

Developing a palliative care service for people severely affected by MS

Multiple sclerosis (MS) is the most common disabling neurological disorder among young adults and around 85,000 people in the UK have MS. MS is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. It provides respite care, a freephone MS Helpline, grants for home adaptations and mobility aids, education and training, MS specialist nurses and a wide range of information. Local branches cater for people of all ages and interests and are run by people with direct experience of MS. The MS Society also funds over 40 vital MS research projects in the UK.

You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer

Contact information

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MS Society Wales
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Temple Court
Cathedral Road
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**National MS Helpline Freephone
0808 800 8000
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Multiple Sclerosis Society
www.mssociety.org.uk
Registered charity 207495

What is palliative care?

Palliative care is a service for people severely affected by advanced, progressive or life-threatening conditions. Its purpose is to maximise quality of life during the advanced stages of the condition. It takes a holistic approach and provides expertise in pain relief and symptom management. It also offers support for complex psychological and social issues to patients and families. All specialist palliative care services are carefully tailored to the needs of the individual. These services can be offered at home (including a care or nursing home), in hospitals and in hospices.

The **MS Society** identified that not enough had been done to look at the role specialist palliative care could play in the care of people severely affected by MS. As a result, the MS Society funded a three-year research project to develop and assess one model of specialist palliative care involvement in MS.

This innovative study included interviews with people with MS, carers and health care professionals. These interviews highlighted important issues which informed the development of the new palliative care service. This new service saw 69 people severely affected by MS over a two year period. The service was evaluated to see how the team worked, what benefits it delivered, and how its work stood up against a comparison group.

This has been the first study of its kind and it has delivered promising results that point the way to future research. It suggests people with MS may benefit from short-term specialist palliative care, but more work is needed to establish what models will work best for people with MS and their carers.

Background to the innovative study in South East London

In recent years, the MS Society has become increasingly aware that people more severely affected by MS have significant unmet needs. The Society therefore commissioned the Department of Palliative Care, Policy and Rehabilitation at King's College London in 2002 to develop and evaluate a new palliative care service for people severely affected by MS. This research project was a collaboration between palliative care and neurology professionals, and had three phases:

- Service design (or modelling)
- Establishing the service
- Evaluation of the service

Phase 1: Service Design

Starting in January 2003, background information was collected to inform the design of the clinical service, involving:

- Consultations with health care professionals and users, both people with MS and their informal carers
- Identification of current best practice
- Identification of appropriate quality of life or other outcome measures to use in the evaluation phase of the study

Forty semi-structured individual interviews were conducted with people with MS (23 interviews) and their informal carers (17 interviews); 12 individual interviews and four focus groups with health care professionals were also undertaken. The content of these interviews was analysed to identify main themes to inform subsequent service development.

The interviews with people with MS identified several important issues:

- A sense of having to fight for everything, particularly services,

adaptations and welfare benefits, linked closely to:

- A lack of coordination or continuity of care - the health care professionals involved seem to constantly change, which meant having to explain everything from first principles over and over again
- Difficulties in accessing appropriate information, particularly around end of life care for the minority of patients that wanted information on this
- Poor quality non-specialist care - non-specialist hospital staff seemed not to know very much about MS
- Concerns about losses and changes in their lives resulting from MS, especially relating to their independence, physical functioning and personal relationships.

The interviews with health care professionals identified issues around:

- Poor continuity of care and communication between professionals
- Limited resources or services
- Unequal provision of and access to services
- The unpredictability of MS
- Problems with cognition, bladder control and sexual function
- Particular needs around the end of a person's life

The priorities for phase two were therefore:

- The development of a new clinical service
- To undertake an education programme aimed at non-specialist professionals
- To promote information exchange between health and social care professionals

- To develop information resources for people severely affected by MS and their carers around advanced care planning
- To map existing services

Phase 2: Setting up the clinical service

The clinical team consisted of:



The clinical service aimed to:

- Provide a specialist palliative care assessment
- Bridge the specialties of neurology and palliative care services
- Enable crisis prevention
- Develop education and support to primary and secondary care
- Provide descriptors of good practice

Clinical Activity

Over the course of the study period, the service saw 95 patients, assessed by the referrer to be severely affected by their MS. An example of some of the work they undertook is given in *Box 1*.

