

Edwina Hart MBE OStJ AM

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/02057/10

Your ref: P-03-295

Christine Chapman AM
Chair - Petitions Committee
National Assembly for Wales
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Welsh Assembly Government

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2 July 2010

P-03-295 paediatric Neuro-Rehabilitaion Services

Thank you for your letter dated 21st June on behalf of the Petitions Committee asking about the provision of rehabilitation services for brain injured children in Wales. I am fully committed to improving services for all people in Wales with neuromuscular conditions, and have put in place a number of different work strands to address this.

From 1 April 2010 responsibility for Paediatric Neurology including rehabilitation by the Paediatric MDT has transferred to the 7 Health Boards, and planning is undertaken through a joint committee, the Welsh Health Specialised Services Committee (WHSSC). It is the responsibility of the Health Boards to drive the improvements that are needed to deliver high quality co-ordinated care and to ensure that patients have access to comprehensive multi-disciplinary and specialist services as close to home as is clinically safe. Improvements to these services will take time.

It is recognised that it may not be practical to provide the initial intensive specialised paediatric neuro-rehabilitation service in South Wales due to the low annual number of patients who require access to this Service. With small numbers of patients relative to the costs of a fully resourced multidisciplinary team, the service would be unsustainable in the long term. However the range of clinical support required relative to rehabilitation needs is being fully investigated and WHSSC are working with Cardiff & Vale University Health Board to address the problems associated with the service and to assess the options available.

Efforts are also being made to identify the potential to strengthen the current service and reduce the length of stay needed at specialist providers in England such as the Children's Trust in Tadworth.

The Welsh Assembly Government is considering how services will improve in the future through the progressive implementation of the Paediatric Neurosciences Standards, which will be published this spring, and the outcome of the review of Adult Neurosciences. As part of this, my officials are engaging with the Muscular Dystrophy Campaign and are working with the Health Boards to develop arrangements for the provision of care advisors. The appointment of two advisors is currently underway, one for North Wales and one for South Wales.

In addition, I recently accepted the recommendations from the Scottish neurosurgeon, James Steers' expert advisory group on care pathways for long term neurological conditions. I have written to the Chairs of Health Boards to endorse the group's recommendations and I expect work to begin implementing the recommendations shortly.

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Edwina Hart MBE OStJ AM

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/02472/10

Your ref: P-03-295

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5 August 2010

Thank you for your letter of 26 July on behalf of the Petitions Committee asking for additional information on Paediatric Neuro-rehabilitation services.

The All Wales Neurosciences Standards, developed as part of the Children and Young People's Specialised Service project were issued to the service in April 2010. The standards and key actions have been developed by external working groups comprising of stakeholders, and provide a basis for service planners and providers to plan and deliver effective services for children and young people.

Standards include access to services and management of children and young people with neurological disease, children and young people recovering from neurosurgery, and those who have a neuro-disability who require access to specialised services.

It is the responsibility of the Local Health Boards (LHB) to ensure that the key actions within the standards are implemented. Some key actions can be delivered within a year while others may take a number of years to achieve. Thus each key action has a timescale for delivery between one and ten years.

The Welsh Health Specialised Service Committee (WHSSC) is currently in discussion with the Cardiff and Vale University LHB to address the problems associated with the Paediatric Neuro rehabilitation services provided to patients resident in South Wales, delivered by the University Hospital of Wales.

As set-out in my previous response to the Committee it is recognised that it may not be practical to provide the initial intensive specialised paediatric neuro rehabilitation service in South Wales, due to the low annual number of patients who require access to this Service. As a result the LHB has been asked by WHSSC to provide a detailed service specification to include the scope of the service - catchment area & historical activity and the service model - staffing, infrastructure and links with other services.

Paediatric neuro-sciences covers many services areas, and it is necessary to get it right in terms of planning the reviews recommendations by the LHB's who are working closely with WHSSC.

Ensuring the implementation of the generic characteristics which James Steers' expert group recommended, should underpin the care of children and young people with long term neurological conditions, which will include neuro rehabilitation.

The quality of care being provided will be evidenced through local and national clinical audit and the monitoring of the implementation of the overarching Standards for Paediatric Neurosciences, which the Welsh Assembly Government published in April.

A handwritten signature in black ink, appearing to read "John H...", is located at the bottom left of the page.

Response from Petitioner

Dear Mrs Chapman

PETITION: P-03-295 Paediatric Neuro-Rehabilitation Services

Thank you for your letter of the 26 July which included the Minister for Health and Social Services response to the committee letter of the 21 June.

