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Published Nov 2007

# Multiple Sclerosis Specialist Nurses

Adding value and delivering NHS targets  
OptiMiSing Standard of Health (DOH 2006)



## Forward for MS Specialist Nurses Document

I am delighted to be asked to write a forward to this MS Specialist Nurses document as I not only have been a strong supporter, researcher and advocate for specialist nurses but I am also a trustee of the Multiple Sclerosis Trust.

My interest in the development of the specialist nurse role goes back to the early days when the first pioneers were trying to make their mark and establish themselves as a key and integral role in the care of patients with specialist nursing needs. There is no doubt that their development was heavily influenced by the demands of the patients themselves, the increasing numbers of patients with long term health care needs and the rise in medical technology, treatment and innovation.

Unfortunately the introduction of specialist nurses has not always been well understood and controlled and there have been instances where posts have been implemented with little thought as to what the post holder will be doing. This has led to confusion over what constitutes the role and has resulted in numerous posts with a variety of titles.

The consequences of this approach, coupled with the need to become more cost conscious has resulted in some specialist nursing posts being put under the threat of closure.

The role of the specialist nurse in MS nursing has been more seriously researched and thought through. There has also been some very useful work completed on the criteria for such posts, but still there is a need in today's modern health care world to justify the value and cost effectiveness of the role.

This present document is an excellent attempt by some of the leading MS specialist nurses themselves to clarify their work and relate it to some of the key standards set out by the government. It focuses on the vital links and relationships between the nurse and the patient, their family and the other members of the multidisciplinary team.

It makes a very persuasive and passionate plea to all those who are involved with the employment and management of such nurses and encourages those considering the future of such roles to listen carefully to what the MS patient is saying about their nurse.

This is an important and innovative paper that gets to the heart of why MS Specialist Nurses exist and I urge you to read it carefully.

Professor Sir George Castledine.

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## Introduction to MS

MS affects 1 in 700 people, which for a typical PCT with a population of 200,000 means there will be approximately 286 families affected by MS, each with a wide variety of health and social care needs.

Multiple Sclerosis (MS) is an autoimmune, neurological condition, it is a chronic and degenerative disease affecting the central nervous system. It is characterised by inflammation, demyelination and axonal loss. Many diagnosed with MS (about 80%) initially present with a relapsing/remitting pattern of the disease but in time most will go on to experience cumulative and/or progressive disability. There is no cure and prescribable treatments have only limited effectiveness.

Every individual with MS will have a different presentation of their disease and as such it is impossible to predict their ultimate course or prognosis. Many people have to live with an unpredictable disease and an uncertain outcome. This causes a great deal of stress as individuals live with anxiety about their future quality of life and many fear and experience physical disabilities, financial difficulties and social isolation. All of these factors have a significant impact on family life.

The person living with MS and their family requires the specialist services of the specialist MS nurse who not only understands the daily fluctuations of MS symptoms and frustrations, but can also provide timely accessible advice and support which is tailored to individual needs. MS Specialist Nurses are involved with families affected by MS across the disease trajectory from diagnosis to end-of-life. **MS nurses** provide care in a uniquely flexible and timely manner ensuring people with MS can access the care they need when they need it and by working in partnership to empower them to self-care and become experts in their own condition.

### Example of MS nurse activity per year of one PCT

+ Phone calls	881
+ MS caseload	308
+ Patients seen	134
+ Ward attenders	12
+ Home Visits	103
+ Clinics	20

## Benefits of Employing MS Specialist Nurses

MS specialist nurses not only provide clinically effective care for people with MS and their families but also bring benefits to their employing Trust by:

- Generating income for clinical activity via local service level agreements
- Reducing the number of emergency admissions in line with the targets set in Supporting People with Long Term Conditions (2005)
- Reducing length of hospital stay so supporting the local Trusts in meeting the 18 week wait target
- Reducing demands on the time of General Practitioners by acting as a first point of contact for people with MS when they have queries or concerns
- Reviewing follow up patients in place of the Neurologist; MS nurses increase capacity within Consultant Neurologist clinics helping to meet waiting list and 18 week wait targets
- Collaborating with patients to develop a responsive service according to their need
- Bringing local services in line with national targets and standards, as in for example the NSF for Long-term conditions (2005), NICE Guidelines for management of MS (2003) and Standards for Better Health (2004) by which all Trusts (acute and primary) are measured
- Facilitating delivery of the MS Risk Sharing Scheme (HSC 2002/004 – revised 11/06), which is mandatory for all primary, and acute care trusts
- Improving communication in providing a seamless service between different providers within the health, social and voluntary care sectors

### Example of how MS specialist nurses can reduce emergency admissions

Data regarding the number of people on the PARR register (Patients at Risk of Readmission) were requested from the local PCT. The data was analysed and compared to patients coded for stroke. Just 20 patients with MS were identified on the register (6.9% of the PCT MS population) compared to 257 coded for a diagnosis of stroke (48% of PCT stroke population). Local stroke services are run along a different model than local MS nurse services with little community support and only short-term follow-up of patients post-discharge.

