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Good practice in hospital care for the dying

ALIX HENLEY

**THE KING'S FUND
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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 it 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 Bloomsbury 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 had recently died in hospital.

The paper outlines agreed 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, 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.

Alix Henley
District Medical Officer's Department
February 1986

Note: 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 Bloomsbury Health District, who have commented on and improved this paper. Any errors or faults are entirely my own responsibility.

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 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 emotionally 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 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

* 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.

Answering questions Patients may ask any member of staff or a 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, should have up-to-date, though not necessarily specialist, knowledge about a patient's condition and should be prepared to talk to patients about their situation. 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.

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 and nausea 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, up-to-date knowledge of symptom control and a flexible approach. A pain chart is often helpful. A very useful leaflet on symptom control is *Drug control of common symptoms* by Dr Mary

Baines (see page 39). Copies of this should be kept on each ward for easy 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. 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 Terminal Care Support Team (see page 36) can often provide the practical help and reassurance that relatives need.

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.

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.

Religious counsel Religious counsel should be offered to all patients and relatives. Ward staff should find out

whether a patient wishes to be visited by a local minister or by someone they already know. Every ward should have a list of local ministers 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, or a local bereavement counsellor.

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.

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 speak regularly in private to visiting relatives, offer them time to discuss worries or questions, and outline their management plan for the patient. They should encourage relatives to contact them whenever they feel the need.

Communicating important information Good communication between the 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 is kept in patients' notes on which all staff, including chaplains, social workers and so on record conversations with patients and relatives, for example, who has been told what, worries, and 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 as 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 the patient and relatives wish, relatives should be able to stay with a patient while nursing and other procedures are carried out. 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 wish it, the young children of a dying patient should also be allowed to visit frequently and to spend time with their parent. If necessary a side room or cubicle should be provided for them. It is most important that children should not be cut off from a 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 need to help with this. It may be helpful to encourage a child to see the parent after death so that the child remembers the parent restful and at peace rather than ill and suffering.

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 is beneficial for others. Relatives should have an opportunity to ask about the donor operation, viewing the body, funeral arrangements, and so on. 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. It must be carried out in private.

Follow-up care Following a transplant, relatives should be thanked by letter, given general information about the use of the donated organ(s) and offered the opportunity for further contact. It may also be necessary to arrange bereavement counselling for relatives.

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 school syllabuses and should also be available on a postgraduate basis. It

should involve discussion, role play and other informal learning techniques aimed at enabling personal development.

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 caring for patients dying of cancer or their relatives, they should call on the Bloomsbury Terminal Care Support Team, currently based at the National Temperance Hospital (see page 36). The team comprises medical, nursing and social work staff and is able to offer guidance to hospital staff on all aspects of caring for dying patients and their relatives. Some Bloomsbury hospitals have specialist cancer counsellors who advise staff and work with patients and their relatives. Staff, patients and families can also get help and advice from the Hospice Advisory Service at St Christopher's Hospice (see page 37).

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. 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.

Organ donation Information about organ donations and their practical and ethical implications, and training in discussing donation with relatives, should be included in medical and nurse training. The regional transplant coordinator 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 patients allowed to answer patients' questions and worries about the likelihood of death, and able to do so? What training and preparation for this do staff at all levels have?
2. Do senior medical and nursing staff regularly offer dying patients the opportunity for private one-to-one conversations?
3. 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?
4. What, if any, special practical arrangements are made on wards for the care of dying patients?
5. If a dying patient has few or no visitors, do members of staff spend time with them?
6. 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?
7. If patients are readmitted to hospital in the final stages of their illness, are they normally admitted to a familiar ward?

8. If a dying patient wishes to go home, what practical arrangements are made to support and help the patient and his or her relatives?
9. 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?
10. 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?
11. Do all ward staff know how to contact local ministers of religion, including minority religions? Are all patients offered religious comfort when they arrive on the ward and if and when they voice such a need? Are local ministers of religion involved in the training of doctors and nurses?
12. Do staff know whom to contact when they themselves are unable to meet the needs of distressed patients and relatives?
13. Who is responsible for speaking to visiting relatives and offering them regular opportunities to discuss developments? Is there a private room where relatives can speak to staff undisturbed?
14. 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?

15. Are relatives of dying patients allowed open visiting?
Are they invited to sit with patients through the night?
16. 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?
17. 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?
18. What provision is made on wards for the young children of patients who are dying?
19. 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?
20. Do all staff know the functions of the regional transplant coordinator and how to contact her/him?
21. 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?
22. How many staff have special training in care of the dying? Are they identified and used as a resource for other staff?
23. 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?

24. Do all staff know of the existence and of the functions of the Bloomsbury Terminal Care Support Team and how to contact it? Where there are specialist counsellors in a hospital, are all staff aware of them?
25. What support is given 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 whom to call if death seems imminent and should record this 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 to the 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 unconscious. It is important to remember that patients who seem unconscious can often hear what is said. Relatives may find it comforting to be encouraged to talk quietly to a dying patient even if he or she does not seem conscious. 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 behaviour patterns 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. Unfamiliar behaviour patterns 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 body 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 after relatives have left the ward and for a least one hour after the death.

A cup of tea in private 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 who were not there at the death. Family members need somewhere private to greet each other and to share their grief. All staff should have training and support in dealing with bereaved relatives.

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

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, immediately after 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.

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 and so on. At present many nursing staff are uncertain about the exact procedures, although relatives often turn to them for guidance. They need clear, detailed information, and possibly a simple one-page guide on what to do next to give to relatives as a reminder.

