Care of the Dying

A GUIDE FOR HEALTH AUTHORITIES

NAHA

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King Edward's Hospital Fund for London

National Association of Health Authorities

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KENSINGTON PALACE

Foreword by H.R.H. Prince of Wales

When I attended the DHSS/NAHA Conference on Care for the Dying at Central Hall, Westminster in December 1985, I referred to the importance of recognising the special needs of the dying. I paid particular tribute to the hospice movement which has done so much to recognise and nurture the special emotional, spiritual and physical needs of people facing death. During the past two decades modern medical technology has discovered ways to prolong life, but it has not made dying easier. It remains necessary for all who provide care for the dying to work together to ensure sensitive and comprehensive care whenever and wherever it is needed.

I am, therefore, delighted to commend the following guidance to Health Authorities to help them, with the assistance of voluntary organisations, to improve their services for the dying. Whether a person dies in hospital, at home or in a hospice, it is clearly imperative that we do our best to ensure that he or she dies with dignity and with as little pain as possible, supported by caring people who are themselves receiving the support that they also need.

Charles

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Introduction

There have been considerable advances in the care of the dying person over the past two decades. It is now recognised that much can be done to relieve suffering and to enable the person to die with dignity. Unfortunately, these advances have not been implemented systematically, with the result that many people are still suffering needless distress.

The desire to improve matters has been gaining momentum—and not only among health professionals. There is a growing interest in terminal care among members of the public, as evidenced by efforts to raise funds to build a hospice for a particular community. For those responsible for the planning of services, however, decisions about the optimum type of provision for the care of the dying are far from straightforward. In this country, a wide variety of services have evolved. In the 1950s and 1960s, evidence that the care of dying patients left much to be desired led to the expansion of the first type of specialist service for the dying—the in-patient hospice. Later came services designed to improve the quality of care for patients nursed at home or in general hospitals—the home support team and the hospital support team. Finally came day care—an additional way of providing support for families caring for their relative at home. Any of these services may be found within the NHS, run by an independent charity or private body, or a mixture of these. Research findings do not as yet show clearly that one particular model of care is preferable in all key respects, and indeed, it is likely that a combination of services is required to meet the various needs of the dying and those who care for them.

Because terminal care is such an important issue, it is essential that all health authorities should be drawing up a strategy for the care of the dying in their area. The Department of Health and Social Security will shortly be issuing a circular which asks health authorities to consider current provision of services for the dying and to plan to rectify deficiencies in meeting their needs.

This publication is addressed to members of health authorities, who have a key role to play in ensuring that their authority embarks speedily on the formulation of a policy for the care of the dying. It aims to assist health authorities in making informed decisions about the pattern of services that should be established to meet the needs of their community most effectively. It is not intended to be a comprehensive 'how to' guide, but sets out to provide an introduction to the issues involved. The contents are in eight parts:

- the principles of good terminal care
- the components of a comprehensive service
- care of the dying in a hospital
- criteria for assessing terminal care schemes
- assessing local needs for terminal care
- funding of terminal care facilities
- training in care of the dying
- further information and advice.

Principles of good terminal care

The hospice movement has pioneered advances in the care of the dying and has shown what can be achieved. The task now is to ensure that these advances are translated into everyday practice throughout the country.

Most of the experience in terminal care has been built up from the care of people with cancer, since they represent the largest single group of patients requiring this type of care. However, it is essential that the principles derived from the care of patients dying with cancer are applied to patients dying with other distressing conditions, such as AIDS and degenerative neurological conditions.

The principles of good terminal care listed below should be used as a reference by health authorities engaged in planning services for the dying, and also as a means of continuously assessing existing services. These principles encompass not only the people who are dying, but also their families and friends, and the staff involved in their care.

● The person who is dying

One of the main aims should be to improve the quality of daily life. This can be achieved by attention to the following issues:

— **the removal or alleviation of unpleasant symptoms,** pain being the foremost but not the only one of these. It should be remembered that severe pain can always be relieved without loss of consciousness.

— **the removal or alleviation of fear and loneliness** by responding sensitively to the needs of those who are dying, by taking into account their preferences as to how, where and by whom they are cared for, and by providing explanations when required.

