

the welsh sleep apnoea society  
*'Those Who Sleep Win'*



2 Greenfield Close  
Pontnewydd  
Cwmbran  
NP44 1BY  
[www.welshsas.org](http://www.welshsas.org)

Mr G D Thomas  
Committee Support Officer  
Petitions Committee  
National Assembly for Wales

08/09/08

PETITION: SLEEP APNOEA P-03-156

Dear Mr Thomas

RECEIVED  
09 SEP 2008

*GDC*

I would refer to your letter of 21/8 concerning the above petition. I trust the following information will prove useful to the Committee.

**MEDICAL:** Apnoea is a Greek word meaning 'without breath'. In around 7% of the population during sleep the throat muscles become flaccid, collapse and block the airway. The patient's brain receives a message to this effect and awakens typically with a loud snort. This 'episode' can occur around 300 times a night but has been measured at around 1000 such episodes. The outcome is lethargy, constant headaches, lack of concentration, loss of libido and constantly falling asleep. This can and often does occur during driving and has led to catastrophic effects. While not suffering from Apnoea the person involved in the Selby rail disaster was suffering from sleep deprivation. It has been medically shown that all the major organs in the body can not replenish themselves when deprived of oxygen during sleep. Therefore untreated Apnoea has led to heart disease, strokes, diabetes and kidney failure.

**TREATMENT:** Treatment for Apnoea is by means of a Constant Positive Airway Pressure (CPAP) machine. This blows air through a mask enabling the airway to remain open, thus resulting in the correct type of sleep. This machine has been recommended by NICE as being the best treatment for 'mild and severe' sleep apnoea. The machine costs from around £300 to £700 depending on specification.

(Continued)

**THE SOCIETY:** The Welsh Sleep Apnoea Society (WelshSAS) was formed around eight years ago to 'promote the understanding of breathing and sleep disorders'. There are around seventy paid members from four clinics in South Wales, Bristol, Swansea and Wrexham. The Society has provided equipment in the form of a bed for the Sleep Laboratory at the Royal Gwent and several diagnostic and treatment tools for the RGH and Nevill Hall. We operate a website ([www.welshsas.org](http://www.welshsas.org)) and a 'helpline' facility for patients and their families. Members receive a magazine twice yearly.

**INVOLVEMENT WITH THE NATIONAL ASSEMBLY:** The Society became aware that an unnamed patient had written to Edwina Hart concerning a CPAP. It seems the gentleman had been informed he couldn't get one on the NHS and had purchased a machine privately. He has written to the Minister requesting a refund of his money. Since a NICE Technology Appraisal earlier this year there has been a legal requirement on the Government and Local Health Boards to provide CPAPs to diagnosed patients. In a letter to the patient the Minister stated that she hoped that 'all diagnosed patients would have access to CPAP by June' (which June wasn't stated). The Society has contacted the Minister concerning this matter and her insistence that Local Health Boards should be funding the equipment despite being re-organised. Until the Society has proof from a patient that they have been unable to obtain a CPAP we are at an impasse with the Minister. The Society then received an email from a couple in Cardiff who had been told that 'diagnosis and treatment of Apnoea was not available on the NHS in Wales'. Knowing that this is not true the Society has contacted the Minister again asking why there is a "Post Code Lottery" for treatment of Sleep Disorders. To date there has been no reply. Copies of the letters have been sent to Nick Ramsay AM and Jonathon Morgan AM as both have expressed an interest in developments. The Society is aware that services for patients with sleep disorders are at best fragmented and at worse non existent.

In the Society's view the Government are 'playing with patient's lives' here. A disorder that can be easily treated, allows patients to return to work, and improves their family life is being completely ignored. Yet an untreated patient with apnoea can kill an innocent bystander and themselves by falling asleep while driving.

I have enclosed copies of correspondence received from the Minister and Nick Ramsay.

I hope this information proves useful to the Committee. If they or anyone else wishes to contact me they should do so either through the website or on 01633 774087.

