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## Palliative terminal care

Palliative care can be defined as the 'active total care of patients whose disease is not responsive to curative treatment'.<sup>1</sup> General practitioners (GPs) have a pivotal role in the delivery of palliative care. Most patients with any advanced disease are under their GP's care during most of their illness. More deaths from advanced cancer occur under the care of GPs (home, community hospitals, nursing homes (51-73%)) than in hospices and acute hospitals.<sup>2</sup> GPs treat many diseases, other than advanced cancer, that benefit from palliative care.

The modern hospice movement spread from the pioneering work of Dr Cicely Saunders at St Christopher's Hospice, London, which opened in 1967. In 1997, there were 223 inpatient units and 408 home-care teams in the United Kingdom and Ireland. Most GPs should therefore have easy access to specialist physicians and nurses. The philosophy of the hospice movement is highly relevant to palliative care in general practice. Key features are the use of drugs in symptom control (particularly pain), good communication, multiprofessional teamworking, the appropriate use of specialist palliative care services, and training of other professionals — particularly that of GPs and district nurses.

Studies from the 1970s exposed serious weaknesses in the GP management of patients with advanced cancer. Severe pain was unrelieved in up to half of patients.<sup>3,4</sup> Carers reported difficulties in getting reliable out-of-hours advice. There is evidence that some improvement has occurred, for example, Jones *et al* in a study of carers' perceptions, from South-West England, published in 1993, reported that pain was better controlled, with only 4% having no relief.<sup>5</sup> Many other symptoms, however, such as vomiting and constipation, were not so well managed. It was reported that up to 25% of the patients had no relief from these other symptoms. A minority of carers felt unsupported. In spite of these concerns, however, 94% of the carers rated the care received as 'excellent' or 'good'.

In this edition of the *Journal*, there are two papers, also from South-West England, which suggest that the quality of care continues to improve, but again highlight clear areas of concern. They compare, for the first time, admissions of patients with advanced cancer to community hospitals with admissions to a hospice. The first paper compares medical and nursing management in these two settings.<sup>6</sup> Although patients who had been admitted to the hospice were more likely to need symptom control, and less likely to be admitted for terminal nursing, comparisons are still worth making. It is encouraging that the authors found that 'prescribing on admission and at death, and indications of active treatment of symptoms were broadly similar'. The poorer quality of community hospital note-keeping may be explained by the reduced level of medical and nursing resources, as compared with a hospice.

The second paper studied the views of the patients' closest

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carer.<sup>7</sup> Again, there is reason to be encouraged. Of the carers interviewed, 90% felt that the 'total care' received by the patient, and themselves, was excellent or good in the community-hospital patients (100% in the hospice group). However, significantly more community-hospital patients' carers expressed concern about poor communication, poor nursing organization and standards, and poor bereavement follow-up. There was regret that some community hospitals did not have overnight accommodation for relatives, which may have prevented them from being at the bedside at the time of death.

Palliative care, as we approach the new millennium, presents GPs with many challenges and opportunities. We need to improve our communication skills. These are now taught and tested in vocational training, particularly using video-recording of real consultations. However, a recent survey found that over 20% of GP principals had received no formal training in communication.<sup>8</sup> This situation could be improved by the use of books, videos, and courses, which are available on subjects such as breaking bad news.<sup>9</sup>

We need to genuinely embrace multiprofessional teamworking. This means working closely with our primary care colleagues as well as appropriately enlisting the skills and knowledge of specialist palliative physicians and home-care nurses.<sup>10</sup> One novel approach in this direction was the 'Facilitator Project', a joint venture of the RCGP and the Cancer Relief Macmillan Fund. Five GPs with palliative care training were successfully used to raise standards in their localities. It was recommended that more appointments of this nature should be made.<sup>11</sup>

The majority of terminally ill patients can be cared for by their GPs either at home, in community hospitals if available, or in nursing homes. As the demand for hospice inpatient beds generally exceed supply, GPs have a responsibility to admit to hospices only those with difficult physical symptoms or psychosocial problems, which need the expertise of the specialist services.

General practitioners are uniquely placed to apply palliative care to other patients, including those suffering from end-stage heart or lung diseases, dementia, and the elderly with multiple pathologies. Increasing numbers of such patients are being cared for by GPs at home, in community hospitals, and in nursing homes. Although some hospices offer their services to patients with diagnoses other than cancer, motor neurone disease, or AIDS, their capacity to treat more patients is limited.

The recent changes in provision of out-of-hours cover by GPs, including the growth of cooperatives, may adversely affect emergency care to patients with advanced cancer. This was raised as a concern in earlier studies.<sup>4,5</sup> It is the GP's responsibility to organize effective cover for these patients, who are small in number but may need urgent and skilled intervention.

Some GPs give their home telephone number to the carer.

This may be the preferred option, but this is not always possible. Cooperatives need to devise a protocol so that appropriate care is delivered. This may require allocating more time for the visiting doctor to spend with the patient. Some palliative care teams offer a 24-hour advisory service.

General practitioners are in an ideal position to organize and, in many cases, provide bereavement follow-up after every death. Bereavement protocols for primary care have been published.<sup>12</sup>

Finally, more audit and research is needed in all these areas. The quality of medical care in nursing and residential homes, where many deaths from advanced cancer occur, is worthy of study. Many GPs, community hospital and district nurses are keen to improve standards and yet work in relative isolation. Is there a need for a national primary care forum to encourage research, audit and education in palliative care?

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## From Acorns to Oak Trees – The Birth of an Institute

The development of general practice as an academic discipline and a medical speciality in its own right has been hampered by the historic split between University departments and graduate training.<sup>1</sup> Although there has been a great deal of co-operation with many GPs being both trainers and undergraduate teachers, there has been little formal co-ordination across the divide. One of the results of the separation has been a lack of a career structure for general practitioners and few opportunities in terms of training and time for general practitioners to undertake research. The Tayside Centre for General Practice in Dundee was the first to achieve an integration in the UK<sup>2</sup> but now a second such centre has been formed: the **Institute of General Practice and Primary Care in Sheffield** which brings together undergraduate teaching, vocational training, research and continuing professional development into a unified whole.

This was the culmination of a ten year strategic plan in which an embryonic undergraduate teaching department set out to establish credentials in teaching and research with the aim of bringing together the undergraduate and graduate components of general practice. Originally a sub-department within the Community Medicine, the department became a full department in 1990, established undergraduate teaching in a revised curriculum, developed a Masters course, and provided a home for the local MAAG and RCGP faculty. In 1996, the department together with other community based clinical departments became part of a new multi-disciplinary School of Health and Related Research (SchHARR) within the Medical Faculty of the University of Sheffield. The new school included the North Trent arm of the Trent Institute for Health Services Research and brought together the medical care research unit, health economics, operational research, health policy and management and information resources. This process enabled general practice to break free of the biomedical ethos of hospital based medicine and spread its wings in a milieu of social science research. The effective combination of research and multi-disciplinary teaching with service development has resulted in the Institute becoming the "natural" academic resource for the North Trent Network for Primary Care. Research income has exceeded £0.7 million in 1997/98; more than 15% of the total medical undergraduate teaching is now community based with participation by 150 North Trent Practices and members of the Institute are, in addition, playing leading roles in recent primary care developments. At last, for Sheffield at least, the magic mix of personalities and premises have come together in time and place to provide an appropriate academic basis for a primary care led health service in the 21st century.

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