— **the maintenance of independence:** this requires the provision of rehabilitation facilities, which aim to provide interesting and stimulating activities, and to enable the person to live as normal a life as possible.

- **spiritual needs:** for the person who is dying, the spiritual dimension may assume particular importance. The support team established to care for the dying should have close links with hospital chaplains and with people within religious groups who can offer sensitive pastoral care.

● The relatives and friends of the person who is dying

One of the main aims should be to provide support to relatives and friends, both before and after the death of the patient. There is a need for care in determining to whom support should be offered. The person closest to the patient might not be the immediate next of kin, or even a blood relative. Staff will need to accept a range of alternative relationships.

Lack of support to carers is often the precipitating factor in the admission to hospital of a dying patient. Good support will require attention to the following issues:

- **Practical support of carers:** this may include instruction in helpful techniques (for example, home nursing, lifting), as well as arranging other services where appropriate. Practical support can be given by general practitioners, community nurses, Macmillan nurses and Marie Curie nurses; night sitting services; physiotherapists and occupational therapists; and social workers or welfare rights officers who can advise about the financial help that is available.

- **Emotional support of carers:** this can be given by medical social workers, who offer skilled counselling. Local voluntary services which can supplement this professional help, such as community care groups and cancer support groups, are also valuable.

- **The provision of day care facilities and of in-patient beds for respite care** where necessary, for example, in a local hospice, hospital or nursing home.

- **Bereavement support:** There is evidence that the unsupported bereaved have a higher rate of morbidity. Some relatives and friends will need to discuss the events surrounding the death with someone trained in bereavement counselling, who can distinguish between natural grief and undue suffering, and respond appropriately. There is a need for follow-up not only soon after the death, but also some months later.

● The staff caring for people who are dying

Good terminal care depends on a strong base of informed and well-supported staff. Attention should be addressed to the following issues:

- **the range of staff involved:** Staff from a wide range of disciplines have a valuable role to play in the care of the dying. It is frequently appropriate to call on the skills of physiotherapists, occupational therapists and social workers, as well as those of doctors and nurses. Trained voluntary workers can also play a valuable role.

- **good communication between staff:** A clear operational policy defining the roles of those with special responsibility for the dying will do much to minimise the risk of a hiatus or an overlap in care, as well as reducing stress on staff.

- **adequate staffing levels,** allowing for the time-consuming nature of good terminal care.

- **adequate and continuous training,** both at pre-qualifying and post-qualifying levels. Lack of training in doctors, nurses and other professionals in terminal care is a major barrier to the widespread diffusion of standards of excellence in the care of the dying. This is discussed in a further section.

- **skilled selection of staff** to work in this field: care is needed in the appointment of staff to work with dying patients. Interviewing panels should include someone already involved in terminal care who is aware of the personal qualities as well as the professional qualifications needed for this type of work.

- **adequate and regular emotional support,** whether in the form of individual or group counselling on both a formal and informal basis, by those qualified to do so.

Components of a comprehensive service for the dying

> *Techniques exist to alleviate the worst miseries of the dying patient.... This is not a matter of new buildings or expensive equipment. It depends primarily on enlightened professional attitudes.*
>
> *....It is more important that medical and nursing staff involved should have an understanding of the problem, an adequate level of knowledge, a positive attitude to the scope for achievement, and reasonable resources.*
>
> (Report of the Working Group on Terminal Care, HMSO, Dd 8212364, 1980).

Most terminally ill patients are cared for on ordinary hospital wards, and, while they are at home, by the primary health care team. But due to lack of specialist training and inadequate resources, the service provided may not reach the high standard of care described in the previous section, and some additional input will be needed. This could take the form of a programme of education and training to improve the skills of existing staff, the development of new services of the type described below, to complement existing services, or by a combination of both these approaches.

This section presents a brief description of the main types of terminal care schemes currently in existence. The intention is to ensure that those involved in the planning of terminal care are aware of the full range of such schemes. This is not to suggest that any one of these schemes is superior to the others, nor that one scheme is necessarily complete in itself. In the words of the report quoted above, 'each type of care, whether it is at home or in hospital, or in a hospice, has special features which may be of benefit to a patient at the point of death or at a particular stage during the terminal illness.'

