

# Multiple Sclerosis Journal

<http://msj.sagepub.com/>

---

## **Moving towards the pan-European unification of Multiple Sclerosis Nurses: a consensus paper**

N Ward-Abel, W Köhler, V Matthews, M Messmer Uccelli, C Mouzawak, A Perrin Ross, L Pyciaková, A Winslow and J Kraus

*Mult Scler* published online 18 September 2013

DOI: 10.1177/1352458513504250

The online version of this article can be found at:

<http://msj.sagepub.com/content/early/2013/09/18/1352458513504250>

---

Published by:



<http://www.sagepublications.com>

**Additional services and information for *Multiple Sclerosis Journal* can be found at:**

**Email Alerts:** <http://msj.sagepub.com/cgi/alerts>

**Subscriptions:** <http://msj.sagepub.com/subscriptions>

**Reprints:** <http://www.sagepub.com/journalsReprints.nav>

**Permissions:** <http://www.sagepub.com/journalsPermissions.nav>

>> [OnlineFirst Version of Record](#) - Sep 18, 2013

[What is This?](#)

# Moving towards the pan-European unification of Multiple Sclerosis Nurses: a consensus paper

*Multiple Sclerosis Journal*  
0(0) 1–3  
© The Author(s) 2013  
Reprints and permissions:  
sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/1352458513504250  
msj.sagepub.com  


**N Ward-Abel<sup>1</sup>, W Köhler<sup>2</sup>, V Matthews<sup>3</sup>, M Messmer Uccelli<sup>4</sup>,  
C Mouzawak<sup>5</sup>, A Perrin Ross<sup>6</sup>, L Pyciaková<sup>7</sup>, A Winslow<sup>8</sup>  
and J Kraus<sup>9</sup>**

The quality of care of people with multiple sclerosis (MS) varies widely throughout Europe, as revealed in the Multiple Sclerosis – Nurse Empowering Education (MS-NEED) European survey.<sup>1</sup> One-fifth of MS Nurses surveyed identified feeling that they lacked sufficient training and education to perform their day-to-day role.

In recent years, with the advent of disease-modifying therapies, there has been an increase in the number of MS Nurses within Europe; however, the role often varies depending on country and regions of practice.<sup>1</sup> Despite the emergence of such posts, there have been no clear guidelines regarding who can call themselves an ‘MS Nurse’, nor is there any accepted consensus on the training, education and skill level required. There is lack of clarity about the scope and competency required of an MS Nurse, a lack of parity between similar roles in different countries and inconsistent outcomes of care.<sup>2,3</sup>

Equitable, safe, effective evidence-based care requires adherence to validated ‘gold’ standards. Despite local variations and contextual nuances across Europe, MS Nurses have the potential to implement such standards, with clearly defined, measurable outcomes. More than 80% of people with MS prefer to discuss their problems with MS Nurses,<sup>4</sup> and, equally important, MS Nurses are able to make the changes needed to improve the lives of those affected by MS.<sup>5</sup>

## Defining the ‘MS Nurse’ within Europe

An MS Nurse is a registered nurse who cares for people with MS and their families, and can work across a range of other neurological conditions. They are experts in the specialist requirements of patients with complex neurological health problems.

The role is dynamic and responsive, and spans the disease trajectory. MS Nurses have disease-specific knowledge alongside experience in care and support activities. Although interventions may vary, key elements remain constant: delivery of high-quality clinical care, symptom management, education of patients,

monitoring and surveillance of therapies, and psychosocial and family support.

MS Nurses are well placed to address the subtle and often ‘silent’ psychological distress of MS. In particular, patients should feel that their emotional concerns and anxieties are heard, understood and acted upon.<sup>4</sup> They also undertake early detection of deterioration and take the necessary pre-emptive action to prevent adverse events or negative experiences (the so-called rescuer role).<sup>6</sup>

MS Nurses are accessible to their patients and as a result of regular interaction, readily establish an ongoing therapeutic relationship. MS Nurses are able to encourage strong lines of communication that foster safety and high levels of confidence. MS Nurses can offer support at times of difficulty, and promote independence and self-care.<sup>4</sup>

The complex, unpredictable nature of MS necessitates input from a range of health and social care professionals. Although these individuals may affect the experiences of people with MS, the MS Nurse remains the central key worker responsible for coordinated care and support. Thus it is essential that they receive ongoing education and are appropriately skilled to work effectively with all members of the multidisciplinary team.

