

## From margins to centre: a review of the history of palliative care in cancer

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Palliative care and hospices have developed rapidly since the late 1960s. The pioneering work of Cicely Saunders was instrumental in drawing attention to the end-of-life care needs of patients with advanced malignant disease. Palliative care began to be defined as a subject of activity in the 1970s and came to be synonymous with the physical, social, psychological, and spiritual support of patients with life-limiting illness, delivered by a multidisciplinary team. Palliative care services have developed in many settings and have often been closely related to oncology. The worldwide need for this type of care remains much greater than the available provision, but there are encouraging signs of recognition by policymakers and influential bodies, and interest in palliative care has never been greater. This paper charts the modern history of such care around the world and concludes on some current issues and future challenges.

### Introduction

In 1959, Cicely Saunders (figure 1), newly qualified in medicine and working as a research fellow at St Joseph's Hospice in Hackney, London, UK, was engrossed in the preparation of her first major medical publication.<sup>1</sup> Writing at the request of the surgeon Ronald Raven, her chapter on "The Management of Patients in the Terminal Stage" was the only important contribution of its kind to a major six-volume series on cancer. At that time, there were only a handful of hospices in the UK, each run by a religious foundation.<sup>2</sup> Little published research existed on the subject of caring for dying patients,<sup>3</sup> the modern hospice movement was yet to get under way,<sup>4</sup> the term palliative care had not come into common use,<sup>5</sup> and no professional societies had been formed to promote interest in the subject.<sup>6,7</sup> Furthermore, the emerging specialty of clinical oncology was showing little interest in the care of those dying from cancer. 40 years on, in 1999, the British government appointed a national director to reform and improve cancer services. This so-called cancer tsar was Mike Richards, a breast cancer specialist and professor of palliative medicine.<sup>8</sup> He built on the work of the Calman–Hine report<sup>9</sup> and the UK Government's Cancer Plan<sup>10</sup> to implement a programme of reform to cancer services, which now gives a core place to palliative care, and which, in collaboration with other groups, is also extending to a national strategy for end-of-life care.<sup>11</sup>

In only four decades, the care of patients with advanced malignant disease and the management of their symptoms during the trajectory of illness has moved from the margins of oncological practice to the very centre of modern cancer care. The way in which this advancement occurred is the subject of a still unfolding history and one which involves the emergence of palliative medicine as a subject of specialisation in a growing number of countries. This worldwide development of palliative care is deeply rooted in the specialty of oncology, which has shaped the conceptual model of palliative care, produced some of its major leaders and innovators, and provided a population of patients with the obvious potential to benefit from a new

approach to the management of those with advanced disease.

This article reviews the history of modern hospice and palliative care and concludes with some issues about future development. This Review draws on a programme of original studies (directed by the author) that goes back to 1995 and which now forms part of the work of the International Observatory on End of Life Care at Lancaster University, UK. This programme contains a large and growing oral history collection and associated digital archives and has been responsible for the cataloguing and safe storage of the personal papers of several key figures in the history of the modern hospice movement.



Figure 1: Cicely Saunders working as a nurse in the 1940s

Furthermore, the programme includes a major collection of published works, offprints, reports, and grey literature, and has been responsible for extensive bibliographical cataloguing of key works in this specialty.<sup>12</sup>

### Oncological origins of the modern hospice and palliative care

In the 1950s, professional and public interest in cancer was mainly focused on the potential for curative treatment, and a patient dying from cancer was, at best, overlooked and, at worst, abandoned by physicians who told their patients to go home, as there was nothing more that could be done. Concern about the medical neglect of patients dying from cancer was, in part, stimulated by the findings of early research that began to appear in the postwar years, and which marked a shift within the professional published work from what had been largely anecdotal accounts of individual cases to more systematic findings of groups of patients in various settings.

During the 1950s, new studies by doctors, social workers, and social scientists provided insight into the social and clinical aspects of care for patients dying from cancer. These studies included Margaret Bailey's survey of patients with lung cancer, done at the Brompton (figure 2) and Royal Marsden Hospitals,<sup>13</sup> research into public opinion on cancer,<sup>14</sup> and an enquiry into delayed help-seeking by patients with cancer, which noted that: "the fact of palliative treatment is not understood, and hospitals appear to be trying to cure all their patients and failing in a high proportion of cases".<sup>15</sup> Evidence from the USA was also accumulating, including a study on terminal-cancer care in 200 patients in Boston<sup>16</sup> and a paper on social casework for patients with cancer.<sup>17</sup> US studies on psychosocial issues, such as truth-telling,<sup>18</sup> anxiety and depression,<sup>19</sup> and anticipatory grief,<sup>20,21</sup> were also emerging. These studies were further supported by the early psychiatric work of Colin Murray Parkes in London, UK, on bereavement and mental illness.<sup>22</sup>

By the mid-1960s research papers by Eric Wilkes—the Derbyshire general practitioner who later founded St Luke's Hospice in Sheffield, UK—on terminal cancer at home were appearing,<sup>23</sup> and, in one of these papers, he noted that: "there seems to be no valid reason why hospital provision for terminal care is so inadequate, or for the National Health Service to lean so heavily on the few Curie Foundation Homes and the devoted but over-worked religious institutions specialising in this work".<sup>24</sup>

Closely associated with these research endeavours was the psychiatrist John Hinton, who, in a 1964 editorial in the *Journal of Chronic Diseases*,<sup>25</sup> stated: "the large number of articles in which remembered experience is distilled into advice on the management of dying awesomely overshadows the few papers attempting to measure the degree of success or failure of treatment".<sup>25</sup> Within a few years sociological interest was beginning to emerge, as shown by the ground-breaking work of Glaser and Strauss<sup>26</sup> in their ethnographic studies of the care of

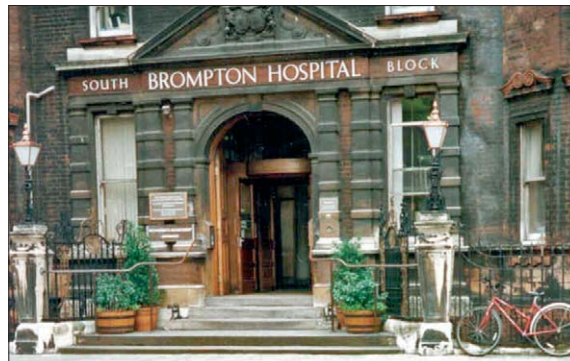


Figure 2: Brompton Hospital

dying patients in US hospitals, and also by Anne Cartwright's 1969 survey<sup>27</sup> of 960 bereaved relatives who were asked about the experiences of the deceased person in the last year of life.

