

# DEVELOPING INTEGRATED HEALTH AND SOCIAL CARE SERVICES FOR LONG-TERM CONDITIONS



Report from a symposium examining the interface between Community Matrons and specialist nurses for Parkinson's disease and Multiple Sclerosis

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# 1. Introduction

Community matrons are central to the Government's strategy on the management of long-term conditions, but this is a new role and there has been concern and confusion among nurses, especially concerning interaction with specialist nurses. The aim of this symposium was to debate the roles of the community matron and specialist nurse in the management of long-term neurological conditions such as Parkinson's Disease (PD) and multiple sclerosis (MS). These discussions would then help to formulate a joint strategy on policy for discussion between the Department of Health England, the Royal College of Nursing, The Multiple Sclerosis Society and the Parkinson's Disease Society of the United Kingdom.

*“My nurse is a brilliant source of help, for information, referrals, directing me to support. Just knowing she's there on the end of the phone, if need be is reassurance. It helps me cope from day to day”* Nigel Hudson with reference to his PD Nurse Specialist



## 2. Setting the scene

### Creating an integrated approach to care

Dr David Colin Thomé

National Director for Primary Care, Department of Health

Long-term conditions affect the lives of the one in three people - or six in 10 adults - in England, but this burden of illness is particularly severe among older people, affecting two - thirds of those aged over 75 (2.64 million people), 45 percent of whom have more than one long-term condition. Long-term conditions also have a significant impact on the National Health Service (NHS) (General Household Survey 2002), accounting for:

- 80 percent of consultations with general practitioners (GPs)
- 40 percent of outpatient activity
- 80 percent of hospital in-patient bed days.

Long-term conditions clearly represent a pressing challenge for the NHS, but the problem is growing due to increasing obesity, more sedentary lifestyles, and an ageing population (by 2030 the number of people aged over 65 will have more than doubled). As the World Health Organisation noted in 2002 (WHO 2002):

'[This trend] places new long-term demands on health care systems. Not only will chronic conditions be the leading cause of disability throughout the world by 2020; if not successfully managed they will become the most expensive problems faced by our health care system.'

#### **A key priority**

The management of long-term conditions is now a key Department of Health priority and HM Treasury public service agreement (PSA) target. The aim is to improve health outcomes for people with long-term conditions by offering a personalised care plan for vulnerable people most at risk; and to reduce emergency bed days by 5 percent by 2008 through improved care in primary care and community settings for people with long-term conditions (Department of Health 2005[a]).

These aims will be achieved through a new model of care that aims to empower and inform patients, and to create prepared and proactive health and social care teams. The process of change is beginning in the infrastructure of health and social care, where decision support tools and clinical information systems are being used to support the care-delivery system. Case management and disease management is central, but supported self-care and the promotion of better public health are also key contributors to the delivery of care.

Crucially, the intention is to match care to need. Case management will be directed towards the 5 percent of people with multiple - comorbidities, who currently account for 42 percent of hospital bed days. People who are less vulnerable but who are still at risk, will be cared for through a disease-management approach, while stable patients will be encouraged to manage their own care through approaches such as the Expert Patient Programme. Finally, public health promotion will be used to help to maintain the health of the general population.

This changing approach is a key part of Government policy on health and social care, which emphasises choice and a move towards a patient-led NHS (Department of Health 2004; Department of Health 2005[b]). Similarly, the need to tackle health inequalities is central to policy (Department of Health 2006), and in this context, personal health services have a major role in promoting equality. This is because these services have a relatively greater impact on severity than on incidence, and inequities in the severity of health problems are even greater than inequities in the incidence of health problems.

## Case management

There are special problems in delivering personal health services for people with long-term conditions:

- 50 percent of people have not been informed about their treatment options
- 25 percent do not have a care plan
- 50 percent do not have a self-care plan
- 50 percent of medicines are not taken as intended.

Many factors contribute to these deficiencies, but lack of co-ordination between health and social care professionals - and within primary, secondary and tertiary healthcare - is a major factor.

Case management represents a solution because it enables the identification of patients with the most complex problems in order to provide proactive care to those with the highest burden of disease. The aim should be to seamlessly manage the patient's journey through all parts of the health and social care system, and the care plan for each patient will therefore be co-ordinated by a community matron, who will use case management techniques to reduce unplanned hospital admissions caused by poor disease control and lack of effective prevention and support.