<sup>1</sup>International Organization of MS Nurses, UK.

<sup>2</sup>Department of Neurology and Neurological Intensive Care, Fachkrankenhaus Hubertusburg and MS Centre Wermsdorf, Germany.

<sup>3</sup>Rehabilitation in Multiple Sclerosis Centres, UK.

<sup>4</sup>Multiple Sclerosis Society, Italy.

<sup>5</sup>Réseau SEP IDF Ouest, France.

<sup>6</sup>International Organization of MS Nurses, USA.

<sup>7</sup>General Teaching Hospital and First Medical Faculty, Charles University, Czech Republic.

<sup>8</sup>European MS Platform, Ireland.

<sup>9</sup>Department of Neurology, Christian-Doppler-Klinik, Paracelsus Medical University, Salzburg, Austria.

### Corresponding author:

Nicki Ward-Abel, Birmingham City University, Bevan House, Westborne Road, Edgbaston, Birmingham, B15 3TN, UK.  
Email: Nicki.Ward@bcu.ac.uk

## The case for MS Nurses

Having MS Nurses in the multidisciplinary team has considerable advantages. They can work alongside the neurologist to address educational needs and risks associated with therapies recommended for consideration.

MS Nurses can ensure successful implementation of treatment decisions and assist with medication concordance by frequently reviewing the treatment plan. As the primary point of contact, MS Nurses are able to inform neurologists of the challenges individuals face in living with MS, so problems can be addressed in a timely manner. Furthermore, involvement of MS Nurses in evaluating, educating, monitoring and supporting the person with MS can optimise the time neurologists dedicate to each person, providing increased capacity and efficiency.

The most important beneficiaries of MS Nursing are people with MS. MS is a long-term condition that requires responsive, consistent care and an understanding of differing coping strategies. MS is dynamic and individuals often experience complex issues that cannot be addressed by one health professional alone. MS Nurses understand the needs of people with MS and coordinate provision of high-quality, evidence-based care.<sup>7</sup>

## A call to action

There is a clear need for recognition of the MS Nursing role across Europe, which many nurses already fulfil without formal acknowledgement. In 2005, the European Commission published a Green Paper – *Modernising the Professional Qualifications Directive* (2005/36/EC) – focused on preparing a national qualification for mutual recognition across member states. It is therefore critical to agree on a curriculum providing alignment of tasks, roles and competencies.

It is hoped that this consensus paper will be the first step towards unification and recognition of MS Nurses throughout Europe. There is a need for MS Nurses to form national organisations that can work together to acknowledge the differences between countries, share best practice, and ultimately improve the safety and consistency of care.<sup>8</sup> Specialised nursing care is proven to result in higher therapy adherence and treatment effectiveness while reducing healthcare costs.<sup>9</sup> MS Nurses require education, training and collaboration to carry out this diverse role successfully.

To this end, the European MS Platform (the umbrella organisation for 37 MS patient societies) has established MS Nurse *PROfessional* ([www.ms-nursepro.org](http://www.ms-nursepro.org)) in collaboration with the European Rehabilitation in MS (RIMS) centres network and the International Organization of Multiple Sclerosis Nurses (IOMSN). MS Nurse *PROfessional* is an online foundation level resource providing a modular, online training curriculum to support the evolving role of European MS Nurses. This educational programme is targeted at MS nurses starting their professional careers as well as those healthcare professionals with

a caseload of MS patients and/or an interest in MS, has been accredited by the UK Royal College of Nursing (RCN) Centre for Professional Accreditation and approved by the International Council of Nurses (ICN) for the award of International Continuing Nursing Education Credits (ICNECs). MS Nurse *PROfessional* has been endorsed by leading national and international patient and professional groups. As recognised in a *Lancet Neurology* editorial titled, ‘Setting new standards in multiple sclerosis care and research’, MS Nurse *PROfessional* could improve care for thousands of people with MS.<sup>10</sup>

## Funding

Excellent editorial support with this paper was provided by Ogilvy HealthPR.

