key issues in her evidence:

“You have a screening programme that gives good written and verbal information about what the test means. If you have the test, you have to have back-up care; otherwise families could be left with devastating news and no support to help them deal with that.”
19. John Burke illustrated the lack of information that was available to him and his wife about the newborn screening test:

“We were not given any information about Duchenne muscular dystrophy prior to the test. Nor were we made aware that if the test was positive there was no treatment for it, or that we may not see any signs or symptoms of the illness for eighteen months to two years at the earliest. We were not given an opportunity to ask questions. We were not spoken to about the test before leaving the hospital where Seth was delivered.”
20. We were extremely alarmed at the shortage of ongoing specialist neuromuscular physiotherapy for patients living with muscle disease. Ray Thomas illustrated this in his evidence:

“There are no specialist physiotherapists out there as far as we know. You go to physiotherapists in hospital, and as soon as they know that you have muscular dystrophy, they don't know what it is and say that they haven't been trained for that.”
21. Evidence was received revealing that for one adult patient, physiotherapy is provided in a six week block of treatment on an interventional model, and after the six weeks it finishes. The patient then has to be referred to be seen again. This appeared to be a recurring theme for many patients and families.
22. We are also concerned about the lack of fully accessible, adequately staffed hydrotherapy pools. Lynne Taylor told us about her local hydrotherapy pool:

“Three miles down the road there is a hydrotherapy pool at University Hospital of Wales but my son can't access it. I've now found that a pregnant woman can access it for back pain. People can go for chronic back pain but my son, who has a life-limiting condition, can't.”
23. Paul Thomas expressed his concerns in his written evidence about the lack of access to both physiotherapy and hydrotherapy:

"What is lacking is any trained physiotherapy service and any access to hydrotherapy. Hydrotherapy is specifically encouraged because of the ability to exercise without putting excessive loads onto muscles. When I enquired as to the availability of hydrotherapy I was told that all I could do was use my local Leisure Centre. This raises issues of accessibility, safety and exercising without guidance."

24. The evidence provided on wheelchair provision showed that while some people are satisfied with the service, it is clear that the standard of wheelchair service provision has significant inequalities and that patients living with muscle disease do not necessarily receive a proper wheelchair assessment. This can cause delays to the delivery of the wheelchair and can lead to people being forced to privately fund their essential equipment. Henry Langen told us in his written evidence:

"I had to raise the money for my Balder wheelchair, so I could improve the quality to my life as much as possible."

25. We were extremely alarmed by the shortage of key support services such as respite care and psychological support. Ray Thomas told us his experiences:

"My son has deteriorated tremendously over the past twelve months both physically and mentally. We had a psychiatrist for two visits which was a waste of space and a psychologist who met with my son on three occasions, but there was no report on the outcome of those visits."

26. Evidence received demonstrated the low level of knowledge and understanding of neuromuscular conditions among many health professionals. Margaret Read told us how she is contributing to improvements:

"I go to see students three times a year. Their neurology teaching has changed quite dramatically and the students are becoming much more aware of my condition. When I talk to other patients there, they say, 'It is amazing how good the students are getting in recognising what is wrong with me.'"

27. We heard from Don Read about the lack of an early response to key issues and the wider implications for everyday life:

"The real problem is the benefits service doesn't contain enough health professionals who would appreciate that these neuromuscular conditions are progressive. It is no good saying, for example, that someone is falling once a week and to leave him until he falls every day of the week. They should be saying that once someone has started falling once a week, take him into the benefits system for the Blue Badge, the DLA mobility component, and things like that."

28. Lynne Taylor expressed her frustrations at the gap in knowledge at GP level:

"What makes me angry is GPs who give a diagnosis and haven't researched it. Any good GP or health professional would research it, and know the condition and who to refer to."

29. Patricia Bevan related in her written evidence her experience of a fundamental lack of knowledge in a hospital where she was being treated:

"My husband went to the department to ask about physio; he was told females do not have muscular dystrophy."

