

DYING WITH DIGNITY



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With a foreword by
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Office of Health Economics

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- To investigate other health and social problems.
- To collect data from other countries.
- To publish results, data and conclusions relevant to the above.

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Foreword

This report from the Office of Health Economics looks at a very important aspect of medical care which is too often ignored. As Jane Griffin points out, about one quarter of all deaths in the United Kingdom are due to the cancers, and when deaths from other chronic diseases and those amongst the frail and elderly are added to this number, a large proportion of the population will end their days as 'terminally ill' patients. Sudden and unexpected deaths are less common.

Yet very little analysis has been carried out into the best and the most effective way to care for the dying. In recent years the hospice movement and the provision of specialist nursing facilities have made an important start towards tackling more systematically the provision of appropriate care for the terminally ill. Yet, as this report points out, to an increasing extent the majority of people die in ordinary hospital wards. These often cannot cater for the deeper social and psychological needs of the dying patient and the family. The majority of people would prefer to die comfortably at home, and their relatives would like that for them too. Yet in practice this does not happen, usually because the necessary nursing and medical support is not available.

Furthermore, while the hospices have set a commendable example in the control and prevention of pain in the dying, too many people still suffer during their terminal illness. In our humanitarian society this is unacceptable.

Finally, although costs should always be considered in relation to the well being of patients, there is a disturbing lack of hard economic information on the costs of different patterns of terminal care. It is clear that good quality hospice care, for example, is not a cheap option, when set against traditional hospital costs. Much more information is needed about both the costs and the benefits of different patterns of care for the dying.

It is greatly to be hoped that this report will focus more attention on the needs of the terminally ill, and will stimulate new research into the ways that patients can most often be allowed to 'die with dignity'.

Cambridge
February 1991

John Butterfield

Introduction

Advances in medical knowledge and medical technology have been for the most part of benefit to the health care of patients. Relieving the suffering and saving the lives of the critically ill where once it was impossible is today feasible. For example, premature babies or those born with serious disabilities who would in the past have died at birth are routinely being saved in special care baby units.

Stories of amazing life saving techniques and operations have become familiar reading in our newspapers and magazines. However, because medical technology can save life so effectively it may mean that a patient's life is preserved only to expose him or her to continuing pain and misery. Alternatively a patient's life may only be prolonged for a few months or years during which time the patient may be in severe discomfort and distress and unable to live independently. As Sir Richard Bayliss wrote in a leading article in the *British Medical Journal* (1982) 'In medical ethics, life is not the absolute good, nor death the absolute evil. Not to harm the patient (*primum non nocere*) has Hippocratic origins. To restore health or relieve suffering does not imply that it is ethically right to prolong life at any cost.'

It is hoped that this paper will assist in the understanding of what can be a complex moral and ethical decision, that is when is it appropriate to switch from curative treatment to palliative treatment. Obviously changing therapy from curative to palliative medicine to avoid the prolonging of life is contentious, but it should be clear from the start that this booklet in no way is advocating what was defined by the British Medical Association Working Party on Euthanasia as 'active intervention to shorten life' (1988). The report of the Working Party made a clear distinction between an active intervention by a doctor to terminate life and a decision not to prolong a life (a non-treatment decision). It is the decision not to prolong a life which is central to the concept of 'dying with dignity'.

Too often members of the medical profession are reluctant to make this difficult decision and one can sympathise with their dilemma. Stopping curative therapy and switching to palliative care is frequently seen as giving up and doing nothing to help the patient (Saunders C, 1984) although in reality the opposite may be true.

The failure to change to palliative therapy may result in the lives of some patients being prolonged although their lives may be of doubtful quality. There are two main groups, admittedly with a large degree of overlap, who are commonly affected in this way. Firstly, the terminally ill. Terminal disease by definition is a disease which has progressed beyond the point at which care aimed at remission or cure is possible, therefore for the terminally ill patient there is no real expectation of cure and death is certain (Soukop & Calman, 1977). The period of survival in a terminal state is highly variable. Terminal disease is commonly associated in the public's mind with cancer (malignant neoplasm). This may be due to the large number of people who die from cancer, in 1987 a quarter of all deaths in the United Kingdom were attributed to some form of malignant neoplasm (OPCS, 1988). However, it should be pointed out that a substantial proportion of patients with malignant neoplasms do make a full recovery.

4 The second group is the infirm elderly; this is not the average elderly

person who is physically well but rather, for example, the elderly person who has suffered a stroke from which he or she has only partially recovered who then contracts pneumonia. This paper concentrates primarily on the terminally ill but, because there is a large degree of overlap between the two groups the concept of care is very similar for both. It is fairly clear that if the number of people in the two groups are combined a substantial proportion of the population can expect to conclude their lives with a period of terminal illness.

What this paper is suggesting is that the form of treatment, for these groups of patients, be altered not purely for straightforward medical reasons but in the light of the patients' circumstances and wishes and the likely outcome of each of the therapies available so as to enable them to die with dignity. For example, it is questionable if it is in the patients' best interests if he is suffering from a terminal malignant disease for which there is no cure to continue to receive invasive, curative therapy which may cause distress. Far better for the patient would be a change to palliative medicine that is aimed at the relief of symptoms such as the associated pain which it is estimated that between 50 and 70 per cent of cancer patients experience (Parkes, 1978; Bonicca, 1985).

Despite the dedication of the medical and nursing staff in hospitals the experience of many patients and their relatives indicate that although hospitals have made great advances over the last few years in effective pain control techniques they are still unable to offer the kind of highly personalised care associated with the smaller hospice unit. There appear to be two main reasons for this failure; firstly, the staff:patient ratio in hospice is much higher than in hospital, being in the region of 1.5 to 2 members of staff per patient plus considerable volunteer support (these staffing levels are more comparable to a hospital acute ward than that of a longstay or geriatric ward); secondly, there is a lack of training for staff in the care of the dying particularly in the area of psychosocial care. Even where there are appropriately trained staff, the hospital ward and the ward schedules are planned in such a way that the atmosphere is not conducive to this kind of care.

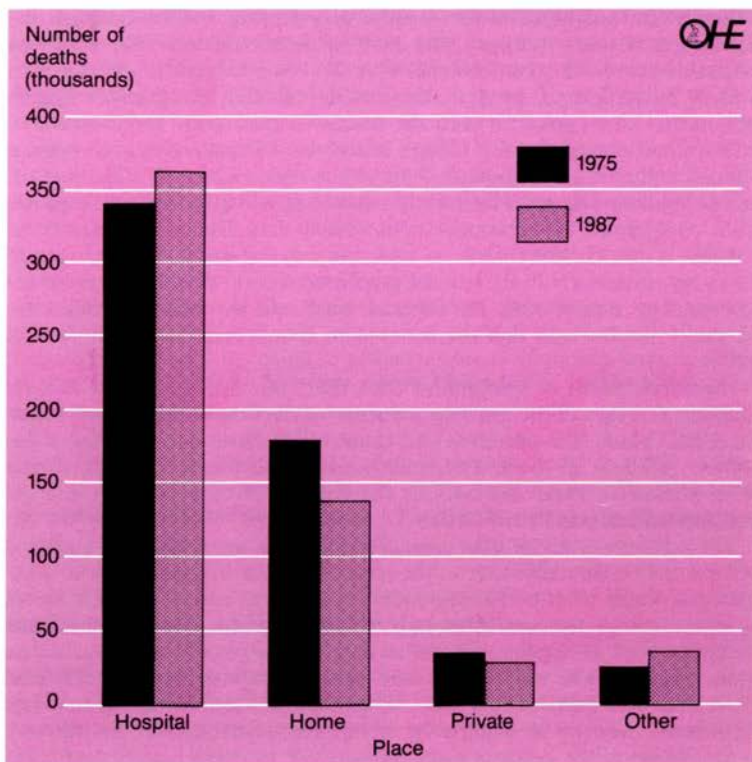
The development of Continuing Care Units attached to District General Hospitals is a sign of the growing influence of the hospice movement within the NHS. There are currently 12 Continuing Care Units, each having between 10 and 25 beds. The units were initially funded by the Cancer Relief Macmillan Fund and built in the grounds of NHS hospitals, but are now funded and run by the NHS.

The different types of care available at home, in a hospital and in a hospice will be discussed later in the paper, however it appears that it is not sufficient simply to state that one form of care is the correct one and should be offered to all patients. Although it should be the aim that the dying patient be kept as comfortable and as pain free as possible the patients and their relatives are individuals and will consequently have different preferences and needs. What may be appropriate care for one patient and their family may not be required by others. The available care, and the care most suitable to the needs of each patient, be it hospital, hospice and home are discussed in the paper.

The costs of providing the care in each of the aforementioned places

together with the perceived benefits to the patients are reviewed. However, it is evident that a considerable amount of research is required in this area. There is a real need for good economic analyses of the costs and benefits of the different patterns of care for the terminally ill. Perhaps what is most needed is a large scale study comparing the costs and benefits of providing terminal care at home, in hospital, in a Continuing Care Unit and in a hospice. At present there is very little hard information about the costs of providing care in each of these settings and what information exists about the benefits to patients and/or the outcomes of care is almost entirely based on anecdotal evidence collected after the patient has died. Better research is essential if we are to ensure that terminal care is delivered appropriately in the future and people end their days in the place most suited to their needs, those of their family and carers and the health service as a whole.

Figure 1 **Place of death, all causes, England and Wales 1975 & 1987**

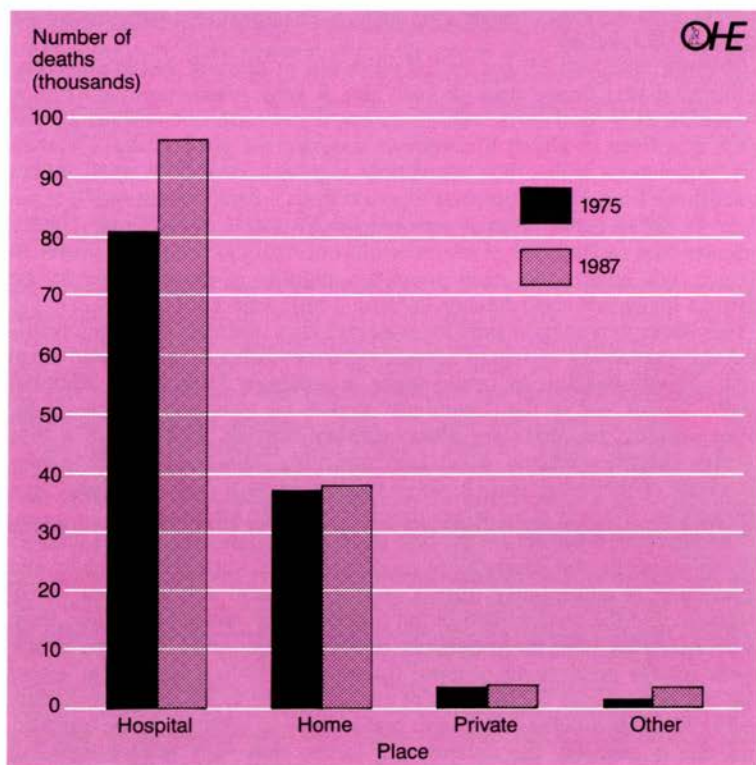


Where people die

Since the 1950s there has been a developing trend towards hospital deaths, this trend can be seen in the pattern for all deaths and for deaths from malignant neoplasms (Figures 1 and 2). If the present trend continues we may approach the situation, current in Scandinavia where 90 per cent of all deaths occur in hospital (Doyle, 1980). In the last 20 years the number of people dying in NHS hospitals has been steadily increasing and in 1987 56 per cent of all deaths in England and Wales took place in an NHS hospital.