## Conflict of interest

MS Nurse *PROfessional* is funded through an unrestricted educational grant by Novartis Pharma AG.

Ward Abel, N: received financial support for attending conferences and personal compensation for consulting services, presentations and/or travelling from Biogen-Idec, Merck-Serono, Novartis, TEVA and Genzyme.

Köhler, W: received financial support for research activities and personal compensation for consulting services, presentations and/or travelling from Bayer, Biogen-Idec, Merck-Serono, Novartis, Sanofi-Aventis, and TEVA.

Matthews, V: received financial support for attending conferences and personal compensation for consulting services, presentations and travelling from Genzyme, Biogen Idec and Novartis.

Messmer Uccelli, M: received no financial support or personal compensation from any source of potentially conflicting interest.

Mouzawak, C: received financial support for attending conferences from Biogen-Idec, Merck-Serono, Novartis, Sanofi-Genzyme, Teva, Bayer and personal compensation for consulting services, presentations and travelling from Biogen-Idec, Novartis, Merck Serono, Teva.

Perrin Ross, A: received financial support for attending conferences and personal compensation for consulting services, presentations and travelling from Bayer Healthcare, Pfizer Inc., EMD Serono, TEVA, Acorda, Genzyme, Novartis, Biogen Idec and Questcor

Pyciaková, L: received financial support for attending conferences and personal compensation for consulting services, presentations and travelling from Merck-Serono, Biogen Idec and Novartis.

Winslow, A: received no financial support or personal compensation from any source of potentially conflicting interest.

Kraus, J: received financial support for research activities and personal compensation for consulting services, presentations and/or travelling from Bayer, Biogen-Idec, Genzyme, Merck-Serono, Medtronic, Novartis, Sanofi-Aventis, Almirall, and TEVA.

## References

1. Hartung HP. Disparities in nursing of multiple sclerosis patients - Results of a European nurse survey. *Eur Neurol Rev* 2011; 6: 106-109.

2. Corry M, McKenna M and Duggan M. The role of the clinical nurse specialist in MS: A literature review. *Br J Nurs* 2011; 20: 86-93.
3. Forbes A, While A, Dyson L, et al. Impact of clinical nurse specialists in multiple sclerosis--Synthesis of the evidence. *J Adv Nurs* 2003; 42: 442-462.
4. Ward-Abel N, Mutch K and Huseyin H. Demonstrating that multiple sclerosis specialist nurses make a difference to patient care. *Br J Neurosci Nurs* 2010; 6: 319-324.
5. Akkus Y and Akdemir N. Improving the quality of life for multiple sclerosis patients using the nurse-based home visiting model. *Scand J Caring Sci* 2012; 26: 295-303.
6. Leary A. Proving your worth. *Nurs Stand* 2011; 25: 62-63.
7. Brodkey MB, Ben-Zacharia AB and Reardon JD. Living well with multiple sclerosis. *Am J Nurs* 2011; 111: 40-48.
8. Harris C, Costello K, Halper J, et al. Consortium of multiple sclerosis centers recommendations for care of those affected by multiple sclerosis. *Int J Multiple Sclerosis Care* 2003; 5: 67-78.
9. Brooten D, Youngblut JM, Brown L, et al. A randomized trial of nurse specialist home care for women with high-risk pregnancies: Outcomes and costs. *Am J Manag Care* 2001; 7: 793-803.
10. Editorial. Setting new standards in multiple sclerosis care and research. *Lancet Neurol* 2012; 11: 835.