

## National terminal care policy\*

### REPORT OF THE WORKING GROUP ON TERMINAL CARE

#### Introduction

**T**HE Working Group was set up on the initiative of the Standing Sub-Committee on Cancer in March 1979. Its terms of reference were to consider the organization of primary, continuing, and terminal care services for cancer and to make recommendations.

It was considered best that the Group should concentrate in the first instance on terminal care services and this report therefore considers this aspect only.

#### Factors in terminal care

We believe that the unmet need in the field of terminal care presents us with an immediate problem. Where the dying are concerned there is, of course, no possibility of trying harder next time. The dead cannot complain and, despite their resentment and grief, the bereaved do so with surprising rarity. Techniques exist to alleviate the worst miseries of the dying patient and there are also ways in which the family can be helped. This is not a matter of new buildings or expensive equipment. It depends primarily on enlightened professional attitudes. Our objective now should be to ensure that every dying patient has access to professional staff who can provide the appropriate care.

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 Organization, 1973). Often this stage lasts only a few days and conventional services are reasonably well appointed and equipped to meet the patient's needs. However, in the case of many cancer patients and certain other diseases this phase can last for months or even years. Terminal care is, therefore, the provision of the very special sort of support required by these patients and their families. It is based, above all, on high-quality nursing, but also may involve explanation and counselling for both the patient and his relatives, help with spiritual or social problems, the adroit use of different techniques of medical palliation, and the use of physiotherapy, occupational or re-

creational therapy, and other methods of enhancing the remaining period of life. The whole range of professionals working in health care should be involved: not only doctors and nurses, but also social workers, physiotherapists, and occupational therapists. Good terminal care has many aspects and it is more easily achieved if it is planned.

It is important that death should not be considered a failure by professional staff. Indeed, as far as the dying patient is concerned, the only failure is if the period before death is not as comfortable as possible. The greatest skill, perhaps, is identifying what is appropriate. Sometimes this will inevitably cause some heart-searching by individual clinicians and their nursing colleagues, who must ensure that no therapy is causing unnecessary discomfort for the patient before death or greater distress for the relatives. The main aims of those providing terminal care should be to improve the quality of daily life by removing or alleviating unpleasant symptoms and helping to prevent the patient from suffering fear or loneliness. Many distressing symptoms may be relieved by good basic nursing care. The nurses will also have an important role in identifying symptoms which have not been adequately relieved. Vomiting, constipation, or diarrhoea, for example, can soon, if left untreated, become more immediately damaging to the patient's well-being than the underlying disease.

Surveys have confirmed that pain is a major problem among terminal cancer patients, and also that most of the pain is unnecessary and due to poor medical management. Some patients may have little or no pain and require nothing stronger than simple analgesics. However, where such medication proves ineffective, opiates will be required. Unfortunately there is considerable evidence to show that many clinicians who prescribe opiates start them too late and in too low a dosage. Drug dependency or major escalation in the patient's need for opiates are often given as reasons for restraint but are, in fact, so rare as to be ignored in practical management. Pain relief needs to be provided regularly to prevent rather than palliate pain. Where opiates are indicated morphine and diamorphine (heroin) are particularly useful. The greater solubility of heroin makes this more convenient if oral medication is not reliable and injections are required. The dosage varies more often than is appreciated and should be tailored to suit

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the individual's needs. Many patients are well controlled by 5 or 10 mgs of heroin four-hourly, but a small minority may need 100 mgs every four hours or even more. Combinations of drugs such as opiates with non-steroid anti-inflammatory rheumatic analgesics should also be considered, as should modern techniques such as phenol nerve-blocks if drug treatment is unsatisfactory.

A patient who is lonely and depressed or who is sleeping badly will be able to tolerate pain less than one who is relaxed and who has friends and family around him. It is therefore of vital importance that existing social contacts are maintained and where necessary new ones encouraged. There should also be support from, and a good relationship with, professional staff. Doctors and nurses, no matter how preoccupied, should make time to talk to the dying patient about daily happenings and his immediate interests.

