The involvement of specialist palliative care in the care of people with motor neurone disease

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## **Introduction**

Motor neurone disease (MND) is a progressive disease with no known cure; death usually occurs within 5 years of the diagnosis. Since the opening of St Christopher’s Hospice in 1967 specialist palliative care services have been involved in the care of people with MND.1,2 However, the exact nature of the care provided to this patient group has been unclear. This study aims to provide further information on the care provided, the extent of collaboration with other services and the involvement with the Motor Neurone Disease Association (MNDA).

## **Method**

A questionnaire was sent to the 220 inpatient units providing specialist palliative care in the UK and Ireland, as listed by the Hospice Information Service at St Christopher’s Hospice. A further copy of the questionnaire was sent to nonresponders after 2 months.

## **Results**

The results are summarized in Tables 1 and 2.

The contact with other services that may be involved in the care of patients with MND was

limited – 14% with local disability services, 23% with neurology services and 36% with the MNDA Regional Care Adviser.

Half of the units (73, 45%) had referred patients with swallowing problems for consideration of the insertion of a percutaneous endoscopic gastrostomy (PEG), and 67 (41%) units had never referred a patient. The number of referrals within the past 2 years were one, 24 units; two, 30 units; three, seven units; four, four units; and five or more, eight units.

Nine units had referred a patient for consideration of noninvasive ventilation, one unit had referred two patients for noninvasive ventilation and three units had cared for tracheostomized patients on a ventilator.

**Discussion**

This study shows that the specialist palliative care involvement in the care of MND patients varies from unit to unit. Many hospices are involved only in the terminal stages of the disease or in providing respite care and later terminal care. A minority of hospices are more closely involved in the care from early in the disease process, and on occasions from the time of diagnosis. As the progression of the disease is a series of losses this involvement in the early stages can be advantageous, as there is the opportunity for easier communication with the patient and for a clearer understanding of the patients’ views on their care.3,4

The involvement of the wider multidisciplinary team also varies from hospice to hospice. There would appear to be a wide acceptance of the need for nursing, medical, physiotherapy and occupational therapy involvement but other specialist involvement is less common. As many of these patients will have speech and swallowing difficulties the lack of speech and language therapy input is surprising. There also appears to be varying collaboration with other agencies, especially the MNDA and neurology services. If we aim to provide comprehensive care for these patients it is important to ensure the close collaboration with all services and expertise, as has been shown in previous studies.3,5,6

Although only a minority of hospices described involvement with a speech and language therapist, many were referring patients for consideration of a PEG. It would seem that the decision to refer was made on a medical or nursing assessment only, rather than a more specialized assessment by a speech and language therapist, although this may be more accurate. The expertise of a speech and language therapist may help in the management of swallowing problems before and after insertion of the gastrostomy. A small minority of hospices had referred or been involved in the care of a patient on ventilation.

This study has shown that many hospices are involved in the care of patients with MND. The extent of their involvement varies and it is hoped that there can now be a sharing of information and expertise so that the care of patients with MND can be developed throughout the country. Moreover, there is a need to develop collaborative relationships with other disciplines and services, in particular the MNDA, so that the care of patients can be provided in a co-ordinated way, in response to and involving patients and their families in the decisions of care.

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**Table 1** Results of questionnaire sent to inpatient units providing specialist palliative care

N %

Units mailed 229

**Units responding** 170 77%

2-15 beds 95/145 62%

18-30 beds 66/72 88%

31+ beds 9/12 75%

**Care for MND patients** 163

Inpatient care 163 100%

Care at home 100 61%

Day hospice 125 76%

In Hospital 47 28%

**Care provided**

Symptom control 150 92%

Respite 149 91%

Terminal stages 138 84%

**Involvement in care**

At diagnosis 28 17%

After 6 months 36 22%

After 12 months 56 34%

Terminal stages 79 48%

**Table 2** Professionals involved in specialist care

Home care Day hospice

n=120 n =125

Specialist nurse 84% 91%

Doctor 75% 94%

Physiotherapist 64% 93%

Occupational therapist 49% 75%

Speech and language therapist 25% 21%

Dietitian 21% Not specified