Yours sincerely

  
Roger Paterson  
(Honorary Secretary)

## **Nick Ramsay AM**

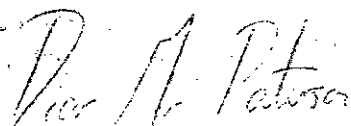
Welsh Conservative Member for Monmouth  
Shadow Minister for Local Government  
and Public Services

Cardiff Bay, Cardiff, CF99 1NA  
Bae Caerdydd, Caerdydd, CF99 1NA

Eich cyf / Your ref:  
Ein cyf / Our ref: ELW/NR/PR1  
September 2008

Ffôn/Tel: 029 20 898337  
Nicholas.Ramsay@wales.gov.uk

Mr Roger Paterson,  
Honorary Secretary – the Welsh Sleep Apnoea Society,  
2 Greenfield Close,  
Pontnewydd,  
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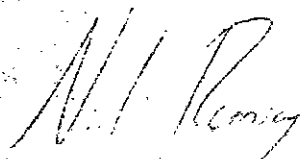
Many thanks for your letter of 18<sup>th</sup> August 2008.

I appreciated the information provided. As you know I am interested in being kept updated on the responses you receive from the Welsh Assembly Health Minister.

I was concerned to hear about the gentleman from Cardiff who has been informed that treatment for the diagnosis of sleep disorders is no longer available on the NHS. As we are both aware through our correspondence with Edwina Hart, all patients diagnosed with Obstructive Sleep Apnoea (OSA) should have access to Constant Positive Airway Pressure machines (CPAP). The fact that there are issues over equity of access in parts of Wales is an issue that needs to be addressed.

I would be grateful if you could send me some further information on your AGM on 11<sup>th</sup> October. Diary permitting, I would hope to attend, so if you could let me know the time and location of the meeting I would really appreciate it.

Kind regards,



**Nick Ramsay AM**  
Welsh Conservative Member for the Monmouth constituency  
Shadow Minister for Local Government and Public Services

## Nick Ramsay AM

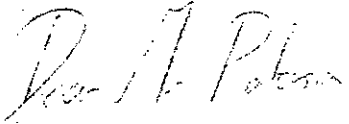
Welsh Conservative Member for Monmouth  
Shadow Minister for Local Government  
and Public Services

Cardiff Bay, Cardiff, CF99 1NA  
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Eich cyf / Your ref:  
Ein cyf / Our ref: ELW/NR/PR1  
13 August 2008

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Mr Roger Paterson,  
Honorary Secretary – the Welsh Sleep Apnoea Society,  
2 Greenfield Close,  
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NP44 1BY.

  
I am writing to thank you for your most recent letter, received on 6<sup>th</sup> August 2008.

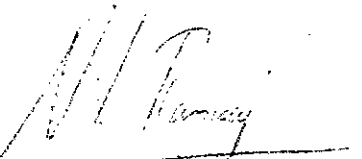
It is a concern that although the Health Minister, Edwina Hart AM, states that all patients diagnosed with Obstructive Sleep Apnoea (OSA) should have access to Constant Positive Airway Pressure machines (CPAP), she admits that there are in fact issues over equity of access in parts of Wales.

As you know, Ms Hart has suggested that any patients who believe they are being disadvantaged should write to the Chief Executive of their Local Health Board. I do however understand your concerns over the potential impact of the reorganisation of the LHBs. I would be grateful if you would keep me updated on any response you receive from the Health Minister regarding this.

I am more than happy to discuss this matter with my colleague, the Shadow Minister for Health, Jonathan Morgan AM, and have therefore copied him into our letters. I am sure that he would be as keen as I am to see that OSA patients are able to access CPAP machines.

Please feel free to contact me again if there is anything further you would like to discuss.

With kind regards,



**Nick Ramsay AM**  
Welsh Conservative Member for the Monmouth constituency  
Shadow Minister for Local Government and Public Services

Cc Jonathan Morgan AM, Shadow Minister for Health and Social Services.