Whilst this data is not conclusive it is indicative that the way MS nurses work can have a significant impact on reducing the number of people with MS admitted as an emergency

“The MS specialist nurse is a total delight for sufferers of this unpredictable disease, providing a pinpoint of light in a very dark tunnel. I have found the MS specialist nurse to be a contact point for all available assistance, avoiding endless time and energy spent trying to find answers to questions.

The availability alone is worth thousands and the NHS should realise what a resource they have for a much misunderstood section of the community. Having had occasion to use the excellent service, rather than see posts withdrawn I want all MS sufferers to have access! ”

Jodie 39yrs

## Risk Assessment if MS Specialist nurses are withdrawn from service

If the MS Specialist Nurse Service is withdrawn:

- The potential for income generation via Nurse led clinics, phone clinics and home visits within the Acute Trust will be lost
- There are likely to be breaches of the 18 week wait target
- Lack of capacity within the Neurologists work load to meet their needs in a timely fashion
- The number of people with MS admitted as an emergency and extended length of stay in hospital is likely to increase
- Local services for people with MS will fall far short of that required meeting NSF and NICE guidelines
- Concordance and adherence with therapy regimes will be poor, which will have an impact on cost effectiveness and efficacy of drugs
- The number of complaints and approaches to PALS (Patient, Advice and Liaison Service) will increase
- Increased pressure on GP services due to patient seeking local consultation

**A SERVICE THAT IS GREATLY VALUED BY PEOPLE WITH MS AND THEIR FAMILIES AND WHICH PROVIDES ADDED VALUE TO NEUROLOGY**

### Example of Reduction to MS Specialist nurse service

One trust had 3.6 wte one year ago; as MS nurses left and were not replaced there is currently 1.6wte. Patient calls take 4/5 days rather than ½ days to respond to, causing frustration, they contact GP practice that does not understand MS. GP contacts registrar on-call and the patient is admitted to the local hospital for relapse management when this should be done as an outpatient.

Courses to help patients manage their condition such as newly diagnosed, symptom management, palliative care can no longer be offered. Ultimately, increasing the physical and economic burden upon the local community.

## Adding Value and Delivering Targets Standards of Health Context

This document has been written at a time of great change within the NHS with an ever-increasing emphasis on delivering Government policy and cost-effective care.

Over the last two years MS Specialist Nurse posts across the UK have been under pressure to provide a more generic service, diluting the services available to people with multiple sclerosis (MS).

Posts have been frozen when MS Specialist Nurses have left and have not replaced. This is having a significant impact on the provision of services available to people affected by MS. Losing MS Specialist Nurse posts and making posts more generic in focus may appear to beleaguere commissioners as an easy and cost effective option at a time when 'balancing the books' is more important than it has ever been within the NHS.

However, this is a false economy and this document has been produced to clearly identify the value and benefits in terms of cost effectiveness as well as clinical efficiency of MS Specialist Nurses.

This document is aimed at all Commissioners, Lead Nurses, PCT fund holders, Finance Directors, Directors of Nursing, Service Managers and any other individuals involved in the provision of services for people affected by Multiple Sclerosis (MS).

Utilising the Standards for Better Health (DH 2006) as a framework, this document highlights how MS Specialist Nurses are already making a very significant contribution towards the Developmental Standards that must be implemented by 2008, as well as demonstrating the clinical and cost-effective nature of our work.

### Domain Outcome

Patient safety is enhanced by the use of healthcare processes, working practices and systematic activities that prevent or reduce the risk of harm to patients.