Ideally, a comprehensive service, including all the elements described in the following pages, should be planned across adjoining districts, and clearly, Regional Health Authorities have a coordinating role to play here. Historically, it has been the in-patient hospice unit which has been responsible for the major advances in the care of the dying, and for many people terminal care is assumed to require the provision of a hospice. However, the in-patient hospice is also increasingly being seen as an educational and professional resource, whether at district or regional level. If it is to fill this role, then further expansion of this type of unit has to be carefully planned and well-resourced. An alternative approach is to begin by establishing a home support team, and add personnel and resources according to proven need and available funds.

It may be helpful to regard the terminal care services described here as the 'building blocks' of a good service: how they are assembled, and in what order is up to the individual health authority, but decisions should be informed by an awareness of the particular needs and resources of the locality. These issues are discussed in more detail on page 24.

Further reading

Taylor, H. (1983). **The hospice movement in Britain: its role and future.** *Centre for Policy on Ageing, Nuffield Lodge Studio, Regents Park, London NW1 4RS.*

Saunders, C. (1986). **Hospice evolution.** *Nursing Times, Vol. 82, No. 43, 22 October.*

The In-Patient Hospice Unit

The environment of the in-patient hospice has been developed specifically to meet the needs of the person who is dying. It has a specially-trained multi-disciplinary team of staff. As well as having a high proportion of trained staff, it also has a high ratio of staff to patients. There is usually an associated home care service consisting of two or more nursing sisters who take the skills developed in the unit into patients' homes, assess their needs and advise accordingly. In some cases they will recommend admission to the unit for further assessment; in other cases, they will liaise with the patients' own general practitioner and other community services to enable the patient to remain at home. There may also be a day care service (see page 18), and a bereavement support service is normally available.

Not all patients go into a hospice to die: many return home once any distressing symptoms are well-controlled; others are admitted for a short time to give relatives a break.

As already mentioned, the in-patient hospice unit is increasingly being seen as a resource for the surrounding area: hospice staff may participate in NHS cancer clinics, and can provide advice and support to staff in hospitals and in the community.

Further reading

Rees, W.D. (1982). **Role of the hospice in the care of the dying.** *British Medical Journal, Vol. 285, 18-25 December, pp. 1766-1768.*

Corr, C.A. and Corr, D.M. (eds). (1984). **Hospice care, principles and practice.** *Faber and Faber.*

The Home Support Team

This is a team of specialist staff set up to offer advice and support to health service staff in the community. The team is usually based on nurses who are part of the community nursing service, with medical and other professional support. Many of these teams have been developed with the help of the Cancer Relief Macmillan Fund (also known as National Society for Cancer Relief), and are known as Macmillan nurses.

The team may be attached to an in-patient hospice unit or to the community nursing service, and augments primary care and community services. It does not take over responsibility from the community nurse or general practitioner, and does not usually deliver bedside nursing care.

The Marie Curie Memorial Foundation also provide home support by means of 4000 part-time Marie Curie nurses. Funded equally by the Foundation and by the NHS they are deployed by 182 health authorities. These nurses are used for extended periods by day or night to give respite to the carer in the patient's own home.

Home support staff have particular expertise in the relief of pain and other symptoms, and can offer emotional support, including bereavement support. They can also arrange for the loan of equipment, for example, syringe drivers and commodes, when these are not immediately available. By complementing the skills and resources of the primary health care team, they help families to continue to care for their relative at home for as long as they wish to do so.

Further reading

Clench, P. (1984). **Managing to care in community services for the terminally ill.** *Patten Press, Richmond.*

Lunt B, Yardley J. (1986). **'A survey of home care teams and hospital support teams for the terminally ill.'** *Obtainable from Cancer Relief Macmillan Fund, Anchor House, 15-19 Britten Street, London SW3 3TY. Tel: 01-351 7811.*

The Hospital Support Team

A possible arrangement here is a multi-disciplinary team based in a hospital, consisting of one or two doctors (full or part-time, hospital doctor, GP, or both), nursing staff, social worker, chaplain, and possibly other professionals. A less elaborate team with two specially trained nurses but with medical support from within the hospital has also been introduced successfully.