Saunders directed her attention to patients in the final stages of cancer, especially those with the most complex problems. She said to a colleague in 1960:

"Carcinoma of cervix I think is the most difficult both from the point of view of pain and of general distress; and I think that carcinoma of breast with bone secondaries probably comes second to that. In both these groups it is the patients between 40 and 60 years who tax our skill."<sup>28</sup>

Her contribution at this time was to focus attention on the terminal stage of illness, when "all curative and palliative measures" had been exhausted, and she was to become instrumental in defining a new knowledge-base of care for those dying from malignancies. Her writings relied heavily on individual patient experiences and she was assiduous in collecting these, having reported on a series of 340 cases in 1960,<sup>29</sup> rising to 1100 by 1967.<sup>30</sup> A striking feature of her papers was her articulation of the relation between physical and mental suffering, seen in almost dialectical terms, each capable of affecting the other. Her description of this relation reached full expression in her idea of total pain,<sup>31</sup> which was taken to include physical symptoms, mental distress, social problems, and emotional difficulties—captured so comprehensively by the patient who told her: "all of me is wrong"<sup>32</sup>

Such ideas were also linked to a hard-headed approach to pain management. Her message was simple: "constant pain needs constant control" and she argued for analgesics to be used in a method of regular giving, which would ensure that pain was prevented in advance, rather than alleviated once it had become established, and that they should be used progressively, from mild to moderate to strong. A lifelong opponent of euthanasia, she pressed tirelessly for the proper relief of suffering without the hastening of death.<sup>33</sup>

Elsewhere, others were also working towards similar goals. In the mid-1960s the Swiss-born psychiatrist

Elisabeth Kubler Ross was running a weekly seminar talking to patients who were dying at the Billings Hospital in Chicago, IL, USA. Her first book,<sup>34</sup> published in the autumn of 1969, became a worldwide bestseller, although her ideas on the stages of dying and how to communicate with patients who were dying did much to polarise medical opinion.

In 1971, US President, Richard Nixon, declared a “war on cancer”.<sup>35</sup> Key components in the so-called battle were the identification and elimination of the causes of cancer, and the development of effective measures to treat those who had malignancies. There was also a softer side to this approach and the predictable course of cancer—the dreaded disease of modernity—and high potential for suffering in the late stages seemed to combine to make this disease an excellent vehicle for the new ideas and approaches found within palliative care; this disease offered both an appeal to public sentiment, which brought support for hospices, and also a new set of clinical challenges, which caught the interest of a new wave of palliative care practitioners.<sup>36</sup> Modern oncological and palliative care, therefore, share a history that is intertwined at several crucial points.

### St Christopher’s Hospice

In 1967, Saunders and her colleagues opened the world’s first modern hospice in London, UK, where clinical care, teaching, and research were combined within an overall philosophy that was seen as a middle way between too much and too little treatment. St Christopher’s Hospice (figure 3) quickly became a source of inspiration to others, and sought to establish itself as a centre of excellence in a new specialty, giving equal weight to clinical care, education, and research.

In the early days, the hospice was associated with major clinical and organisational studies that played a large part in the advancement of palliative care. Research was done on pain control and the underlying pharmacokinetic mechanisms at work in the administration of strong opiates. This research began with close scrutiny of some of the methods of pain relief favoured by the early hospices and terminal-care homes, especially the use of the so-called Brompton Cocktail,<sup>37</sup> which had been gaining popularity throughout the 20th century and had appeared in print for the first time in the 1950s. This cocktail was said to be a mixture of morphine hydrochloride, cocaine hydrochloride, alcohol, syrup, and chloroform water, with many local variants and names. In her early writings, Saunders had been eager to promote this rather exotic mixture. However, the mixture was scrutinised in detail by Robert Twycross, a research fellow at St Christopher’s Hospice, in what became a series of classic studies and the first of their kind to be undertaken in the hospice setting. He concluded that the Brompton Cocktail was no more than a traditional way of administering oral morphine to patients with cancer who were in pain, and he urged that its use should be quietly



Figure 3: St Christopher’s Hospice, opened in 1967

abandoned in favour of simpler approaches of administering morphine.<sup>38</sup> The actions of morphine, the development of new approaches to its administration, and the teaching of health-care professionals about its appropriate use alongside other analgesics and adjuvant drugs all became rich territory both for research and teaching in the context of palliative care.

Research at St Christopher’s Hospice began even before the first patient was admitted. Parkes built up a cohort of patients over time, consisting of 276 patients who had died from cancer in two London boroughs, 49 of whom were still under active treatment at the time of death. He discovered that many of the patients had died with unrelieved pain, whether the patient died in hospital or at home. As new patients entered the study, he was able to show that people with serious pain problems were largely relieved from their pain if referred to the hospice from the start.<sup>39</sup> This study was repeated 10 years later as part of a continued assessment of the work of the hospice. Although pain and symptom control improved in the hospital setting over time, psychosocial needs and continuity of care continued to be better approached in the hospice.<sup>40</sup>

The success of St Christopher’s Hospice was remarkable, and it soon became the stimulus for an expansive phase of hospice development. In the UK there was a golden period of such growth, which peaked in the 1980s when about ten new hospices were opened per year. Some of these hospices were located and funded within the National Health Service (NHS)—eg, Oxford, Southampton, Dundee, and Aberdeen—where their ability to have a wider effect on care services was heightened.

