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

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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.¹ 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.¹ 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.^{2,3}

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,⁴ and, equally important, MS Nurses are able to make the changes needed to improve the lives of those affected by MS.⁵

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.⁴ 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).⁶

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.⁴

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.

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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.⁷

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.⁸ Specialised nursing care is proven to result in higher therapy adherence and treatment effectiveness while reducing healthcare costs.⁹ 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.msnursepro.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.¹⁰

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Conflict of interest

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