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Good practice in hospital care for dying patients

ALIX HENLEY

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PREFACE

Alix Henley, who has been responsible for pioneering work in identifying problems connected with the delivery of health care to ethnic minorities, now works for the Bloomsbury Health Authority. In her new capacity she has turned her attention to a quite different, but equally important and poignant subject, namely the management of the care of those who are dying in hospitals. This project paper has been written quite clearly for the benefit of those being cared for within the Bloomsbury Health Authority and for those who provide care. It is our belief in the King's Fund that what she has described from the eminently practical standpoint that she has adopted gives guidelines which could readily be taken over by others, and is in this belief that we think that the paper should be published and widely distributed.

The care of the dying, whether it be in hospitals or in the community, is a difficult and emotive subject, and one of the most rewarding features of the many debates on health care in recent years has been the increased attention that has been given to the practical aspects of the care of the dying. We believe that this paper, although it has been written for a particular health authority, has within it material which can be readily used in many others. It is our hope that it will be so used and that it will be of direct benefit to those who have the very onerous task of providing care.

W.G. Cannon
Director, King's Fund Centre
March 1986

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INTRODUCTION

In response to the DHSS circular *Patients Dying in Hospital* (DA(84)17), the District Management Team asked for an examination of the way that dying patients and their relatives are cared for in Bloomsbury hospitals. This paper arises out of that examination and also out of discussions with nurses, doctors and other people who care for dying patients and their relatives, and with relatives of patients who have recently died in hospitals.

The paper outlines agreed good practice and focuses particularly on areas where people felt that current hospital provision was not always adequate. Although many of the good practices described here are already routine in most Bloomsbury hospitals, the introduction of others may involve changes in priorities or organisation. A few may require policy decisions. It is intended that this paper, and particularly the checklists at the end, should help Unit, hospital and ward staff to assess current practice and to make improvements where appropriate.

The paper deals chronologically with care before death, at the time of death, and after death. Two key themes recur all the way through: first, the tremendous importance of good communication between staff, patients and relatives, and between all the different members of the team of staff caring for a patient; and second, the need for more training and support for doctors, nurses and other staff, to ensure that they are able to offer dying patients and their relatives the individual emotional and practical care they need.

These two themes were stressed by everyone I spoke to. There was general agreement that they should receive particular attention when improvements in provision are being planned.

This paper deals mainly with issues surrounding the care of adult patients. It does not cover the specialist areas of caring for dying children or of perinatal death. Although the principles of good care remain the same, these specialist areas also make particular demands on Health Service staff and may need special provision. Staff working in these areas may like to compile their own good practice documents combining parts of this paper with recommendations specific to their field of work.

I should like to thank the many people, both inside and outside Boomsbury Health District, who have commented on and improved this paper. Any errors or faults are entirely my own responsibility.

Alix Henley
Department of Community Medicine
February 1986
Revised January 1987

Care for patients and their relatives before death

PATIENT CARE

The aim of hospital staff caring for patients who are dying or who may die is to ensure that each patient's death is handled as helpfully and sensitively as possible and that adequate support is offered to relatives* both before and after the death. This requires skill and sensitivity and can be very enotionally demanding and time consuming. Staff at all levels are likely to need support and training to carry out this part of their role successfully.

Giving time to dying patients Medical, nursing and other staff who find death and dying difficult to deal with may avoid dying patients and their relatives. At the same time, people who are dying may be extremely sensitive to the way other people behave towards them and are likely to be in special need of human contact, comfort and reassurance. Dying patients are as important and need at least as much practical and emotional care as patients who will survive. This must be taken into account when planning work on the ward, though it may be particularly difficult on a busy acute ward. If dying patients have few or no visitors, staff should make a special effort to spend time with them.

Private conversations Most patients find it difficult to ask

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* Throughout this paper 'relatives' includes close friends. It may be necessary for staff to identify one or more close relatives and friends who take prime responsibility for the patient and who will communicate with other family members and friends.

important questions about their prognosis, or to discuss their worries and feelings, in public or in front of a group of staff. They should be offered regular opportunities for private one-to-one conversations with senior doctors and nurses.

Help in breaking bad news A doctor with bad news for a patient may find it helpful to take an experienced counsellor, such as a cancer counsellor or social worker, to the interview. Together, they may be better able to help the patient to understand the diagnosis and to cope with it; they can also discuss immediate and long term questions and worries. The counsellor may also be able to maintain contact with the patient and give support as it is required.

'Telling' the patient Although most patients wish to know their prognosis, some do not. It is important to let each person decide what he or she wants to know and when, and to answer any questions as honestly as possible. The patient is the best judge of how much knowledge he or she can handle at any time. If worried relatives ask medical and nursing staff not to tell a patient the truth, staff must remember that their first responsibility is to the patient, and to answer honestly any question he or she may choose to ask. It is important to explain this to the relatives and, if possible, to encourage them to speak openly with the patient.

Answering questions Patients may ask any member of staff or student at any time about their prognosis, and wish to discuss their feelings, hopes and worries. All nurses, and doctors, however junior and including students, and other staff who provide care for patients, should have up-to-date, though not necessarily specialist, knowledge about a patient's condition. They should feel able to give time to patients when they wish to talk and should know how to get help if they feel out of their depth. Non-professional staff should be advised how to deal with patients' questions, including, where appropriate, calling a senior member of staff to talk to a patient. Any member of staff with whom a dying patient has developed a close relationship should be recognised as an important person in the care of that patient. Staff at all levels have shown how quickly they can handle this role.

The language barrier If a patient speaks little or no English it is important to have a competent interpreter readily available. In some cases a member of the patient's family who speaks good English will be able to stay with the patient and act as interpreter. But a hospital interpreter will still be needed to enable doctors or nurses to speak privately to the patient and to discuss any problems that the patient does not feel able to discuss through a member of the family. There may also be times when communication is urgently needed and the family member is not there. Interpreters working in these stressful situations will need training and support from other staff.