30. We received alarming evidence of the lack of assistance and advice offered, both in health and social care, to enable people living with muscle disease to find work and the financial impact this has. Charles Gibbs, who has limb girdle muscular dystrophy, told us in his written evidence submission:

"Extensive research into my re-entering the work place culminated in my GP, a Job Centre Plus Disability Employment Advisor and a Shaw Trust Employment Advisor all recommending that I 'go home and look after myself'. I have found that my being disabled has had a very profound effect on my family's financial security."

31. Margaret Read told us how shocked she was at the difference in services between Scotland and Wales:

"I came down to South Wales in 1981 and I had been in Glasgow for 20 years. The difference between the two lots of treatments I received was quite extraordinary. Glasgow was far superior to here, I didn't realise I would have to wait every time I wanted to go to hospital."

32. Ian Griffiths, who has Duchenne muscular dystrophy, shared his frustrations in his written evidence about the lack of the specialist multi-disciplinary care that he should be receiving:

"I am very concerned and unhappy with the non-existence of physiotherapy, a social worker, a muscle specialist (vital for Duchenne muscular dystrophy), occupational therapy, orthopaedics, a psychologist or the Speech and Language Therapy team. It's non-existent so the quality is non-existent as well."

Section 3

Evidence Summary

Importance of the role of the Care Co-ordinator

Oral evidence was provided by:

Shirley Crosby – Regional Care Advisor, Liverpool

Robert Meadowcroft – Director of Policy and Services,
Muscular Dystrophy Campaign

Rachel Salmon – Newborn Screening Specialist Nurse, Cardiff

33. We are extremely concerned that Wales is currently the only country in the UK without a neuromuscular Care Advisor. We received overwhelming evidence regarding the severe effect this was having on countless families living with muscle disease in Wales so the Cross Party Group deemed it necessary to hold a special session on this issue.
34. We are encouraged by the fact that since the special Review session on 3 March 2010, the Welsh Assembly Government has recognised this major gap in service provision and agreed to the appointment of two new neuromuscular Care Advisor posts in North Wales and South Wales. We hope to see these appointments made as soon as possible and welcome the Muscular Dystrophy Campaign's proactive assistance offered to the Welsh Assembly Government to facilitate the process.
35. We heard about the crucial ongoing support, information and advice that a Care Advisor provides, which people living with muscle disease in Wales are currently being denied. Shirley Crosby emphasised the vital importance of the posts and outlined her NHS-funded permanent post as a Care Advisor in Liverpool:

"I provide information, support and advice to patients, families and carers. I attend clinic appointments when children and adults come to the clinic. I sit in when children or adults and families are being given the diagnosis, so I am there at the time to give support. I always follow up a new diagnosis with a home visit within a week to give support to the families, to go over any questions that they have, to offer emotional support."

"The posts are cost effective – early support and building good relationships at the beginning and throughout patients' journeys. It saves a lot in the long term – it is much better to have a fence at the top of the cliff than to fund an ambulance at the bottom. It is much more cost effective to put a small amount of money in at the beginning rather than a huge amount when things go wrong and fall apart and families are faced with a crisis."

36. We fully believe that neuromuscular Care Advisors need to be funded by and embedded within the NHS and to be a central part of a multi-disciplinary specialist service to meet the needs of all ages. Robert Meadowcroft highlighted the need for these posts to be secure within the NHS:

"We have taken a very firm line with the NHS this year to say that from 1 April 2010 the Muscular Dystrophy Campaign will not fund the posts in the same way, and all those posts are now moving into the NHS. By 1 April 2011, all those posts will be NHS funded, just like Shirley's post is. That is important because they will then be secure, embedded within the NHS, not reliant on charitable fundraisers and with succession planning for the long-term. That is how it should be and that is exactly what Wales needs as well."
37. We were alarmed that the Care Advisors based in Liverpool are unable to provide the same vital support and advice to patients across the border in North Wales that they provide to patients in North West England. Shirley Crosby explained the inequality of the service:

"We feel that it is absolutely vital for the families to have this service, and we feel really bad that you do not have this service here in Wales. When families come across to Alder Hey or the Walton Centre in Liverpool for appointments, we feel bad that we can't give the same level of support to families from Wales as families from North West England. That frustrates us – we can only give telephone advice and support for families and patients in Wales."
38. Evidence was received from Rachel Salmon about the remit of her role as the newborn screening specialist nurse, which does not include additional support and advice; any extra support is only provided at the discretion of the post-holder. Rachel Salmon told us:

"My remit covers Wales when the results come in from the lab that the creatine kinase (CK) is elevated for Duchenne muscular dystrophy. I then contact the primary healthcare team, arrange a meeting with the health visitor, the GP, and the paediatrician of whatever area of Wales it is to provide information, knowledge, the genetics of Duchenne muscular dystrophy, and where to go from there."

39. We had clear evidence that there is an alarming lack of support and advice available for families if a diagnosis of a neuromuscular condition is made. Rachel Salmon detailed how she has attempted to provide as much support as possible in addition to her core role:

“I have been working more closely with the health visitors on the primary healthcare team and I have had more contact with families. I have been trying to set up support days across Wales for families with Duchenne muscular dystrophy so they can receive specialist knowledge, hear speakers, and establish a network to support them. There is no infrastructure so it is difficult. I have attended clinics and have been with families on diagnosis. That has evolved because they have met me. I have been on home visits providing support, information and signposting.”

40. We established that a far stronger and more robust care, support and advice service exists for Cystic Fibrosis (CF) patients in Wales. Rachel Salmon described the research that has been carried out:

“There are four CF nurses based in Cardiff and I know that it is a robust service. We send out questionnaires to families to do the auditing and research. In answer to the question about who sees the family on diagnosis and was there a visit, 95% of the answers back is a health visitor and CF nurse, and they all score much higher than the other diseases because they have got that additional support and the qualitative data backs that up.”

41. We are deeply concerned that there is an absence of succession planning for several key posts in multi-disciplinary specialist care provision in Wales, of which the Care Advisor is a key part. Robert Meadowcroft explained the need for a comprehensive neuromuscular network in Wales:

“We need more consultants’ time in Wales – patients in Wales deserve a good quality service. This starts with expert clinician time, and then Care Advisor support, specialist physiotherapy and a comprehensive service that reaches down to the communities, so we need a neuromuscular network to be established. It is not ground-breaking as one exists in Scotland and in South West England. We have campaigned for it and secured it in the South West. We need improvements to services in Wales – there are services under threat and there is a lack of succession planning.”

Section 4

Evidence summary

Commissioning, planning and delivery of specialist services

Oral evidence was provided by:

Dr Bruce Ferguson – Medical Director, Abertawe Bro Morgannwg Health Board

Dr Victoria Lidstone – Clinical Lead for Transition in Palliative Medicine

Dr Karen Rafferty – TREAT-Duchenne UK Coordinator

42. We are alarmed that existing services are heavily reliant on the enthusiasm and expertise of individuals who have been developing and delivering specialist services. Dr Bruce Ferguson explained to us:

“The people who are delivering the service have the competencies and experience to do that, which they are carrying within a far more general job. It has been through the enthusiasm and expertise that people have brought to their posts that the present services have developed.”

43. We would like to see swift action to address the gaps in both paediatric and adult services. Dr Victoria Lidstone described the situation to us:

“Adult services lag woefully behind paediatric services, and even paediatric services, although there are pockets of excellence, have quite a lot of things missing.”

44. After hearing that Jan Williams has been appointed as the Health Board Chief Executive lead for muscular dystrophy, we are keen that she takes urgent action to implement improvements to neuromuscular services.

45. Dr Ferguson welcomed the announcement of two new neuromuscular Care Advisors in Wales and advised that they need to be working within a planned and delivered network of services:

“It is wonderful that resources have been found and instructed to create two new Care Advisors. The important thing from my perspective is getting them working within a network that has begun to be recognised and begun to be planned and delivered as a proper network working across the Local Health Boards.”