Mrs Harts letter of response of 2 July provided an overview of the current situation in Wales in relation to paediatric neuro-rehabilitation services but did not deal with the specifics of our current petition. I welcome the committee's agreement to write to the Minister on the following issues:

- What specific improvements are planned in paediatric neurology within Wales and on what timeframe?
- How many patients in Wales require the intensive specialised paediatric neuro-rehabilitation service?
- When will the review into clinical support for rehabilitation services identified by the Minister be completed?
- How will the implementation of the recommendations of the advisory group on care pathways for long term neurological conditions be monitored, in the context of the review of clinical support for rehabilitation services, in order to avoid variation in provision throughout Wales;

I note that you have requested further information on the recommendations of the expert advisory group on care pathways for long term neurological conditions. I have read a copy of this report and would be interested in the Ministers comments on the recommendations of the report and particularly the sections regarding early specialist rehabilitation and community and longer term rehabilitation.

The Ministers response stated that specialist care such as that provided at the Childrens Trust in Tadworth would continue to be utilised and at present Kyle is receiving his second period of rehabilitation at the facility in Tadworth. This is following three months of rehabilitation at the Univeristy Hospital of Wales of a care package recommended by the Childrens Trust at the University Hospital of Wales, a care package agreed by the Minister in a meeting I had with her on the 20 April but was not delivered as per the specifications set out by the Childrens Trust.

The Childrens Trust have again assessed Kyle and have recommended a further 3 months of continuing rehabilitation at their facility, however, The Welsh Health Specialised Services Committee (WHSSC) funding is only being provided for 6 weeks, how can the Minister say that these facilities will continue to be utilised when they can't be fully funded.

Yours sincerely

Katherine Simmons

Edwina Hart MBE OStJ AM

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

Our ref: EH/04087/10

Your ref:

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23 December 2010

Dear Christine,

Thank you for your letter dated 7 December about the expected timescale for completion of the neurology service specification from Cardiff and Vale University Local Health Board (LHB) and asking for details of how many patients in Wales require intensive specialised paediatric neuro-rehabilitation services.

LHBs are responsible for planning and securing health services in Wales. As paediatric neuro rehabilitation is specialised, LHBs fulfil their role through their joint work on the Welsh Health Specialised Services Committee (WHSSC).

I have, therefore, forwarded your letter to Dr Cerilan Rogers, Director of Specialised and Tertiary Services at WHSSC and asked her to reply to your specific queries direct.

I hope you receive a satisfactory reply from WHSSC.

A handwritten signature in black ink, appearing to be 'Edwina Hart'. The signature is written in a cursive style and is positioned at the end of the letter.

Response from WHSSC

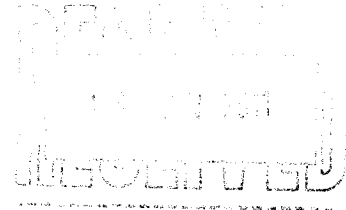


GIG
NHS

Pwyllgor Gwasanaethau Iechyd
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Dear Mrs Chapman

P-03-295 Neuro rehabilitation Services

I would like to confirm that WHSSC has been working closely with Cardiff & Vale University Health Board to ensure there is a sustainable plan for the provision of Paediatric Neurorehabilitation Services.

WHSSC initiated discussions with Cardiff & Vale University Health Board to address the problems in this area in July 2010 and I can confirm that a plan has now been received from the University Health Board.

WHSSC had asked the University Health Board to provide a detailed service specification to include the scope of the service (catchment area and historical activity) and the service model (staffing, infrastructure and links with other services). Whilst the plan is well-developed, some of this information remains unclear and we are meeting with the University Health Board shortly to discuss this further.

However there is already enough detail in the plan, including costs, for the proposal to be considered as part of the WHSSC prioritisation exercise for 2011/12. This exercise is preparatory to WHSSC finalising its annual plan for 2011/12.

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Director of Specialised and Tertiary Services/Cyfarwyddwr Gwasanaethau Arbenigol a Thrydyddol: *Dr Cerilan Rogers*

With regard to the numbers of patients who have required intensive specialised neurorehabilitation, in the financial year 2011/12 WHSSC supported two Welsh paediatric patients who needed this level of care.

I would also like to confirm that WHSSC agreed to provide funding on a temporary basis to Cardiff & Vale University Health Board to support the neurorehabilitation service and, in particular, to care for Ms Simmons' son, Kyle. Despite receiving the interim funding, the Health Board unfortunately experienced difficulties with recruiting staff and this led to some elements of care, that were originally planned, not being provided.