Religious and cultural minorities Behaviour at a time of serious illness varies between cultures. It is important to ensure that all patients and families, of whatever ethnic group, receive the practical and emotional care they need. Cultural attitudes towards different patterns of family involvement, physical care, modesty and so on must all be taken into account. For some patients it may be important that the whole family visits them together. Food that is both appetising and religiously acceptable may have to be provided. All staff should have training on these issues and should be encouraged to ask ethnic minority patients and their families about their needs and preferences.

People with disabilities Staff in acute hospitals often feel embarrassed or uncertain when caring for patients or relatives with physical, psychiatric or learning disabilities, and particularly for people with limited speech and, apparently, limited understanding. It is important to recognise that people with limited speech generally understand a good deal more than their speech, tone of voice and posture indicate, and that they are often particularly sensitive to another person's tone of voice and non-verbal signals. Where possible, relatives should be asked how best to communicate with a disabled patient. It is crucial that disabled patients and relatives are given the same respect and sensitive care as other people.

Control of symptoms One of the most common fears of dying patients is unbearable pain. Most of the symptoms of terminal illness such as pain, breathlessness, nausea and constipation can now be controlled. A major aim of terminal care is to control distressing symptoms and to maintain each patient in the maximum possible physical comfort. Many patients also need constant reassurance that their pain will not be allowed to become severe and that pain relief will be given whenever it is needed. This requires good communication with the patient and other team members, up-to-date knowledge of symptom control and a flexible approach. A pain chart is often helpful. Useful publications on symptom control are *A Supplement on prescribing and symptom control* available from the Bloomsbury Support Team and *Drug control of common symptoms* by Dr Mary Baines (see page 46). Copies should be kept on each ward for reference.

Individual practical care Practical care for each patient should be based on his or her individual needs. Routine medical or nursing interventions, for example daily temperature taking, blood pressure measurement, blood tests, x-rays, should be discontinued if they upset or disturb a dying patient.

Allowing a patient to die The decision to allow a patient to die is often very difficult. However, much distress can be caused to dying patients, to their relatives and to staff if efforts are made to resuscitate them when their quality of remaining life will clearly be poor. Although the final decision whether to resuscitate a patient usually falls to a doctor, the views of nursing staff and relatives should be taken into account. All staff should be aware of what has been decided with regard to particular patients. Where no decision has been recorded and no doctor is available, senior nursing staff should feel able to decide not to resuscitate a patient.

Where to care for dying patients The decision on where best to care for a patient dying in hospital depends largely on his or her own wishes and needs, and on the facilities available on the ward. Some patients may wish for peace and quiet and prefer to be moved to a side room, although it is important not to allow them to become isolated. Others may prefer to be part of life on the ward. Some patients may like to be moved closer to the office or staff desk. Patients who go home for a while but return to hospital in the final stages of their illness should normally be admitted to a familiar ward.

Going home to die Some patients wish to go home to die. This should be organised wherever possible, provided relatives feel they can cope and appropriate support is available. The Bloomsbury Support Team (see page 42) can often provide the practical help and reassurance that relatives need. Some patients wish to spend their last days or weeks in a hospice. Hospital staff should try to help organise this whenever possible.

Keeping the GP informed General practitioners are often unable to offer the support they would wish to give to dying patients and their relatives because they are not kept informed of developments. The GP should be informed promptly both when a patient is admitted or discharged, and if there are any important changes in the patient's condition. This information should normally be conveyed by telephone and followed up by a letter sent within 24 hours by first class post.

Recognising the GPs role GPs are often well acquainted with their patients and their relatives and can provide invaluable support. To enable them to do so, it is most important that they are kept fully informed of what the patient and relatives have been told. If hospital staff are not sure how to handle a particular situation, they should seek the advice of the patient's GP.

Informing the referring doctor It is also important to inform doctors from other hospitals who have transferred patients to Bloomsbury. Relatives often expect the referring hospital staff to be informed of the patient's progress. They may seek advice and guidance from these staff, whom they have come to know well. The referring doctor should be informed, again by telephone and first class letter within 24 hours, of any important changes in their patient's condition and of any progress.

Knowing whom to contact To enable fast and efficient communication, each patient's nursing record must contain clear and full information about how to contact the appropriate relatives, the patient's GP and, where relevant, the referring doctor. In cases where a seriously ill patient is moved to theatre or ITU, or between wards, it is particularly important that staff know where to find this information.

Spiritual counsel Spiritual counsel should be offered to all patients and relatives. Ward staff should find out whether a patient wishes to be visited by a hospital chaplain, a local minister or by someone they already know. Every Bloomsbury hospital has at least one Church of England, Roman Catholic and Free Church chaplain, and a Jewish rabbi, on whom it can call. They can usually give advice on the religious requirements of patients of other faiths, and how to contact representatives of those religions. Every ward should have an up-to-date list of local ministers of religion for all the religions likely to be represented among hospital patients. Ministers of religion should be welcomed when they visit wards and should also be involved in the training of doctors and nurses.

Trained counsellors In special cases where staff are unable to meet the needs of patients or relatives who are particularly distressed they should be able to call on a trained counsellor, possibly a hospital social worker, a cancer counsellor, a chaplain, or a local bereavement counsellor.

PATIENTS WITH AIDS

Liaison with community services In this district we look after many patients suffering from AIDS and can expect to look after many more in the future. Most people will be cared for at home for most of the time after AIDS has been diagnosed, but may come into hospital during acute phases or when they are dying. The physical and emotional needs of AIDS patient vary greatly and it is essential to provide good multi-disciplinary care for them whether they are at home or in hospital. This places a particular responsibility on hospital staff to liaise with the different services in the community.

Fear and stigma A patient with AIDS who is dying needs the same sympathetic and caring support from staff as other dying patients. The fear attached to AIDS may result in them having a special need for contact and affection and to know that they are not being rejected. Their relatives and friends, and health and community workers, may be reluctant to visit or touch them because of their own fears and the fears of their families. It is important to reassure them that AIDS cannot be caught through normal domestic contact. For health workers caring for AIDs patients, basic good clinical practice is synonymous with safety.