46. We received overwhelming evidence from many sources that neuromuscular services should be planned at a national level as a specialised service rather than on an ad hoc basis.
47. Evidence received also suggested that there is a widespread lack of succession planning, which Dr Ferguson elaborated on during his evidence:

“The frustration around succession planning is that planning occurs without a service first being established. I can see that there is a degree of succession planning that happens through the workload that any department takes on, so it is likely that that workload is going to be shared, and in that sharing there is an element of succession planning. However, I know that in certain areas, there isn’t any succession planning for individuals who are working in the team, such as physiotherapist.”

48. We would like to see the Welsh Health Specialist Services Committee, as the newly created successor to Health Commission Wales, take a leading role in terms of looking at how the service can be expanded. Dr Ferguson highlighted this to us:

“The need for expansion in the service has got to be considered in a structured way against expansions in other services. That is what I see the role of the Welsh Health Specialist Services Committee as being.”

49. We heard about several extremely concerning occurrences of health professionals lacking adequate knowledge of neuromuscular conditions. We are keen to see neuromuscular conditions properly included in the Continuing Professional Development of health professionals.
50. We received evidence regarding the standards of care guidelines for Duchenne muscular dystrophy, which contain information on diagnosis and neuromuscular management. Dr Karen Rafferty highlighted the importance of stable standards of care for clinical trials and explained the purpose of the guidelines:
- “The idea of the standards of care guidelines is to get care up to a certain level. It basically sets out the need for a multi-disciplinary approach to the care for Duchenne muscular dystrophy, how that can be achieved and the need for Care Advisors.”
51. We learned that there is currently a lack of consistency and equality in the transition from children’s to adults’ services. Dr Lidstone told us:

“The transition may be from age 14 for one child and 22 for another, it doesn’t matter when, as long as the process is carefully thought through and carefully done at the time. At the moment that is happening sometimes but it is very haphazard, so we need to get consistency, good access and equity for everybody.”

52. We are keen that emotional and psychological support should be offered to people living with a neuromuscular condition.
53. Jan Williams, the newly appointed Health Board Chief Executive lead for muscular dystrophy, was unable to attend this session but was asked to address key issues in written evidence, as set out below:

What discussions have the Health Boards in Wales held about improving specialist care in Wales?

54. All Health Boards are engaged fully in the Neurosciences Review.

What measures have been taken by the NHS in Wales to identify strengths and weaknesses in the current provision of neuromuscular services?

55. A sub-group of the Neurosciences Review is focusing specifically on neuromuscular disease and is currently mapping the services to identify strengths and opportunities for improvement.

Can you update the Group on the progress of recruitment for the new Care Advisor posts in North and South Wales, as outlined by the First Minister on Tuesday 20 April, including the location and timeframe of appointments?

56. The Local Health Boards’ (LHB) Nurse Directors are currently finalising the role description, with a view to appointing to the two posts by September 2010. The Nurse Directors will agree on the most appropriate locations and employment arrangements.

We have heard in previous sessions about insufficient succession planning being put in place to ensure that key posts in the specialist multidisciplinary team are embedded in the NHS long-term. What improvements will be made to succession planning in Wales?

57. Services for patients with neuromuscular conditions are delivered by a wide range of clinical teams across each of the Health Boards in Wales. Within each Health Board, there are specific arrangements regarding the recruitment and succession planning necessary in order to ensure the sustainability of their clinical services.

Can you outline the role of the new Welsh Health Specialist Services Committee in ensuring that specialist neuromuscular services are commissioned and delivered by Health Boards in Wales?

58. Under the new planning arrangements, LHBs are responsible for planning and funding specialised health services. They undertake this role through a joint committee, the Welsh Health Specialised Services Committee (WHSSC).

59. The LHBs have agreed that planning for neurology services will be done locally by each LHB, while the WHSSC will be responsible for planning specialised neurosciences services, including Neurosurgery, Neurorehabilitation and Spinal Injuries Rehabilitation. In addition to these services, WHSSC plans a number of other specialised services which are accessed by patients with neuromuscular disorders. These include:

- Posture and Mobility services - provided through the Artificial Limb and Appliance Service;
- Genetics Service - provided by the All Wales Medical Genetics Service;
- Rare Neuromuscular Disease Service at Newcastle.