Many problems can be prevented if information is effectively communicated. When the dying patient asks for information, the truth should usually be given in a kindly and optimistic way, but still in a form which is recognizably the truth. As the illness progresses patients often wish to know more and past lies may form a barrier so that they feel anxious and isolated. Similarly, lack of information can make the relatives feel uncertain and embittered. It is important that when the doctor tells a relative that the patient is going to die this is done in simple language, as fully as possible, in a quiet room where the interview will not be interrupted. The relative should be given ample opportunity to ask questions and a second interview should be arranged so that any further information required may be provided when the full impact of the news has been absorbed.

Professional staff should not consider the death of a patient as the end of their responsibility, since by preparing the patient's family emotionally before the death the relatives are more likely to adjust well to their bereavement. There is very strong evidence that bereavement, like divorce, can have an obviously adverse influence on physical health. We recommend that advice and support should be given to the relatives of the terminally ill both before and after death. This is a preventive measure and good clinical practice.

Because death is an experience which affects the whole family, there are clear benefits to be derived from involving the family in the care of their terminally ill relative. Helping with the routine care can increase confidence, and help the family to achieve good communication and mutual support. It is also a comfort in bereavement for relatives to know that they have helped as much as possible. For obvious reasons, it is easier for families to feel useful in their own homes. However, it is also possible to involve relatives in care when the patient is in hospital, and the model of family involvement developed by those working in paediatrics is particularly useful here. Hospitals should have facilities at least for simple meals, a room to talk, and overnight accom-

modation for the nearest relative of a dying patient. Open visiting is also desirable.

### **Where to provide care**

At present the care of the dying is shared between the primary health team, the general hospital, and the hospice or special unit. Fifty-nine per cent of all deaths take place in hospital and 30 per cent at home. The majority of patients with terminal cancer (60 per cent) die in NHS hospitals in general wards, about one third die at home, and about five per cent die in non-NHS hospitals and hospices.

It is common for the patient to be admitted to hospital for a few days immediately before death, so general practitioners are involved in the terminal care of far more patients than the figure for those dying at home suggests. However, a large proportion of cancer patients (42 per cent) spend between two weeks and two months in hospital before death, compared with only 28 per cent of patients dying from other causes.

Many people feel that the ideal death is one which occurs peacefully in one's own bed, so why do the majority of patients die in hospital? An over-optimistic prognosis from the doctor, or a natural disinclination on the part of patient or relatives to accept the imminence of death, may lead to a lack of preparation on the part of all concerned. Relatives may also lack confidence that they will be able to cope with the increasing personal needs of the dying patient. Ageing relatives tire and younger relatives have other family responsibilities. The use of a deputizing service in urban areas may be totally justifiable, but the use of a deputy for dying patients is not compatible with the commitment required in good family practice. There is much anxiety among relatives that the necessary support will just not be available when it is needed.

In general, it is not possible to identify one place as providing the best care for all patients; it very much depends on the individual's own wishes and needs and those of his family and the facilities available. Each type of care, whether it is at home, 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.

### *Care at home*

When it is successful, care provided in the familiar surroundings of home, under the supervision of the patient's general practitioner and with the support of the primary health care nursing team, can undoubtedly produce the very best of terminal care. The willingness of the general practitioner to undertake such care is an essential factor. Unfortunately some general practitioners are not fully aware of what can be achieved in domiciliary care and it seems likely that the most distress as well as the least occurs at home.

It is, of course, essential to ensure that adequate

symptom and pain relief is available whenever it is needed. The family need to know that if problems arise they can contact their general practitioner or a trusted and known community nurse in the evening or during the night. Simply possessing the telephone number of a member of their own care team can be enormously reassuring. Not all parts of the country provide a night nursing service and the nurses provided by the Marie Curie Memorial Foundation play an invaluable role here. Sitting services provided by some local authorities and voluntary groups can also be very helpful. An important and often forgotten factor is the family's financial situation; if necessary, the help of the National Society for Cancer Relief can be sought and quickly obtained. Supplementary benefit may also be applicable.