Support for families The families of AIDS patients may also need a good deal of support and help. They can be referred to specialist counsellors and health advisers through James Pringle House; telephone 01-323 4819.

CARE FOR RELATIVES

Care for the patient includes care for the family of which he or she is part. Appropriate support for relatives before, at and immediately after a death can also help with the grieving process.

Knowing the family A nurse or other staff member should be made responsible for discovering what family exists, how they wish to be involved, and what special needs they have. This should preferably be done at the time of the patient's admission. All staff should be briefed about the family and should consider them a vital part of the caring team.

A key member of staff It may be useful to identify one key member of staff to get to know the relatives well and to have a special responsibility for keeping them informed and making sure that they receive the care they need. This responsibility should continue into the period after the death and the staff member should try to see the relatives if they come back to the hospital for any reason. He or she could also contact the relatives a few days after the death to find out if they need help or have any questions to ask, and could suggest and organise bereavement counselling if it is appropriate.

Welcoming relatives Many relatives have been caring devotedly for patients for some time before they come into hospital. Their care and involvement up to then, and their continuing importance in the care of the patient, must be acknowledged by staff. They should not be made to feel that they have failed when the patient is re-admitted to hospital. They should be offered the chance to help with the day-to-day practical care of the patient, if they wish, as well as given opportunities to take a break. The welcome given to relatives, and their involvement in the care of patients, are among the most appreciated features of hospice care. Staff can also often learn a good deal from the care that relatives give to dying patients.

Talking to relatives in private Relatives need information and opportunities to ask questions and express their feelings. Too often they find it difficult to get reliable information or to find out what is happening and are made to feel pushy and unreasonable if they insist. Senior medical and nursing staff should try to talk to the patient and close relatives together whenever necessary. This ensures that everyone receives the same information. Staff should also offer visiting relatives time to discuss their worries and ask questions in private. Relatives should be encouraged to contact staff whenever they feel the need.

The language barrier If the relatives speak little or no English an interpreter will be needed to make sure that they understand the situation, can ask questions and discuss worries.

Communicating important information Good communication between staff on a ward is essential. For example, failure by staff to communicate or take into account an important piece of personal or family information can cause great distress. In some hospitals a special card or coloured sheet is kept in patients' notes on which all staff, including chaplains, nursing auxiliaries, social workers, chiropodists and so on, record important conversations with patients and relatives – for example, who has been told what, their worries, and their requests. This both improves standards of care and lessens the stress on staff. Such a system should be considered in those wards where it is not already in use. Relevant information should also be discussed by staff after ward rounds or at team meetings.

Keeping relatives informed Relatives should be kept informed of developments in the patient's condition as they occur and particularly when death seems imminent. The relatives of patients undergoing major surgery should be kept closely informed of progress and developments.

Facilities for visitors Dying patients should be allowed 24-hour visiting if they wish. A family member or close friend may wish to sit with them through the night. Relatives who visit frequently or stay with terminally ill patients will need special support and facilities. These include comfortable chairs by the bedside, easy access to meals and refreshments, and a pleasantly furnished room in which to relax and talk privately. Relatives who find travelling to and fro difficult or do not live in the area, should be offered a room in which to stay.

Caring together If relatives, with the consent of the patient, wish to stay with a patient while nursing and other procedures are carried out they should be allowed to do so. During the precious last days of a dying patient, staff should endeavour to be as supportive and flexible as possible in response to the patient's and relatives' needs and wishes.

Children of dying patients Provided the patient and the family agree, the young children of a dying patient should be allowed to visit frequently and to spend time with their patient. If necessary a side room or cubicle should be provided for them. It is most important that children should not be cut off from their dying parent. Adult members of the family may find it difficult in their own grief to give children the comfort they need and staff may have to help with this. It is almost always beneficial to allow a child to see its parent after death so that the child is helped to accept the reality of the death and remembers the parent restful and at peace rather than ill and suffering.

LIFE-SUPPORT MACHINES

Brain death When a patient on a life-support machine is diagnosed as being brain-dead, it is important to discuss what this means with the relatives, to explain the procedure for turning off the life-support machine, and to say what is likely to happen when the machine has been turned off. The machine should only be turned off by a consultant or senior registrar. Relatives should be told as soon as this has been done.

Support for relatives Some of the patient's organs or systems may function for a time after the life-support machine is switched off. There may be, for example, cardiac activity or spinal reflex movements. This can be distressing and confusing for relatives. They may worry that the patient was not in fact dead, and may also find it very difficult and stressful to keep saying their 'last goodbyes'. Staff should be ready to explain what is happening and to reassure the relatives in order to minimise distress as far as possible.

ORGAN DONATION

Approaching the relatives In cases where a dying patient's organs are requested for donation, the relatives must fully understand that the outlook for the patient is hopeless, that there are safeguards for establishing brain death, and that organ donation will benefit others. Relatives should have an opportunity to ask about the donor operation, viewing the body, funeral arrangemants, and so on. They should be asked if they would like to know how the donated organs were used. A good deal of time may be needed for discussion and for the relatives to consider their decision.

Private discussion The best time to approach relatives about organ donation is often after the first brain death criteria have been fulfilled. The interview with relatives should be carried out in private by the most appropriate person or people; for example, the doctor in charge of the patient, a member of the transplant team, a senior nurse from the ward, the family's GP and/or a hospital chaplain.

Follow-up care Following a transplant, those relatives who expressed a wish for further contact should be thanked by letter and given general information about the use of the donated organs.

STAFF TRAINING AND SUPPORT

Training for all staff Medical and nursing staff should receive specific training in communicating with dying patients and their relatives, breaking bad news, listening, and offering opportunities to talk. Such training should be built into the medical and nursing shool syllabuses and should also be available on a postgraduate basis. It should involve discussion, role play and other informal learning techniques aimed at enhancing personal development. Experienced staff should act as role models, with less experienced staff observing them until they feel able to cope themselves.

Specialist training Medical and nursing staff with a particular interest in the care of the dying should be encouraged to have special training. Staff with such training should be used as a resource for other staff.