As professional case managers, community matrons will work across boundaries and in collaboration with social services and secondary health care. Community matrons will be nurses because they will be undertaking a challenging role that requires a combination of clinical and case management skills in order to plan, manage and coordinate the care of people with complex long-term conditions and high-intensity needs who live in their own homes and communities.

## References

- Department of Health. Choosing health: making healthy choices easier. London: Department of Health 2004
- [a] Department of Health. Supporting people with long-term conditions: an NHS and social care model to support local innovation and integration. London: Department of Health 2005
- [b] Department of Health. Creating a patient-led NHS: delivering the NHS Improvement Plan. London: Department of Health 2005
- Department of Health. Tackling Health Inequalities: Status report on the programme for Action August 2005  
<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/HealthInequalities/fs/en> (accessed 1 February 2006)
- Office for National Statistics. General Household Survey 2002 ONS London
- World Health Organisation Fifty-fifth World Health Assembly 18th May 2002 WHA55.23 Agenda item13.11 Diet, physical activity and health WHO Geneva

### 3. Models of care

## Community matrons: the context of development

Sally Bassett  
Nursing Advisor, Department of Health

The demographic revolution has been a key influence on the development of the concept of community matrons. People born during the 'baby boom' of the late 1940s and the early 1960s are beginning to approach late middle age, when they are increasingly vulnerable to the risk of long-term conditions. While the current generation of elderly people tend to be accepting of or grateful for care, the baby boomers will have higher expectations and will not tolerate current health and social care services. At the same time, however, the decline in births in the 1980s means that there will be fewer younger people to care for them. Furthermore, these young people have been taught to be consumers and are likely to be attracted by higher salaries in areas of employment outside health and social services.



*“Flexible collaboration between community matrons and specialist nurses will clearly be essential”* Sally Bassett

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#### Community matrons

Health and social care services will begin to feel the impact of these demographic trends in five to 15 years' time. This explains the urgent need to change from a reactive to a proactive model of care delivery, as outlined in the Department of Health and PSA targets for 2008 (Department of Health 2005). Nurses will make a significant contribution to reshaping the NHS since, irrespective of their job description or place of employment, one of their most constants is their role in developing programmes of care.

Policy makers have learned the lessons of the past, and the new competencies management framework is intended to establish national standards of practice while clearly distinguishing between community matrons and case managers. All components of the framework are also designed to be evidenced based and consistent with NHS practice. The competencies management framework is divided into domains, including an Advanced Nursing Practice domain that is crucial to protect the general public and vulnerable patients.

Community matrons will be leaders within the new service environment, and workshop discussions with nurses have identified several key components of their role, including the ability to:

- Influence strategy
- Work collaboratively
- Negotiate with a high degree of political astuteness
- Build partnerships with providers and users of services.

Flexible collaboration between community matrons and specialist nurses will clearly be essential; for example, the management of people with more than one long-term condition is always difficult and will become more challenging as the NHS workforce shrinks in size. In such circumstances in highly complex patient care situations it may well be appropriate for the specialist nurse to step back, acting as a consultant to the community matron who manages the care plan.

## References

Department of Health. Supporting people with Long Term Conditions. Liberating the talents of nurses who care for people with long term conditions. London Department of Health 2005

Department of Health How a Community Matron can help you with your long term conditions London Department of Health 2006

# Perspective: the community matron

Helen Lyndon, Lead Community Matron, Cornwall Health Community

The Eldercare Project in Cornwall (EPIC) began in 2004, and has employed community matrons to proactively manage the health of older people who have one or more long-term conditions and a history of repeated, unplanned admissions to hospital. On first-year evaluation, EPIC has been assessed as being very successful, and the scheme will cover the entire county by 2007.

As Lead Community Matron for EPIC, I am involved with three primary care trusts (PCTs) and with 12 community matrons. The role of community matron has developed rapidly, but the core objectives have always been to:

- Improve quality of life for patients and carers
- Co-ordinate care
- Strengthen interfaces of care
- Reduce unplanned hospital admissions
- Minimise time in hospital
- Review medication and improve the quality of prescribing.