The team provides skills developed in the hospice in controlling distressing symptoms and giving emotional support to patients and their families. They act as advisers to hospital staff dealing with dying patients, and can therefore have a direct effect on raising the general standard of care. They may also work in the community, caring for patients after their discharge in the same way. The degree of contact after discharge will depend on the operational policy which defines boundaries of responsibility.

The team does not take over the management of patients, but works by supplementing existing care, and helping patients to spend as much time as possible at home. Bereavement support is normally available. By virtue of its location, the team can bring the principles and benefits of hospice care to patients at home or in hospital at an earlier stage than might previously have been thought to be appropriate.

Further reading

Bates, T. et al. (1978). **The St. Thomas' Hospital Terminal Care Support Team—a new concept of hospice care.** *British Medical Journal, Vol. 1, pp. 1201-1203.*

St Thomas' Hospital Terminal Care Support Team Eighth Annual Report *(1985). Obtainable from The Secretary, Hospital Support Team, St. Thomas' Hospital, London SE1 7EH*

The Continuing Care Unit in a Hospital

A few hospitals have designated a particular ward as having special responsibility for patients whose illness cannot be cured. Such units offer continuity of care and active symptom control. Care is provided by staff with special expertise in the management of terminal illness, in a setting more suited to the needs of those for whom further curative treatment is inappropriate. The emphasis is on the physical and emotional well-being of the individual patient.

The location of units such as these offers an excellent opportunity for the improvement of standards of care in the hospital as a whole, not only for the dying but also for patients at an earlier stage of their illness who require advice on symptom control.

Day Care

A growing number of hospices and hospitals are providing day care facilities for patients who are being cared for at home. In addition to medical and nursing input, the staff may include a social worker, physiotherapist and occupational therapist. Recreational therapy is usually offered, with a carefully-thought-out programme of activities, as well as practical training for relatives in the care of the patient at home. The centre provides baths, showers and toilet facilities suited to the disabled, and a hairdressing and beauty salon may also be available.

Day care is of particular value for patients who are not ill enough for admission to a hospital or hospice, but who need more than consultations in an out-patient department or with a general practitioner. It can function as an early-warning system in alerting general practitioners and hospital doctors to medical problems as they arise. It allows patients to lead less restricted lives and offers respite to relatives on a regular basis. It is particularly valuable to those with elderly relatives and those with other family or work commitments.

Further reading

Wilkes, E. et al. (1978). **A different kind of day hospital—for patients with pre-terminal cancer and chronic disease.** *British Medical Journal, 14 October, pp. 1053-56.*

Day Hospice Care *(1986). Obtainable from Help the Hospices, General Office, BMA House, Tavistock Square, London WC1H 9JP. Tel: 01-388 7807*

Care of the dying in a hospital

The types of schemes described above are all examples of ways in which the principles of good terminal care, reviewed at the start of this guide, can be implemented. However, in practice, the terminally ill patient is likely to spend at least some time on an ordinary ward on a general hospital, and approximately two-thirds of patients will actually die there.

There are several obstacles to the provision of good terminal care in a general hospital. On a busy ward, the needs of dying patients may remain unmet: control of unpleasant symptoms may be inadequate, staff may be hard-pressed to provide the necessary emotional support and there may also be a lack of privacy for patients and their families and friends. But because dying patients will continue to be admitted to general hospitals, attention must be given to the environment and the facilities on general wards. Certain requirements must be fulfilled on any ward caring for dying patients in any number:

- the ward must be adequately staffed, so that there is always someone available to comfort, talk to and listen to the person who is dying, and to relatives and friends;
- staff must have sufficient expertise to be able to control distressing symptoms, and to know when to stop intrusive and stressful procedures;
- attention should be given to the need for tempting and nourishing food for dying patients: centralised kitchens may lack the flexibility to provide food as and when patients fancy it;
- the needs of relatives should be taken into account, with the provision of facilities for simple meals, adequate privacy, and overnight accommodation. Open visiting is essential, as is the opportunity for relatives to be involved in the care of the patient;
- there must be adequate support for staff, including those still in training.

Further reading

Henley A (1986). **Good Practice in Hospital Care for the Dying.** *King's Fund Project Paper obtainable from King's Fund Centre, 126 Albert Street, London NW1 7NF. Tel: 01-267 6111*

Criteria for assessing terminal care schemes

In planning the development of terminal care services for a health district, health authorities may want to consider the schemes described above in the light of particular criteria.