Getting help and advice In cases where staff feel that they need additional help and advice in any aspect of caring for patients dying of cancer or their relatives, they should call on one of the specialist hospital cancer counsellors or the Bloomsbury Support Team (see page 42). Staff, patients and families can also get help and advice from the Hospice Advisory Service at St. Christopher's Hospice (see page 44).

Support for grieving staff Kind and caring staff, both senior and junior, inevitably become emotionally involved with some dying patients and their relatives. Staff who are distressed by a death should receive support from their managers and colleagues and should feel able to express their grief. Students experiencing the death of a patient for the first time may need special help. Lack of support or disapproval from senior colleagues or peers may lead staff to withdraw and to develop a brusque or uncaring manner towards patients and their relatives.

Team discussion and support Where staff have been particularly distressed by a death, or the circumstances have been unusual, a senior doctor and nurse should meet the junior staff and students on duty the same day to review what happened and how the case was handled, pick up any problems, and enable the staff involved to discuss their reactions.

Going outside the team Staff may sometimes find it helpful to go outside their own management structure for help in dealing with grief and stress. They may, for example, like to speak to someone at Oasis, a service that can provide counselling and assistance for all grades of staff in Bloomsbury, to a chaplain, a social worker, to one of the Bloomsbury Cancer Counsellors or to a member of the Bloomsbury Support Team (see page 42).

Organ donation Information about organ donations and their practical and ethical implications, and training in discussing organ donation with relatives, should be included in medical and nurse training. The regional transplant co-ordinator should be involved in running or planning such training.

Checklist: Care for patients and their relatives before death

1. Are all the nursing and medical staff involved in the care of a patient allowed to answer patients' questions and worries about the likelihood of death, and able to do so? What training and preparation for this is available for staff at all levels?

2. Do senior medical and nursing staff regularly offer dying patients the opportunity for private one-to-one conversations?

3. Are competent interpreters available to enable staff to speak to patients and their relatives whenever necessary? What training have they had for this difficult task? Who is responsible for giving them support?

4. How do staff keep themselves up-to-date in the latest developments in symptom control for terminally ill patients? What means are used to record progress in controlling a patient's symptoms? Do medical and nursing staff communicate well about symptom control?

5. What, if any, special practical arrangements are made on wards for the care of dying patients?

6. If dying patients have few or no visitors, do members of staff spend time with them?

7. Who is responsible for deciding whether or not to resuscitate a terminally ill patient and to discontinue unnecessary or distressing intervention? Who is involved in this decision and where is it recorded? Are the views of the patient, the relatives and other staff always

taken into account? Can senior nurses decide not to resuscitate a dying patient?

8. If patients are readmitted to hospital in the final stages of their illness, are they normally admitted to a familiar ward?

9. If a dying patient wishes to go home, what practical arrangements do the ward staff make to support and help the patient and his or her relatives?

10. Who is responsible for informing the GP and, where relevant, the referring doctor by telephone if a patient's condition changes, and about discharges and admissions? Are such 'phone calls always followed up by letters sent by first class post within 24 hours?

11. Do each patient's nursing notes always contain clear and full information about how to contact appropriate relatives, the patient's GP and, where relevant, the referring doctor?

12. Do all ward staff know how to contact the hospital chaplains and local ministers of religion, including minority religions? Are all patients offered spiritual counsel when they arrive on the ward and if and when they voice such a need? Are hospital chaplains and/or local ministers involved in the training of doctors and nurses?

13. Do staff know whom to contact to speak to distressed patients and relatives when they themselves are unable to meet their needs?

14. Who is responsible for speaking to visiting relatives and offering them regular opportunities to discuss develop-

ments? Do they also try at least once to speak to the patient and relatives together? Is there a private room where relatives can speak to staff undisturbed?

15. How do staff record and keep track of what has been said to dying patients and their relatives about the likelihood of death, what fears and worries have been discussed with whom, and what wishes have been expressed?

16. Are relatives of dying patients allowed open visiting? Are they allowed to sit with patients through the night if they wish?

17. Are relatives invited to help with the practical day-to-day care of the patient if they wish? Are relatives welcomed and recognised as an important part of the 'caring team' in the broadest sense?

18. What support and facilities are available to relatives spending time with dying patients? Are they encouraged to feel that they have a right to be there and to use hospital facilities? What special provision is made for relatives who live far away from the hospital?

19. What provision is made on wards for the young children of patients who are dying?

20. Does the hospital have clear policies on requesting organ donations, including how to talk to relatives, what information to give, and communication with relatives after a transplant?

21. Do all staff know the functions of the regional transplant coordinator and how to contact her/him?

22. What training do medical and nursing staff have in communicating with and caring for dying patients and their relatives? Is this adequate? Where can they go for more advice and guidance?

23. How many staff have special training in care of the dying? Are they identified and used as a resource for other staff?

24. Does the training of medical and nursing students include information about organ donations and what they entail, and advice on discussing donations with the relatives of potential donors?

25. Do all staff know of the existence of the Bloomsbury Support Team, how it functions, and how to contact it? Where there are specialist counsellors in a hospital, are all staff aware of them?

26. What support is given, and by whom, to staff who are distressed by a death?

Care for patients and their relatives at the time of death

AT THE MOMENT OF DEATH

Calling relatives Relatives often wish to be with a patient at the moment of death, even at night, and are distressed if they have not been called. Staff should discuss with relatives whether they wish to be called during the night if death seems imminent, and whom to call. This should be recorded clearly in the patient's notes. Using the telephone to call relatives to the bedside of a dying patient, or to inform them of a death, can be extremely difficult. All staff should be trained in the skills of breaking bad news, both over the telephone and in person. Staff should also know how to call on the police or other agencies to break bad news, particularly where it is unexpected or where the relative is known to live alone.