Information Exchange

Alongside clinical assessments, the service undertook a comprehensive mapping exercise of services available to patients severely affected by MS in South East London (the six boroughs of Lambeth, Southwark, Lewisham, Bromley, Bexley and Greenwich).

Box 1: Mr XY

This 46 year old man with secondary progressive MS, who lived alone, was referred for symptom control and a specialist palliative care opinion by his district nurse. He had severe and constant nerve pain in both legs. Severe contractures of both legs made sleeping in his bed impossible. The palliative care service started him on a new pain killer for nerve pain (pregabalin) and his pain resolved. Special funding was applied for to buy a profiling bed so that he could sleep. Subsequently his swallow deteriorated and he was not keen to undergo insertion of a feeding tube, despite recurrent aspiration leading to a number of chest infections. He discussed these issues with the team. The speech and language, and dietetic teams gave advice and the patient decided against the feeding tube. With the team, he devised an advance directive explaining that he did not want artificial hydration or nutrition, and that he would like oral antibiotics for any chest infection but did not want admission to an acute hospital. He was referred on to his local community palliative care team who visited him regularly at home. He developed a bad chest infection which did not respond to antibiotics orally, so was admitted to his local hospice and despite a trial of intravenous antibiotics, he died peacefully in the hospice.

A Neurodegenerative Special Interest Group was established for professionals in Greenwich and Bexley.

Educational initiatives

A 'Palliative care for people with MS' education programme was undertaken and evaluated, delivering a programme accessible to health and social care professionals working with people with MS across South East London. Nine study half days were undertaken, covering:

- Palliative care for people with MS
- Common symptoms and how they are managed
- Issues around impaired cognition and competency
- Facilitating patient choice: Advanced Planning and End of Life care

The education programme was formally evaluated, with 182 out of 234 (77 per cent) participants describing each topic as quite or very useful.

Phase 3: Evaluation of the clinical service

The aim of the service evaluation was to:

1. Describe the activity, working patterns, nature of problems seen and dealt with and satisfaction of patients and their carers receiving the service
2. Identify which aspects of the service are most useful to patients, carers and healthcare professionals
3. Compare the experience of patients having received the service with a matched comparison group

In order to build a comparison group into the evaluation phase of the study, patients that were referred and consented to be part of the evaluation of the service were randomised to be seen by the service either as soon as possible (fast-track) or routinely after three months (standard intervention). Patients were excluded from the trial if: (1) they were recruited before the full service (with all staff) and trial commenced, and (2) they were considered as having urgent needs or refused participation.

Evaluation results

Sixty-nine people with MS were referred to the service during the study period (see Table 1).

All groups of patients were of a similar age (53 to 54 years), with 49 female and 20 male patients. The average year of diagnosis was 1987, with the range being from 1950 to 2005. There was no difference between those in study and those excluded from the study in most stated reasons for referral, including symptom control, psychosocial needs, and end of life planning. However, people with MS excluded from the study were more likely to have needs in terms of advance directives.

Only one person with MS had any contact with specialist palliative care prior to the study.

The demographics of the two study groups were equally matched in terms of age, sex, ethnicity, time from diagnosis, type of MS and disability, as measured using the United Kingdom Neurological Disability Score. There were no differences between the groups at the

time of the first interview in clinical problems or scores in the outcome questionnaires (Multiple Sclerosis Impact Scale, Palliative Outcome Scale (POS) and POS-MS-Symptoms).