Hospital support teams for terminal care (as it was then called), were pioneered in the UK in 1976 when a team was established at St Thomas’s Hospital, London. A notable short-lived example was reported in the *British Medical Journal*,<sup>41</sup> but their subsequent development was given impetus by departmental guidelines published in 1987. Between 1982 and 1996 the number of hospitals with either a multidisciplinary palliative care team or a specialist palliative care clinical nurse grew from five to

275.<sup>42</sup> A review of the efficacy of hospital-based palliative care teams, in 2002, noted that they were still at an early stage in their development; nevertheless, the available evidence lends some support to their work and there is a great need for well-designed evaluative studies.<sup>43</sup> Such teams vary widely in character but they are the principle interface between oncologists and palliative care specialists and merit closer attention on the part of researchers.

Two major UK cancer charities were also important in promoting change. The Macmillan organisation was founded in 1911, and in the mid-1970s underwent a period of unprecedented expansion, becoming increasingly involved with palliative care and supporting training programmes, specialist professional posts, and academic positions as well as capital and service developments. Recently, the organisation has switched its focus to more direct support for people affected by cancer and indicated this in a change of name to Macmillan Cancer Support.<sup>44</sup>

The Marie Curie Memorial Foundation was established in 1948 and went on to create nursing homes, a domiciliary nursing service for patients with cancer, and a laboratory-based scientific research programme. In the 1980s the Marie Curie nursing homes underwent a transition to specialist palliative care centres and the charity supported a wide range of educational activities, and some research activities, in palliative care. More recently, this organisation has been closely associated with the development of a national end-of-life strategy and has also been engaged in lobbying for new legislation to support palliative care.<sup>45</sup>

Hospice ideals and practices began to be disseminated into other settings from the 1970s, so that by the mid-1990s there were over 1000 specialist Macmillan nurses working in palliative care in the UK, about 400 home-care teams, and over 200 day-care and 200 hospital-based services, along with some 5000 Marie Curie nurses providing care in the home. In 2004, there were 196 inpatient units in the UK, consisting of 2730 beds, albeit just 19% of which were within the NHS, with the remainder under the governance of independent hospices. There was also a large array of other services: home care (341); day care (237); hospital-based care (324); hospice at home (full multidisciplinary 24-hour care; 97).<sup>46</sup>

### Specialisation

As hospices and palliative care in the UK underwent a vigorous period of expansion in the 1980s, three factors conjoined to build a platform for the broad consolidation of this active discipline: a medical association was formed to support its practitioners; a scientific journal was established; and recognition was given to palliative medicine as an area of specialisation.<sup>47</sup> By 1985, plans were being developed in the UK for the creation of an association to represent the interests of physicians working in palliative care.<sup>48</sup> After some early discussion about whether to include the term hospice in the name, the group soon became the Association for Palliative

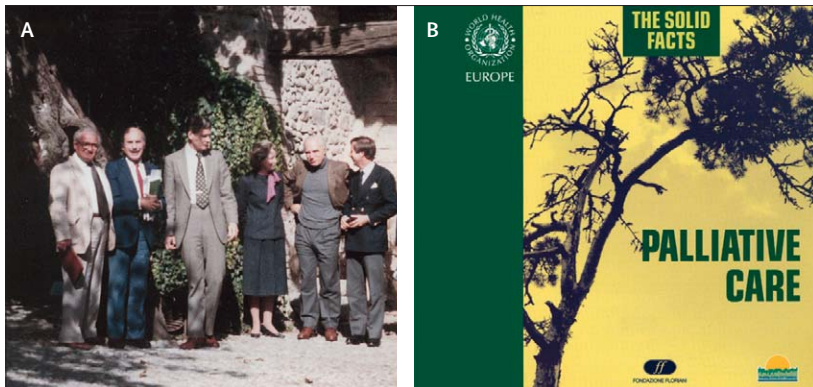
Medicine for Great Britain and Ireland. Dialogue then got underway with several key committees within the royal colleges of Physicians and General Practitioners, including the Intercollegiate Committee on Oncology, and ideas were developed about how a training programme for palliative care could be put together.

In 1987, palliative medicine was established as a subspecialty of general medicine, initially on a 7-year novitiate, which, once successfully concluded, led to the creation of a specialty in its own right.<sup>49</sup> Developments in Ireland then took a similar path when, in 1989, the first post of consultant physician in palliative medicine was created, and in 1995 the specialty was formally approved.<sup>50</sup> Similar recognition followed in Australia and New Zealand in 1998 and will occur in the USA in 2008. Palliative medicine has varying degrees of recognition in other countries, including Canada, Romania, Poland, Slovakia, and Germany, and is seeking accreditation in several more.

### Cancer pain

Before the 1970s, pain caused by cancer had received little international attention as either a clinical or a public health problem and was often regarded as an inevitable, not fully controllable, consequence of the disease.<sup>51,52</sup> The spread of modern hospices and palliative care and the increasing number of studies being done on this subject encouraged a small number of pioneering oncologists to organise the first International Symposium on Cancer Pain, held in Venice in 1978.<sup>53</sup> Research presented at this and subsequent conferences suggested that physicians had the means to relieve even severe cancer pain and that the principal factors contributing to poor management of pain were legal barriers against opioid use and a lack of knowledge in the subject. The issue of cancer pain was tackled from two directions. In addition to the work of the hospice movement, there was also the work by Patrick Wall (inventor of the gate theory of pain and an early pioneer of modern pain medicine) and the International Association for the Study of Pain. The coming together of pain specialists with palliative medicine specialists and relevant oncologists led to the development of improved methods for management.<sup>54</sup>

In 1982, the WHO (figure 4) enlisted the help of palliative care leaders, cancer-pain specialists, and pharmaceutical manufacturers to develop a global Programme for Cancer Pain Relief, on the basis of a three-step analgesic ladder with the use of adjuvant treatments, incorporating the use of strong opioids as the third step.<sup>55</sup> WHO representatives launched an international initiative to remove legal sanctions against opioid importation and use, relying on national coordinating centres to organise professional education and to disseminate the core principles of the so-called pain ladder. However, the WHO programme met with only partial success. The use of opioids rose substantially between 1984 and 1993 in ten industrialised countries,