Sitting with dying patients If no relative or friend is present when death is imminent, a member of staff should hold the patient's hand, even if the patient appears to be unconscious. It is important to remember that patients who seem to be unconscious can often hear what is being said. Relatives may find it comforting to be encouraged to talk quietly to a dying patient, even if he or she seems to be unconscious. Nothing should be said in the presence of a dying patient that the speaker would not wish the patient to hear.

Religious support Members of some religious groups may like to have a minister of religion with them at the time of death to carry out religious rites. Details of how to contact representatives of the different religions should be kept on each ward.

Different responses to death Cultural patterns and values become particularly significant when someone dies; for example, members of some ethnic groups prefer to mourn quietly and privately, others are more overt. Members of different ethnic and religious groups will naturally wish to follow their own religious practices. Different responses may cause problems and resentment unless staff are both well informed and sensitive to the importance of allowing and encouraging dying patients and their relatives to grieve and react in their own way. In some cases it may be necessary to move a patient into a side ward to avoid disturbing other patients. Information about cultural and religious aspects should be included in medical and nurse training.

WHEN A PATIENT HAS JUST DIED

Sitting by the patient Relatives should be left to sit with a patient who has just died for as long as they wish. Curtains should be drawn around the bed for privacy. The face of a dead patient should not be covered while he or she remains in bed on the ward. Covering the face is distressing for relatives who may arrive to see the body and makes death unnecessarily frightening and mysterious. If false teeth have been removed they should be replaced as soon as possible. The last offices should be left until relatives have left the ward.

A cup of tea in private Bereaved relatives need time to themselves in an unhurried atmosphere. It should be given freely. When the relatives are ready, the nurse or doctor who knew and looked after the patient should take them to a quiet room where they will not be disturbed for a cup of tea, and to sit or talk as they wish. Often other relatives arrive after the death and need somewhere private to greet each other and to share their grief. All staff should have training and support in looking after bereaved relatives.

Choosing not to see the patient after death Many relatives will wish to see the patient after death and spend some time with the body. However, it is important also to be sensitive to the wishes of those relatives who prefer not to do so.

Discussing the death with a senior doctor or nurse Relatives should be offered the opportunity to speak in private to a doctor or nurse who knew the patient about the death and the circumstances surrounding it, both immediately after the death and later. It is often a good idea to make an appointment for them to see the senior doctor involved in the case. Relatives and ward staff often also need time to say goodbye to each other.

Bereaved children and parents In certain cases, for example when children or adolescents lose a parent, or when parents lose a child, it may be particularly important to ensure that the family receives counselling. Help given immediately may prevent long-term emotional and psychiatric problems. Hospital staff should, as a matter of routine, make enquiries about the welfare of immediate family members, including children, find out what help, if any, they are getting, and, where necessary, refer the family to a suitable source of support. In Bloomsbury these include the specialist cancer counsellors, the Bloomsbury Support Team, and the Bloomsbury Department of Child, Adolescent and Family Psychiatry (see page 43).

Explaining what will happen next Nursing staff should explain briefly to relatives before they leave the ward what they will need to do regarding death certificates, patients' possessions, registering the death and so on. At present many nursing staff are uncertain about the exact procedures, although relatives often turn to them for guidance. Staff need clear, detailed information, and possibly a simple one-page guide on what to do next to give to relatives.

The language barrier If the patient's relatives speak little or no English an interpreter will be needed to enable ward staff to answer questions and to explain what the relatives will need to do. Relatives coping with a death in unfamiliar surroundings, and in a society they do not understand, may need a good deal of help and support.

Offering an opportunity to view the body Relatives should also be offered the opportunity to view the patient's body in the mortuary chapel the next day. At present, staff are often reluctant to do so, because they feel that the chapel and its surroundings, and the laying out of the body, are less than ideal. Facilities and arrangements should be improved where necessary, so that staff can feel confident in offering relatives the opportunity to view the body.

Relatives living alone Where a relative has been alone with a dying patient, staff should check whether the relative is going back to an empty home and that someone will be there for company. This is particularly important in the case of sudden, unexpected deaths. With the relative's consent it may be necessary to alert other relatives, neighbours, a minister of religion or the family doctor, to ensure that support and care is provided during the first few days of distress and shock. If no family member or friend can be contacted, hospital volunteers may be used to accompany a relative home and stay there for a few hours.

Removing bodies from the ward Many people are unhappy about the way in which patients' bodies are removed from the ward. Ward staff and porters should review the procedures on each ward to ensure that bodies are always removed with dignity and respect. In some hospitals it is traditional to draw curtains round all the beds when a body is removed. This apparently sensitive procedure can cause more distress to the other patients – who can hear everything that happens – than the sight of a suitably covered trolley being taken from the ward in a dignified and respectful manner, accompanied by a nurse. Nurses may still decide it would be better to draw curtains round certain patients' beds while the body is being removed, but they should not do so without telling the patient what is happening.

Mortuary trolleys It is important to make as little noise as possible; for example, by inserting a plastic mattress to cushion the impact when the body is placed on the trolley, and ensuring that the trolley wheels do not squeak. Bodies should not be removed from the ward during meal times. It is better to leave a body on the ward during a changeover period than to remove it in a hurry or at an unsuitable time.

Patient's property Bad handling of patients' property often gives to great distress among relatives. A note should be made of any valuables and other possessions taken by relatives from the ward immediately after the death. The rest of the property should be carefully packaged to be taken to Administration or to be collected by relatives from the ward. Half-eaten boxes of chocolates, fruit, bottles of squash, damp flannels, and so on should not be included but kept on the ward in case relatives ask for them when collecting the property. Soiled clothing should either not be included or wrapped in a separate bag. Valuables should be listed and put into a separate envelope. Relatives should receive deceased patients' possessions in an acceptable bag.

INFORMING OTHER PEOPLE OF THE DEATH

Informing the other patients Other patients on a ward or in a bay should normally be told individually about a patient's death. Even though patients may already know about it, this formal public acknowledgement of a death is very important and 'allows' patients, if they wish, to talk to staff about the dead person. Attempts to deny a death or pretend it has not happened are likely to add to the fear and mystery which already surround death and are not helpful to the other patients or to staff. It is also important for other terminally ill patients to realise that their own deaths, when they come, will not be hushed up and hidden as if shameful or frightening, and that even in death they will be cared for with dignity and respect.