I can confirm that WHSSC has supported Kyle's stay at the Children's Trust, Tadworth, whilst there has been clinical and medical benefit. WHSSC has been in contact with the clinicians at the Children's Trust and any decisions, made in relation to funding, have been based on clinical information received from the Trust and advice on what is available locally from Cardiff & Vale University Health Board.

We know that local services have been working on a care plan for Kyle's discharge, however a final plan is yet to be fully agreed. We have been in contact with the University Health Board to ensure that the agreement of a final discharge plan is prioritised.

In the meantime, Kyle's ongoing funding has been approved to enable WHSSC to review his needs with the Children's Trust and the progress being made by all stakeholders in relation to his discharge, to ensure that he receives the most appropriate care.

Yours sincerely



Dr. Cerilan Rogers
Director of Specialised and Tertiary Services

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Response from the petitioner

Dear Mrs Chapman

PETITION: P-03-295 Paediatric Neuro-Rehabilitation Services

Thank you for your letter of 26 January informing me of the recent consideration of the petition at the last committee meeting on the 25 January, seeking my views on the information gathered so far as well as the adequateness of the support Kyle has received to date.

I appreciate the work the committee has done in seeking further information from the Health Minister and various other organisations. As I am sure the committee is aware this information has been sketchy at best.

However, as admitted in the WHSSC response, upon Kyle's return from the Childrens Trust in Tadworth, despite receiving interim funding, there were difficulties in recruiting staff and this led to some elements of care, that were originally planned, not being provided. This was an issue I raised in my letter to the committee in November, which I have reproduced below and is in my view an admission of inactivity by the WHSSC:

'The Ministers response stated that specialist care such as that provided at the Childrens Trust in Tadworth would continue to be utilised and at present Kyle is receiving his second period of rehabilitation at the facility in Tadworth. This is following three months of rehabilitation at the University Hospital of Wales of a care package recommended by the Childrens Trust at the University Hospital of Wales, a care package agreed by the Minister in a meeting I had with her on the 20 April but was not delivered as per the specifications set out by the Childrens Trust'.

The WHSSC in their letter confirm that they have been supporting Kyles stay at the Childrens Trust in Tadworth but this is not an accurate reflection of the situation as at present the WHSSC is not funding Kyles stay in Tadworth and this is being funded by Health and Social Services due to WHSSC withdrawing their funding of Kyles stay in Tadworth on the 25th January.

The care package for Kyle when he returns home has not yet been formally confirmed or outlined in writing and this is indicative of communication problems between organisations and as a consequence Kyle has had to remain in Tadworth and I have been informed that Kyle will be returning home permanently on the 16 March. At present I am expected to perform the role of a carer when Kyle returns which was not agreed when I met with care providers previously as I work full time so that I can provide a level of normality, as best as possible given the situation that Kyle and I face.

I would like to raise an issue which ties in with the petition 'National Strategy on Independent Living' (reference P-03-288). The Deputy Minister for Social Services in response to this petition refers to the Direct Payments Scheme which empowers individuals to make their own choices as to how and when the care arrangements to meet their assessed needs are delivered. At present Direct Payments are not available in Wales under the Health Act 2009, it is my understanding that a pilot scheme for health direct payments is running in England and I would urge the Welsh Assembly to consider commencing the powers within Wales to allow for Health Direct Payments or too at least

conduct a pilot in to its feasibility in Wales. The option of Direct Payments are not available to me at present but the introduction of them would reduce the over reliance and subsequent red tape on certain services and provide myself with more autonomy in arranging care for Kyle.

With the committee meeting on the 15 March being the final meeting before the dissolution of the committee are you able to provide any guarantees that this petition will continue to be taken forward by the new petitions committee following the Assembly elections?

Yours sincerely

Katherine Simmons



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Dear Mrs Chapman,

I am writing in response to your letter received on 3rd February with regards to Neuro Rehabilitation Services.

In the first instance I would like to confirm that the Plan received by WHSSC from the Cardiff & Vale University Health Board in relation to Neuro Rehabilitation Services continues to be progressed through the Welsh Health Specialised Services Committee (WHSSC) financial planning process.

WHSSC are holding a workshop with representatives from all seven Health Boards on Monday, 28th February 2011 to review the schemes that WHSSC are recommending are incorporated into the Annual Plan. We hope that after this workshop WHSSC will be able to produce an annual plan that will be signed off by the WHSSC Joint Committee at the end of March.

I would like to reassure you that WHSSC continues to work with Cardiff & Vale University Health Board to ensure that patients have access to the services they require.

Yours sincerely,

Dr Cerilan Rogers
Director Tertiary and Specialised Services

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