Many factors play a part in this trend, but the implications have far reaching consequences both for the medical and nursing professions and the community services. Attitudes to death and medical advances as well as a number of inter-related demographic, economic and social factors have contributed to this change in the place of death from home to hospital.

Figure 2 **Place of death for neoplasms in England and Wales 1975 & 1987**



Source: Hospital In Patient Enquiry

Between 1961 and 1986 the number of one person households increased from 12 per cent of all households in 1961 to 25 per cent in 1986 (General Household Survey (GHS)). The elderly are more likely to live alone than any other age group and it is calculated that in 1986 29 per cent of those aged 65 to 74 and 48 per cent of those aged 75 and over did so. This compares with a figure of less than 10 per cent for people living alone in other age groups. Elderly women are particularly likely to live alone, reflecting the fact that women live longer than men. Clearly if people are living alone, particularly if they are also elderly (71 per cent of all patients with malignant neoplasms are over the age of 65), there are problems in caring for them in their own homes should they become terminally ill.

Another factor which may in part explain the trend towards hospital deaths is the fact that young adults frequently move away from the area in which they were brought up, usually to improve their employment prospects. Unfortunately, this means that an increasing number of elderly people live alone with no relatives nearby to care for them should the need arise. In addition, there is the increasing trend for women (who in the large majority of cases are the carers) to continue working after marriage. In 1986 63 per cent of married women were employed (General Household Survey). This obviously means that there is less scope for them to care for terminally ill relatives.

However, although 56 per cent of all deaths in England and Wales occur in hospital this figure may in fact give a false impression of what is happening at a local level. Whilst statistical data are not collated by the OPCS in a form in which it is easy to compare the place of death among rural populations with urban populations it is fairly clear from small studies which have been carried out that a person from a rural community is more likely to die at home than a person from an urban area. Doyle (1980) indicates that the number of urban deaths occurring in hospital is nearer to 70 per cent whereas in rural areas the majority of deaths occur in the patient's home (see also reference to Herd, 1980, page 18).

This distinction may in part be explained by a different attitude towards and the availability of health service resources between urban and rural areas. People residing in urban areas increasingly look to the National Health Service and/or the community services for assistance and whilst for many patients hospitals are alien territory (Taylor, 1983) with a bias towards curative medicine, which may mean that they are less able to meet the needs of the dying patient, there appears to be a prevailing belief that hospitals are the only place where serious illness can be treated.

The idea that hospitals are the best place for patients with serious illnesses fails to recognise the strengths of modern primary care and the skills and experience of community nurses, many of whom are attached to GP practices, and the contribution of the hospices. This notion would also seem to be in conflict with the commonly held view that, given a choice, people would usually prefer to die at home (Lamerton, 1980). It would also appear that not only would the majority of patients prefer to die at home (Parkes, 1985) but their families would also prefer death to occur at home provided, and this is probably the determining factor, that they receive sufficient support from health care professionals and social services (Wilkes, 1984).

only three per cent of relatives of patients who died at home subsequently stated that they would have preferred that the death had occurred in hospital. Parkes (1980) found that in a study of domiciliary care in which nearly all the patients had either died in hospital or a hospice, 62 per cent of patients who died in the hospice were said by their relatives to have wanted admission, the remainder had accepted admission reluctantly. In contrast the same study found that only 24 per cent of patients who had died in hospital had wanted to be admitted.

In a recent study conducted by Townsend *et al* (1990) to assess the preference of terminally ill patients with cancer for their place of final care it was found that 84 per cent of the patients interviewed stated a preferred place of final care. Of those who stated a preference 58 per cent indicated that they wished to die at home given existing circumstances, 20 per cent wished to die in hospital, 20 per cent wished to die in a hospice and two per cent wished to die elsewhere. However, whilst their own home was the preferred place of care for 94 per cent of patients who died there, 69 per cent of patients who died in hospital had previously stated a preference to die elsewhere.

While fewer patients actually die at home than in hospital, recent improvements in medical techniques together with developments in community care have resulted in the length of time which dying patients actually spend in hospital being considerably shortened. For the most part, patients will be cared for at home with a final admission of only a few days (Taylor, 1983).

The need for care for the terminally ill

The terminal patient has been defined as one in whom, following accurate diagnosis, the advent of death is certain and not too far distant and for whom treatment has changed from the curative to the palliative (Yorkshire Oncology Organisation, 1973). The terminal stage for many patients lasts for only a few days and conventional services are therefore reasonably well equipped to meet the patient's needs. The difficulty arises for patients with certain cancers, conditions like Hodgkin's disease, motor neurone disease and more recently AIDS, where the terminal phase may last for months or even years. Conventional services have in the past proved to be unwilling or unable to cope with the severe physical and mental distress that may follow.

For the purposes of this paper attention has primarily been focused on patients with malignant neoplasms (this includes all cancers, leukaemia and Hodgkin's disease). The main reasons for doing this are firstly, the fact that the care available for these patients outside and increasingly within the NHS is better developed. Secondly, although it is by no means perfect, the statistical information required is more readily available. Thirdly, the number of patients dying from all forms of malignant neoplasms, now and projected, is far higher than any other terminal illness. The type of care required by all patients who are terminally ill is very similar and much of what will be stated later in the paper can be applied to patients with other terminal illnesses and also to the infirm elderly.

Estimates of the need for terminal care are difficult to assess but are vital to any rational planning of services. In 1987 a quarter of all deaths in the United Kingdom were attributed to some form of malignant neoplasm and 71 per cent of the deaths from malignant neoplasms occurred in those aged 65 and over (OPCS, 1988) (see Table 1). Malignant neoplasms accounted for 23 per cent of all deaths among the over 65 age group and 18.5 per cent among the over 75s. The number of deaths by age and sex in England and Wales in 1987 for all causes and for neoplastic disease are given in Figures 3 and 4. It is projected that (if there is a 1 per cent rise per annum) in 2031 in the United Kingdom there will be 342,959 deaths attributed to malignant neoplasms (see Figure 5), over 77 per cent of these deaths occurring in those aged 65 and over.

The growing elderly population has important implications for the planning of terminal care services. In 1985 there were 429,000 NHS hospital admissions¹ for patients with malignant neoplasms in England (HIPE). This figure represents 8.5 per cent of admissions for all causes but this rises to 13.8 per cent of admissions in the over 65 age group. Two severe drawbacks of Hospital In-Patient Enquiry data are that they fail to identify readmissions and do not identify the sizeable proportion of patients with malignant neoplasms who make a full recovery. It is therefore not clear how many of 429,000 discharges and deaths were new cases and how many were readmissions.

However, if it is taken that patients with terminal malignant neoplasms are admitted on between two and three separate occasions in their final year (Doyle, 1980 calculated that a patient with terminal cancer will spend 90 per cent of their final year of life at home) it is clear that with a mean

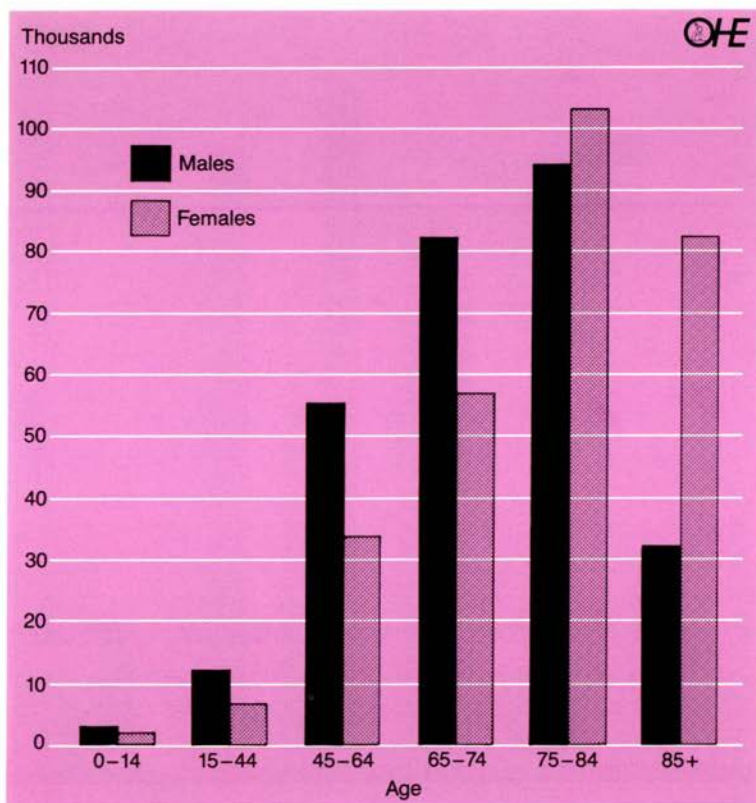
Table 1 Age and sex distribution of deaths from malignant neoplasms, United Kingdom* 1988

Sex	<i>Number of deaths by age (% of total)</i>					<i>All</i>
	<i>0-44</i>	<i>45-64</i>	<i>65-74</i>	<i>75-84</i>	<i>85+</i>	
Male	2,660 (2)	20,205 (13)	28,794 (18)	25,780 (16)	5,727 (4)	83,166 (53)
Female	3,561 (2)	18,505 (12)	21,526 (13)	23,239 (14)	10,119 (6)	76,950 (47)
Total	6,221 (4)	38,710 (25)	50,320 (31)	49,019 (30)	15,846 (10)	160,117 (100)

* Figures based on OPCS figures for England and Wales and adjusted for population size.

¹ The Hospital In-Patient Enquiry (HIPE) gives data relating to all deaths and discharges occurring in hospital. However, in terms of this report it makes more sense to talk of hospital admissions and it has been therefore assumed that all patients recorded in HIPE have been admitted to hospital prior to their discharge or death.