Table 1:
Patients Referred During Study

52 included:

- 26 randomised to the Fast Track Intervention (FI) and 26 to the Standard Intervention (SI) group

17 excluded:

- 5 for clinical urgency
- 5 refused
- 4 were unable to consent
- 1 was withdrawn following a protocol violation
- 1 lived outside the study area
- 1 had no MS diagnosis

25 patients were seen before the trial and full service commenced and a clinical assessment undertaken

Four patients died during the study: three from the Standard Intervention group at 4, 16 and 22 weeks and one from the Fast Track Intervention group at 25 weeks.

Box 2: Study group overview

Key characteristics of the study group (52 people with MS) were:

- 26 had primary progressive MS,
- 23 had secondary progressive MS
- 48 used a wheelchair all or most of the time
- 44 reported problems with their legs, which were either severe or overwhelming for 75 per cent
- 39 had problems with arm function ranging from mild problems to no function
- Fatigue, lack of energy, sleepiness and spasms occurred in 75 per cent
- More than 50 per cent had pain
- 50 per cent had a permanent catheter fitted, or otherwise experienced daily incontinence
- Nearly half experienced constipation
- One in four had nausea

Analysis so far has concentrated on comparing the Standard Intervention (SI) and Fast Track Intervention (FI) groups at two time points: (1) 4-6 weeks, and (2) 3 months, after enrolment in the study.

- (1) After 4-6 weeks, people with MS in the FI group had a small but significant improvement in nausea compared to those in the SI group. In the FI group, people with MS were also more likely to have seen a paid carer more recently than those in the SI group.
- (2) By three months, the improvement in nausea amongst fast-track people with MS was maintained but was borderline significant. There was no difference in time since last seeing a paid carer between the groups. However, informal carers in the FI group reported lower suffering of health, less loss of control over their life and more reported that they had learned new skills than in the SI group.

Further analysis will be conducted following people with MS up to six months from their inclusion into the study, and will explore other differences between SI and FI groups. An additional exit survey with patients, carers and relevant health care professionals, which obtained their views on the service received, will be analysed

Outputs of the Study

Resource for Health and Social Care Professionals

This is a publication aimed at supporting care professionals managing people with advanced MS. It includes guidelines on how to manage symptoms and outlines trigger points for specialist palliative care involvement. It also signposts professionals to the resources to run education programmes locally, based on the education element of this project.

Advanced MS - how to get appropriate care now and plan for the future

This forms part of the MS Society's MS Essentials series. This publication includes:

- What is Palliative Care?
- Who is it for?
- Where to get it?
- What it helps you with?
- Common symptom issues
- Common legal issues (for example, decision-making, advance statements)

Service Directory

Information from the service mapping has been collected from:

- Primary care trusts
- Acute tertiary referral settings
- Statutory and voluntary organisations
- Neuro-rehabilitation, therapy and disability teams

This information has been shared with the South East London NHS Direct Information and Access project and has been collated into an electronic (web-based) and paper directory to provide a one stop reference of all services that might be appropriate for people with MS and their carers in South East London.

Implications of the Study

This is the first study to describe the needs of a population of people severely affected by MS.

Many people with MS have:

- Severe disability – specifically notable problems with upper and lower limb function
- Fatigue, lack of energy and sleepiness
- Other symptom issues such as spasms, pain, constipation and continence problems

The symptom burden is at least as severe as other groups of patients with advanced disease for whom palliative care is more widely available.

Involvement with the palliative care service appears to affect nausea and informal carer wellbeing but not other outcomes, although analysis is still continuing. This effect is strongest following the initial contact.

This study suggests that short term interventions from specialist palliative care may be beneficial for some patients but further work is required to determine the most appropriate model(s) of service delivery to best meet patients' and carers' needs.

A copy of the full project report, training resource, and the South East London Directory will be available via the MS Society website from May 2006 (www.mssociety.org.uk). For further information, please contact the service development team of the MS Society by email on servicedevelopment@mssociety.org.uk or call **020 8438 0742**.