All EPIC community matrons are very experienced hospital or community nurses. This is important because community matrons act as case managers - a demanding role that involves advocacy, education, advanced clinical skills, and the ability to act as an autonomous practitioner who is first point of contact and care coordinator.

The most common long-term conditions on an EPIC community matron's caseload include chronic obstructive pulmonary disease (COPD), falls, ischaemic heart disease, diabetes, heart failure, dementia, Parkinson's disease, stroke and hypertension. Specialist nurses work in all these areas in Cornwall, and it has therefore been essential for community nurses to work in close collaboration with specialists for each disease area.

There is clearly the potential for tension between generalists and specialists and confusion for patients, especially given problems with shared record keeping. However, if the patient is at the forefront of care at all times and there is clarity of roles and a good understanding on both sides, the interface between community matrons and specialist nurses is very positive. By sharing care and acting as a link between the patient's specialist nurse and general practice, community nurses have enabled specialist nurses to support more patients who need specialist input. In turn, specialist nurses have been involved in development of the EPIC service, by teaching on the community-matron training course and providing ongoing education and support.

The most frequent interventions by EPIC community matrons include medication review, coordination with other agencies or services, patient education, liaison with family carers, facilitation of hospital discharge, advocacy and improving inhaler technique (because of the large COPD population). My own experience of the role of community matron has made important differences to my practice. I now actively identify patients, spending time with the patient to identify early signs of deterioration. I also make direct referrals, coordinate discharge plans, act as first point of contact and take managed risks. The latter is clearly a challenge for me as a nurse, but it should be recognised that proactive case management may be challenge patients and an important role for community matrons is to reassure patients that they can be safely and successfully managed within the community.



*“By sharing care and acting as a link between the patients specialist nurse and general practice community nurses have enabled specialist nurses to support patients who need specialist input. In turn specialist nurses have been involved in teaching on the community matron course and providing ongoing education and support. Its good team work really!”* Helen Lyndon

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# Perspective: the Multiple Sclerosis Specialist Nurse

Bernie Porter

Multiple Sclerosis Nurse Consultant, Islington, London

Islington Primary Care Trust (PCT) is responsible for commissioning appropriate acute and mental health care services for the population of Islington, a borough in north London. The PCT employs 750 staff, including nurses, therapists, consultants and support staff, and manages eight health centres with a commitment to the delivery of equitable care across the borough.

There are 175-200 people with multiple sclerosis (MS) in Islington, and service delivery is shared between primary and secondary care, and social care teams. Lack of clear responsibility and the absence of co-ordination meant that it was a challenge for patients to access services, and when patients were in the system, the quality of services was extremely variable at all stages of the disease.

To remedy the problems identified the PCT is planning a long term modernisation strategy that will aim to provide an equitable responsible service for all people living with MS in Islington. The service currently under development will provide a single integrated patient focused pathway of care that will ensure that all patients are able to play an active role in making informed decisions about their care. In this area a clear role for an outreach MSSN to support community matrons in delivering care has been identified.

Any service delivery begins with information and support with a care plan based on the individuals needs. The aspirations of this new service are that, when established, it will enable the nurse to work closely with general practitioners and neurologists to ensure people with MS are supported at diagnosis to encourage them to develop skills in self management. Similarly the proposed outreach nurse will be an integral part of local community teams. This will ensure optimal rehabilitation, flexible services and packages of care to support people and enable them to live independently at home. Links with palliative care will aim to improve services in late stage disease, Nurses will then be able to provide support for family and carers and help to ensure appropriate medical care when people with MS are in hospital for the treatment of co morbidities.

Clearly this aspirational model for nurse involvement goes far beyond hands-on-advanced clinical practice and will require hard work, effort and commitment. However it is hoped that co-operation and joint working will enable Islington PCT to deliver the improvements envisaged and subsequently the Quality requirements outlined in the National Service Framework for Long-term conditions.

# Perspective: the Parkinson's disease nurse specialist

Alison Forbes

Parkinson's Disease Nurse Specialist, University Hospital Lewisham, London; Chair, Parkinson Disease Nurse Specialist Association

The Parkinson's disease nurse specialist (PDNS)'s role is defined by skilled communication, patient and carer assessment, medicines management, the ability to provide patients with ongoing support and advice, referral to other specialists and education (PDS 2005). Parkinson's disease (PD) is generally described in four stages - diagnosis, maintenance, complex and palliative - which do not represent distinct phases but a continuum of care needs. PD nurse specialists (PDNS) aim to provide continuity of care based on the right service for the individual patient throughout the time course of the disease.