Edwina Hart AM MBE

Y Gweinirddor o'r Isreolaeth a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Our ref: EH/03796/08

Your ref:

Llywodraeth Cynulliad Cymru  
Welsh Assembly Government

Mr Roger Paterson  
Honorary Secretary  
The Welsh Sleep Apnoea Society  
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Llinell Ymholiadau Cymraeg: 0845 010 4400  
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E-Bost: Correspondence.Edwina.Hart@Wales.gsi.gov.uk

*Dear Mr Paterson*

3<sup>rd</sup> August 2008

Thank you for your further letter of 28 July about the provision of Continuous Positive Airway Pressure (CPAP) machines for patients suffering from sleep apnoea.

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I can assure you that the reorganisation of the NHS in Wales will not effect the high standards of care provided to patients. I can only repeat the advice in my earlier reply that you advise your members who have not received a CPAP machine in accordance with the NICE guidance on Sleep Apnoea to address their concerns to the chief executive of their Local Health Board, drawing their attention to the statutory obligation to fund implementation of the NICE guidance.

*Edwina Hart*

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Edwina Hart AM MBE

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

Our ref: EH/03150/08

Your ref:

Roger Paterson  
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7 July 2008

*Dear Mr. Paterson*

Thank you for your letter of 23 June about the provision of CPAP machines for patients suffering from sleep apnoea.

I confirm my expectation that, in the light of the recent NICE technology appraisal, any patient prescribed a CPAP machine should receive one. I am, however, aware that there are issues over equity of access in parts of Wales.

May I suggest that you advise any members who believe they are being disadvantaged to write to the Chief Executive of their Local Health Board setting out their concerns, and asking that their case be investigated.

*Edwina*

## Nick Ramsay AM

Welsh Conservative Member for Monmouth  
Shadow Minister for Local Government  
and Public Services

Cynulliad National  
Cenediaethol Assembly for  
Cymru Wales

Cardiff Bay, Cardiff, CF99 1NA  
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Eich cyf / Your ref:  
Ein cyf / Our ref: ELW/NR/PR1  
26 June 2008

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Mr Roger Paterson,  
Honorary Secretary – the Welsh Sleep Apnoea Society,  
2 Greenfield Close,  
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I am writing to thank you for your letter regarding the recent NICE Technology Appraisal and the supply of CPCPs (Constant Positive Airway Pressure) to those diagnosed with OSA (Obstructive Sleep Apnoea).

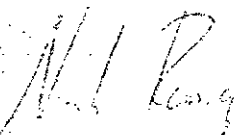
I was interested to read the Health Minister's statement that 'all patients diagnosed with OSA will have access to a CPAP by the end of June', as this would certainly be a welcome development.

However, it is a concern that the Sleep Clinic has no new money to provide for the twenty patients waiting – some as long as eight months. Furthermore, only two of the six Local health Boards who are responsible for allocating funding have contacted the Sleep Centre concerning the appraisal.

I have therefore contacted the Minister, as requested, to further raise this matter. I am interested to know what she is doing to ensure that patients with OSA do indeed have access to a CPAP and I promise to contact you again as soon as I receive a response.

In the meantime please feel free to contact my office if there is anything further you would like to discuss.

Kind regards,



Nick Ramsay AM  
Welsh Conservative Member for the Monmouth constituency  
Shadow Minister for Local Government and Public Services

Edwina Hart AM MBE

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

Our ref: EH/01983/08

Your ref:

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28 April 2008

*Dear Mr Row*

Thank you for your further letter dated 9 April about reimbursement of the costs of the Continuous Positive Airway Pressure (CPAP) machine you purchased privately for sleep apnoea problems.

As I stated in my previous letter dated 25 February, I was sorry and disappointed to hear that you felt unable to rely on NHS Wales to provide you with a CPAP machine and opted to pay for one privately. There is no policy in Wales for the NHS to refund equipment or treatment purchased privately.

You ask about access to these machines now that NICE has formally recommended them as a possible treatment for adults with moderate or severe sleep apnoea. LHBs are under a statutory obligation to fund implementation of this guidance within three months. By the end of June, I would expect that all patients who have had CPAP machines prescribed would have been provided with them.

*Edwina Hart*