



Multiple Sclerosis Society  
Cymru

## **MS nurse petition – briefing for the Petitions Committee** **March 2012**

*MS Society Cymru is concerned that the future of MS and other specialist nurses is uncertain due to budget cuts and current Welsh Government policy.*

*This briefing paper is designed to give some background to MS Society Cymru's campaign to protect MS nurse posts and provide useful information for a supplementary question.*

### **Background**

Multiple sclerosis specialist nurses (MS nurses) are a vital source of support for people affected by MS. They provide a wide range of services, from managing relapses, giving advice on drug treatments through to acting as a gateway to physiotherapy, counselling and other functions of the multidisciplinary team. MS nurse posts are currently under threat. MS Society Cymru has launched a campaign to protect these posts.

### **Why are MS nurses a vital frontline service?**

*"The MS nurse is the human face of the NHS. Doctors are excellent, but it is the nurse who can take the time to get to know individuals, to explain symptoms and treatments. For me, when frightening first diagnosis was made, it was the MS nurse who was able to bring back some perspective and reassurance for me and my loved ones. Without the nurse, having MS could be frightening and lonely, not just for me but for my partner and relatives. She provides the reassurance and her experience inspires confidence." (Person affected by MS.)*

People affected by MS have consistently told us that access to an MS specialist nurse is invaluable to them. Nearly 1000 people affected by MS responded to a UK-wide survey on MS nurses in 2010. The responses showed just how much people value their MS nurse and how much more difficult life would be without their support. The findings from the survey are contained in the report: ***Experiences of people using MS specialist nurse services***. Key findings from the report include the following:

- **Over 60%** of respondents reported that their MS nurse always helps them when they want to know about different treatments, or their current medication.
- **Over 70%** stated that their MS nurse is always the first point of contact when they have any questions about their MS.
- **80%** said their MS nurse had provided support to their family and carers.

We also know that the withdrawal of MS nurses could negatively impact other MS services as MS nurses play a **key role in training other professionals**. Their skills and knowledge are highly valued by consultant neurologists, many of whom call on MS nurses for information. Neurologists have told us that the loss of MS nurses would be a great disadvantage to the healthcare system and people with MS.

Not only do MS nurses provide the specialist care that people with MS need, there is also evidence to suggest that they may contribute to considerable **cost savings for NHS Wales**. By providing care in the community and educating patients about managing relapses, MS nurses are able to promote self-management, prevent unnecessary hospital admissions and reduce lengthy episodes in hospital.

- Data collected by the Royal College of Nursing in 2010 showed that almost £10 million could be saved every year in Wales by MS specialist nurses intervening early and managing MS relapses at home rather than in hospital.
- The nurses have the skills and the equipment to assess and treat problems such as a Urinary Tract Infection (UTI) at home, rather than the person being taken into hospital at an average cost of £1,000 per emergency admission
- Expensive orthopaedic admissions can be avoided by MS nurses recognising “dropped foot”, a common symptom of MS leading to falls and broken bones. They make referrals to use Functional Electrical Stimulation (FES) therapy at an annual cost of less than £1,000. In contrast a broken leg would cost the NHS over £10,000

“Of all the developments in nursing, the role of the specialist nurse has been one of the most exciting, but also one of the least understood and valued” – RCN

### **Why are posts under threat?**

The former NHS Wales Operating Framework 2010/11 and other policies could lead to reductions in the number of MS specialist nurses over the next 3 years. The Operating Framework stated:

“All organisations are expected to work towards achievement of a 3% reduction in staff in Agenda For Change Bands 5 and above, with a reflected increase in staff in Bands 1 to 4, per annum, between 2010 to 2013 and a 10% increase in the proportion of staff providing services in a community setting, to be achieved between 2010 to 2013.”<sup>1</sup>

Although this framework covered all staff, and not solely nurses, this combined with financial pressures on Health Boards could see a threat to the MS nurse posts.

There is also concern that the Welsh Government’s new Community Nursing Strategy does not acknowledge the important role of MS specialist (and other condition specific) nurses as being responsible for managing the holistic health care needs of the person living with the condition.

<sup>1</sup> Welsh Government (2010): NHS Wales Annual Operating Framework 2010/11

The strategy states:

“Specialist nurses need to be developed and focused around specific population need and a review of the many disease specific specialist nurses needs to be undertaken focusing on common disease groups.”<sup>2</sup>

It is understood that several MS nurses from other parts of the UK have been asked to justify their posts; roles are under review and some services have been diluted (where a nurse has been asked to treat newly diagnosed patients only, for example). Whilst currently 35 MS nurse posts are ‘under threat’ in England despite the ‘ring-fencing’ of health in that country.

### **What does MS Society Cymru want?**

We believe that the role of specialist nurses is poorly understood by Health Board managers and by the general public. This has led to a false perception of the nurses being an “expensive luxury,” rather than appreciating the savings that are currently being made and the further savings that could be made by them working in the community.

We want the Welsh Government to ensure that the numbers of MS nurses are not reduced and for Health Boards to aim to provide 1 nurse for every 300 people living with MS. At the moment there are no nurses in Powys and just one in North Wales, so we would like to see further investment in at least one post in North Wales, and one post in Powys.

We would like the Petitions Committee to refer our concerns to the Health and Social Care Committee and recommend an inquiry into the role of specialist nurses in Wales. This would allow for a thorough examination of the role of specialists nurses across a whole range of conditions (including MS) in the Welsh NHS, and allow public scrutiny of the costs and potential savings generated by these roles.

### **About Multiple Sclerosis and MS Society Cymru**

Multiple Sclerosis is the most common disabling neurological disorder affecting young people in the UK with more than 100,000 affected by the condition. It is estimated that over 4,000 people are affected in Wales. It is a condition of the central nervous system. MS is unpredictable and can cause a wide variety of symptoms such as loss of mobility, pain, fatigue, vision problems, numbness, loss of balance, depression and cognitive problems. The condition may progress steadily or involve periods of relapses followed by periods of remission.

Multiple Sclerosis Society Cymru (MS Society Cymru) is the Wales-wide charity dedicated to supporting people who have MS, as well as providing help for their families, friends, carers and colleagues. A significant number of the MS Society Cymru National Council and volunteers either have MS or have a personal connection with MS.

The Society provides care and support through services which include a national information and helpline service, publications, a website that receives more than 40,000 visitors each month, welfare grants, funding research and funding MS specialist nurses.

MS Society Cymru is a democratic organisation and has a network of branches delivering local services to people with MS across Wales.

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<sup>2</sup> Welsh Government (2009): A Community Nursing Strategy for Wales