#### *Care in hospital*

General hospitals are capable of providing terminal care of a high standard. However, the care which many terminal patients receive falls short of what is possible. Sometimes the more pressing demands of other patients can lead them to feel neglected and staff may feel ill equipped to cope with their emotional needs.

Many consultants do, however, consider it an important part of their clinical role to provide care for their patients even when the prognosis is poor, and will re-admit a patient for terminal care as a normal part of their continuing responsibility for that patient. If the patient has received earlier treatment at the same hospital he and his family may find the familiarity of the routine and staff comforting.

#### *Care in a terminal care unit*

The specialist skills of a terminal care unit often provide a range of resources to assist those caring for the dying at home. In some instances it may be helpful for the patient to go to the unit as an outpatient or a short-stay patient, to achieve good symptom control. Also, because such units have beds available they can provide a valuable service when home care is no longer appropriate. In other instances, however, the unit may go to the patient, in the form of a unit-based home care team which aims to work with the general practitioner and the district nurse, at their invitation, to help provide terminal care of a high standard in the community.

There are about 50 of these units and they cater for a very small proportion of those requiring terminal care. Why not build more units? The success of the hospice movement has been based to a large extent on the great skill and the very high level of commitment of the staff working in these units. It is not easy to generate this sort of enthusiasm, nor are the specialist staff readily available at present.

Some patients and their families find the idea of admission to a special terminal care unit distressing. Indeed, it might be argued that there was something unhealthy with any society which felt the need to hide

dying patients away in separate institutions. From a professional viewpoint there are also some disadvantages in detaching terminal care from other aspects of care. Both hospital staff and the primary care team can feel a commitment to care for their own patients through their last illness and consider it to be a rewarding experience. While recognizing the need for specialist advice in some instances there is concern lest a new service develop to interpose between the established care teams and their patients.

It is more important that the medical and nursing staff involved should have an understanding of the problems, an adequate level of knowledge, a positive attitude to the scope for achievement, and reasonable resources. Individual patients have a variety of needs and each professional team, whether in the hospital, in the hospice, or in the community has its own contribution to make. An important factor is the wish of the patient, although there can only be real choice if the patient and his family have been given the information they require about the facilities available.

#### **The pattern of future provision**

The techniques and attitudes used in terminal care have developed relatively recently and many professional staff have not yet had an opportunity to acquire the necessary skills. We believe that the shortage of trained staff and the shortage of reliable sources of revenue funding would dilute the quality of care that additional specialist units would be able to provide, and they would lack the off-setting advantages of hospital or home care. We do not consider, therefore, that there would be any advantage in promoting a large increase in the number of hospices at present and we recommend that the way forward is to encourage the dissemination of the principles of terminal care throughout the health service, and to develop an integrated system of care with emphasis on co-ordination between the primary care sector, the hospital sector, and the hospice movement.

#### *Role of the hospital*

We believe that the district general hospital has a large role to play, especially where there is no special unit locally. Expert advice on pain control and relief of other symptoms should be available from district general hospitals. There are already several examples of hospital teams, similar to those operated by special units, which provide a point of reference for informal consultation, either in the hospital itself or by going out to the community.

#### *Home care*

Because the number of terminal patients represents a small proportion of the primary care nursing workload, we believe that this should enable high quality care to be given. Should home care increase, health authorities will need to review nursing establishments in the primary

care section, with a view to ensuring that they reflect adequately the nursing requirements of the terminally ill.

### *Role of special units*

We believe that special units and hospices will have a continuing position as the initiators of new approaches to symptom relief, as centres for research, and for the training of staff in the techniques of terminal care. We share the view of the pioneers of the hospice movement that such units are not, nor ever should be, simply the way to provide beds for dying patients, but rather are dynamic and outward-looking centres of skill. It is not easy to replicate the type of service which has been developed by the existing units. We recommend that those considering establishing new units should make sure that the resources and skills will exist to meet the essential features of a special unit.