Figure 3 All deaths; England and Wales 1987

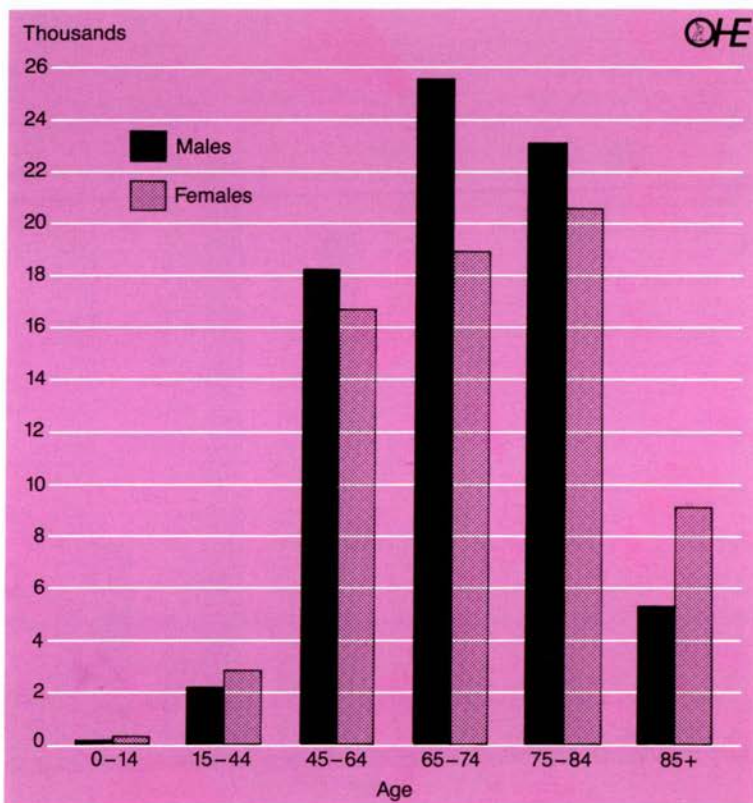


Source: OPCS

duration of stay of 11.6 days and 429,000 admissions giving a total of nearly 5 million bed days (HIPE, 1985) a considerable amount of NHS hospital resources are being expended. Unless there is a change from the management of terminal cancer patients in hospitals it is to be expected that the increasing number of elderly in the population will increase their share of hospital resources.

If there is to be a change in the management of terminal cancer patients towards home based care and for death where possible to take place at home consideration will have to be given to the fact that not only are the numbers of elderly growing but also that a substantial and increasing proportion of them live alone. The 1987 General Household Survey indicates that 38 per cent women in the age group 65-74 and 61 per cent in the over 75 age group live alone. This contrasts with men among whom 16 and 28 per cent live alone in the same age groups.

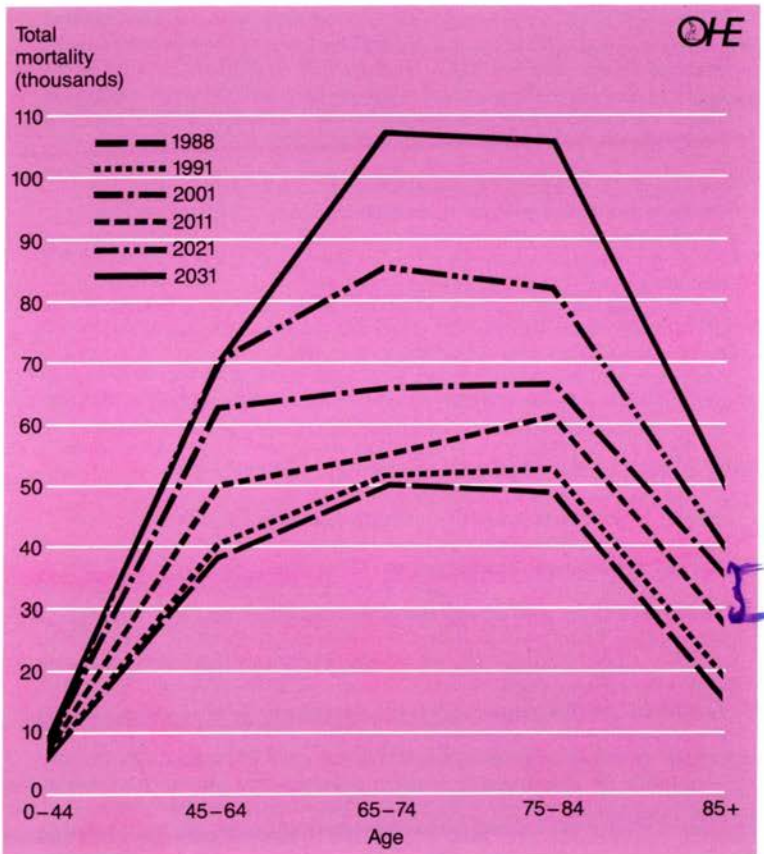
Figure 4 Deaths from neoplastic disease; England and Wales 1987



Source: OPCS

A further related difficulty is that where the patient does not live alone but with their spouse, who usually acts as the main carer, it follows that if the patient is elderly their spouse is likely to be of a similar age and may also be in poor health. It has been found that at least 70 per cent of all carers (Cartwright, 1972; Johnson *et al*, 1988), who are usually either the patient's spouse or a close relative, are women (see Table 2). In addition, more than 2.5 million elderly people are looking after someone older, more ill and frail than themselves. Of the estimated six million carers nationally who provide a regular unpaid service to friends or relatives 42 per cent are over the age of retirement (Carers' National Association, reported in *The Times*, May 1990). The age of the carer is significant. Wilkes (1984) found that the difficulties of the relatives were more often a cause for hospital admission than those of the patients.

Figure 5 **Estimated UK cancer mortality - assuming 1 per cent annual rise for all ages**



Source: OHE

NHS hospital, 12.1 per cent died in other hospitals or institutions for the care of the sick outside the NHS, this figure would include hospices outside the NHS and only 26.8 per cent died in their own homes (the remaining 5.9 per cent of patients died in a variety of other institutions both public and private including psychiatric hospitals and prison). Whilst these figures, together with the sheer numbers of patients affected, show something of the scale of the problem and the need for care, the symptoms, distress and pain are not revealed. These figures also do not show the numbers of terminally ill patients who are nursed at home, often for long periods of time, until their families are no longer able to cope and they have to be admitted to a hospital or hospice.

Table 2 **Principal carers**

<i>Carer</i>	<i>%</i>	<i>Numbers based on Carers' National Association figures*</i>
Husband	20	1,200,000
Wife	53	3,180,000
Son	2	120,000
Daughter/in-law	20	1,200,000
Other	5	300,000

Source: Johnson *et al.* 1988 Carers' National Association. 1990.

* There are an estimated six million carers nationally.

Models of care

In the last twenty-five years great advances have been made in the care of the terminally ill. The majority of these advances are due to the work of the hospices and health workers like Dame Cicely Saunders (for a history of the hospice movement see Box 1). When Dame Cicely established St Christopher's Hospice in 1967 the aim was to provide a place not only where effective care could be given to the terminally ill but also where research and teaching could take place. St Christopher's became the catalyst and the model for hospice care both in the United Kingdom and the United States. The philosophy of hospice care has been to offer the patient a service tailored towards palliative rather than curative care, an acceptance of dignified death and a focus on the psychological and social needs of the patient and his family. Although originally established for the care of patients with cancer, hospices usually accept patients with motor neurone disease and today some are beginning to accept patients with AIDS (Box 2).

It has not always been possible to build a special purpose-built institution and a variety of approaches are evident today (Figure 6). Prominent in the United Kingdom has been the involvement of the National Society for Cancer Relief which since 1975 has been involved in the establishment of many of the Continuing Care Units and home care programmes.

Box 1 **The history of the hospice movement**

From the fourth century AD Christians welcomed pilgrims on their journey to the holy sites into what came to be known as hospices. The hospices offered a special kind of hospitality with a common religious commitment recognising the importance of their guests and of the pilgrimage they were undertaking. Gradually they undertook to care for the sick and elderly and by the Middle Ages the hospices could almost be described as providing a form of national health service.

Following the dissolution of the monasteries by Henry VIII the sick and poor suddenly found that they had nowhere to go. Gradually some of the old hospices reopened, although the name was rarely used, but the new hospitals had taken over the care of the sick.

In the mid-nineteenth century Mary Aikenhead opened the first modern hospice in Dublin. She had founded an order of nuns called the Irish Sisters of Charity, one of their main duties was to care for people who were dying. The nuns began by caring for the patients in their own homes, however, it became clear that there was a need for a special kind of nursing home which was quieter and smaller than a busy acute hospital but also had the same facilities for bedside nursing. It was Mary Aikenhead who first applied the old name of hospice to this special kind of home. She considered death to be the beginning of a journey, a thoroughfare not a terminus, and the old name of the resting places on the pilgrimage to the Holy Land seemed appropriate.

At the beginning of the twentieth century the Irish Sisters of Charity opened a similar house in London, St Joseph's Hospice. At around the same time St Luke's Home for the Dying Poor (now known as Hereford Lodge) was opened by the Methodist West London Mission.

However, it was not until the 1950s and 60s that the hospice movement really began to become the movement that is recognised today. Two developments in the 1950s provided the necessary impetus for change. Firstly the establishment of the Marie Curie Foundation which aimed to fight the consequences of malignant disease. An early survey by the Foundation highlighted the need for more hospices to be opened and today the Foundation provides 11 homes and 4,800 part-time Marie Curie nurses who nurse patients in their own home.

The second development started through a Polish refugee named David Tasma who whilst dying in a London teaching hospital discussed his needs with the social worker. The social worker's name was Cicely Saunders. David Tasma left her £500 in his will 'to be a window in your home'. This set Cicely Saunders on what was to be her life's work. Already qualified as a nurse she gave up social work to study medicine. On qualification she went to work at St Joseph's Hospice as its first full-time medical officer. She strongly believed that pain for the dying was unnecessary and set about proving it.

After years of researching pain control and planning for a special kind of home and its care, in 1967 Dr Saunders opened St Christopher's Hospice, Sydenham. From the development of her ideas a whole system of terminal care has emerged both in the United Kingdom and abroad.

Source: Lamerton, 1980 and Saunders, 1988.

Box 2 Provision of care for people with aids

Whilst much of what has been stated in this report can be applied to terminal care for AIDS patients there are some differences with the majority of other terminal conditions which are worth noting. Firstly, people with AIDS are, in the vast majority of cases, male homosexuals or drug abusers and although it is anticipated that there will be a substantial increase in the incidence among non-drug abusing heterosexuals a stigma has become attached to AIDS unlike any other disease.