There are, however, likely to be particular needs at each stage of the disease. For example, at diagnosis the PDNS will help patients to accept the diagnosis, reducing distress and controlling symptoms. During the maintenance phase, the PDNS can support patients in gaining a realistic expectation of or accommodation with PD, helping them to maintain their health, preventing complications and providing education and support. As PD progresses and management becomes more complex, the PDNS will oversee drug treatment, encourage concordance with medication, where appropriate refer patients for specialist treatments such as surgery or apomorphine infusion, and - most importantly - act as an advocate for patients and support for their family carers. Finally, in the final, palliative stage of the illness, the PDNS will manage withdrawal of drugs, prevent complications, and continue to support patients and their families.

PD is a complex and incurable condition, but its effects can be mitigated through effective management and timely intervention. This can only be achieved through liaison between patients, doctors and other health professionals. 'Exactly what a PDNS can bring about.' (Bell 2004)

## References

Parkinson's Disease Society UK, Parkinson's Disease Nurse Specialist Association, Royal College of Nursing. Competencies: an integrated career and competency framework for nurses working in Parkinson's disease management Parkinson's disease Society 2005  
Bell, L. Changing roles. Parkinson's Disease Society UK London 2004

## 4. The patient's perspective

### The experiences of four people with long-term neurological conditions

Sheila Harvey George, Nigel Hudson, Sheila Bayram, Moira Pedroz

Patients believe that support from specialist nurses is particularly important because generalist community health professionals usually have little knowledge or awareness of the complexities of managing a long-term neurological condition. At present it can also be extremely difficult to access services quickly - for example, an appointment with a neurologist must be made six to 12 months in advance - and out-of-hours services are variable in capacity and quality.

As a result, patients in the community can feel extremely isolated and specialist nurses are generally highly valued; for example, the ability to call the nurse's mobile telephone is a source of reassurance, as is the nurse's capacity to act as an advocate for patients and a supporter for carers. Patients recognise that early intervention by a nurse can help to maintain wellbeing and independence, but nurses also make an important contribution simply by listening to patient's concerns.

However, the high turnover of nursing staff and specialist nurses' heavy workload mean that there is on occasion some confusion in follow-up, and there is certainly a role for the community matron in promoting continuity and co-ordination of health and social care services. A unified database would be a major contribution to achieving these objectives, but there was some concern about patient confidentiality in a system where a number of professionals have access to patient records.

All too often, patients are simply told that they have a chronic degenerative neurological condition and are left to learn about the implications without input from a professional. The Expert Patient Programme is a valuable experience for some patients, providing practical information, support and problem-solving skills. However, the Programme is not the solution for everyone, and all patients need information and education as soon as they receive their diagnosis. Involvement in patient organisations has been extremely rewarding for some patients, but patients agree that timely education and information offered by a specialist nurse is critical in improving the patient's journey.

## 5. What does the evidence tell us?

### The evidence from PD specialist nursing

Jacqui Handley

Parkinson's disease nurse specialist, Dorset County Hospital Dorchester.

Parkinson's Disease Nurse Specialist (PDNS) have a multifaceted role and, as with many other nursing roles, extensive trials have not been undertaken to examine all of these distinct elements. There are, however, three major randomised studies that have examined the effects of involving the PDNS in the delivery of care (Jahanshahi et al 1994; Jarman et al 2002; Reynolds et al 2000).

In these studies, there was limited evidence of improvement in direct measures of outcome, but this is unlikely in patients with a degenerative disease such as Parkinson's. Most of the reported benefits relate to the overall patient experience of the delivery of services, including the monitoring of medication and the provision of information. Specifically, the presence of a PDNS, enabled more rapid implementation of good prescribing practice and cost neutrality to achieve this. This evidence has been sufficient for National Institute of Health and Clinical Excellence Guidelines in Parkinson's disease (NICE 2006) to recommend that people with PD should have regular access to a PDNS for monitoring and altering medication appropriately, providing a continuing point of contact for support including home visits and as a reliable source of information about clinical and social matters of concern to people with PD and their carers.