— **Opportunities to improve standards** in hospitals and in the community directly and by teaching: In-patient hospice units are often an important resource in an area, influencing the care of patients in general by initiating new approaches to symptom relief and providing training for staff generally. It is increasingly the norm for home support teams and hospital support teams to undertake teaching of colleagues: by virtue of their regular contact with staff in general hospitals and in the community, they are well-placed for this.

— **Flexibility to respond to the varying needs of the patient:** In the course of the last phase of their illness, patients' needs may change. For example, a sudden deterioration may require extra resources — either an increase in community nursing input, or admission to an in-patient facility.
A terminal care service should be able to respond to these varying needs. An in-patient hospice unit with home care and day care facilities can provide this degree of flexibility, as could a home support or hospital support team which has access to in-patient beds. The ability to respond promptly to patients' needs is, of course, contingent on adequate staffing levels.

— **Costs:** This is obviously a major consideration for health authorities. Issues to be addressed will include capital expenditure and revenue consequences, the rate at which a service can and should be implemented, and the possibility of shared funding with national or local charities. The section on funding later in this guide presents the major permutations to be found among current schemes.

In planning new services for the dying, it is also necessary to allow for the fact that the new service may lead to financial savings elsewhere, often for a relatively small outlay. For example, the establishment or extension of a home or hospital support team may enable more patients to remain at home for longer periods, thus releasing expensive beds, as well as meeting the wishes of many dying people. Even where actual expenditure is increased, a more effective use of expensive acute resources may be achieved.

— **Acceptability to patients:** Recent research has shown that patients speak highly of all of the types of care we have described. However, while some patients and families welcome referral to a specialist facility where they can benefit from the expertise available, others may view it with trepidation. A hospice may be seen as 'somewhere you go to die,' but as we hope to have shown in our description of the in-patient hospice unit, this image is crude and misleading. There are ways in which this can be changed: by better publicity of the work of the hospice service, and by location of other facilities such as day care or meetings of a cancer support group at the in-patient hospice.

Since we live in a multi-cultural society, it is important that services are planned and care provided in such a way that the diverse needs of each community's various ethnic, religious and cultural groups can be met appropriately.

— **Acceptability to colleagues in hospitals and in the community:** It is not only members of the public whose understanding of these services may be incomplete: terminal care services may also be viewed with suspicion by other staff initially, who may perceive these services as unnecessary or intrusive, or feel threatened by them. Experience has shown that these problems can be avoided by good communication starting well before the service is established, good management, and a clear operational policy. In this way, the risk of antagonism, confusion and overlap will be minimised.

— **Location:** This is an important consideration for a service for the very ill, many of whom are elderly, with elderly relatives. Thus, an in-patient hospice should be accessible by public transport, or there must be a good hospital car service, and attendance at a day care centre should not involve a long journey for the patient, who will be easily tired.

Assessing local needs for terminal care

If effective terminal care services are to be established, attention should be paid to the particular needs of the district in question. There are four types of information that health authorities should be examining:

- information about the characteristics of people dying in their locality;
- information about the locality itself;
- information about resources currently available;
- information about the adequacy of resources in meeting needs.

A review of these data will assist considerably in making a decision about the type of service that should be set up.

Information about local deaths

Certain statistics are collected routinely for every health district. They can be supplied by the district's community physician, or by the information officer in districts where there is no community physician in post. They include information about the number of deaths in the district and about particular characteristics of the deceased: age, sex, cause of death and place of death.

Having obtained this basic information, the next step is to interpret it. Health professionals will be able to supply answers to the following questions:

— of all causes of death, which conditions commonly have a recognised 'terminal care' period, i.e. when death is certain and not too far distant?

— of the common conditions requiring terminal care, which have special needs, for example, in terms of pain relief?

Information about the locality

Another source of information which may be relevant to the planning of services for the terminally ill is the census. Data from the census can be supplied and interpreted by the district community physician, and can provide clues as to the physical characteristics of an area: for example, the quality and type of the housing stock, the proportions of elderly, and the ethnic composition of the area. Data such as these can give some indication of levels of need.