**Figure 4: WHO endorsement has been important to the ongoing development of palliative care**  
 (A) The first WHO Expert Group on Cancer Pain, Milan, Italy. Left to right: John Bonica, Mark Swerdlow, Robert Twycross, Kathleen Foley, Vittorio Ventafridda, Jan Stjernswärd. Reproduced with permission from Elizabeth Swerdlow. (B) WHO guidance on palliative care for policy makers. Reproduced with permission from Elizabeth Davies, Irene Higginson, eds. Palliative care. The solid facts. Copenhagen, WHO Regional Office for Europe, 2004.

but showed much smaller increases throughout the rest of the world.<sup>56</sup> Furthermore, substantial differences in the pattern and extent of opioid use continued to be seen within and between global regions.<sup>52</sup> Nevertheless, the interest of WHO raised further debate about the relation between palliative care and oncology. Recognition increased that curative care and palliative care are not mutually exclusive, and that as long as curative oncological treatment is out of reach for many patients in the developing world, then the allocation of resources should shift towards a greater emphasis on palliative care.<sup>57</sup>

### International collaboration

From the 1980s, pioneers of hospices and palliative care worked to promote their goals in many countries, increasingly building on international networks of support and collaboration (figure 5).<sup>58</sup> In 1976, the First International Congress on the Care of the Terminally Ill was held in Montreal, Quebec, Canada, and was then organised every 2 years thereafter by Balfour Mount and colleagues. In 1980, Josefina Magno and others formed the International Hospice Institute, which, in 1999, became the International Association for Hospice and Palliative Care. The European Association for Palliative Care was formed in Milan, Italy, in 1988, and Vittorio Ventafridda became its first President the year after. In 1990, the well established Hospice Information Service at St Christopher's Hospice in London began its international newsletter, which quickly became an invaluable source of information on hospice innovation around the world. 9 years later, the Eastern and Central European Palliative Task Force came into being at a congress held in Geneva. This group aimed to gather data on hospices and palliative care in the region, share experiences of achievements and obstacles, influence the institutions of government, set standards to meet local needs, and raise awareness. At the same time, the Foundation for Hospices in sub-Saharan Africa was established to serve hospice developments in the region.

In the new millennium, the year 2000 saw the creation of the Latin American Association of Palliative Care and in 2001 the Asia Pacific Hospice Palliative Care Network was founded, representing 14 countries. The UK Forum for Hospice and Palliative Care Worldwide became operational in 2002, with aims to coordinate the work of relevant groups in the UK, to support education, to advocate, to provide information, and to raise funds. Finally, in 2003, the African Association for Palliative Care was founded, seeking to represent all palliative care interests across the continent. Many developments also took place at the country level, and substantial published work on national developments in hospices and palliative care showed important achievements and many successes in the face of adversity.<sup>59</sup>

### The Americas

Hospice services in the USA grew from the founding organisation in New Haven, CT, in 1974, to some 3000 providers by the end of the 20th century. However, these services developed differently in the USA where there is much less contact with oncology and a much greater focus on non-cancer patients than in the UK. US hospices mainly focus on home care, and the idea of hospital teams and inpatient hospice beds is much less developed. In 1982, a major milestone was the achievement of funding recognition for hospices under the US Medicare programme, and in the 1990s several further key developments occurred. National bodies started to put greater emphasis on palliative care as a specialised subject of activity, with some changing their names to represent this idea—eg, the National Hospice Organisation became the National Hospice and Palliative Care Organisation and the American Academy of Hospice Physicians became the American Academy of Hospice and Palliative Medicine.

At the same time, two major foundations developed extensive programmes concerned with improving the culture of end-of-life care in US society—the Robert Wood Johnson Foundation created the Last Acts initiative and the Open Society Institute established the Project on Death in America. An influential report by the Institute of Medicine,<sup>60</sup> published in 1997, sought to strengthen professional understanding of the need for good care at the end of life. This was followed, in 2001, by a further report from the Institute of Medicine<sup>61</sup> listing ten recommendations addressing the role of the National Cancer Institute in promoting palliative care. In 2004, the National Institutes of Health held a so-called State-of-the-Science meeting on Improving End-of-Life Care,<sup>62</sup> which brought together prominent clinicians and researchers to focus on defining end of life, understanding major considerations related to end-of-life care, and developing interventions for symptom management, social and spiritual care, and caregiver support.

Meanwhile, in neighbouring Canada, where Balfour Mount first coined the term palliative care in 1974,<sup>63</sup> a

Senate report in 2000 stated that no extension of palliative care provision had happened in the previous 5 years, and set out recommendations for further development of the country's 600 services.<sup>64</sup> In Latin America, there was evidence of faltering progress, with palliative care services existing in seven countries, with the greatest amount of development in Argentina.<sup>65</sup> A large problem here, as in other developing regions, was the problem of poor opioid availability, an issue highlighted in the 1994 Declaration of Florianopolis.<sup>66</sup>