Secondly, while 75 per cent of cancer patients are over 60 years of age AIDS patients tend to be relatively young. This presents great problems both for the patient in coming to terms with dying but also for their friends and family who may experience a confusing array of emotions. These relate both to the kind of disease AIDS is perceived to be and the youth of the patient and may range from a very obvious sense of bereavement, both before and after death, to a partner's fear that he might too develop AIDS. For some families the feeling that they are unable to talk openly about their relative's condition, a parent will frequently say to friends and neighbours that their son or daughter is dying of cancer rather than give the truth. At the same time there is the not unreasonable hope in an area of intensive medical research that they might be the lucky ones and a cure will be found.

Thirdly, the very nature and pattern of AIDS as a disease means that patients who seem to be in the final stages of the illness and are in need of constant nursing care can make a recovery to the point at which they are able to live to a large degree independently. Whilst this not a problem in itself it does mean that the hospice concept of palliative care cannot always be strictly applied. Many AIDS patients will continue to receive curative/interventionist therapies like AZT and blood transfusions even in the final stages of their illness.

The hospice movement has played an important part in the planning of services for patients with AIDS. In the few units which deal exclusively with AIDS patients the model of care is similar to that of hospices in that it is nurse intensive and patient orientated rather than a medical model of care. Whilst many hospices do accept patients with AIDS, others for a variety of reasons do not. Some hospices will not accept patients unless they have cancer, they may be bound by the terms of their trust or they feel that until they are able to meet all the needs of cancer patients in their community they are not in a position to help other groups. Other hospices refuse AIDS patients because they feel that they would not be able to meet the particular needs of this group of people.

In 1989, the Elizabeth Unit at the Mildmay Hospital, Hackney was selected as the national model for AIDS hospice care. The Mildmay is an independent, Christian charitable hospital. The unit offers terminal care to anyone who is considered by their general practitioner/consultant to be in the terminal phase and for whom admission to the unit would be geographically appropriate. In addition continuing care in the form of short term convalescence and rehabilitation, respite care to give both the patient and carer a break, and long term care for those for whom constant nursing supervision is needed and home care is not practicable are provided. The table below demonstrates the variations in duration of stay for 100 patients at the unit.

continued

Length of stay

(100 admissions = 80 patients)

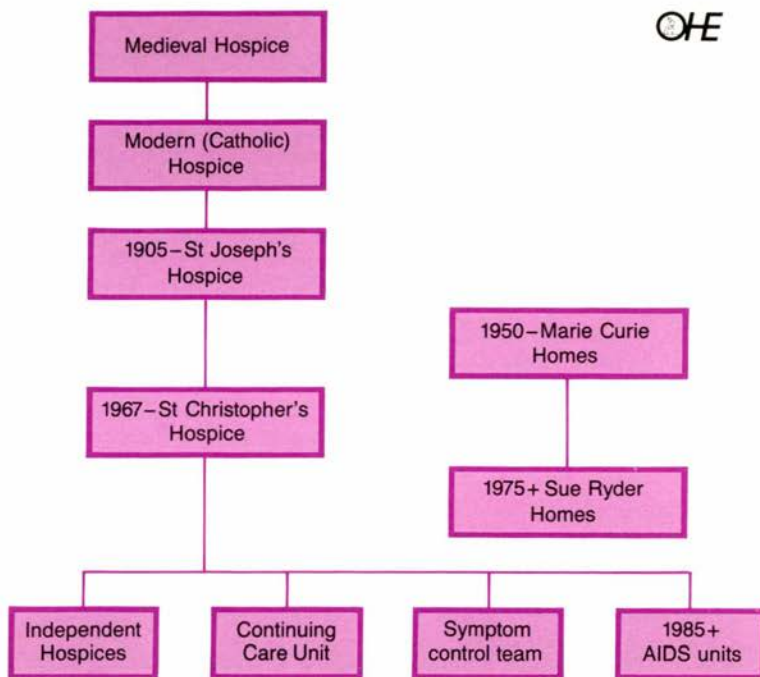
<i>Length of stay</i>	<i>Percentage of Patients</i>	<i>Comment</i>
< 24 hours	5	
1-7 days	27	
8-14 days	18	
15-28 days	21	Problems with housing often leads to patients staying longer than expected initially. Some need extended stays for rehabilitation.
29-42 days	7	
43-84 days	11	
> 85 days	11	9 were admitted for long term care.

Source: Elizabeth Unit, Mildmay Hospital, Hackney.

The unit provides individual in-patient facilities for 17 patients at any one time at a cost per day per bed of £160.60 in 1990. Contracts for the beds are held with the four Thames Regional Health Authorities and each pay a percentage of the running costs according to their use. The annual budget for running the unit plus the home and day care services is in the region of £3 million. The Department of Health makes a care revenue contribution of £130,000 but even with charitable donations it is anticipated that in 1990 there will be a deficit of £24,000. The largest portion of expenditure (as with most hospices) goes on staffing. It has a high nursing staff to patient ratio (1 nurse to 1.5 patients over 24 hour period) and in addition to medical staff has two full-time counsellors, a patient welfare officer, a physiotherapist, occupational therapist, music and art therapists as well as 72 trained volunteers (approximately 220 hours of time per week).

It is expected that the Mildmay home care team will cost £392,000 to run in 1990. The team enables people to remain at home if that is their wish and receive continuing care. The team co-operates with existing statutory and voluntary services to offer symptom control advice, nursing advice, support and counselling for both patients, relatives and carers and bereavement support. The day care services, it is projected will cost £147,500 in 1990 to operate. It had been hoped to expand both these facilities but at the present the Mildmay is prevented from doing so by lack of funds.

Figure 6 **The development of hospice care**



Source: Adapted from Twycross, 1980

There are various models of care for the terminally ill. At present the majority of all patients die in hospital. For the terminally ill this often means dying on a busy acute ward because of the lack of bedspace in side wards and without the attention of staff specially trained in the care of the dying and pain control. There are often inadequate facilities and a lack of privacy for relatives who wish to be with the patient and/or there may be no satisfactory place for the professional staff to interview and support patients (Walsh and Kingston, 1988). Wilkes (1984) found that over 50 per cent of junior doctors and nurses thought that their training in terminal care had been inadequate and most of the nurses felt that the wards were too busy to be suitable for the care of the dying.

In a study of 157 patients who died of malignant disease in West Cumbria, a semi-rural area, (Herd, 1980) following a period of terminal care longer than a week, it was found that 53 per cent of patients died at home compared with metropolitan areas where estimates vary between 24-41 per cent. In addition over a third of patients who died in hospital were in for a week or less and of these patients over a half were in acute wards which are generally acknowledged as being unsuitable for dying patients. The nurses in this study were especially critical, 34 per cent felt their nursing training was inadequate for the problems encountered and 30 per cent considered

that they were unable to give the care that they wished due to the ward being too short staffed to allow them time to attend to the needs of the dying patient. One quotation helps to demonstrate the position in which nurses were placed, 'sometimes we did not have enough time to spend with X, just to talk or listen to him. He did not have a lot of visitors, so a lot of the time he was on his own. I would - we all would - have liked more time to spend and just sit with him' (Herd, 1980). It is clear from this quotation that a decision about the best use of the available resources - in this case the nurses' time - has been made. Whilst this decision is not necessarily a conscious one, the result is that spending time talking to dying patients has effectively been judged to be less important than other demands on the nurses' time.

Patients are generally admitted to hospital as a result of a combination of three main factors. Firstly, the inability to control symptoms of disease adequately, for example the associated pain, constipation and loss of appetite. This may be due simply to inadequate planning. The non-availability of pain relieving drugs for emergencies and infrequent assessment of needs both in terms of drug requirement and medical and nursing support may lead to a patient's admission to hospital.

Secondly, for some dying patients there may be no family and friends to care for them at home, making it impossible for them to remain there despite support from nursing and Social Services and their general practitioner. Where a patient does have a family and or friends to care for them there may come a time when the carers are no longer able to cope even with support.

Thirdly, patients may be admitted as a result of a lack of Social Service support. Carers are often unaware of what resources are available to assist them until it is too late and either the situation has deteriorated to a level where admittance is necessary or the patient has died. The services provided by the Social Services include (not all these services are available in all areas) nursing aids like ripple mattresses and sheepskins to prevent bedsores; bathing aids like hoists or seats; meals on wheels; home help; laundry services and financial help with heating bills and care allowances. In an audit of terminal care in one general practice conducted in 1988 (Blyth, 1990) the views of available relatives of 50 patients who had had terminal illnesses and had died in 1987 were asked whether they were satisfied with the terminal care given and what aspects of health they would have liked more help with. Whilst in the main the results showed that most relatives were satisfied with the care received, in 16 per cent of cases the doctors were dissatisfied with the terminal care given and in 18 per cent of cases the relatives were dissatisfied. The main reason for dissatisfaction by relatives was poor communication between the doctor and themselves whereas the doctors were not only dissatisfied with poor communication but also poor symptom control (see Table 3).

When relatives were asked what aspects of health care they would have liked more help with (although requests for help had been few) comments received suggested that there was a greater need for assistance than that being provided. Several relatives said that they would have welcomed more help and advice on bathing, others thought they would have coped better if they had been given bath aids. One relative was not aware that

Table 3 Cases in which relative or general practitioner, or both were not completely satisfied with care given in terminal illness.

<i>Sex</i>	<i>Age (years)</i>	<i>Place of death</i>	<i>Relative's comments</i>	<i>Doctor's comments</i>
F	67	Hospital	Poor communication	Poor communication poor symptom control
F	81	Hospital	Poor communication GP could have improved communication	Poor communication
F	64	Hospital	Nursing help offered too late	Poor symptom control
M	53	Hospital	Refused to be interviewed	Poor symptom control
M	75	Home	No relatives living locally to be interviewed	Not satisfied: family distressed at patient dying alone
F	79	Hospital	Satisfied	Unable to carry out terminal care at home
M	96	Hospital	Satisfied	Poor symptom control
M	79	Hospital	Satisfied	Inadequate support for family
F	71	Hospital	Wanted more GP support	Satisfied
M	69	Hospital	Wanted more help with bathing aids	Satisfied
F	92	Hospital	Poor medical care	Satisfied

Source: Blyth, 1990

incontinence pads were available. Several relatives stated that they had not thought to ask for support or that help had arrived too late. The results of this study clearly indicate that relatives were often unaware of what services and nursing aids were available and may also have been reluctant to mention some of their problems to their doctor, to have an outsider in their home or even admit that they were in need of help. From an economic viewpoint it is likely that these services and nursing aids could be provided relatively cheaply and it is probable that the benefits received by patients and their carers would far outweigh the costs.