As with the figures on local deaths, these data need to be supplemented with local information from health professionals. What do they see as the distinctive features of their locality? Are there many people without local family support? Is the character of the area changing?

Information about local services

The data available from routine statistics will have provided information about some of the services currently being used in the care of the dying, for example, particular hospital wards, hospices, or other institutions. This should be supplemented with a review of other services. Information will need to be collected from health practitioners as well as from published figures. The following questions could usefully be asked:

— are the services of specialist cancer nurses available, for example Macmillan nurses, Marie Curie nurses?

— what other staff resources are there? Are there staff with a particular interest in the care of the dying? What proportion of nurses, for example, have had training in terminal care?

— what is the workload on general staff? Many GPs, community nurses and hospital staff will be providing terminal care without any formal recognition as part of their day-to-day work.

— what other specialist services are available—for example, is there a day centre for the terminally ill? Is there a pain control clinic?

— what resources exist in adjoining areas, for example is there a hospice whose facilities are available to other districts?

Information about the adequacy of services currently available

There are a number of ways in which the adequacy of current provision for the care of the dying can be assessed. These may be grouped into three broad categories — research, quantitative indicators, and local knowledge.

Research

A well-established method of assessing whether a service needs to be changed is to carry out a survey. With a sensitive topic such as terminal care, the resources necessary to mount a properly constituted investigation may not be available in many health districts. However, there is quite a large volume of research findings already available (see 'Further Information and Advice' section, page 42), and the bulk of findings all point to the fact that current services are inadequate. These findings, from research undertaken in this country and in the United States in the past twenty years, can be summarised as follows:

— too many patients have unrelieved physical symptoms and emotional distress;

— the provision of practical help and advice to families coping at home is poor;

— communication problems between health professionals of all kinds and patients and families are common.

Rather than looking for further evidence that these problems exist, those responsible for planning services might do better to assume that such problems do exist in the absence of any firm evidence to the contrary, since whenever systematic surveys are undertaken, these problems are found. Research efforts might be better reserved for the evaluation of any new services which are established.

Quantitative indicators

In every health district, some quantitative indicators of the adequacy of terminal care services can be found. For example, letters of complaint to Health Authorities and to Community

Health Councils may suggest that particular services need to be examined, or that particular needs are not being met.

If there are already specialist services in an area, for example, a hospice or a pain clinic, waiting lists provide some indication of the degree of unmet needs; and in any service involved in the care of the dying, whether a specialist unit or a general hospital ward, attention should be paid to any indicators of undue stress on staff, for example, high turnover or high levels of absence on health grounds.

Local knowledge and opinion

It has already been emphasised that information derived from statistics and from other written records should be interpreted with the help of local practitioners engaged in the day-to-day care of the dying. In assessing the adequacy of current services, and obtaining a broad-based commitment to change, it is important to canvass the views of all those involved—not only health service personnel, but also the Community Health Council, voluntary organisations and interested members of the public.

It is vital that existing health service staff do not perceive proposals for new services as reflecting adversely on their capabilities, nor as supplanting the care that they already give to the dying. A constructive approach is to ask a range of staff in the community and in hospitals what problems they are currently having in caring for the terminally ill, and what help they need to give an improved service.

An effective method of obtaining views from a wide range of people is to hold a workshop or seminar. If attended by representatives of people from different disciplines and backgrounds, it will be possible to establish what both staff and members of the public see as major problems, and what form of care could best be introduced to meet local needs. Details of help available in setting up a workshop are given in the 'further information and advice' section, page 33.

Funding of terminal care facilities

The provision of terminal care facilities of a high quality is a health service responsibility. As in certain other areas of health care, there has been and continues to be great public interest in the care of the dying: many current services owe their existence to voluntary effort, and there is as yet no dimming of interest in raising money for further services. The public's involvement in establishing a terminal care service to meet local needs can be of great value, in so far as it allows for an input from potential users of the service and provides a focus for innovative community effort. This public enthusiasm should be exploited, but regardless of the extent of voluntary effort, health authorities are ultimately responsible for planning and coordinating terminal care services and ensuring that proper services are provided. Early NHS involvement helps to ensure that voluntary effort is used in the way that best meets the needs of the community.