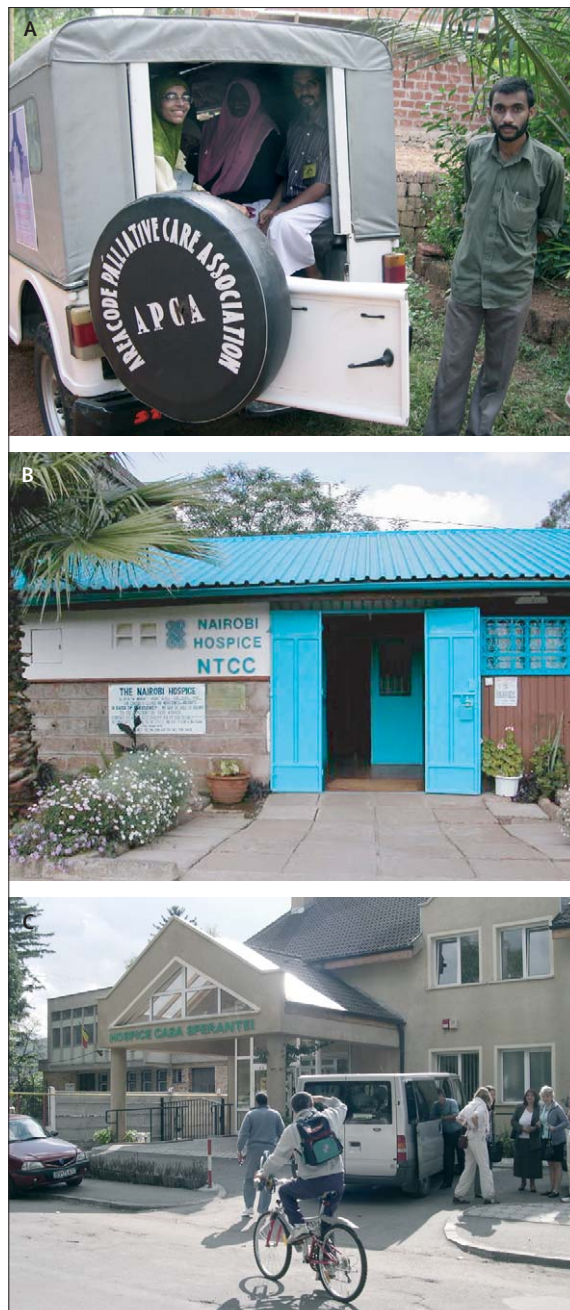
### Asia Pacific

The first evidence of hospice developments in the Asia Pacific region came with a hospice service for dying patients in Korea, at the Calvary Hospice of Kangung, established by the Catholic Sisters of the Little Company of Mary in 1965; the number of different services in the whole region had increased to 60 by 1999.<sup>67</sup> The first hospice in Japan also had a Christian base, established in the Yodogwa Christian Hospital in 1973; by the end of the century the country had 80 inpatient units.<sup>68</sup> In Australia, the country that established the world's first professor in palliative care, Commonwealth and state funds for palliative care increased steadily from 1980, and palliative medicine was recognised as a specialty in 2000. By 2002 there were 250 designated palliative care services nationwide.<sup>69</sup> Protocols for the WHO three-step analgesic ladder were first introduced into China in 1991 and, as a result, by 2002 there were said to be hundreds of palliative care services in urban areas.<sup>70</sup>

An extensive review of hospice and palliative care developments in India has mapped the existence of services state-by-state and explored the perspectives and experiences of those involved, with a view to stimulating new development.<sup>71</sup> This study found that 135 hospices and palliative care services exist in 16 states. These services are usually concentrated in large cities, with the exception of the state of Kerala, where services are much more widespread. Non-government organisations and public and private hospitals and hospices are the predominant sources of provision. Palliative care provision could not be identified in 19 states or union territories. Nevertheless, successful models exist in Kerala for the development of affordable, sustainable community-based hospices and palliative care services,<sup>72</sup> which might have the potential for replication elsewhere.

### Africa

About a million Africans will develop cancer every year, but for most, treatment remains unattainable.<sup>73</sup> The need for palliative care is now hugely increased by the epidemic of HIV and AIDS. Wright and Clark<sup>74</sup> have mapped the existence of services country-by-country in a review of hospice and palliative care developments in Africa, and have explored the perspectives and experiences of those involved.



**Figure 5: International collaboration for palliative care**

(A) Neighbourhood networks in palliative care have proved effective in Kerala, India. Reproduced with permission from the *International Journal of Palliative Nursing*. (B) Hospice and palliative care innovations are developing rapidly in Africa. Photographed by Jenny Hunt. (C) Hospice Casa Sperantei in Brasov, Romania, has had a leading role in developing palliative care services in eastern Europe.

The 47 countries studied could be grouped into four categories of palliative care development: no identified hospice or palliative care activity (21); capacity-building activity underway to promote hospices and palliative care delivery (11); localised provision of hospices and palliative

care in place, often supported by external donors (11); hospices and palliative care services achieving some measure of integration with mainstream service providers and gaining wider policy recognition (4). Major difficulties included: opioid availability; workforce development; achieving sustainable critical mass; absorption capacity in relation to major external funding initiatives; and coping with the scale of HIV and AIDS-related suffering. The authors concluded that models exist in Uganda, Kenya, South Africa, and Zimbabwe for the development of affordable, sustainable community-based hospices and palliative care services, and that the newly formed African Palliative Care Association has huge potential to promote innovation, in a context where interest in the development of hospices and palliative care in Africa has never been greater.

A small number of further studies have also appraised the development of palliative care in sub-Saharan Africa<sup>75-77</sup> and stimulated interest in the assessment of services.

### Europe

In the former communist countries of eastern Europe and central Asia, there was little development of palliative care in the years of Soviet domination. Most initiatives can be traced to the early 1990s, after which many projects got underway. These have been documented in detail<sup>78</sup> and show evidence of some service provision in 23 of 28 countries in the region. Poland and Russia have the most advanced programmes of palliative care, with substantial achievements also made in Romania and Hungary. Nevertheless, in a region of over 400 million people there were only 467 palliative care services in 2002, more than half of which were in one country, Poland.

Palliative care in western Europe made rapid progress from the early 1980s, but by the late 1990s there were still striking differences in provision across different countries in this region.<sup>79</sup> After the foundation of St Christopher's Hospice in the UK in 1967, 10 years elapsed before the first services began to appear elsewhere: Sweden (1977), Italy (1980), Germany (1983), Spain (1984), Belgium (1985), France (1986), and Netherlands (1991). In all of these countries the provision of palliative care has moved beyond isolated examples of pioneering services run by enthusiastic founders. Palliative care is being delivered in a variety of settings (eg, domiciliary, quasidomiciliary, and institutional) although these are not given uniform priority everywhere.