Informing other staff All professional and non-professional staff, including domestic staff and volunteers, who cared for the patient but were not there at the time of death should also be formally told. If the patient had been transferred from another ward in the hospital, the nursing staff in the other ward should also be informed.

Informing the GP and referring doctor Many general practitioners visit bereaved relatives as soon as possible after a death to offer comfort and support and to make sure that they can cope. A telephone call shoul be made as soon as reasonably possible after death by ward or administrative staff to the patient's GP, giving essential details and information. This should be confirmed within 24 hours in writing and followed within a week by a more detailed letter from the hospital doctor in charge of the dead patient. Referring doctors from the hospitals should be informed in the same way. Letters to GPs and referring doctors should be sent by first class post. Other departments, including records and outpatients, should also be informed promptly. Much unhappiness can be caused to families if, for example, appointment letters are sent to patients who have died, or ambulances turn up to take them to outpatients.

SUDDEN AND UNEXPECTED DEATH

Support for relatives Support for relatives is equally important when a patient comes into a hospital ward or into an accident and emergency department acutely ill and dies within a few hours or days. A sudden unexpected death can be very difficult to accept and may leave long term emotional scars. At the same time, staff may find it very dificult to establish a relationship with relatives in such cases, since they are often shocked, disoriented and anxious. Doctors and nurses may need to provide special support for relatives and to mobilise health service and other resources in the community.

A responsible doctor and nurse It is particularly important in these cases that a named senior doctor and nurse are assigned to look after the patient and their relatives. They should keep the relatives informed of developments, support them, give them an opportunity to talk and ask questions, coordinate all arrangements, and contact the patient's GP. They should also contact the family a few days after the death to find out if they need help or to answer questions.

Mutilated bodies In general, it is desirable that relatives should view the body since this seems to help them to accept the reality of the death. Very occasionally, however the body of someone killed in an accident may be so badly mutilated that it cannot be made presentable. In such cases a senior nurse or doctor should warn relatives that they may find the sight of the body distressing and prefer not to see it. Alternatively, they may suggest viewing the body the next day after it has been made as presentable as possible.

Checklist: Care for patients and their relatives at the time of death

1. Where do staff record relatives' and patients' wishes about what should be done and who should be called when death is imminent?

2. What is the procedure for calling close relatives to the bedside of a dying patient or informing them of a death? What training do staff have in doing this?

3. Do all staff know how to contact the police to ask them to break unexpected bad news? Do they give the police helpful information in such cases?

4. What training and information do staff have about different cultural patterns and religious rites in death and bereavement?

5. Do all staff know how to call someone to interpret for dying patients or their relatives? What training and support do interpreters have in carrying out this difficult task?

6. Are relatives left for as long as they wish with a patient who has just died?

7. How is the body left while it is on the ward? When are porters called to remove the body? How are bodies removed from the ward?

8. Is there a quiet room where relatives can talk and have a cup of tea undisturbed?

9. Are relatives offered the opportunity to speak to the appropriate doctor or nurse about the death and the circumstances surrounding it? Who makes this offer? Can relatives take it up at a later stage?

10. Are all relatives offered the opportunity to view the patient's body in the mortuary chapel or room? Who makes this offer? At what stage? Who accompanies them?

11. Are all nursing staff fully informed about the administrative procedures surrounding death and what relatives have to do? Do they have a simple one-page guide to give to relatives covering the necessary administrative details?

12. What arrangements do staff make if a bereaved relative is going back to an empty home? Can hospital volunteers be called upon to accompany a relative in such a case?

13. Who informs other patients in a ward or bay when a patient has died?

14. Who informs staff who were not there at the time of death?

15. Who is responsible for informing a patient's GP and, where relevant, the referring doctor, of the death? How and when is this done?

16. What is the procedure for packing patient's property and giving it to relatives? How are perishables and soiled clothing dealt with? Are patients' possessions given to relatives in an acceptable bag?

17. How do staff provide support for relatives of very ill patients who come into the hospital for a short time only and who may die suddenly? Do ward staff know how to mobilise health service and other resources in the community?

Administrative and other procedures after a death

Few people are familiar with the administrative procedures surrounding death and relatives are likely to need guidance through the system. Administrative procedures should be carried out as smoothly and efficiently as possible so that no unnecessary distress or delay is caused to relatives.

Fragmented care Provision in hospital following a death can be uncoordinated and disorganised. Relatives may feel that there is little or no continuity and find the system impersonal and uncaring. To ensure that care is coordinated and that high standards are always maintained, one person in the hospital should have management responsibility for provision. His or her overall responsibilities will include property, death certificates, the areas where relatives wait and are seen, the viewing chapel and access to it, the care given at this time by administrators, nurses, doctors, porters, cleaners and so on.

The administrator The administrators who deal with bereaved relatives should be chosen for their calm, kind and sympathetic personality and their ability to be efficient without being officious. Their role is to guide relatives through the necessary administrative steps, advise them on matters such as funeral arrangements, sort out any complications, and present a human face to bureaucratic regulations. They need training and support, a decent office, enough time, and recognition that this is an important job.

The language barrier An interpreter will be needed if the relatives speak little or no English. Coping with the unfamiliar organisational side of death and funerals in Britain can be particularly distressing for ethnic minority families. They may need a good deal of practical help and advice.

Smooth organisation Patients' possessions and valuables, death certificates and so on, should normally be collected together by the administrator concerned early in the morning before the relatives arrive. Relatives should be asked to come at a time that enables the administrator to be ready for them. In a hospital which has a large number of deaths, the times of arrival should be staggered to avoid long waits.

Cooperation from medical staff All new medical staff should be informed of the local procedure for filling death certificates, cremation forms and so on, and about the hospital's administrative arrangements concerning death. For example, the importance of signing death certificates promptly, and filling them in to conform with the Registrar's requirements, should be stressed.