This section describes the costs and sources of funding of the various types of terminal care schemes reviewed earlier in this booklet. It begins, however, with a review of the range of options open to health authorities wishing to support voluntary initiatives. Having established the need for a particular facility, the health authority may wish to assist in any of the following ways:

- by making available land for building at a peppercorn rental, for example on a hospital site.
- by making a contribution to capital costs: health authorities are empowered to make capital grants to voluntary bodies, provided the scheme in question fits within the authority's own programme.
- by a contractual arrangement to fund the revenue costs of beds and home care, based on the degree of use by a particular district.

- by providing certain services, either free or at cost. This is facilitated if the unit is situated close to a district service.
- by providing particular stock items or items of equipment, either free or at cost.
- by making a district supplies department available for the purchase of equipment or supplies.
- by providing administrative support, for example with regard to employment of staff—by handling the payroll, National Insurance and income tax payments.

Costs and funding arrangements for in-patient hospice units

The cost of establishing an in-patient hospice unit will depend on the overall size of the unit, on whether it offers day care and home support as well as in-patient care, and on whether existing premises are converted or a new building constructed. Current costs for building a 16-bed in-patient unit with day care and home support are close to £1 million. The running costs of such a unit would be in the region of £400,000, or £25,000 per bed per annum. For this type of comprehensive service, a full-time consultant-level appointment is considered necessary if the service is to achieve its full potential as an education and training resource for the surrounding area.

As far as the size of the unit is concerned, the original hospice units tended to have between 20 and 30 beds. With the increasing use of home support and day care, the need for in-patient beds may decrease. For this reason, a larger unit would need to draw patients from a wider catchment area.

The diversity of current funding arrangements may be summarised as follows:

1. Some units have been established by the Cancer Relief Macmillan Fund (also known as National Society for Cancer Relief) in conjunction with the health authorities. They are

known as continuing care units, and are all located on hospital sites. The Society has provided capital funding and the health authority has assumed total responsibility for revenue costs.

2. At the other extreme is the totally independent hospice, where the bulk of capital costs have been raised by voluntary effort, and where a proportion of the running costs may be met by health authorities on the basis of contractual arrangements. Research by Hill and Oliver (Health Trends, Vol.16, No.1, p. 9, 1984) shows that a majority of independent in-patient hospice units are receiving considerably less than 50 per cent of their running costs. Thus, many independent hospices are having to raise something in the region of £200,000 per annum from other sources.

This being the case, collaboration between health authorities and members of the public wishing to raise funds for a hospice should occur at as early a stage as possible. This is advantageous to both parties: the health authority can ensure that proposed plans are compatible with its own and adjoining districts' strategic plans, as well as in line with current good practice. For the fund-raising committee, it provides an opportunity to establish at the outset how much help they can expect from the health authority and what form this help will take.

Costs and funding of home support services

The approximate annual cost of a home support nurse is £15,000. This covers salary and other expenses: uniform, telephone, travelling, ongoing training. A common arrangement is for Cancer Relief Macmillan Fund (National Society for Cancer Relief) to meet the cost of a minimum of two nurses (known as Macmillan nurses) for an initial period, after which the health authority takes over the cost. In some instances, where a health authority has already started a home support scheme, the Fund can help to expand the service.

Costs and funding of hospital support teams

As with home support teams, the primary cost is for salaries of the staff, as other resources, such as beds and services are deployed from within the hospital. Costs will depend on the number and grade of staff. The core of the team consists of nurses, with or without social work and secretarial backup. It is essential that the team has medical support from a designated and respected doctor with relevant expertise.

Costs and funding of day care

The cost of a new building, offering a reasonable range of day care facilities would be approximately £150,000, with annual running costs of £65,000. However, many schemes convert established premises for a sum considerably less than this. Where a day centre has been grafted on to an existing health service, for example, a hospital or hospice, both capital expenditure and running costs are reduced.

Detailed funding information about particular schemes can be obtained from Cancer Relief Macmillan Fund and from the Hospice Information Service (see 'further information and advice,' page 33).