In 1989 and 1992 the European Parliament adopted resolutions on counselling and care of the terminally ill but showed little further interest in end-of-life issues until January, 2005, when a question was put to the Parliament, by a member of the Council of Europe, about what action the Commission had taken to prepare a strategy for palliative care. The Council of Europe published a set of European guidelines on palliative care in 2003, and described this care as an essential and basic

service for the whole population. The Council's recommendations seem to have been used actively in some countries with less-developed palliative care systems, especially in eastern Europe, where they have been used for advocacy and lobbying.

Policy issues relating to end-of-life care in Europe have also been raised by other non-governmental and inter-governmental organisations. At palliative care conferences held in 1995 (Barcelona, Spain)<sup>80</sup> and 1998 (Poznan, Poland)<sup>81</sup> exhortatory declarations were made, calling for government action on palliative care at the national level and drawing attention to key problems and issues facing palliative care as it develops internationally. By 2003, the European Society for Medical Oncology was giving greater recognition to palliative care as a discipline.<sup>82</sup> In 2004, the European Federation of Older Persons launched a campaign to make palliative care a priority topic on the European health agenda.<sup>83</sup> The same year, WHO Europe produced an important document on Better Palliative Care for Older People.<sup>84</sup> The aim of this document was "to incorporate palliative care for serious chronic progressive illnesses within ageing policies, and to promote better care towards the end of life". An accompanying document, Palliative Care: The Solid Facts, is a resource for policymakers in a context where "the evidence available on palliative care is not complete and...there are differences in what can be offered across the European region" (figure 4).<sup>85</sup> However, despite the powerful symbolic language of these and other documents, evidence of their effect remains unclear.<sup>86</sup>

### Future challenges

In 2006, a detailed picture emerged from the first study to our knowledge ever to attempt an estimate of the global provision of palliative care.<sup>87</sup> In total, 115 of the world's 234 countries have established one or more hospice-palliative care services. However, only 35 (15%) of the 234 countries have achieved a measure of integration with other mainstream service providers together with wider policy recognition. Such a picture must be set against the stark realities of global need: 56 million deaths per year, with an estimated 60% who could benefit from some form of palliative care. Current provision of palliative care reaches only a tiny proportion of these patients, and the solution lies in better palliative care within mainstream health-care systems.

The global burden of cancer will increase from ten million to 24 million during the next 50 years, 17 million of whom will be in developing countries. Of the estimated ten million people who are diagnosed with cancer every year, more than half are living in the developing world and many will have incurable disease at the time of diagnosis. Cancer pain is common, and two-thirds of those with advanced disease, and a third of those undergoing active treatment, suffer with this pain. Until referral and diagnosis are made earlier than current

### Search strategy and selection criteria

Information for this Review was found by hand and electronic searches in the English language using the following key words and phrases: "hospice", "palliative care", "cancer pain", "history", and "international development". The search was limited to papers published between 1945 and 2007.

practice and standard treatments are able to be deployed for most patients with cancer, pain relief and palliative care will remain the most relevant provision for large numbers of people affected. Meanwhile, both cancer and palliative care remain low priorities on the global health agenda.<sup>88</sup>

The WHO first formally defined the term palliative care in 1989.<sup>89</sup> The most recent definition from WHO of palliative care, published in 2002,<sup>90</sup> states that: "palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".<sup>90</sup> Palliative care has become more expansive in its goals and has sought to move its influence upstream to earlier stages in the disease progression. In doing so, definitional and boundary problems are encountered in relation to supportive care provided by oncologists. In the UK, an attempt to bridge this gap can be seen in the the National Institute for Health and Clinical Excellence guidance on supportive and palliative care.<sup>91</sup> The key recommendations here are: that people affected by cancer should be involved in developing cancer services; there should be good communication and people affected by cancer should be involved in decision making; information should be available free of charge; people affected by cancer should be offered a range of physical, emotional, spiritual, and social support; and those with advanced cancer should have access to a range of services to improve their quality of life, including support for people dying from cancer, with a trained workforce to provide these services. There is a great need worldwide for more integrated guidelines on the supportive and palliative care of people with cancer so that a seamless service is delivered to these patients across the trajectory of illness.

The history of modern palliative care covers little more than four decades, and, during that time, this subject has received a growing acceptance within the world of oncology. As cancer patients become increasingly likely to have access to appropriate care at the end of life, another huge challenge now awaits: the delivery of expert palliative care to those with non-malignant disease.

### Conflicts of interest

The author declared no conflicts of interest.