What is the current situation regarding the respiratory sleep study service in Cardiff, which was cancelled and then temporarily reinstated?

60. Following the departure of the consultant who ran the Cardiff respiratory sleep study service, the Health Board has established an interim service to manage urgent inpatient cases.

61. The Health Board plans to re-introduce the services in autumn 2010.

What arrangements are currently in place for Health Boards to fund cross-border services where patients require treatment in England?

62. The WHSSC commissions a range of specialised services from England on behalf of the LHBs. These include services which are accessed by patients with neuromuscular disorders, including the Rare Neuromuscular Disease Service at Newcastle.

What benefits would a managed clinical network bring in terms of the provision and coordination of specialist services and community based services?

63. The development of integrated health organisations, under the reorganisation of NHS Wales, will facilitate improved planning and coordination for a wide range of services, including those accessed by patients with neuromuscular conditions. By adopting a collaborative approach, either through partnership working or a clinical network, Health Boards will be able to work together to coordinate and plan services on a local, regional and national level. Such an approach will ensure closer integration across primary, secondary and tertiary care services.

64. We welcome the clarification on the schedule for the Care Advisor posts and the sleep study service but the Cross Party Group would also welcome further discussions with Jan Williams on the need for a Managed Clinical Network for neuromuscular conditions and the key specialist posts required within this network.

Costings Data

65. Based on NHS data in English regions, we have calculated that, for the estimated 3,432 people with muscle disease in Wales,¹ there would be some 1,355 emergency admissions each year at a total cost of £3.92 million. We believe that access to high quality, specialist multi-disciplinary care would significantly reduce the considerable cost of these unplanned emergency admissions.
66. The following table illustrates the recommended posts which are necessary for patients living with neuromuscular conditions across Wales to prevent the service from collapsing:

Posts required	£s recurring
1.5 WTE Consultants (inc. secretarial support) specialising in Neuromuscular conditions	£195,000
3 WTE Care Advisors/Specialist Nurse (band 7 – mid range)	£129,036
1 WTE Specialist Physiotherapist (band 7 – mid range)	£43,012
0.5 WTE Psychologist (mid grade band 8a)	£25,533
0.5 WTE Occupational Therapist (band 7 – mid range)	£21,506
1 Network Manager (band 7 – mid range)	£43,012
0.5 WTE Administrator (band 5 – mid range)	£14,591
Total investment required (full year cost)	£471,690

67. The cost per patient per year would be just £161.80, or £13.48 per month.
68. We have expressed our concern elsewhere in this report at the lack of succession planning both before and after the retirement of Dr Jane Fenton-May in Cardiff. Although there is the provision of a physiotherapy service, there is an absence of the specialist physiotherapy post solely for neuromuscular conditions, which could also be very useful in the training and educating of community physiotherapists.
69. There appear to be two options, which do not have to be mutually exclusive, in providing access to specialist neuromuscular care in the whole of Wales. One option would be for an all-Wales service, with specialised service provision within Wales. The decision to appoint Care Advisors in North and South Wales will be welcome additions to the service. Outreach clinics are currently run by clinicians but we believe that there should be the capacity to increase the clinical time and frequency of these clinics. The other option, which could complement increased clinical time within Wales, is for increased outreach cross-border clinics from Oswestry and Liverpool.

1. Muscle disease: The Impact, Incidence and Prevalence of Neuromuscular Conditions in the UK, Muscular Dystrophy Campaign, January 2010

Appendix

The Cross Party Group Review

The Review was launched in November 2009 to carry out an in-depth investigation of access to specialist, multi-disciplinary care for people living with neuromuscular conditions. This arose from the concerns of the Cross Party Group that people living with muscle disease were not receiving the specialist care provision that they are entitled to.

The Cross Party Group Review has received both written and oral evidence that underlines the need for urgent action to improve and strengthen multi-disciplinary health care for this vulnerable group of patients living with rare and very rare conditions.