Further reading

Cancer Relief Macmillan Fund. **Macmillan Green: a planning concept.**
Enquiries to: Cancer Relief Macmillan Fund, Anchor House, 15-19 Britten Street, London SW3 3TY. Tel: 01-351 7811

West Midlands Regional Health Authority. **Regional Strategy 1984-1994.** *(Section devoted to 'hospice services to provide continuing care').*
Enquiries to: Planning Department, West Midlands Regional Health Authority, 146 Hagley Road, Birmingham, B16 9PA. Tel: 021-454 4828

Training in care of the dying

Whether or not specialist services are already available in a particular district, health authorities should be seeking to systematically expand training opportunities for general staff in hospitals and in the community. In this way, the overall standard of care will be raised.

Training can be provided in the following ways:

- Nursing staff can attend English National Board Course No. 931, 'Care of the dying patient and the family.' This course is available at a number of centres in this country, but waiting lists are long.
- Staff can attend study days and conferences. Further information about these can be obtained from the following organisations:

Hospice Information Service, St. Christopher's Hospice,
51-59 Lawrie Park Road, Sydenham, SE26 6DZ. Tel: 01-778 9252

Lisa Sainsbury Foundation, 8-10 Crown Hill, Croydon,
Surrey CR0 1RY. Tel: 01-686 8808

Royal College of Nursing Symptom Control and Care of the
Dying Forum, Henrietta Place, Cavendish Square, London
W1M 0AB. Tel: 01-580 2646

Help the Hospices, General Office, BMA House, Tavistock
Square, London WC1H 9JP. Tel: 01-388 7807

Macmillan Education Unit, Department of Therapeutics,
London Hospital Medical College, Turner Street, London E1 2AD.
Tel: 01-377 7105

Marie Curie Memorial Foundation Institute of Oncology,
28 Belgrave Square, London SW1X 8QG

- It is increasingly the practice for specialist staff in hospices and home support teams to undertake teaching of all staff and volunteers. Hospital support teams in teaching hospitals play an important role in training the next generation of doctors and nurses. Health authorities engaged in creating new specialist posts should ensure that a teaching responsibility is built into the job description.

Further information and advice

A booklet of this size and scope cannot go into the amount of detail that health authorities need for the effective planning of services for the dying. However, there are several organisations who have the experience and expertise to provide specific information to health authorities on request.

- **Hospice Information Service** aims to keep abreast of developments in terminal care, and is a resource and a link for those interested in improving services. It publishes a Directory of Hospice Services which lists more than 200 terminal care schemes in the UK and the Republic of Ireland. The objective of the service is not to hand out 'how to' guidance, but rather to put people in touch with each other, to encourage workable schemes, to discourage duplication of effort, and to provide specific or background information to members of the public and of the professions.
  St. Christopher's Hospice, 51-59 Lawrie Park Road, Sydenham SE26 6DZ. Tel: 01-778 1240

- **Cancer Relief Macmillan Fund,** formerly the National Society for Cancer Relief, has promoted a range of terminal care services, with particular emphasis on home care. They can offer detailed information and advice about all aspects of establishing and running a continuing care service.
  Anchor House, 15-19 Britten Street, London SW3 3TY.
  Tel: 01-351 7811

- **Lisa Sainsbury Foundation** has as its prime aim the care of those caring for the terminally ill, with special reference to nursing staff. They can arrange workshops in any part of the country, and can also provide information about terminal care in the form of booklists, video tapes, a newsletter, and publications on caring for the dying.
  8-10 Crown Hill, Croydon, Surrey, CR0 1RY. Tel: 01-686 8808

- **Help the Hospices** is interested in funding specific projects, equipment, education and research in the field of terminal care. It runs or supports management policy, counselling and family therapy workshops and clinical courses in this field. It does not support major construction work or the routine running costs of established units.
  General Office, BMA House, Tavistock Square, London
  WC1H 9JP. Tel: 01-388 7807

- **The King's Fund** has as its aim the acceleration of the introduction of new ideas and practice in the planning and management of health and social services. It encourages the exchange of information and ideas in all parts of the health service.
  King's Fund Centre, 126 Albert Street, London NW1 7NF.
  Tel: 01-267 6111

- **Marie Curie Memorial Foundation** provides eleven homes, a community nursing service, an Institute of Oncology and a research institute. Head office, 28 Belgrave Square, London SW1X 8QG. Tel: 01-235 3325.