### References

- 1 Saunders C. The management of patients in the terminal stage. In: Raven R, ed. *Cancer*, vol 6. London: Butterworth and Company, 1960: 403–17.
- 2 Humphreys C. "Waiting for the last summons": the establishment of the first hospices in England 1878-1914. *Mortality* 2001; 6: 146–66.
- 3 Clark D. Cradled to the grave? Pre-conditions for the hospice movement in the UK, 1948-67. *Mortality* 1999; 4: 225–47.
- 4 Clark D, Small N, Wright M, Winslow M, Hughes N. *A bit of heaven for the few? An oral history of the hospice movement in the United Kingdom*, 2005. Lancaster: Observatory Publications.
- 5 Clark D, Seymour J. *Reflections on palliative care: sociological and policy perspectives*, 1999. Buckingham: Open University Press.
- 6 Clark D. History, gender and culture in the rise of palliative care. In: Payne S, Seymour J, Ingleton I, eds. *Palliative care nursing. Principles and evidence for practice*. Maidenhead: Open University Press, 2004: 39–54.
- 7 Clark D. Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957-67. *Mortality* 1998; 3: 43–63.
- 8 Burke K. Health tsars. Professor Mike Richards. *Br Med J* 2004; 328: 12.
- 9 Expert Advisory Group on Cancer. *A policy framework for commissioning cancer services: a report by the expert advisory group on cancer to the Chief Medical Officers of England and Wales*, 1995. London: Department of Health and Welsh Office.
- 10 The NHS Cancer plan: a plan for investment, a plan for reform. London: Department of Health, 2000.
- 11 Department of Health. End of life care. <http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/EndOfLifeCare/fs/en> (accessed March 28, 2007).
- 12 International Observatory on End of Life Care. *Historical analysis*. <http://www.eolc-observatory.net/history/index.htm> (accessed March 28, 2007).
- 13 Bailey M. A survey of the social needs of patients with incurable lung cancer. *The Almoner* 1959; 11: 379–97.
- 14 Paterson R, Aitken-Swan J. Public opinion on cancer; a survey among women in the Manchester area. *Lancet* 1954; 23: 857–61.
- 15 Aitken-Swan J, Paterson R. The cancer patient: delay in seeking advice. *Br Med J* 1955; 1: 623–27.
- 16 Abrams R, Jameson G, Poehlman M, Snyder S. Terminal care in cancer. A study of two hundred patients attending Boston clinics. *N Engl J Med* 1945; 232: 719–24.
- 17 Abrams R D. Social casework with cancer patients. *Soc Casework* 1951; 52: 425–431.
- 18 Brauer PH. Should the patient be told the truth? *Nurs Outlook* 1960; 8: 328–33.
- 19 Bard M. The psychologic impact of cancer. *Il Med J* 1960; 118: 155–59.
- 20 Lindemann E. Symptomatology and management of acute grief. 1944. *Am J Psychiatry* 1994; 151: 155–60.
- 21 Aldrich CK. The dying patient's grief. *JAMA* 1963; 184: 329–31.
- 22 Parkes CM. Recent bereavement as a cause of mental illness. *Br J Psychiatry* 1964; 110: 198–204.
- 23 Wilkes E. Cancer outside hospital. *Lancet* 1964; 18: 1379–81.
- 24 Wilkes E. Terminal cancer at home. *Lancet* 1965; 1: 799–801.
- 25 Hinton J. Problems in the care of the dying. *J Chronic Dis* 1964; 17: 201–05.
- 26 Glaser BG, Strauss AL. *Awareness of Dying*. Chicago, IL: Aldine, 1965.
- 27 Cartwright A, Hockey L, Anderson JL. *Life Before Death*. London: Routledge, 1973.
- 28 Cicely Saunders to Dr A N Exton Smith. In Clark D, ed. *Cicely Saunders. Founder of the hospice movement, selected letters 1959-1999*. Oxford: Oxford University Press, 2001: 38
- 29 Saunders C. Drug treatment of patients in the terminal stages of cancer. *Cur Med Drugs* 1960; 1: 16–28.
- 30 Saunders C. The care of the terminal stages of cancer. *Ann R Coll Surg* 1967; 41 (suppl): 162–69.
- 31 Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders 1958-67. *Soc Sci Med* 1999; 49: 727–36.
- 32 Saunders C. The symptomatic treatment of incurable malignant disease. *Prescriber's Journal* 1964; 4: 68–73.