Some units have recently established day care centres for terminal patients who are being cared for in the community. Day care provides the opportunity to give the patient more concentrated attention than a consultation without admission to hospital. It provides an opportunity to assess and control symptoms; it also gives the patient an opportunity to meet others and join in group activities which can alleviate any feelings of isolation. It enables the patient to establish relationships with the staff, which are of value if and when admission is required. Day care can also allow relatives a welcome break and perhaps indirectly help prevent breakdowns in home care caused by family stress. The advantages of day care should be examined carefully by terminal care and other suitable units.

### *Need for research*

The special unit differs from hospitals in that the large majority, if not all of its admissions, will be for terminal care. It does, therefore, provide a unique opportunity for research into the needs of the dying. We consider that there is a need for high quality research work to be undertaken in this sphere. Further evaluation of hospice-based home care teams would be useful. There is also more work to be done in establishing effective pain control régimes for those living alone and in assessing the role of counselling in terminal care. Additional information on the economic aspects of terminal care provision is needed. Terminal care units should be encouraged to undertake high quality research.

A concentration of patients requiring terminal care provides an excellent opportunity for both nurses and doctors to acquire experience of this type of work quickly and under supervision. The special unit can also seek actively to inform colleagues in other specialties of new developments in terminal care. For these reasons we believe that terminal care should have the capacity to educate and inform and there are strong advantages in linking units with nursing and medical training schools.

### *Local needs*

We recognize that local needs vary and depend on many factors. For example, in rural areas family ties are stronger and travelling to a special unit or hospital might create difficulties; consequently, greater emphasis should be given to the provision of terminal care at home. In our larger towns and cities many people live alone or in very small families and transport is easier; consequently, there will be a great role for a special unit and for the hospital. The pattern of care should be developed, therefore, at local level to meet local needs. We recommend that every regional health authority should plan for terminal care provision, taking into account both NHS and voluntary resources and after consultation with those voluntary bodies which help fund terminal care services.

### *Large cities*

We believe that the major cities pose real problems to those aiming to provide good terminal care. They should have a service for terminal care which fully involves the primary care sector and hospital service, and includes a special unit. There may well be advantages in appointing a co-ordinator at local level to ensure that the service operates as flexibly as possible.

### **Training and education**

Nurses and doctors have always had patients who die and death occurs in all specialties. However, many recently trained nurses and doctors have received little training to equip them to cope with their own reactions to death, let alone help them to provide the support a dying patient and his family require. Lack of training manifests itself in many ways, but a common reaction is for staff to set up an emotional barrier and minimize contact with the dying patient in order to protect their own feelings. Sadly, this is the opposite of the sensitive and open approach required if good care is to be achieved. Adequately trained professional staff have sufficient confidence to face the problems of a dying patient with an understanding of the ways in which they can employ their skills to help overcome them.

### *Training for nurses*

Because good terminal care begins with high standards of nursing care, the quality of terminal care will reflect the quality of basic nurse training and we are of the view that the fundamental techniques of nursing, such as mouth care and pressure area care, should continue, despite the pressure of technology, to be given a very high priority in nurse training. We recommend that greater emphasis should be given to 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 fulfil their front-line role in relation to both patients and relatives.

#### *Training for medical students*

Medical students should have an opportunity to learn at an early stage in their clinical training how to identify the patients where efforts should be concentrated towards palliation rather than cure. They should also understand that all their clinical ingenuity is required if symptoms are to be adequately relieved. We consider that a terminal care component should be included in the training of medical students. We also consider that they would, like nurses, benefit from instruction in counselling techniques.

In terminal care practical experience is of the greatest importance and we believe that all trainee nurses and student doctors should have an opportunity to observe the work of a hospice or special unit. It is essential, therefore, that nursing and medical schools should be linked to such a centre.