Peace and privacy Relatives waiting to see the administrator should wait in a quiet and pleasant area of the hospital. Only one, or, at most, two sets of relatives should be waiting at any time. The room in which relatives see the administrator should be quiet and pleasant. The interview should not be interrupted by routine phone calls or other disturbances. They should be intercepted by someone else.

Guidance for relatives Relatives should be given clear guidance by the administrators on how and when to register the death, and, where appropriate, advice on funeral arrangements and so on. They should be offered the use of the administrator's telephone to make arrangements and to deal with urgent matters. They should be given a leaflet on the procedures and clear maps showing them where to go.

Arrangements for viewing Relatives who wish to view the dead person's body in the hospital in the days immediately following the death should be offered this opportunity and told whom to contact. The viewing chapel or room and the passages leading to it should be pleasantly decorated and well kept. Suitable facilities should be available for non-Christian relatives. The body should be decently and attractively laid out for viewing. A nurse from the patient's ward should always check that this is done and accompany the relatives to the viewing chapel. Some relatives may prefer to be accompanied by a minister of religion. It should be possible to view at weekends and after hours, as well as during normal working hours.

Small hospitals In some small Bloomsbury hospitals, bodies are removed for storage and viewing elsewhere and relatives have to go to an unfamiliar hospital to deal with the administrative side of death. They are unable to benefit from the support and help of the staff who know them. In some cases it may be possible to change this arrangement so that everything is dealt with at the hospital where the patient died. If this is not possible, relatives need very clear guidance from staff on the ward about where they are to go and what they should do. Staff at the receiving hospital should make a special effort to ensure that such relatives do not suffer additional stress.

Coroner's cases In cases where a death is referred to a coroner, a senior doctor should explain to the relatives the role of the coroner, why the case has to be referred and what is likely to happen.

Asking for post-mortems Though often useful and desirable, hospital post-mortems should normally be requested only for specific clinical purposes. Medical staff in teaching hospitals may sometimes ask for a post-mortem for educational reasons. Permission to carry out a post-mortem examination should always be sought by the patient's consultant or senior registrar. In some cases the patient's religion or the relatives' distress may make a post-mortem particularly undesirable. Pressure should never be used to obtain agreement. Relatives should be asked whether they wish to be informed of the results of the post-mortem: if they do, it should be organised. Some relatives who agree to a post-mortem in the confused hours following a death later regret their decision.

Special conditions Where only a limited examination has been requested and agreed the pathologist must be told. Hospital post-mortems should not delay funeral arrangements. This may be particularly important for Jewish, Muslim and other religions which require burial within 24 hours.

Avoiding unnecessary delay If relatives have come from far away, routine administrative procedures should be speeded up as much as possible to avoid forcing people to stay unnecessarily in London overnight.

Checklist: Administrative and other procedures after a death

1. Is one person responsible for monitoring and maintaining standards of care in the period following a death?

2. Are all the necessary administrative procedures following a death organised as well and as smoothly as possible to avoid delaying or distressing bereaved relatives?

3. Are the possessions and valuables, death certificates and so on, of patients who have died in the previous 24 hours ready and collected in the administrator's office before relatives begin to arrive? Do the administrative staff responsbile for seeing bereaved relatives have enough time and support to organise this properly?

4. If a patient dies in the early morning can relatives deal with all the administrative arrangements the same day?

5. Are relatives asked to come to administration at a suitable time? In hospitals with a large number of deaths, are relatives given staggered appointments to avoid undue waiting? Do appointment times take into account the Registrar's opening hours?

6. Are all new medical staff informed about hospital administrative procedures surrounding death, how to fill in death certificates, policies on speaking to bereaved relatives and so on? Who is responsible for doing this? When is it done?

7. Are all death certificates signed promptly and filled in acceptably? What action can the administrator take if they are not?

8. Is the area where relatives wait to see the administrator pleasant and quiet?

9. Is the administrator fully informed about the necessary procedures? What training has he or she had in carrying out this task?

10. Is the room in which relatives are seen pleasant and quiet? Are routine telephone calls and interruptions intercepted? Can relatives use the telephone to ring the coroner or undertaker, or to make urgent phone calls?

11. Are relatives given clear guidance on the necessary administrative procedures surrounding death?

12. What written supporting information are relatives given by the administrator? Are all maps, leaflets and so on clearly laid out and attractively presented? Do they contain all the information the relatives need?

13. In what minority languages is this information available?

14. Does the administrator know how to call someone to interpret for relatives when necessary?

15. What are the arrangements for viewing the body of a dead patient? Can the body be seen in the evening and at weekends?

16. Is the mortuary chapel or room, its surroundings and approaches decently decorated?

17. Who is responsible for ensuring that the chapel or viewing room are well kept and that the body is suitably prepared when relatives come to view it? Who accompanies relatives when they go to view the body?

18. At some small hospitals the administrative side of death is dealt with elsewhere. Bearing in mind the additional stress this can cause relatives, is it necessary? If it is necessary, are all arrangements for guiding relatives and for transferring death certificates and property, as efficient as possible? In these cases, who accompanies relatives to the chapel or viewing room if they want to see the body?

19. If a coroner's post-mortem is required, who is responsbile for explaining this to the relatives?

20. What is the hospital policy on post-mortems? Who asks for them? Are relatives always offered the opportunity to be informed of the results?

21. Are bodies always neatly repaired after a post-mortem has been carried out? Do post-mortems delay funerals? If they do, are relatives told when a post-mortem is required or requested?

22. Does every hospital have a clear written procedure to be followed when a patient dies? Does it include statements about the quality of care to be given to patients and their relatives around the time of death? Are all staff familiar with it? Who is responsible for monitoring the quality of care at this time?

23. Can procedures be speeded up so that relatives who have come some distance do not have to stay overnight in London against their wishes?