There is also evidence of the potential cost effectiveness of a PDNS service. For example a descriptive economic analysis of a PDNS service at one year (Hobson et al 2003) found that the estimated cost saving of employing a PDNS was £54,992, which included £8,296 potentially saved by community visits and £1,203 by inpatient visits. There is, however, more than financial benefit, since the PDNS can address the unmet need that still continues in the community, where patients still do not receive regular review or essential services such as physiotherapy, occupational therapy and speech and language therapy (Mutch et al 1986).

#### References

- Jahanshahi M, Brown RG, Whitehouse C, Quinn N, Marsden CD. Contact with a nurse practitioner: A short-term evaluation study in Parkinson's disease and dystonia. *Behavioural Neurology* 1994; 7:189-96
- Jarman B, Hurwitz B, Cook A, et al. Effects of community based nurses specialising in Parkinson's disease on health outcome and costs: randomised controlled trial. *BMJ* 2002; 324: 1072-5
- Reynolds H, Wilson-Barnett J, Richardson G. Evaluation of the role of the Parkinson's disease nurse specialist. *Int J Nurs Stud* 2000; 37: 337-49
- Hobson P, Roberts S, Meara J The economic value of a Parkinson's disease nurse specialist service. *Health and Ageing* (3) ii-iii 2003
- National Institute for Health and Clinical Excellence Clinical Guidelines Parkinson's disease: diagnosis, management and treatment of adults with Parkinson's disease in primary and secondary care. 2nd Consultation 2006 NICE London
- Mutch WJ, Dingwall-Fordyce I, Downie AW, Paterson JG, Roy SK Parkinson's disease in a Scottish City *BMJ* 1986; 296:534-6

# The evidence from MS specialist nursing

Professor Alison While & Dr Angus Forbes

The Florence Nightingale School of Nursing and Midwifery, King's College, London

There have been no randomised controlled trials assessing MS specialist nursing. However, a systematic literature review of all English-language published literature (Forbes et al 2003) concluded that the various dimension of the Multiple Sclerosis Nurse Specialist's (MSSN's) role fitted well with patient needs and published guidelines - conclusions echoed by the results of a survey of a representative sample of MS patients carried out in 2002.

A recently prospective published study (Forbes et al 2006) has added to the evidence by evaluating the impact in general neurology and rehabilitation centres of a MS Society-funded nurse programme. This quasi-experimental questionnaire study involved 1,510 patients and 470 carers at four intervention sites where MS nurse posts were introduced, and two control sites without MS nursing input. Data were collected prospectively at three time intervals: before the appointment of the MS nurse, and then at 12 and 24 months.

Role evaluation is always difficult, especially in this kind of complex study where there were different levels of MSSN contact at the various sites. There are also no data on cost-effectiveness, since the study did not include an economic analysis. However, at the intervention sites, the quality of patient information was consistently higher, there was improved contact between patients and professionals, patients were more likely to be able to get help in an emergency, and the risk of pressure sores was significantly reduced. Furthermore, the MSSNs seem to have acted as catalysts in improving services, with intervention sites improving by 20 percent in the first 12 months and a further 10 percent in the second 12 months of follow-up compared to an overall 4 percent improvement in the control sites.

This study attempted to describe how MSSNs contribute to the wider complex of care, and confirms that these specialist nurses have a multifaceted role that has the potential to achieve multiple improved outcomes.

## References

- 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: 442-62
- Forbes A, While AI, Mathes L, Griffiths P. Evaluation of a MS Specialist Nurse Programme. *Int J Nurs Stud* 2006 Jan 10 [epub ahead of print]

## 6. Commissioning and service development

### The PDNS/MSSN perspective

Beverley Hopcutt

Therapy Services Manager, Central Manchester Primary Care Trust

The introduction of a patient-led NHS with practice-based commissioning means that community matrons and specialist nurses will be competing with other health professionals and must influence general practitioners and other primary healthcare professionals to commission services for patients with long-term neurological conditions.

The first step is to identify how services will help commissioners to meet Government targets - for example, by freeing up specialist neurology capacity, specialist nurses can help to reduce emergency bed days and the 18-week maximum interval between referral and treatment. Equally, specialist nurses can help commissioners to meet targets in implementing care standards in NICE guidelines and National Service Framework milestones.