- 33 Saunders C. (Member of Church of England Board of Social Responsibility Working Party) On Dying Well: An Anglican contribution to the debate on euthanasia. London: Church Information Office, 1975.
- 34 Kubler Ross E. On Death and Dying. London: Tavistock, 1969.
- 35 Grob GN. The deadly truth. A history of disease in America. Cambridge, MA; Harvard University Press, 2002.
- 36 National Council for Palliative Care. The distinctive characteristics of cancer. London: The National Council for Palliative Care, 2006.
- 37 Clark D. The rise and demise of the "Brompton Cocktail". In: Meldrum ML, ed. Opioids and pain relief: a historical perspective. Progress in pain research and management, vol 25. Seattle, WA: IASP Press, 2003: 85–98
- 38 Twycross R. 'The Brompton Cocktail' In: Bonica JJ Ventafridda V, eds. Advances in pain research and therapy, vol 2. New York: Raven Press, 1979.
- 39 Parkes CM. Home or hospital? Terminal care as seen by surviving spouses. *J R Coll Gen Pract* 1978; **28**: 29–30.
- 40 Parkes CM, Parkes J. 'Hospice' versus 'hospital' care - re-evaluation after 10 years as seen by surviving spouses. *Postgrad Med J* 1984; **60**: 120–24.
- 41 Herxheimer A, Begent R, MacLean D, Phillips L, Southcott B, Walton I. The short life of a terminal care support team: experience at Charing Cross Hospital. *Br Med J* 1985; **290**: 1877–79.
- 42 Clark D, Seymour J. Reflections on Palliative Care. Buckingham, UK: Open University Press, 1999.
- 43 Higginson IJ, Finlay I, Goodwin DN, et al. Do Hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* 2002; **23**: 96–106.
- 44 We are Macmillan. Cancer Support. <http://www.macmillan.org.uk/Home.aspx> (accessed March 28, 2007).
- 45 Marie Curie Cancer Care, <http://www.mariecurie.org.uk/> (accessed March 28, 2007).
- 46 National Council for Palliative Care. Minimum data sets project update. London: National Council for Palliative Care, 2005.
- 47 Clark D. The development of palliative medicine in the UK and Ireland. In: Bruera E, Higginson I, Ripamonti C, von Gunten C, eds. Textbook of palliative medicine. London: Hodder Arnold, 2006: 3–9.
- 48 Cicely Saunders to Derek Doyle, 15 October 1985. In: Clark D, ed. Cicely Saunders. Founder of the hospice movement. Selected letters 1959–1999. Oxford: Oxford University Press, 2002: 262.
- 49 Doyle D. Palliative medicine: the first 18 years of a new sub-specialty of General Medicine. *J R Coll Physicians Edinb* 2005; **35**: 199–205.
- 50 O'Brien T, Clark D. A national plan for palliative care – the Irish experience. In: Ling J, O'Siorain L, eds Palliative Care in Ireland. Maidenhead: Open University Press, 2005: 3–18.
- 51 Seymour J, Clark D, Winslow M. Pain and palliative care: the emergence of new specialties. *J Pain Symptom Manage* 2005; **29**: 2–13.
- 52 Seymour J, Clark D. The modern history of morphine use in cancer pain. *EJPC* 2005; **12**: 152–55.
- 53 Bonica JJ, Ventafridda V. International symposium on pain of advanced cancer. New York: Raven Press, 1979.
- 54 Reynolds LA, Tansey EM. Innovations in pain management. Welcome witnesses to twentieth century medicine, vol 21. London: The Wellcome Trust Centre for the History of Medicine, 2004.
- 55 Meldrum M. The ladder and the clock: cancer pain and public policy at the end of the twentieth century. *J Pain Symptom Manage* 2005; **29**: 41–54.
- 56 Stjernsward J, Joranson DE. Opioid availability and cancer pain—an unnecessary tragedy. *Support Care Cancer* 1995; **3**: 157–58.
- 57 Higginson I. Palliative care: a review of past changes and future trends. *J Public Health Med* 1993; **15**: 3–8.
- 58 Clark D. History, gender and culture in the rise of palliative care. In: Payne S, Seymour J, Ingleton I, eds. Palliative care nursing. Principles and evidence for practice. Maidenhead: Open University Press, 2004: 39–54.
- 59 Stjernsward J, Clark D. Palliative care – a global perspective. In: Hanks G, Doyle D, Calman C, Cherny N, eds. Oxford textbook of palliative medicine, 3rd edn. Oxford: Oxford University Press, 2003.
- 60 Field MJ, Cassel CK. Approaching death. Improving care at the end of life. Washington, USA: National Academy Press, 1997.
- 61 Foley KM, Gelband H Improving palliative care for cancer. Summary and recommendations from the National Cancer Policy Board, Institute of Medicine, and National Research Council. Washington, USA: National Academy Press, 2001
- 62 Grady PA. Introduction: papers from the National Institutes of Health State-of-the Science Conference on Improving End-of-Life Care. *J Palliat Med* 2005; **8** (suppl 1): 1–3.
- 63 Mount B. The Royal Victoria Hospital Palliative Care Service: a Canadian experience. In: Saunders C, Kastenbaum R, eds. Hospice care on the international scene. New York, USA: Springer, 1997.
- 64 Carstairs S, Chochinov H. Politics, palliation and Canadian progress in end-of-life care. *J Palliat Med* 2001; **4**: 396–69.
- 65 De Lima L. Advances in palliative care in Latin America and the Caribbean: ongoing projects of the Pan American Health Association (PAHO). *J Palliat Med* 2001; **4**: 228–31.
- 66 Stjernsward J, Bruera E, Joranson D, et al. Opioid availability in Latin America: The Declaration of Florianopolis. *J Pain Symptom Manage* 1995; **10**: 233–36.
- 67 Chung Y. Palliative care in Korea: a nursing point of view. *Progress in Palliative Care* 1999; **8**: 12–16.
- 68 Maruyama TC. Hospice care and culture. Aldershot: Ashgate, 1999.
- 69 Hunt R, Fazekas BS, Luke CG, Priest KR, Roder DM. The coverage of cancer patients by designated palliative services: a population-based study, South Australia, 1999. *Palliat Med* 2002; **16**: 403–09.
- 70 Wang XS, Yu S, Gu W, Xu G. China: status of pain and palliative care. *J Pain Symptom Manage* 2002; **24**: 177–79.
- 71 The International Observatory on End of Life Care. A collaboration for global development. India. [http://www.eolc-observatory.net/global\\_analysis/india.htm](http://www.eolc-observatory.net/global_analysis/india.htm) (accessed 10th April, 2007).
- 72 Shabeer C, Kumar S. Palliative care in the developing world: a social experiment in India. *EJPC* 2005; **13**: 76–79.
- 73 Morris K. Cancer? In Africa? *Lancet Oncology* 2003; **4**: 5.
- 74 Wright M, Clark D. Hospice and palliative care development in Africa. A review of developments and challenges. Oxford: Oxford University Press, 2006.
- 75 Harding R, Stewart K, Marconi K, O'Neill JF, Higginson IJ. Current HIV/AIDS end-of-life care in sub-Saharan Africa: a survey of models, services, challenges and priorities. *BMC Public Health* 2003; **3**: 33.
- 76 Sepúlveda C, Habiyambere V, Amandua J, et al. Quality care at the end of life in Africa. *Br Med J* 2003; **327**: 209–13 .
- 77 Harding R, Higginson IJ. Palliative care in sub-Saharan Africa. *Lancet* 2005; **365**: 1971–77.
- 78 Clark D, Wright M. Transitions in end of life care. Hospice and related developments in Eastern Europe and Central Asia. Buckingham: Open University Press, 2003.
- 79 ten Have H, Clark D, eds. The ethics of palliative care: European perspectives. Buckingham: Open University Press, 2002.
- 80 Barcelona Declaration on Palliative Care. *EJPC* 1995; **3**: 15.
- 81 Poznan Declaration. *EJPC* 1998; **6**: 61–65.
- 82 Cherny NI, Catane R, Kosmidis P. ESMO takes a stand on supportive and palliative care. *Ann Oncol* 2003; **14**: 1335–37.
- 83 EURAG project. <http://www.eurag-europe.org/palliativ-en.htm> (accessed March 28, 2007).
- 84 Davies E, Higginson IJ, eds Better palliative care for older people. Copenhagen: World Health Organisation, 2004.
- 85 Davies E, Higginson IJ, eds. Palliative care: the solid facts. Copenhagen: World Health Organisation, 2004.
- 86 Clark D, Centeno C. Palliative care in Europe: an emerging approach to comparative analysis. *Clin Med* 2006; **6**: 197–201.
- 87 Mapping levels of palliative care development: a global view. [http://www.eolc-observatory.net/information/presentations/flash/mwright\\_250107.swf](http://www.eolc-observatory.net/information/presentations/flash/mwright_250107.swf) (accessed March 28, 2007).
- 88 Sloan F, Gelband H, eds. Cancer control opportunities in low- and middle-income countries. Washington, USA: The National Academies Press, 2007.
- 89 World Health Organisation. Cancer pain relief and palliative care. WHO Technical Report Series 804. Geneva: World Health Organisation, 1990.
- 90 Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organisation's global perspective. *J Pain Symptom Manage* 2002; **24**: 91–96.
- 91 NICE. Support and palliative care. <http://www.nice.org.uk/guidance/csgsp> (accessed March 28, 2007).