## Domain One: Safety

MS Specialist Nurses achieve this by:

- Undertaking timely assessment and management of acute and chronic symptoms responding to patients needs when they are most vulnerable.
- Providing emotional support, holistic assessment, appropriate intervention and referral to other members of the multi-disciplinary team when required.
- Promote and monitor concordance and compliance of disease modifying treatments.
- Giving accurate information for example, regarding "quack cures", people with MS are often very vulnerable as they search for a "cure".
- Being advocate on patients behalf in case conferences and with other services/agencies as required.
- Timely referrals and intervention for people at risk of developing complications of MS.
- Promoting self-care for individuals to identify when they need to seek information or advice.
- Work across primary, secondary and tertiary care to reduce emergency admissions, length of stay and the need for GP and neurologist follow-ups

## Pregnancy and MS

**Sarah has MS and had just found out she was pregnant. Sarah was worried the pregnancy may make the MS worse and worried about how she will cope once the baby is born.**

The MS nurse was able to reassure and advise Sarah, liaise with the midwife and provide continuity of care throughout the pregnancy and beyond giving practical advice on management of MS symptoms such as increased fatigue, bladder issues and reduced mobility that may also be present in normal pregnancy and exacerbated for the lady with MS. By supporting the mother and family through the pregnancy and during the post natal period the MS Nurse reduces the impact on GP and midwifery services, which mums with MS who are unsupported, may require.

## Complications of MS

People with more severe MS can develop significant problems with swallowing which if untreated can quickly lead to lengthy and frequent hospital admissions due to aspiration pneumonia. MS nurses monitor patients each time they see them for any difficulties with swallowing and if an individual is thought to be experiencing problems the MS nurse will refer them in a timely manner for specialised assessment and ultimately for an insertion of a percutaneous gastrostomy tube (PEG) to reduce the risk of aspiration pneumonia and improve their quality of life and nutritional status.

### Domain Outcome

Patients achieve healthcare benefits that meet their individual needs through their healthcare decisions and services based on what assessed research evidence has shown provides effective clinical outcomes

## Domain Two: Clinical Effectiveness

The MS specialist nurse achieves this by:

- Delivering a patient-centred, flexible and responsive service which provides specialist knowledge and support for people affected by MS
- Working with patients and carers to empower them to manage their own condition and promote health e.g. via provision of educational courses for people newly diagnosed with MS
- Providing specialist information and advice regarding symptom management based on National guidelines, best practice and the available evidence base
- Providing information and advice regarding treatments in MS to people affected by MS and other health professionals
- Working across acute trusts and the community offering Nurse led clinics, home visits and telephone support ensuring a responsive, patient centred service
- Dissemination of best practice between MS nurses and other health and social care professionals is facilitated via various publications and attendance/presentation at national forums and conferences
- Raising awareness of MS in the community

### MS Nurses and Disease modifying Therapies – promoting cost-effectiveness and reducing complications

Disease Modifying Therapies (DMTs) are effective in approximately 15% of total MS population in reducing the number, duration and severity of MS relapses. They are all administered via self-injection and can each cause significant side effects that without effective management strategies can affect concordance and impact on an individual's day-to-day living. The DMTs are costly drugs averaging £800 per month per person. Once an individual has been prescribed a DMT the MS Nurse educates, trains and supports the individual and their partner in treatment expectations, administering the injections and management of the side effects. This promotes concordance to therapy and ultimately ensures cost effectiveness.

#### MESSAGE LEFT ON MS NURSE ANSWERPHONE

“Richard just to update you on my injections, last few have been a bit weird. Wanted quick chat, with you, I don't know if I'm going too far or too deep into the muscle? The muscles are bubbling away. I don't know if its spasms? Its quite painful and staying sore. The other day I did my arm and its still tender and sore to touch. I wanted to run it by you, other than that its going brill, Is this normal? ”

### Example of how MS nurses generate income via activity

- + An MS Specialist Nurse clinic run weekly and supports a template for 8 MS follow up slots of 30 minutes each.
- + Each follow up slot at an average local tariff generates £80 for the Trust, Estimating 44 clinics over a 12 month period with an average of 7 patients attending per clinic gives a total gross income of £24,640 pa.
- + Deducting average costs for clinic overheads during a 12-month period of £5000 gives a net income of £19,640 pa

### Cost Effectiveness:

The MS specialist nurse achieves this by:

- Generating income for the local Trust via clinical activity that is centrally recorded and invoiced via local tariffs (See Box)
- Home Visits and telephone clinics can also generate income if correctly coded at local level and included in service level agreements with commissioners

#### MS SPECIALIST NURSES SAVE MONEY AS THEY:

- Reduce the number of follow up appointments by neurologists thus increasing their capacity to see new patients
- Reduce the need for GP appointments in people with MS
- Reduce emergency admissions and length of stay
- Improve concordance and adherence

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### Example of an MS nurse's activity in 4wk period

- + 96% required direct contact
- + 64% contacts made by phone requiring advice, support, reassurance
- + 32% required visits by Ms nurse
- + **MS Nurse avoided**
- + 19 GP visits,
- + 14 consultant appointments
- + 9 outpatient appointments
- + 4 non-elective hospital admissions

**MS Specialist Nurse ensure people with MS receive consistent, high quality care and contribute to the cost effectiveness use of NHS resources**

### Domain Outcome

Managerial and clinical leadership and accountability, as well as the organisations systems and working practices ensure quality assurance; quality improvement and patient safety are central components of all the activities of the health care organisation.