The value of community nursing services is well known to the new commissioners because these nurses work closely with primary-care services. In contrast, general practitioners are unfamiliar with the contribution of specialist nurses, since many are based in secondary or tertiary care. Specialist nurses must therefore raise their profile; for example, by developing links with community nurses in order to take specialist services into primary care.

Specialist nursing services cost money, but commissioners will buy services if they are convinced that they are an investment that will save money in the long term. Furthermore, under payment by results provisions, there will be a financial incentive for PCTs if they can demonstrate a shift of activity from acute trusts to the community. For example, following discharge from hospital, a PDNS follow-up appointment in the community rather than an appointment with a neurologist or geriatrician at a hospital clinic would generate savings of £80-£100. Similarly, intervention by a specialist nurse to reduce length of stay in hospital would release cash to the PCT. Such financial information would be all the more compelling if disease prevalence statistics are used to demonstrate to GPs how specialist nurses can reduce general practice workload - for example, by making home visits to patients with long-term neurological conditions.

PDNS and MSSN will need to market their services if they are to attract the new commissioners. This will involve a willingness to contemplate new roles, such as those of a community matron for neurological conditions or a specialist nurse delivering care for several neurological conditions. In short, to convince PCTs of their value, specialist nurses must raise their profile in the new commissioning marketplace.

## 7. Next steps

The needs of patients with neurological conditions are complex, and community matrons promise to perform a valuable service for highly complex patients in ensuring each receives timely and appropriate care throughout the course of their condition.

To achieve this objective, community matrons and specialist nurses must work in close collaboration, each using their complementary skills to ensure the best outcomes for patients. Nurses have often acted as a catalyst for the introduction of new methods of working, and delegates had a clear conception of a service designed to address current deficiencies in provision and improve care for people with long-term neurological conditions.

The Department of Health's focus on long-term conditions provides the opportunity to make this service a reality, especially as the National Service Framework for Long-Term Conditions provides a template structure of a new professional workforce. At present, however, there are many areas of uncertainty and delegates identified important topics requiring clarification from the Department of Health.



“The Department of Health must make a statement that reinforces the valuable role of and need for disease specific specialist nurses as well as community matrons. Without this commissioners will not understand the importance of these distinctly different roles”

## Improving services for people with neurological diseases

Following a roundtable discussion, delegates concluded that the ideal service for people with neurological conditions is:

- *Equitable.* There must be equity of access and provision for people with all neurological conditions, especially those living in deprived areas where access to care has historically been sub-optimal.
- *Responsive and proactive.* In order to prevent a decline into greater disability, care must be provided at the level and at the time appropriate to each patient's needs. This might involve the identification and registration of vulnerable people within each district, since case finding is an essential component of the service. At the same time, however, the service must be open access, responding rapidly to patients' requests.
- *Personalised.* Care must be personalised, so that patients have access to appropriate health and social care throughout the course of their condition - beginning with diagnosis by a specialist and ending by referral to palliative care if appropriate. Care must also be tailored to the disease area, but the service must avoid assuming patient need based on a stereotype of the condition. Equally, the service must recognise the impact of a long-term condition on the lives of each patient's family carers or relatives.
- *Communicative.* At present all health professionals working in the community hold useful information about a disease area and specific patients. While preserving patient confidentiality, the service must include the opportunity to share information between professionals and patients, possibly through the introduction of secure electronic patient records and patient-held records.
- *Efficient.* It is essential to ensure the most effective use of resources and expertise. The aim must be to ensure that patients have rapid access to a specialist, and are not lost to the system after discharge, but are monitored to ensure that they receive timely intervention. For example, diagnosis, assessment and treatment plans might be provided at the specialist centre; if possible over the course of one to two days. Patients would then be discharged to the community to be managed by multidisciplinary teams that would include both specialist and generalist health professionals.
- *Evidence based.* The service must disseminate the latest evidence-based research and guidelines to ensure that all professionals follow best practice. In particular, generalist health professionals must be well trained so that they are able to make rapid and appropriate referrals to specialists.