Help and support should be offered and should not have to be asked for. At present, although only 30-40 per cent of patients die at home the average patient will spend 90 per cent of their final year at home under the care of the general practitioner (Doyle, 1987). Therefore, it is the general practitioner who is in the best position to anticipate the problems that relatives are likely to experience and plan the use of the available professional services.

In a study to identify the reasons for admitting terminally ill cancer patients to hospital, where they subsequently died, in Trafford Health District (Walsh & Kingston, 1988), it was found that 40 per cent of patients admitted were so seriously ill with pain, medical or nursing problems that their carers could not manage at home and hospitalisation was therefore required. In addition 27 per cent of patients admitted had no family or friends to nurse them at home. In the remaining 33 per cent of patients planned admissions and better supportive communications might have allowed these patients to die at home. The study concluded that there were three principal reasons for continuing to provide hospital beds for terminally ill cancer patients. Firstly, to provide medical and nursing care, secondly, to provide care for those patients with no family or friend carer support and thirdly, for the teaching of the management of the terminally ill by senior staff.

An alternative to hospital admission for some patients may be found in the hospice movement. However, with only in the region of 2,600 (1989) in-patient hospice beds facilities are very limited and only six to seven per cent of cancer patients actually die in a hospice. Hospice care is provided in a variety of ways, through independent hospices (Box 3), Macmillan Continuing Care Units (Box 4), NHS funded units and teams, and also by two national charitable organisations, the Marie Curie Memorial Foundation and the Sue Ryder Foundation. A summary of established UK hospice in-patient units as at 31 December 1989 is given in Table 4. Although all these models of care are guided by the same aims, that is to ensure that the life remaining to any given patient is of the highest possible quality, the means by which the aims are achieved may be slightly different.

Admission to an independent hospice may be as a result of a referral by either the patient's general practitioner or by their hospital doctor. The Continuing Care Units, also predominantly take referrals from the community. However, because they are usually situated in close proximity to an NHS hospital, they are in a position to give considerable advice to the staff in the hospital and take over the care of patients with particularly difficult problems (for example, patients in whom it has been found difficult to control their pain). Independent hospices and Continuing Care Units

Box 3 The development of the Dorothy House Foundation, Bath

In common with most hospice services the Dorothy House Foundation was established in response to a perceived need. The Foundation is a Christian one, organised to provide skilled and appropriate care for patients in the terminal phase of illness, and to support the whole family at this time and in bereavement. It seeks to further understanding in this field and to provide opportunities for skill development among both professional staff and the local community. It works in close co-operation with the NHS to supplement the existing facilities in the Bath Health District.

The first stage in the planning of the Dorothy House Foundation was to provide a domiciliary service and this was set up in January 1977. The original aim of the service was to provide additional help and support for terminally ill patients within the framework of the primary care team. The service expanded in response to its use and now receives referrals from a majority of general practitioners in the Bath Health District. The service is therefore available to a population in the region of 365,000, of whom approximately 80,000 live in Bath. In 1990 there are now 10 Macmillan nurses in the domiciliary team covering up to 150 patients at any one time. Of these 10 nurses, nine are funded by the local health authority.

The second stage in 1979 was to acquire a property to be used as a temporary back-up to the domiciliary service, providing some facilities for day patients and accommodation for six in-patients. The purchase was financed solely by specially designated gifts including a national appeal. Dorothy House is defined as an Assessment Unit which implies that its primary objective is to stabilise patient's care on a short stay basis, having said that it is possible for some patients, if the need arises, to remain until their death. Many patients who ultimately die in the unit have been able to return home prior to their final admission.

As a result of the prior establishment of the domiciliary service few patients have been referred only a few days before their death, for example in 1989/90, 90 per cent of admissions were from domiciliary referrals and of those admitted less than 30 per cent died in the unit, the majority being discharged home under the supervision of the domiciliary team. For hospices without the scale of support given by this home care team the pattern of admissions and discharges is significantly different.

The Dorothy House in-patient assessment unit is staffed by 10.02 whole time equivalent nurses (includes 3 part-time nursing auxiliaries) and 0.93 whole time equivalent volunteers (35 hours per week) plus one senior nurse manager. The mean occupancy of the six-bedded unit in 1988/89 was 73 per cent at a cost per occupied bed per day of approximately £82.26 (the cost has been calculated in the same way as that done for the NHS and is therefore directly comparable).

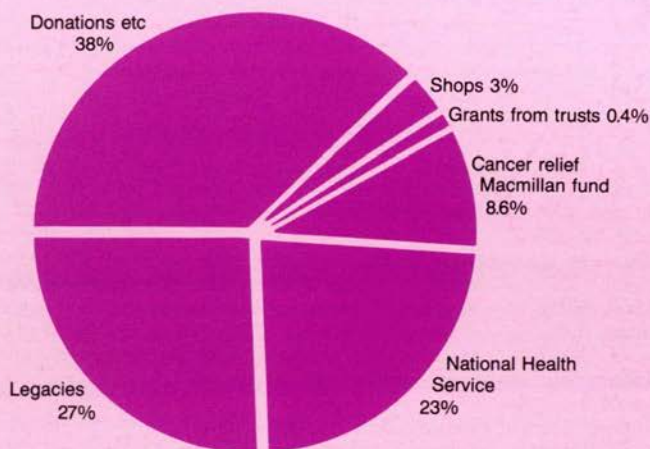
The third stage was to develop the educational programme and to make it available to professional staff and visitors. The education team is composed of a physician in Palliative Medicine and nurse consultants in Macmillan Services and Paediatric Services. Courses and workshops are available to a variety of professionals including doctors, clergy, district nurses and health care visitors. In addition, the team is becoming increasingly involved with the training of junior hospital doctors and student nurses.

continued

Perhaps because of its standing in the local community the Foundation has around 150 active volunteers who have been trained to deal with patients and others who perform a variety of administrative and maintenance tasks. Trained volunteers are carefully matched with patients in terms of age, interests and personality so that for example the patient will always have the same volunteer to drive him to the day centre and it is hoped that gradually a rapport and even friendship will develop. Obviously it is difficult for a volunteer if the patient that he has been involved with dies and the Foundation has found it increasingly necessary to set up support groups for volunteers. In general, volunteers are those members of the community who have spare time and are therefore frequently active retired men and women.

Financial support for Dorothy House comes from a variety of sources. A breakdown of the income for the year 1988/89 is given in the pie chart below. The Foundation is fortunate in that it is well established within the community and has the not inconsiderable financial support of the NHS. Few other independent hospices are as well placed.

Where the money came from – INCOME 1988/89



OHE

Source: Clench, 1984 and discussions with the staff of Dorothy House, 1990

Box 4 The development of Continuing Care Units

The Cancer Relief Macmillan Fund began building Continuing Care Units with the NHS in 1973. The first modern hospice in the UK, St Christopher's, had opened in 1967 and public attention had been focused on the inadequacies of the health service in meeting both the physical and emotional needs of patients with advanced cancer. The Continuing Care Unit was created to meet public demand for special facilities where patients could receive expert medical and nursing care in a busy hospital ward.

The majority of the units have 25 beds and are sited on hospital complexes so that whilst they are separate from the hospital they are linked to it for all 'hotel' services. Since 1973, 13 units have been built as well as eight two-bed mini units in Wales. The units were built on the basis that Cancer Relief raise the money for the building and equipment and the Health Authority take over the day to day running costs.

In the last twenty years advances in cancer patient care have been rapid. These developments have brought with them increased demand for further facilities and the units have had to adapt to meet patients' needs. In addition progress in pain and symptom control gave patients a much better quality of life. As a consequence in the late 1970s the approach to patient care became more multi-disciplinary incorporating a range of additional services.

Continuing care is essentially about enabling people to live and be cared for at home for as long as possible. The introduction of specialist Macmillan nursing teams was a major factor in improving the support available to help care for patients wishing to remain at home. Most of the home care teams in the UK are Macmillan nurses which have been funded, at least in part by Cancer Relief. Also of great importance was the development of day care to provide additional medical and social support for home-based patients. Together, these helped to reduce the need for in-patient admissions. Whilst beds were still required for assessment and respite care the number needed was clearly reduced.

The guiding principle underlying continuing care, whether in the community or hospital, is the notion of shared care. The multi-disciplinary skills centred in the unit are at the disposal of both the primary care team and hospital staff to help them enhance their ability to care for their patients. Cancer Relief believe that it is only by sharing their knowledge and working alongside other health care professionals that the care of cancer patients as a whole will improve.

In this light, the purpose behind Continuing Care Units was to provide an integrated service and education resource for a whole health district. Being sited in hospital complexes has meant that links can be established with major clinical departments in hospitals (oncology, radiotherapy etc) which not only can facilitate the sharing of care and the development of joint education but also ensures that all cancer patients whether at the point of diagnosis or receiving curative or palliative care can benefit from the facilities, skills and support the unit and its staff can provide.

Source: Cancer Relief Macmillan Fund, 1987.

Table 4 Established UK hospice in-patient units - at 31 December 1989

	<i>Number of units in each category</i>
Independent free standing units	91
Macmillan Continuing Care Units	12
Macmillan mini units	7
NHS Continuing Care Units	14
Sue Ryder Homes	10
Marie Curie Memorial Foundation	11
Total	145

Source: Adapted from Hill & Oliver (1988) and the Directory of Hospice Services (1990).

therefore differ in the type of care offered. A Continuing Care Unit, because of its special relationship with the hospital, is involved in many patients' care very early on in the 'incurable phase'.

The in-patient care provided in hospices and Continuing Care Units tends to be aimed at either symptom control and/or respite care. What is noticeable is the difference in discharge rates between hospices and Continuing Care Units. There are possibly two reasons for this difference, firstly Continuing Care Units try to ensure that patients return as soon as possible to their own homes with, if required, the support of a home care team and day care service. Patients may be admitted on more than one occasion prior to death but usually for short periods of time. Secondly, whilst most hospices would also aim to get patients back home with appropriate support they often become involved in the patient's care much later when the family is no longer able to cope at home or traditional in-patient facilities are unable to help further or are inappropriate. This is particularly the case if the hospice itself does not have a domiciliary service. They are therefore primarily concerned with the relief of the patients' symptoms, be they physical or psychological, and with supporting the family.

In addition to these in-patient facilities there are currently (1989) 277 home care teams. Most of these teams are funded by the Macmillan Cancer Relief Fund and are known locally as the Macmillan Service. Of these 277 teams, 102 are attached to in-patient units.