USEFUL CONTACTS AND ADDRESSES

Bloomsbury Health Authority

Bloomsbury Support Team
National Temperance Hospital
Hampstead Road, London
NW1 01-387-9300 ext 5358

Cancer counsellors
(provide a service for patients, relatives and staff)

Carmel Brennan
(working especially with leukaemia patients)
c/o PPW2
University College Hospital
01-387-9300 ext 8271

Teresa Curtis, Senior Nurse
Susan Kibler, Sister
c/o Oncology department
Middlesex Hospital
01-636-8333 ext 4407
(Bleep 2068)

Kati Gray
(working especially with women)
c/o Elizabeth Garrett Anderson Hospital
01-387-4646 ext 202 or bleep

Linda Masters
(working especially with patients with head and neck malignancies)
c/o Royal National Throat, Nose and Ear Hospital
01-837-8855 ext 4127
(Bleep 138)

Joady Mitchell
(working especially with children and their families)
c/o Hardy Roberts Ward
Middlesex Hospital
01-636-8333 ext 3262/8

Ann Tait
(working especially with breast cancer patients)
c/o Oncology department
Middlesex Hospital
01-636-8333 ext 8162
or Breast Clinic,
University College Hospital ext 8162

Jane Watson
(working especially with children with brain and spinal tumours and their families)
c/o Great Ormond Street Hospital
01-242-5800

Bloomsbury Department of Child, Adolescent and Family Psychiatry
c/o Outpatients department
Middlesex Hospital
01-636-833 ext 4583

Others

Camden Bereavement Service
Coordinator: Aileen Walker-Smith
Voluntary Action Camden
25–30 Tavistock Place
London WC1H 9SE
01-388-2071

Westminister Bereavement Service
Coordinator: Jill Dunbar
42 Warwick Avenue
London W9 2PT
01-289-6597

NE Thames Regional Transplant Coordinator
Bridget Watson
Transplant Unit
The Royal Free Hospital
Pond Street
Hampstead
London NW3 2QG
Radiopage via 01-794-0500

Oasis
(Counselling, careers advice and information for all Bloomsbury staff)
Warwickshire House
60 Gower Street
London WC1
01-388-9800 (from March 1987)

Compassionate Friends
(Support for bereaved parents)
6 Denmark Street
Bristol BS1 5DQ
0272-292-778

Stillbirth and Neonatal Death Society
(Support for bereaved parents)
Argyle House
29–31 Euston Road
London NW1 2SD
01-833-2851

The Foundation for the Study of Infant Deaths
(Cot death research and support)
(5th floor)
4 Grosvenor Place
London SW1X 7HD
01-235-1721/01-245-9421

Cruse
(Organisation for the widowed and their children)
Cruse House
126 Sheen Road
Richmond
Surrey TW9 1UR
01-940-4818

The Hospice Advisory Service
(Advice for staff, patients and families)
St Christopher's Hospice
Lawrie Park Road
London SE26
01-778-9252

Lisa Sainsbury Foundation
(Support, training and publications for professionals caring for dying people)
8–10 Crown Hill
Croydon, Surrey CR0 1RY
01-686-8808

Terence Higgins Trust
(Information, advice and help on AIDS)
BM AIDS
London WC1N 3XX
01-833-2971

RECOMMENDED READING

There is an increasing number of excellent articles and books on the care of dying people and their relatives. Here is a small selection.

An investigation to identify symptoms of distress in the terminally ill patient and his/her family in the general medical ward. J Hockley. City and Hackney Health District Nursing Research Paper, November 1983.

Barriers to psychological care of the dying. P Maguire. British Medical Journal 291: 1711-13.

Bereavement: studies of grief in adult life. C Murray Parkes. Harmondsworth, Penguin, 1975.

Bereavement counselling after sudden infant death. Sharon Woodward and others. British Medical Journal 290: 363-5.

Breaking bad news: why is it still so difficult? Robert Buckman. British Medical Journal 288: 1597-99.

Care of the dying: a guide for health authorities. National Association of Health Authorities, Birmingham, 1987.

Caring for dying people of different faiths. Julia Neuberger. Austen Cornish, 1987.

The courage to grieve. Judy Tatelbaum. London, Heinemann, 1981.

Directory of Hospice Services (Lists hospices, home care teams etc throughout the UK), St Christopher's Hospice 1986.

Drug control of common symptoms. Edited by Mary Baines. London, St Christopher's Hospice, 1986.

Dying. John Hinton. Harmondsworth, Penguin, 1979.

Emotional pain in dying patients and their families. E Earnshaw-Smith. Nursing Times 78: 1865-67

Grief counselling and grief therapy. J William Wordner. London, Tavistock Publications, 1983.

Hospice care: principles and practice. Edited by C A Corr and D A Corr. London, Faber and Faber, 1983.

How to obtain permission and relatives' attitudes. C Wright. Proceedings of the European Dialysis and Transplant Nurses Association 10. London, EDTNA, 1982.

Letting go. Peter Speck and Ian Smith. London, Society for Promoting Christian Knowledge, 1982.

Life before death. Ann Cartwright and others. London, Routledge and Kegan Paul, 1973.

The management of terminal disease. Edited by Cicely M Saunders. London, Edward Arnold, 1978.

A source book of terminal care. Edited by Eric Wilkes. Sheffield University Press, 1987.

A supplement on prescribing and symptom control. Bloomsbury Support Team, 1987.

Teaching terminal care at Queen's University of Belfast.
Part I. W G Irwin. British Medical Journal 289: 1509-11.
Part II. W G Irwin. British Medical Journal 289: 1604-5

Terminal care: evaluation of effects on surviving family of care before and after bereavement. Jean Cameron and Colin Murray Parkes. Postgraduate Medical Journal 59: 73-8.

Terminal care: report of a working group. Standing Medical Advisory Committee (Chairman: Professor E Wilkes). London, DHSS, 1980.

Terminal care: their death in your hands. Suzanne Conboy-Hill. The Professional Nurse, November 1986.

Thanatology in a liaison psychiatry setting. R K Shelley. Bulletin of the Royal College of Psychiatrists 10: 352-3.

What is the presence we have to share with the dying? Jacques Pol. London, St Christopher's Hospice, 1983.

£2·25