#### *Lack of postgraduate training*

There is a need to ensure that there are adequate numbers of appropriately trained doctors in terminal care and we deplore the current lack of postgraduate training in this field. We believe that this problem should be considered seriously by the Joint Committee on Higher Medical Training and the relevant advisory committees on specialist training. Those bodies responsible for oncology, radiotherapy, general medicine, anaesthetics, and general practice should consider whether trainees in their specialties might usefully undertake a six-month option in terminal care. Many clinicians working in these disciplines may not choose to work entirely in terminal care but will be interested in undertaking such work on a regular part-time basis through a terminal care option in their postgraduate training.

#### *Other professionals*

As we have noted, social work support and the skills of physiotherapy and occupational therapy are essential components in the provision of good terminal care. We believe, therefore, that the needs of the terminally ill should be specifically recognized in the basic training for these professions. Where qualified professionals move to a post where a large part of their work will consist of dying patients, they should be able to undertake the appropriate specialist training.

#### **Conclusion**

Terminal care depends heavily on good communications both within the caring team and between hospital and community teams. Good communication in this sphere as in others relies on an ability to relate to other people and an adequate understanding of the ways in which

different professions contribute to the care of the whole individual. We believe that poor quality communication with patients and relatives often coincides with poor communication between professional colleagues. We consider that the capacity for teamwork is today an essential but neglected professional skill. We recommend, therefore, that nursing and medical students should receive training to help them work closely with other professions.

#### **Appendix**

##### *Summary of recommendations*

1. Advice and support should be given to the relatives of the terminally ill both before and after death.
2. Hospitals should have facilities for relatives, such as simple meals, a room to talk, and overnight accommodation.
3. There would be no advantage in promoting a large increase in hospices. An integrated system of care should be developed with emphasis on co-ordination between the primary care sector, the hospital sector, and the hospice movement.
4. The district general hospital has a large role to play, especially where there is no special unit locally.
5. If terminal care at home increases, nursing establishments in the primary care sector should be reviewed.
6. Those considering establishing new units should ensure that the resources and expertise will be available to support their work.
7. The advantages of day care should be examined by terminal care and other units.
8. Terminal care units should be encouraged to undertake high quality research.
9. Terminal care units should have the capacity to educate and inform. There would be advantages in linking units to nursing and medical schools.
10. Every regional health authority should plan for terminal care, after consultation with funding voluntary bodies.
11. Major cities should have a service for terminal care which fully involves the primary care sector, the hospital service, and includes a special unit.
12. Voluntary bodies should consider the supply of specialist nurses to provide community support, night nursing, day care facilities, and resources for staff training as especially deserving a high priority.
13. Greater emphasis should be given to the psychological aspects of dying and bereavement in basic nurse training courses, which should also include an introduction to counselling.
14. A terminal care component and instruction in basic counselling should be included in undergraduate medical training.

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#### Addendum

Members of the working group were: Professor E. Wilkes, OBE, MA, FRCP, FRCGP, FRC.Psych, DRCOG (Chairman), Professor of Community Care and General Practice, Department of Community Medicine, University of Sheffield Medical School; Mrs G. Harnett, SRN, Nursing Officer (Home Nursing), Barnet Area Health Authority; Dr D. E. M. Speed, MB, Ch.B, Senior Lecturer in Medicine and Hon Consultant Physician, Horder Ward, Royal Marsden Hospital; Dr R. L. Meyrick, FRCGP, General Practitioner, London.

## Improving continuity of care

In July 1977, the Hollywood Family Practice Unit of the University of Miami Department of Family Medicine was relocated eight miles from its former structure. Analysis of patient encounter data gathered by one resident during the two six-month periods prior to and following the move showed little effect of the relocation on five indexes of continuity of care. According to four indexes (percentage of revisits, percentage of revisits for new problems, percentage of revisits for previously recorded problems, and percentage of families with more than one member attending), the author experienced a gradual and uninterrupted increase in continuity of patient care. A fifth index, percentage of psychosocial diagnoses, dropped slightly during the third study period. Overall continuity was low, however, when compared with established practices. Although family practice residencies should accept disruption in continuity of patient care due to their structure and purposes, steps are noted which can be taken to improve continuity of care.

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