Home care teams are usually composed of a doctor specialising in terminal care, often with a background in radiotherapy or general practice, senior nurses, usually with a background in district nursing, and a social worker. Some teams also include a physiotherapist and a chaplain. The source of a referral to a home care team is in the majority of cases the patient's general practitioner but referrals may also be made by hospital consultants and by the supporting hospice.

The general practitioner is ultimately responsible for the care of the patient at home and the home care team should complement not undermine the services provided by the primary health care team. The aim of the home care teams is to support and advise general practitioners in

symptom relief, to provide emotional support for the patient and relatives, co-ordinate existing services, provide liaison with other specialist services and to enable admission should it prove necessary. Visits to individual patients vary according to the patients' needs. For some patients the visits may be weekly or less, whilst for some, often those referred late, visits may be daily or twice daily. Frequently this is more for the sake of the family rather than the patient.

The availability of adequate support services plays an important part in keeping patients at home. It is often thought that by the time a patient has reached the stage of requiring the services of a home care team maximum available use will have already been made of nursing services, home helps, social workers and local volunteers. In a study carried out in 1980 by Doyle in Edinburgh it was found that this was not the case (see Table 5). Although this study was undertaken ten years ago there is little evidence to suggest that the situation throughout the UK has improved.

Townsend *et al.* (1990) in a study of patients from Northwick Park Hospital and local community nursing services between August 1986 and September 1987 assessed that nearly two thirds of the patients in hospital for the last admission did not need 24 hour care but could have been adequately looked after with the support of visits from the continuing care and district nursing services, short term use of equipment such as pressure relieving mattresses and some home care support. Townsend *et al* estimated that over a quarter of those dying in hospital had a carer willing to look after them at home and wished for this option which would have been possible with fairly short term support from the health and social services. The study concluded that including the 29 per cent of patients who died at home for whom this was both their and their carers' place of choice, 44 per cent of patients could have been supported to die at home.

Table 5 The use of support services prior to the intervention of home care teams - Edinburgh 1979

<i>Support services involved</i>	<i>Percentage patients</i>	
	<i>Male</i>	<i>Female</i>
District nurse	52	64
Home help	14	29
Meals on wheels	3	4
Social worker	7	8
Church volunteers	20	31

A large proportion of hospices and Continuing Care Units run a day care programme for patients being cared for at home. These provide an opportunity for professional staff to assess how patients are managing practical chores, to arrange physiotherapy, a bath or other treatments requiring assistance and to assess medication. For patients who have been discharged from the hospice, the day care programme provides a continuing link with the in-patient staff, and for those patients who need to be admitted but who are reluctant to go into the hospice, it provides an opportunity for them to overcome their fears (Clench, 1984).

Perhaps of equal importance is the fact that the day care programmes provide a break from the routine, not only for the caring relatives and friends but also the patient. Frequently, diversionary activities are organised by staff and volunteers: these might include hairdressing, lunches and even occasional outings (see Box 3).

An extension of the hospice movement into the acute hospital sector is the establishment of Hospital Support Teams, of which there are now more than 40. These teams provide skills in symptom control and pain relief and give emotional support to patients as well as carers and in addition play an important role in the education of professional staff within the hospital. The team may be called in to advise on problems of pain or other distress by all the departments of a hospital. Some of these services also supplement the available care in the community.

The variety of methods, such as home care programmes and symptom control teams, by which care is given to the terminally ill by the movement emphasises that hospice is a concept of care rather than simply a specific type of institution. Twycross argues that the concept is not new but is instead an attempt to redress the balance in medicine. 'We are witnessing an attempt to re-emphasize that doctors, nurses and paramedics are in business to cure sometimes, to relieve often, to comfort always' (Twycross, 1980).

The philosophical and theoretical basis for hospice care is the nursing model. Much health care in society is still based on the traditional medical model of care, which is orientated more towards treating the condition/disease rather than the whole person, cure rather than palliation, concentration on the patient to the exclusion of the family, playing down the impact of psychosocial factors on physical well-being and an authoritative control of the patient by the doctor. The nursing and modern medical model of care emphasises the whole person, inclusion of the family and maximising the quality of life. All professionals practising hospice care broaden their focus beyond that defined within the traditional care setting. The emphasis is on meeting the patients' and their families' needs effectively rather than on maintaining professional boundaries.

The provision of care

Much of the practice of modern medicine expresses a basic denial of death rather than a confrontation of its reality as part of life (Fallowfield, 1990). Part of this is due to the substantial technological advances which have been made. But whilst more diseases are treatable (they may not also be curable) it should not be the norm merely to apply treatments because of their availability without first evaluating the likely benefits to be gained from active curative therapy as opposed to proper palliative support, that is skilled and compassionate nursing and effective pain control.

Although many doctors are able to provide and act with a great deal of care and concern for the quality of the dying patient's life, some are still unable to see death as anything other than a personal failure (Olin, 1982). Feifel (1976) found that medical students feared the whole concept of death more than other university students studying another subject and that qualified practising doctors feared death more than medical students. From this Feifel suggests that these doctors may find it difficult to accept that in the terminally ill patient certain therapeutic measures will not work and that they will persist in following active interventionist therapy, thereby denying the inevitability of death.

It is therefore easy to understand why patients are so often not told that they are dying. This is not to say that they do not know that they are dying, in fact the majority are aware that they are terminally ill. If they have not been told outright they usually pick up a series of verbal and non-verbal clues from both staff and relatives. A sudden visit from a friend or relative who has not been seen for years conveys a very definite message even if nothing has been explicitly said.

Fortunately, this attitude is beginning to change since misguided evasion may add considerably to a patient's distress and delay their adjustment to the idea of their impending death (Fallowfield, 1990). For those patients who, because of the desire of the medical staff to avoid distressing disclosures, fail to make the necessary adjustments are often unable to enjoy to the full the remainder of their lives. 'Experience has repeatedly shown that if a person is given the opportunity to learn the facts of his case, little by little, at his own pace, and provided he is encouraged to share with others the feelings which these facts evoke and provided that others are not constantly feeding back to him their own fears, he will move progressively closer to a full realisation of the situation without suffering overwhelming panic and despair' (Parkes, 1978).

Relatives who ask doctors to withhold the truth from the patient on the grounds that the patient would not be able to cope with the knowledge may in reality be expressing as much about their own fear of discussing the subject of death as an anxiety for their relative. Hinton (1980) interviewed a group of 80 married dying patients (the cause being a variety of malignant neoplasms) on average 10 weeks before their death and found that only 62 had previously discussed the fact that they were dying. Of these 62 patients, 69 per cent spoke of dying to their spouse, 35 per cent to the staff, but 85 per cent spoke at length to the interviewer who was previously unknown. This study indicates that whilst three quarters of patients are aware of and are willing to discuss their impending death only a minority talk to

members of staff. Clinicians, in particular, should recognise therefore that many more patients dying of cancer are aware than tell staff and that the staff's and relatives' attitudes towards death will naturally affect what patients disclose. Hinton found that in general patients were happier when they felt able to speak frankly and openly about dying with the staff.

The hospice movement has grown up to provide special facilities for dying patients some of which are gradually being adopted by hospitals. It offers a unique approach to death and dying which does not deny the fact of death but ensures that the troubles that precede it, whether they be of body, mind or spirit, receive attention and care (Ford and Pincherle, 1978).

In terminal illness the primary aim is no longer to preserve life but to make the life that remains as comfortable as possible (Twycross, 1980). Therefore what may be appropriate treatment in an acutely ill patient may be inappropriate in the dying. Cardiac resuscitation, artificial respiration and antibiotics are for the most part supportive measures for use in acute illness to assist a patient through the initial period towards the recovery of health. The use of such measures in the terminally ill or the infirm elderly, where there is no expectation of a return to health is generally inappropriate (Twycross, 1980).

Although active medical intervention may often be inappropriate in the care of such patients this does not mean that nothing can be done to alleviate the discomfort and distress of dying. It is therefore not a question of whether or not to treat, but rather what is the appropriate treatment in view of the patient's personal and social circumstances.

The main aims of those providing terminal care should be to improve the quality of remaining life by removing or alleviating unpleasant symptoms and helping to prevent the patient suffering fear or loneliness. Many distressing symptoms may be relieved by good basic nursing care. Nurses have an important role to play in identifying those symptoms which have not been adequately relieved (Report of the Working Party on Terminal Care, 1980). Often, if left untreated, nausea, constipation and bed sores for example, may become more distressing and uncomfortable to the patient

**Table 6 Commonest symptoms in advanced cancer:
St Christopher's Hospice 1979 (n = 647)**

<i>Symptom</i>	<i>Percentage</i>
Pain	69.5
Anorexia	64.75
Weight Loss	59.25
Weakness	49.0
Constipation	45.5
Dyspnoea	42.0
Nausea/Vomiting	36.75
Oedema/Effusion	30.75
Cough	29.0
Insomnia	27.0

Source: Walsh and Saunders, 1984.

than the underlying disease. For those living at home these symptoms may result in admission to an in-patient unit. The commonest symptoms of patients with advanced cancer found in a study carried out at St Christopher's Hospice (Walsh and Saunders, 1984) are indicated in Table 6.

Terminal care is consequently the provision of a special kind of support required by these patients and their relatives. It is based upon high quality intensive nursing. Care may involve explanation and counselling for both the patient and his family, help with spiritual or social problems, the use of different techniques of medical palliation, physiotherapy, occupational therapy and other techniques to enhance the final days of life (Report of the Working Party on Terminal Care, 1980).

There are various fears associated with advanced cancer commonly held by the public, these include the fear of pain, of pain-relieving drugs which they believe will both swamp their personality and inevitably lose their effect, of dependence and isolation and of being kept alive by technology without having any choice in the matter (Saunders, 1984). The prevalence of pain among cancer patients has been variously estimated as being between 30 and 45 per cent in patients when cancer is diagnosed (Bonicca, 1987), up to 50 per cent in children and adults receiving cancer treatment (Foley, 1979) and 70 per cent in those with advanced disease (Bonicca, 1985).

Several studies have found, however, that with carefully adjusted treatment pain can be controlled adequately in virtually all patients over a long period of time, and without producing addiction or drowsiness. When morphine and other drugs (see Table 7 for drugs commonly used for the treatment of cancer pain) are used to relieve pain approximately 80 per cent of patients obtain relief, 10 per cent experience significant side effects and 10 per cent have no relief; of the 20 per cent who do not obtain relief with narcotics in combination with other drugs the use of nerve blocks will relieve the pain of the majority. Overall giving a total of 96 per cent of patients obtaining relief from pain (Lipton, 1989).

Table 7 A basic analgesic ladder

<i>Category</i>	<i>Parent drug</i>	<i>Alternatives</i>
1. Non-narcotic	Aspirin	Paracetamol
2. Weak narcotic	Codeine	Dextropropoxyphene
3. Strong narcotic	Morphine*	Diamorphine (Heroin) Levorphanol Buprenorphine Methadone Dextromoramide Phenazocine

Source: Adapted from WHO, 1986.