## Domain Three: Clinical Governance

MS specialist nurses achieve this by

- Facilitating delivery of best-practice by applying and disseminating national protocols, procedures and pathways
- Assessing, planning, prescribing and implementing care that responds to the variability of MS symptoms and their management
- Using audit to benchmark current service provision against local and national standards and implement service developments as indicated
- Undertaking research to enhance MSSN practice and facilitating the evidence based care of people with MS
- Disseminating evidence-based practice with other MS Nurses and health professionals
- Facilitating implementation of national targets such as the NICE guidelines for management of MS in primary and secondary care (2003), NSF for long term conditions (2005), Our Health, Our Care, Our Say (2006)

### Example of Patient and Public Involvement work by MS nurses

**An audit of MS services against the quality requirements of the NSF for long-term conditions showed that information giving was poor. It was proposed that a website giving information of local services be set up.**

An information grant from the MS Society to set up the website and then worked with volunteers from the MS Society was obtained to canvass the opinion of local service users regarding the content and structure of the web site. The MS Nurse also consulted the members of the Greater Manchester MS Special Interest Group to ensure the website also met the needs of professionals working with people affected by MS.

### Example NSF

#### NICE GUIDELINES

- + Recommend a named person with clinical expertise who is able to respond to any inquiry on clinical problems and to guide the person to the most appropriate local service.
- + The person should have contact with someone with specialist knowledge of MS and be offered written information about disease and support organisations including rehabilitation services.

#### NSF QUALITY REQUIREMENTS LONG TERM CONDITIONS

- + A person centred service
- + Early recognition, prompt diagnosis and treatment
- + Early and specialist rehabilitation
- + Supporting family and carers

#### OUR HEALTH, OUR CARE, OUR SAY

- + Patients want a timely service according to their needs at a time they need it
- + Provide the bridge between healthcare in primary and secondary care

**“It is very helpful to have a direct contact, to be taken seriously, at a time I need it rather than a 6 month appointment, I know I can have access to the Consultant whenever the need arises but I can always get hold of the MS nurse if I am having any problems”**

Ann 32yrs

## Domain Four: Patient Focus

### Domain Outcome

Healthcare is provided in partnership with patients, their carers and relatives respecting their diverse needs, preferences and choices in partnership with other organisations whose services impact on well-being

MS specialist nurses achieve this by

- Providing patient-centred care to promote self management.
- Working in partnership with people affected by MS to offer a flexible and responsive service, delivering care in the most appropriate way for each individual via Nurse-led clinics; home visits and telephone help lines
- Enabling patients to understand the variability of their particular symptoms and how to manage them appropriately without necessarily requiring the input of a health professional
- Develop, promote and provide courses and educational opportunities for people affected by MS at all stages of the disease to facilitate understanding and self-management
- Liaising with MS charities at local, regional and at national levels to aid service user feed back and support service user involvement in the development of local services
- Involve patients and service users to promote innovative practice

**“ Meeting other people on the newly diagnosed course helped me to adjust to living with MS and the support the MS nurse gave me at the time of diagnosis was invaluable ”**

Jodie 36

**“ Being part of the User Group is great – the MS nurse really listens to what we think and involves us in any changes that happen in the service – I’ve met some really great people there too? ”**

Martin 49

**“ I was diagnosed in 1991, but didn't have access to a MS specialist nurse until 2001. I can't emphasise enough the incredible difference she has made to my care and general well - being. She is always at the other end of the phone for support /advice - my GP admits she knows a lot more about MS than he does! She has arranged extra clinic appointments when necessary and acted as a 'go-between' with neurologists, occupational therapists and physiotherapists ”**

Sharon 45yrs

**VARIOUS COURSES ARE OFFERED TO PEOPLE AND THEIR PARTNERS THROUGHOUT MANY STAGES OF THEIR MS, SUCH AS, COURSES FOR PEOPLE NEWLY DIAGNOSED, SYMPTOM MANAGEMENT, FATIGUE, HEALTHY LIFESTYLES, NUTRITION, COGNITIVE AND MEMORY, ALL WITH AN AIM TO ASSIST INDIVIDUALS TO BECOME COMPETENT IN SELF-CARE MANAGEMENT.**

### Domain Outcome

Patients receive services as promptly as possible, have choice in access to services and treatments and do not experience unnecessary delay at any stage of service delivery or of the care pathway

## Domain Five: Accessible and Responsive Care

MS specialist nurses achieve this by:

- Being the primary point of contact for people affected by MS and being responsive to their ever changing needs or symptoms of MS
- Bridging the gap across organisational boundaries between acute trusts and the community, offering both nurse-led clinics and home visits to meet patients varying needs
- Providing verbal and written information for people affected by MS and health professionals as required
- Providing continuity of care -patients are never discharged, they always have access to the service throughout the continuum of the disease and its unpredictable changes
- Working across the service trajectory to reduce emergency admissions and length of stay in hospital
- Operating telephone advice lines which reduce appointments with GPs and neurologists, e.g. directing people with relapse to appropriate services as they need it
- Undertaking timely referrals to other members of the multi-disciplinary team when required

“ Before the MS nurse started I had 5 minutes with the Neurologist – or one of his Juniors- every year – now I see the MS nurse whenever I need to or know that if I have a relapse – or any other problems - I can pick up the phone and she will sort me out – that means an awful lot more peace of mind ”

Phil 28yrs

### Example of Relapse clinic

**John contacted the MS specialist nurse on Monday reporting that four days ago he had started with blurred vision in the left eye which had now become double vision; he had no strength in his left leg and was finding it difficult to walk; he also felt exhausted, had not gone into work and could not drive. Normally John was independent, able to walk without any difficulty and went to the gym 3 times per week.**

Following some questions by the MS nurse to establish that there were no signs of infection and symptoms were not improving spontaneously she arranged for him to come to relapse clinic on Wednesday. John was assessed by the MS nurse, neurologist and therapists whom confirmed he was having a relapse of MS and arranged for him to have a course of high dose methyl prednisolone. The MS nurse reviewed John 6 weeks later and found that he had responded well to the steroids and was making a good recovery: planning to return to the gym in the next couple of weeks, had been able to drive again within a week of finishing the medication and had returned to work within 3 weeks of his treatment.

The telephone help line service gives advice regarding symptom management and relapse; supports concordance of DMTs; facilitates effective titration of medication; allows timely referral to other members of the multi-disciplinary team and ensures that people with MS and their families can access psycho-social support as required.

Hi it's Nicola. When you get a chance ring me. I'm struggling at the mo and its getting worse. I feel like someone has separated my head from my body. I feel like I've got cotton wool in my head and cannot concentrate. Is this normal? My back is aching, feet and legs feel fizzy. I'm scared I've had to take a day off work so if you could ring me at home please; I need to speak to you.

MESSAGE LEFT ON MS NURSE ANSWER PHONE

## Domain Six: Care Environment and Amenities

MS specialist nurses achieve this by:

- Offering care in a variety of different environments appropriate to individual patient need across primary, secondary and tertiary care
- Ensuring implementation of local and national guidelines for hygiene and infection control

“ The MS Nurse was able to direct me to services for respite for my wife that made a difference to my life and my family's ability to cope with advancing disability.

It made such a difference being able to see the MS nurse at home, I didn't feel pressured like I do sometimes in the clinic and we were able to have a really good chat and sort everything out ”

George 70 yrs

“ A vital part of my MS treatment is just knowing that the MS nurse is available – this creates security of mind and allows patients to have control over their own care ”

Sandra 56yrs

### Typical environments MS nurse will make contact with patient

- + Outpatients
- + Wards
- + Home
- + Community Hospital
- + Nursing Homes
- + GP Practices
- + MS support centres
- + Community rehabilitation centres
- + Voluntary sector meetings
- + MS society meetings

### Domain Outcome

Programmes and services are designed and delivered in collaboration with all relevant organisations and communities to promote, protect and improve the health of the population served and reduce health inequalities between different population groups and areas

## Domain Seven: Public Health

MS specialist nurses achieve this by:

- Advising and supporting people with MS in accessing public health programmes e.g. vaccinations, cervical smears etc.
- Advising people with MS about public health issues e.g. stopping smoking, weight management etc.
- Liaising with other health care professionals about managing health problems beyond the scope of the MS nurse
- Ensuring the culture and diversity of individuals is addressed sensitively and appropriately

**Language can be a barrier when working with people whose first language is not English and interpreters are used whenever required to facilitate a thorough and sensitive assessment and to enable psychosocial needs of the service users to be met.**

**MS nurses provide advice about following a healthy lifestyle and encourage MS patients to attend preventative health screens such as flu vaccination, smear testing, mammograms, prostate cancer testing etc in addition to stopping smoking, reducing alcohol intake and following a healthy diet and appropriate exercise regime.**

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#### Acknowledgement

Nicki Abel, Vicki Matthews, Diane Watts  
MS Trust  
MS Society

Support by **UKMSSNA**