## **Achieving the service**

In order to achieve this ideal, delegates agreed that it is essential to preserve the best features of the current service, including the excellent generalist care provided by many primary care professionals. Equally, the special skills, knowledge and expertise of the specialist nurse must be retained - for example, their role in educating not only patients but also fellow professionals to ensure competency in care. However, at a time of demographic change it will be necessary to examine the role of specialist nurses to ensure that they are able to make best use of their skills in ensuring equity of access.

It will then be important to define the areas of responsibility for the community matron, specialist nurse and social care worker in order to avoid overlap and confusion within the new service. A useful contribution to achieving this objective might be the appointment of a generic assessor - who could be a nurse, occupational therapist or physiotherapist - to act as the key coordinator and to network between colleagues so that patients can access specialist support as required.

Many delegates regarded commissioning arrangements as the main barriers to improving services, citing past experience in accessing or gaining authorisation for the care needed by patients. However, there was some optimism that the new focus on long-term conditions may offer the opportunity to improve the current 'Cinderella' status of neurological disease, since it will be more difficult for commissioners to avoid accountability to the large patient populations that will result from the merger of primary care trusts.

The new service will necessitate more frequent delivery of services in primary care, and delegates were concerned that the infrastructure required for a primary care-led service has not been sufficiently considered. For example, an out-of-hours triage service will be essential to ensure that care is delivered promptly to vulnerable patients. Furthermore, since specialist nurses based in primary care can easily become isolated, arrangements should be in place to ensure that they have regular access to the specialist centre for continuing education.

In general, the service must change from one that reacts to crises to a service that is proactive in addressing patients' needs for care; for example, by contacting patients within a short time of their diagnosis and in identifying vulnerable patients. To achieve this model, not only nurses but also other professionals must change their practice, and there must be an end to 'turf wars' that are a feature of current services. These objectives might be achieved through a multidisciplinary steering group accountable for delivering care to people with neurological conditions within a specific geographical area.

Such a group might also help to resolve problems arising from the current lack of joint working by community health and social services. Collaboration ought to be improved by the introduction of unified care budgets, but delegates emphasised that it will be crucial to ensure that social-service professionals are educated to improve their knowledge and awareness of the needs of people with neurological conditions.

Delegates considered that the service would benefit from greater collaboration with voluntary-sector organisations and user groups. For example, there may be a role for patient organisations in partnering local statutory services. While some patient organisations might welcome such involvement, it must be recognised that partnership would be daunting for others. Delegates also noted that there is a potential for some individual patients to be challenged by the new service, in particular by the possibility of loss of financial benefits if intervention reduces their disability.

### **Topics for clarification**

During group discussion, delegates identified a number of topics that will require clarification from the Department of Health:

- The definition of the complementary roles of specialist nurses and community matrons, possibly through a policy statement from the National Directors.
- Publication of the results of the Department of Health consultation on community matrons.
- Cost-benefit analysis of the specialist nurses' role in order to provide a benchmark for the Department of Health.
- How to achieve target numbers for specialist nurses during the introduction of a community-matron service.
- Arrangements to ensure that nurses are involved in the commissioning of services.
- How to use the Agenda for Change and Skills for Health to make clear to commissioners the distinction between the roles of general practitioners and nurses (whether specialist nurses or community matrons).
- How to resolve potential conflict between general practice targets and meeting the needs of people with long-term conditions.
- Recognition of the role of specialist nurses in ensuring that NICE guidelines are translated into clinical practice.
- Systems to ensure that community professionals can access the details of care plans; for example, through shared databases and IT systems, patient-held records and telecare.
- Education of social care professionals to ensure that they are aware of the needs of patients with neurological conditions.
- Arrangements to ensure that patients have out-of-hours access for specialist advice.
- Arrangements to ensure that patients are able to play an active role in decision making about their care.



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promotes excellence in practice and  
shapes health policies



**Parkinson's**  
Disease Society

Registered Office:  
**Parkinson's Disease Society of the United Kingdom**  
**215 Vauxhall Bridge Road**  
**London**  
**SW1V1EJ**  
**Tel: 0207 931 8080**  
[www.parkinsons.org.uk](http://www.parkinsons.org.uk)

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**Multiple Sclerosis Society**

**Multiple Sclerosis Society**  
**MS National Centre**  
**372 Edgware Road, Staples Corner**  
**London NW2 6ND**  
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