* Substained release morphine is particularly useful in the home situation, especially where compliance is a problem.

One of the most important reasons for unrelieved pain is the failure of doctors and nurses to appreciate fully that pain is not simply a physical sensation. Pain has been described as a somatopsychic experience (that is both physical and psychological) with its intensity depending both on the extent of tissue damage and on the patient's psychological state (Baines, 1989). It follows therefore that a patient's pain threshold will vary according to mood and morale. Factors which have been found to affect the pain threshold can be listed as follows: discomfort, insomnia, fatigue, anxiety, fear, anger, sadness, depression, boredom, time of day (worse at night), mental isolation and social abandonment.

Good management of terminal illness is dependent upon staff being trained firstly to distinguish between what is appropriate treatment and what is inappropriate treatment at each stage of a patient's illness; secondly, to accept the change of direction of treatment from cure to care; thirdly, to learn the special medical, nursing and social work skills necessary for good terminal care; fourthly, to understand family relationships and friendships and; finally to ensure good lines of communication within the caring team and between its members, the patient and the family (West, 1984).

These criteria of what constitutes good management and care of terminal illness are the essence of hospice care. However, despite the various methods of delivering care the hospice movement cannot be expected to reach all terminally ill patients. What should be hoped for is the dissemination of the philosophy of hospice care to others involved in this area, to the general practitioner and nurses caring for the patient dying at home and to planners, managers as well as health care workers in hospitals.

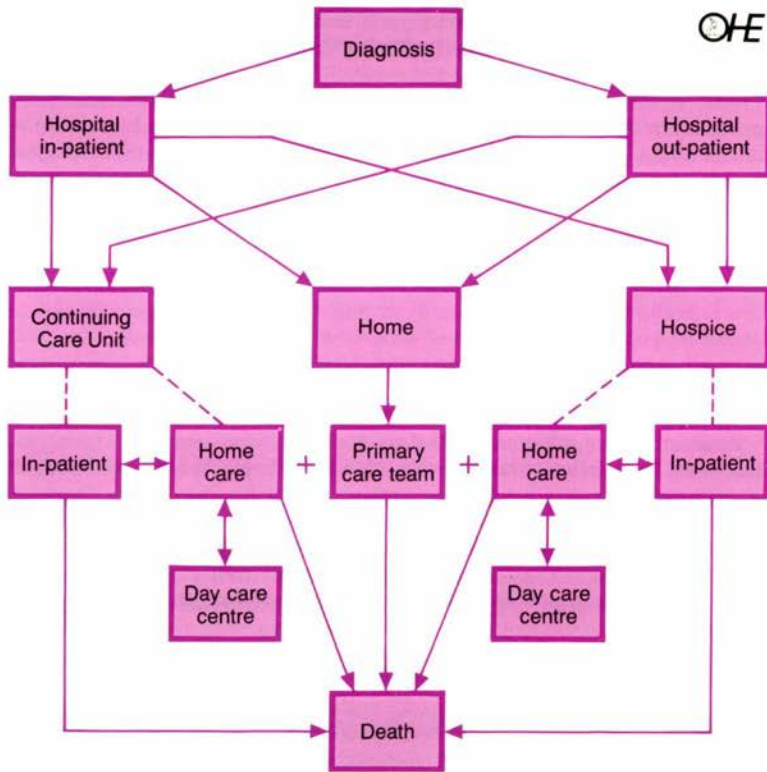
The costs and benefits of care

The hospice movement has expanded considerably in the last two decades, and as was discussed previously, the range of services offered now extends beyond the traditional residential or hospital based in-patient unit. Types of care now include home care nursing and day care centres, bereavement counselling and sitting services. Figure 7 helps to demonstrate (in a very simple form) the way in which patients may use the different forms of care available for the terminally ill.

The general move towards forms of care other than those provided on an in-patient basis can be seen to be a response to the 1980 Report of the Working Party on Terminal Care which recommended that 'there would be no advantage in promoting a large increase in the number of hospices at present...' and instead emphasised the value of 'the dissemination of the principles of terminal care throughout the health service...' through education, training and the co-ordination of services.

The recognition that hospice is a concept of care rather than a specific type of institution (Twycross, 1980) has resulted in a growth in the number of home based hospice services. Unfortunately, until the latter part of the 1980s when the situation has begun to be rectified, the lack of co-ordination between the National Health Service and the voluntary and charitable bodies which principally fund the hospice services resulted in the uneven distribution of these home care services throughout the country.

Figure 7 Pattern of care for the terminally ill - flow chart



With an increasing elderly population which will bring with it an increased morbidity and prevalence of terminal illnesses the demand for hospice services is certain to increase. For example, Table 1 showed that almost two thirds of cancer deaths occur in the age groups where the greatest increase is expected, between 65 and 84. In addition the role of hospices in the provision of services for people with AIDS, already substantial, is likely to become more important in the future.

However, it is important to recognise that the resources available for the care of the terminally ill are finite and that policy decisions made as to the form of the provision of services will have important implications in terms of the benefits foregone by choosing one form in preference to another (Goddard, 1989). An evaluation of both the costs and benefits of alternative provision, be it hospice orientated or the more traditional hospital and general practitioner care, can help ensure that informed policy decisions are made and that choices are made which maximise benefits both to the terminally ill themselves and to their carers.

modes of provision of care and the projected increased demand for services for the terminally ill (Figure 5) little evaluation has been undertaken in the UK on the services they provide or as a comparison with traditional hospital in-patient services. Many assumptions have been made about hospice care with very little supporting evidence. For example, it is frequently assumed that hospice care is better than the more traditional care provided by hospitals or by general practitioners. This in turn has developed into the belief that home based hospice care is preferable to in-patient hospice care.

In addition, and again with little evidence in support, it is often assumed that hospice care and home based care are cheap alternatives to traditional services for the terminally ill (it should be pointed out that this is not a claim that those working in the hospice movement would make). Proper hospice care because it is so nurse intensive is an expensive form of care. Whilst the importance of economic evaluation in the assessment of services provided in different locations has been recognised for other groups, for example the mentally ill (O'Donnell *et al.* 1988) this has not been the case in terminal care (Goddard, 1989) and this is despite the fact that estimates of the cost of services for this group in 1988 (excluding hospital costs) suggest a figure in the region of £65 million per annum (excluding capital development) in total. £55 million on hospice in-patient care and £10 million on home care and day care services (Hill and Oliver, 1988).

Part of the explanation for this omission might be that to apply a more calculating approach to the care of the terminally ill is frequently considered to be in bad taste. Thus, despite the fact that terminal care often involves intensive and expensive therapy the question of whether the cost is too high or wasteful of resources is repressed. However, ultimately it is not possible to ignore matters of costs and economics.

Very little costing work has been done on the provision of services for the terminally ill, in any sector. In the UK the only material which has been published to date is an analysis of the cost of in-patient hospice care which was undertaken in 1983 and again in 1987 on a sample of hospices (Hill and Oliver, 1984, 1988). In the 1987 survey 40 hospices were selected on the basis that they were able to provide up-to-date financial information. In calculating the cost of in-patient care the costs of teaching, home care, day care and research were excluded as were all capital costs and non-relevant running costs, for example interest payments. A summary of the findings, updated by Goddard (1989), can be seen in Table 8.

Table 8 Costs (£ 1988) of in-patient hospice care.

Number of beds:	5-9	10-14	15-19	20-29	30+
	£				
Average cost/bed/week	611	475	454	407	440
Range of costs/bed/week	424-804	355-658	335-635	257-559	329-683
Average cost/patient/week*	743	655	627	559	601

Sources: Hill and Oliver (1988) and Goddard (1989).

* Product of cost per bed per week and bed occupancy.

Table 9 **Costs of in-patient hospice care.**

Cost per bed per week (£)	Number of beds				
	All	1-50	51-100	101-300	>300
Acute bed					
1987	712.73	408.80	569.73	672.49	751.24
1988*	773.32	443.55	618.16	729.65	815.65
Geriatrics					
1987	311.43				
1988*	337.90				

Source: DoH and OHE.

* OHE estimated figures.

As can be seen from the table there are a range of costs, the average cost per bed per week ranging from £407 to £611 this compares with the cost per bed per week in the hospital sector of between £444 and £816 (average cost in England of acute beds in hospitals of various sizes) and the average cost of a geriatric hospital bed of £338 per week in 1988 (Table 9, OHE, 1990). It is worth noting that differences in activity will mean that the hospital costs include some items which might not be received by a terminally ill patient, for example some expensive support services such as electrocardiography (Goddard, 1989).

The main problem with both the 1983 and 1987 surveys, as regards the economic evaluation of services for the terminally ill, is that they intentionally omit the costs of day and home care. There have been no complete economic evaluations of the costs of providing services in the alternative models of care in any controlled study nor have there been analyses of the comparative benefits in terms of both quality and quantity of life.

A review of the literature on the effectiveness of services for the terminally ill (Goddard, 1989) found that the vast majority of the UK evaluation had been concentrated on the outcomes of in-patient and domiciliary services at world renowned St Christopher's Hospice. In-patient services at this hospice were first examined in 1969 (Parkes, 1979) by interviewing the spouses of patients who had died in the hospice and in a neighbouring hospital. It was found that patients who had died in the hospice had experienced less pain than hospital patients when 'mean' pain was taken as the indicator in order to avoid the effects of fluctuations in the pain level. In a repeat of this study ten years later (Parkes, 1979) the difference was less marked.

The domiciliary service at St Christopher's has also been examined by comparing patients who received this additional service with those who did without (Parkes, 1980). Whilst it was found that those patients in the domiciliary group were able to remain at home for a longer period before death thus avoiding an in-patient stay the stress experienced by families and also the pain and symptoms felt by patients appeared to increase.

In a study of four groups of patients in acute hospitals, a Marie Curie Foundation home, a hospice in-patient unit and a hospice domiciliary service, interviews were carried out with patients, relatives and staff and the results used to assess the patients' spirits. Hinton (1979) found that those receiving hospice care were least distressed and anxious and of these patients those who were being cared for on an in-patient basis were less troubled than those being cared for at home.

Apart from these studies no systematic evaluation of outcomes for the different modes of care for the terminally ill has been undertaken in the UK. The studies mentioned were conducted over a decade ago and their limitations are severe. The fact that they have been predominantly conducted in the same hospice (Hinton does not state the location), which may mean that the results cannot be expected to apply to all other hospices, combined with the fact that the studies are not controlled trials, means that confidence in their findings cannot be as great as that in a fully randomised control trial.