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 surroundings of the chapel or viewing room 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. It may be necessary to alert other relatives, neighbours, a minister of religion or the family doctor, with the consent of the relative, to ensure that support and care is available in the first few days of distress and shock. If no family member or friend can be contacted, hospital volunteers might 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 should review the procedures on their ward to ensure that bodies are removed with dignity and respect.

Patient's property Bad handling of patients' property often gives rise to great distress among relatives. A note should be made of any valuables and other possessions taken by relatives from the ward. The rest of the property should be carefully packaged for administration. 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 patient's 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, this formal public acknowledgement of a death is very important. 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 when dead they will be cared for with dignity and respect.

Informing other staff All professional and non-professional staff who cared for the patient but were not there at the time of death should also be formally told.

Informing the GP and referring doctor Many general practitioners visit bereaved relatives as soon as possible after death to offer comfort and support and to make sure that they can cope. A telephone call should be made as soon as reasonably possible by ward staff to the GP when a patient has died, 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 other 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 of the death. Much unhappiness can be caused to families if, for example, appointment letters are sent to patients who have died.

SUDDEN AND UNEXPECTED DEATH

Support for relatives Support for relatives is equally important when a patient comes into a hospital ward or 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 difficult to establish a relationship with relatives since they are often shocked, disorientated and anxious. Doctors and nurses may need to provide special support for relatives in these cases 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 and give them an opportunity to talk and ask questions, coordinate all arrangements and contact the patient's GP.

Mutilated bodies Very occasionally 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.

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?
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 go and 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?
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 sending it down to administration? 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 hospital for a short time only, and whose death may be sudden? 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. The person in the hospital who deals with the administrative details following a death should have enough time to deal with them properly and efficiently.

The administrator The administrators who deal with bereaved relatives should be chosen for their calm, kind and sympathetic personalities 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 what are often bureaucratic regulations. They need training and support, and recognition that this is an important job.

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, times of arrivals should be staggered to avoid long waits.

Cooperation from medical staff All new medical staff at the hospital should be informed of the local procedure for filling in death certificates, 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 also be quiet and pleasant. The interview should not be interrupted by routine phone calls or other disturbances. Someone else should deal with them.

Guidance for relatives Relatives should be given clear guidance by the administrator 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 of where to go.

Arrangements for viewing Some relatives will wish to view the dead person's body in the hospital in the days immediately following the death. The viewing chapel or room and the passages leading to it should be pleasantly decorated and well kept. Suitable facilities should be made available for non-Christian relatives. The dead person's 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 relatives do not suffer additional stress.

Coroner's cases When 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 purposes. They should always be requested 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. Some relatives who agree to a post-mortem in the confused hours following a death later regret their decision.

Special conditions Relatives should be asked whether they wish to be informed of the results of the post-mortem. 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. Are all the necessary administrative procedures following a death organised as well and as smoothly as possible to avoid delaying or distressing bereaved relatives?
2. 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 responsible for seeing bereaved relatives have enough time and support to organise this properly?
3. If a patient dies in the early morning can relatives deal with all the administrative arrangements the same day?
4. 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?
5. Are all new medical staff informed about hospital administrative procedures concerning 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?
6. Are all death certificates signed promptly and filled in acceptably? What action can the administrator take if they are not?
7. Is the area where relatives wait to see the administrator pleasant and quiet?

8. Is the administrator fully informed about the necessary procedures? What training has he or she had carrying out this task?
9. 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 calls?
10. Are relatives given clear guidance on the necessary administrative procedures surrounding death?
11. What written supporting information are relatives given by the administrator? Are all maps and leaflets clearly laid out and attractively presented? Do they contain all the information the relatives need?
12. In what minority languages is this information available?
13. Does the administrator know how to call someone to interpret for relatives when necessary?
14. What are the arrangements for viewing the body of a dead patient? Can the body be seen in the evening and at weekends?
15. Is the mortuary chapel or viewing room, its surroundings and approaches decently decorated?
16. 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?

17. 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?
18. If a coroner's post-mortem is required, who is responsible for explaining this to the relatives?
19. What is the hospital policy on post-mortems? Who asks for them? Are relatives always offered the opportunity to be informed of the results?
20. Are bodies always neatly repaired after a post-mortem has been carried out? Do post-mortems delay funerals? If they do, are relatives told this when a post-mortem is required or requested?
21. Does every hospital have a clear written procedure to be followed when a patient dies? Does this include details about the quality of care to be given to patients and their relatives around the time of death? Are all staff familiar with it?
22. How often are procedures 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 Terminal
Care Support Team
National Temperance
Hospital
Hampstead Road
London NW1
01-387 9300 ext 553

Camden Bereavement
Service
Coordinator: Aileen
Walker-Smith
Camden Council of
Social Services
Lonon WC1H 9SE
01-388 2071

Westminster
Bereavement Service
Coordinator: Jill Dunbar
42 Warwick Avenue
01-289 6597

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

Bridget Watson
Transplant Coordinator
(North-East Thames
Region)
Transplant Unit
The Royal Free Hospital
Pond Street
Hampstead
London NW3 2QG
Radiopage via
01-794 0500

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

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 &
publications for
professions caring for
dying people)
8-10 Crown Hill
Croydon
Surrey CR0 1RY
01-686 8808

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.

Arrangements for terminal care in the NHS (especially those for cancer patients). Gillian R Ford and G Pincherle. *Health Trends* 10; 73-6

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 Buckham. *British Medical Journal* 288: 1597-99.

Care of the dying. DHSS. Reports on health and social subjects No 5. London, HMSO, 1973.

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. 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

Procedures following deaths in hospitals. Anne Williams. London, Institute of Health Service Administrators, 1982.

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.

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

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