Witnesses

The Group would like to thank all the expert witnesses, both from a patient and professional perspective, who gave oral evidence and submitted written evidence describing and analysing a wide range of key issues. The CPG greatly appreciates the very useful and informative evidence which it can now take forward through the recommendations in this report.

Below is a list of the witnesses who provided oral evidence for the Inquiry:

18 November 2009 – “What constitutes a specialist neuromuscular service?”

Dr Jane Fenton-May – Associate Specialist in Medical Genetics, Cardiff (retired May 2010)

Dr Louise Hartley – Consultant Paediatric Neurologist, Cardiff

Dr Gareth Llewelyn – Consultant Neurologist, Newport

Dr Mark Rogers – Consultant Clinical Geneticist, Cardiff

Dr Cathy White – Consultant Paediatric Neurologist, Swansea

27 January 2010 – “Living with muscle disease”

Don Read – Penarth, husband and carer for Margaret Read

Margaret Read – Penarth, living with Charcot-Marie Tooth disease

Lynne Taylor – Cardiff, mother of young man with Duchenne muscular dystrophy

Ray Thomas – Neath, father and carer for two sons who lived with Becker muscular dystrophy

3 March 2010 – “Importance of the role of the Care Co-ordinator”

Shirley Crosby – Regional Care Advisor, Liverpool

Robert Meadowcroft – Director of Policy and Services, Muscular Dystrophy Campaign

Rachel Salmon – Newborn Screening Specialist Nurse, Cardiff

12 May 2010 – “Commissioning, planning and delivery of specialist services”

Dr Bruce Ferguson – Medical Director, Abertawe Bro Morgannwg Health Board

Dr Victoria Lidstone – Clinical Lead for Transition in Palliative Medicine

Dr Karen Rafferty – TREAT-Duchenne UK Coordinator

Terms of Reference

The formal Terms of Reference for the Review are: “To determine the current provision and quality of specialist services in Wales for people with muscular dystrophy and related neuromuscular conditions; to highlight areas of best practice and recommend possible solutions where improvements are necessary.”

Written Evidence

Access to Specialist Neuromuscular Care: The Walton Report.
All Party Parliamentary Group for Muscular Dystrophy, August 2009

*Acute/emergency admissions April 2009 to end of March 2010
for neuromuscular patients*
Dr Ros Quinlivan, Consultant in Paediatrics and Neuromuscular Disorders,
Robert Jones and Agnes Hunt Hospital, Oswestry, June 2010

Building on the Foundations: Focus on Physio. Muscular Dystrophy Campaign,
May 2008

Building on the Foundations: State of the Nation – The 2008 National Survey.
Muscular Dystrophy Campaign, September 2008

*Building on the Foundations: The Need for a Specialist Neuromuscular Service
across Wales,* Muscular Dystrophy Campaign, February 2008

Duchenne muscular dystrophy standards of care guidelines. Treat-NMD, June 2010

*Muscle disease: The Impact, Incidence and Prevalence of Neuromuscular Conditions
in the UK.* Muscular Dystrophy Campaign, January 2010

*Muscular Dystrophy Campaign's Evidence to the Welsh Affairs Committee Inquiry into
the Provision of Cross-Border Public Services for Wales.* April 2008

National Patient Survey 2010. Muscular Dystrophy Campaign, April 2010

Neuromuscular services in Wales – a clinician's perspective.
Dr Mark Rogers, April 2009

Response to Cross Party Group on Muscular Dystrophy Review.
Jan Williams, June 2010

Dr Victoria Lidstone, All Wales Clinical Lead for Transition in Palliative Care, Cardiff

Rachel Salmon, Newborn Screening Specialist Nurse, Cardiff

Patricia Bevan, Gwent

John Burke, Cardiff

Charles Gibbs, Cardiff

Ian Griffiths, Mid Glamorgan

Henry Langen, Dyfed

Paul Thomas, Cardiff

The Thomas Report:
Access to Specialist Neuromuscular Care in Wales

Cross Party Group on Muscular Dystrophy

July 2010