The issues raised by economic and outcome evaluation should be of particular importance to hospices due to the very nature of their funding. The majority of independent hospices rely to some extent on financial support from the NHS usually as a contribution towards the running costs of some of the beds. In a study by Hill and Oliver (1988) the range of support from the NHS for hospices was between 0 and 100 per cent, with an average of 29 per cent. In addition in the case of the Continuing Care Units and some home based services after an initial 'pump priming' role by charitable organisations the NHS take on the revenue costs. In the light of the recent government National Health Service reforms some local health authorities may find that they are unable to continue to support the hospices at their current level.

In the Health Service reforms there is a commitment to 'core' services. These are services that have to be provided locally by the health authority and include casualty services, most general surgery and medicine, geriatric and psychiatric services, most out-patients services and various public health and community services. However, hospice and terminal care services are not specifically mentioned as being 'core' services. It appears that the provision of terminal care services will be, as now, for local decision and option.

For the patient who is terminally ill and requires in-patient treatment the health authority or fund holding general practitioner will have several options. A bed could be purchased in an NHS hospital, a private hospital or nursing home or in a hospice. Whilst the quality of care provided will be an important factor in any decision so will the relative cost.

If the health authority decided that it did wish to provide in-patient beds for the terminally ill a hospice could offer the authority a contract to buy all the beds at their actual running cost therefore funding 100 per cent of the hospice's running costs. An alternative might be for the hospice to offer a contract of 50 per cent of the bed cost per week and continue to raise the remainder of the money from charitable sources. Effectively this is merely an extension of the contractual arrangements which already exist between some hospices and their health authorities. If the health authority has decided to make special provision for the terminally ill then a 50/50 split

would clearly be an attractive option and is one which the Government would support (Statement by The Minister of Health, Virginia Bottomley MP, DoH Press Release, December 1989).

There are also other possibilities which are less favourable to the hospices. Firstly, the authority could decide not to make any special provisions for the terminally ill and rely on the voluntary sector to make all the provisions from charitable funding. Secondly, the authority could refuse to accept a 50/50 arrangement and negotiate the contract down so that the NHS contributes only 10, 20 or 30 per cent of costs. If a hospice was placed in this position, the organisation Help the Hospices believes that hospices would have little option but accept the arrangement, however, the demand for hospice beds is such that they might be able to offer the beds to a neighbouring authority. Thirdly, an NHS or private hospital keen to fill surplus beds could offer them to the health authority as terminal care beds at a very low price in order to generate some income rather than leave them empty altogether. These same principles will also apply to the provision of day care and home care services.

In order that informed policy decisions can be made it is of prime importance to know the benefits and costs in order to make the best use of the available resources. It may be that hospice care is more expensive than conventional hospital care for some groups of patients and less expensive for others. It is possible that correct patient selection would therefore be crucial to efficient resource use. If hospice care is more expensive in some cases the question is then whether or not the benefits of hospice care justify the additional expense. The future of services for the terminally ill and the hospice movement in the post-NHS reforms world will depend to some extent on receiving answers to the questions regarding costs and outcomes of the different modes of care.

To the future

Doctors and nurses have always had patients that have died and deaths have occurred in all specialities. But many doctors and nurses have never received any training to equip them either to cope with their own reactions to death or to provide the support a dying patient and their relatives will require. A lack of training in hospital staff in this area can be seen in many ways but a common reaction is to set up an emotional barrier and minimise contact between themselves and the patient. Unfortunately, this approach is the direct opposite of the kind of care that the dying patient needs at this time. Professional staff trained in the care of the terminally ill have sufficient confidence in their abilities to face the problems of the dying and know how they can use their skills to help overcome them.

This is not to say that trained staff will never be distressed at the death of a patient, particularly if they have been involved in their care over a period of time, but they will be better able to adjust to the loss. In addition, staff working in the area of terminal care learn to support each other at such times. Staff who are not given the opportunity of sharing their strain and distress will either leave this area of work altogether or learn to hide their emotions behind a barrier of professionalism (Saunders, 1983).

In 1980 the Working Group on Terminal Care recommended that '...greater emphasis should be given to the psychological aspects of dying and bereavement in basic nurse training courses, with special provision made to help new trainees to accept caring for the dying patient as an integral part of their work as nurses. An introduction to the techniques of counselling would assist nurses to fulfil their frontline role in relation to both patients and relatives.' The Working Group also recommended that a terminal care component should be included in the training of medical students and as with the nurses it was thought that they too would benefit from instruction in counselling techniques.

Since the report was published, increasing attention has been given to the psychological aspects of care, including bereavement, in nurse training. Emphasis has also been placed on improving nurses' communication skills by increasing the content of this topic area in the training curriculum. These developments have been continued in the new Project 2000 courses² (English National Board for Nursing, Midwifery and Health Visiting - private communication, 1990).

Unfortunately, the developments in nurse training do not seem to be reflected in that given to medical students. The General Medical Council (GMC), recommendations on basic medical education have not been revised since before the publication of the report of the Working Party on Terminal Care. Whilst the GMC recommends that medical students should be taught 'to communicate effectively and sensitively with patients and their relatives' there is no specific mention of training in the care of patients who are terminally ill or the development of counselling techniques.

Much of the training for doctors and nurses in the care of the terminally ill is given at a postgraduate level or is acquired with experience. Hospices have a vital role in the training and education of professional staff. A number of hospices run training courses on the care of the dying both for general practitioners, trained nurses, nursing auxiliaries and volunteers. These courses play an important role in the communication of the philosophy of the hospice movement and the care of the dying to staff working in and with the more traditional institutions which provide care for the terminally ill.

As has been discussed previously, good terminal care does not have to be restricted to a geographically separate unit like a hospice, it should be available both in the patient's home and in hospital. Hospices will continue to be needed for patients with intractable problems and for research and teaching in the care of the terminally ill but most patients will, as now, die in hospital or in their own homes and health care professionals should be learning how to meet the particular needs of the dying. Until this happens, reports of patients dying in severe pain or spending their last weeks semi-comatose because pain relieving drugs are being inadequately regulated; or dying in distress because they have had no one to talk of their fears with, will continue to abound.

² Project 2000 was introduced in 1986. One of the main recommendations was that the role of nurses be extended to create a new grade of nurse practitioner thus elevating the status of the nurse to that of primary therapist.

Patients, be they dying of cancer or AIDS or are infirm elderly, should be enabled to live their lives to the limit of their physical and mental capabilities with as much independence as possible until they die. Too often the person's individuality and independence are suppressed by the health professional's need to deal with the patient's medical and physiological problems. The patient can be left feeling that they are no longer in control of what is happening to them and they are nothing more than a collection of symptoms.

Patients should end their lives in the place most appropriate for them and for their families and, if possible, have a choice in the matter. For many this will be their own homes, for others the hospital and staff who have carried out previous treatments, while some will require the smaller community feeling of the hospice. The alternatives need to be planned ahead, thus avoiding a rushed decision. The patient and their family should be fully involved in decision making, visits to the different locations arranged if required and flexibility maintained.

The very real problem of large numbers of patients dying in hospital when they and their carers have expressed a preference to die at home needs to be urgently addressed. It is certain that some expansion of health and social service community support for the terminally ill will be required to assist those who wish to die at home (Report of Working Party on Terminal Care, 1980). From 1 October 1990, a person with a terminal illness (which is likely to cause death within six months) could claim a weekly attendance allowance immediately. Provided that certain conditions are met they do not have to satisfy the six month qualifying period or the attendance needs test. This will hopefully remove some of the financial difficulties and worries of many such patients and their carers. However, as important in solving this problem will be sufficient numbers of trained nursing staff, home helps and equipment such as bathing aids and pressure relieving mattresses.

In addition, in many areas there are at present not as many hospice beds as patients would like and there is a need for complementary hospital care to provide in-patient palliative and terminal care including provision for relatives to support the community team. This would alleviate some of the problems of caring for dying patients on a busy acute hospital ward (the cost would be considerably less than that of acute beds) and would provide back-up for patients being cared for at home.

Above all, there is a need for more economic analysis of the relative costs and benefits of different patterns of care for the terminally ill. Detailed studies within the health service, in the private sector and in the social services must be undertaken, so that the increased social and economic challenges from these patients in the future can be tackled in as rational a way as possible. At present such cost information as is available is based on almost anecdotal evidence and no systematic large scale studies have been undertaken in Britain, to produce realistic costings for terminal care in different settings. As always, comparative costs can only become meaningful when they are related to the outcomes which they produce. The physical, social and psychological state of the patient must also be assessed with greater care. In addition, the impact of the patient's circumstances on their relatives or carers is important.

Pointers for action

Health Authorities have a key role in taking account of the quantity and quality of the services provided in their district. It should be possible for them to analyse the numbers dying in the hospitals with which they have contracts: for example numbers in different age groups, the diagnostic categories of the beds occupied and such information as is available about cost per day and per episode of treatment. They should also be able to obtain more limited information about care provided in hospices, which may or may not be supported by the authority.

In addition, Health Authorities must take account of the needs and opinions of both the users and providers of terminal care. A survey of the attitudes of patients and relatives to the care they are receiving would obviously provide important information but needs to be conducted with sensitivity. It might be possible for it to be undertaken as part of a wider survey of patient satisfaction in a unit or ward with a high proportion of terminally ill patients. The views of general practitioners and other members of the primary health care team should be sought on the suitability of care arrangements and any important weaknesses. There is a need also for discussion with provider units and their staff of local quality control arrangements including the possible role of medical audit in reviewing success in areas such as the relief of pain and reviews of the training experience and attitudes to terminal care of medical and nursing staff.

Armed with as much information as it is practicable to obtain from these sources, Health Authorities need to assess what the priorities are for improvement in the quality of service, what weight it should be given in relation to other demands and how it can best be met whether through contracts with provider units and trusts or collaboration with hospices or local people interested in establishing hospices.

Regional Health Authorities must keep in touch with developments at district level and in particular identify districts which because of local pressures or initiatives have an interest in these services and may be able to pioneer forms of analysis and research which will be of value to other districts.

The Department of Health needs to ensure that there are clear national policies for example on whether and in what circumstances care of the dying is to be regarded as part of the core services for which each district must contract, and whether there are to be any national standards or decisions to be left to health authorities. The Department of Health should also maintain contact through Regional Health Authorities with local developments in order that it can assess whether and when central initiatives are required: for example to establish common forms of analysis or to promote national research projects.

All of these tasks must be given the priority which the important challenge of terminal illness deserves. It is a subject which has received too little attention in the past and the current reorganisation of the health services provides a useful opportunity to redress this balance, and to ensure that the dying are always treated with dignity and respect.

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