KF

REPORTS

Professional Priorities and Problems in Terminal Care

Report of a King's Fund Centre conference
4th July 1985

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PROFESSIONAL PRIORITIES AND PROBLEMS IN TERMINAL CARE

Report of a King's Fund Centre Conference held on Thursday, 4 July 1985, by Pat Young

The aims of this conference were, in the words of Chairman, Dr. Gillian Ford, who is Director of Studies at St. Christopher's Hospice, to identify the problems that are particular to those working in terminal care, to find ways of solving them, and to look at the future development of the specialty. Two features distinguish terminal care from other medical care, she said: the need to relieve pain that is physical, emotional, and spiritual; and the emphasis placed on the importance of teamwork. The teams cross boundaries, of etiquette but not of ethics, and are subject to all sorts of pressures. Teams may be small, and feel they lack "clout". Some team members may have to work in isolation, and feel deserted and alone, finding it difficult to combat the problems of isolation and stress. A common problem is the need to sustain professional standards without adequate training courses; another is how to assess the quality of work. All these topics would be considered, both by the individual speakers and by the discussion groups.

The nurse

Sister Jo Hockley, Terminal Care Liaison Sister at St. Bartholomew's Hospital, London, was the first of two speakers to describe the problems and priorities of the specialist nurse in terminal care. She began by quoting some words of Dame Cicely Saunders, who had stated the aim of hospice care as "to do all we can to help patients to die peacefully, and to live until they die". Yet the risk for a nurse working on her own is that she may forget the team approach and try to become all-in-all to her patients; this might be an ego trip for her but was not always effective for the patient. The Macmillan Nurse and the clinical nurse specialist are most vulnerable to this risk. A recent survey had shown that nurses are the pivot of the service; they respond most eagerly to the challenge of terminal care, so are most in danger of trying to be "all-in-all" to patients, allowing their role to encroach on that of the doctor, social worker, and chaplain. Nurses need to be aware of boundaries, not only in the multidisciplinary team but also in the professional hierarchy.

Sister Hockley expressed the fear that specialist care for the dying will be squeezed out of the general syllabus for nurse training unless minimum requirements are established now, especially for student nurses. The ward sister is the vital member of the hospital team in influencing standards of care, she said, and through her District Management teams can become convinced of the need to improve standards; middle management may obstructive.

Macmillan Nurses and district nurses have to work in a hard, front-line battle position, and their confidence may be drained, she continued. They need both clinical experience at ward sister level and hospice experience. The hospice study day is a rejuvenating experience for them, which can help them to face their difficulties. Working in terminal care is not only emotionally draining through continual contact with dying patients and bereaved relatives, but also frustrating through the constant struggle to maintain standards of care by other nurses, encouraging them, for example, to be open with patients about death, which does not normally happen in hospital.

Sister Hockley ended by saying that as her own multidisciplinary team develops, she is relieved to find her colleagues becoming fired with the same enthusiasm and aiming for the same goals. Eventually there should be one doctor fully involved in the team, two nursing sisters, and a full-time social worker. She referred to the safe environment of the team, and the advantage of being able to discuss problems openly and sort them out. All nurses, in her view, from the student nurse up to the nurse manager, can be influenced by the team to improve the standards of care given.

The second nurse speaker was Pamela Spearing, a Macmillan Nurse working for the Durham Health Authority, in the Easington District - a deprived, predominantly mining area with many exhausted pits and a high rate of unemployment. The contrast with the affluent south is marked, she said, but the people have one great advantage: good family and community support, which is particularly valuable in times of crisis such as a terminal illness.

Mrs. Spearing began by discussing her priorities. Her first priority, she said, is the patient, and building up an honest relationship with him so that trust can be established. It is also a privilege to be invited into a patient's life at this crucial and sacred time, and offers a special opportunity for worthwhile service. The nurse may find herself acting as the patient's advocate in a difficult and confusing situation - with the family, or with her fellow professionals, or with others involved. For instance, she sometimes has to act as a communication link with the patient's GP.

Her second priority is the family, who are no less important and must not be taken in isolation from the patient. Indeed, in some cases they need more support than the patient, and the nurse's primary function is to provide that support through and after bereavement. It often helps the patient greatly to know that his family will be cared for after his death. There must be good communication with and between the patient and his family, as additional stress can be caused if communication is poor - particularly when the family do not wish the patient to know his diagnosis. Adequate time for listening is essential, and Mrs. Spearing said she sometimes finds herself aiming to be a catalyst in bringing harmony between patient and family.

The third priority, she continued, is other professionals: that is to say, the primary health care team. As a Macmillan Nurse she has more time to spend with the patient and family, and good communication between all members of the team is vital.

Fourth in priority is symptom control, explaining to patients the importance of regular medication, and making sure they understand the instructions. A major difficulty is incorrectly or inappropriately prescribed medication; many GPs are reluctant to accept that a nurse may know more about symptom control than they do, but it may be a top priority to advise the GP and the patient in the whole area of medication.

Fifth in priority is knowledge of all the services and benefits available, such as Cancer Relief Fund grants, of which the patient may be unaware. And Mrs. Spearing said her last priority was herself, knowing her own limitations and being able to pace her workload, so that she does not accept more work than she can give full attention to.

Turning from priorities to problems, Mrs. Spearing remarked that frustration heads the list, as it is frequently difficult to persuade GPs to prescribe properly for symptom control. Working alone comes second, as working in a team must be easier with the daily sharing of problems. Ignorance of the role of the Macmillan Nurse can also create problems, and there is sometimes difficulty in getting patients referred. Finally, Mrs. Spearing said, cultural problems can be acute in her area; in one town with nine GPs, only two have English as their first language, which leads to obvious difficulties in communication. There may also be different attitudes towards pain, death, and bereavement.

Summing up, Mrs. Spearing thought that of all the demanding functions of a Macmillan Nurse, top priority should be given to keeping her personal boilers and engines in good condition and running order, so that she can serve the dying and the bereaved in a fully compassionate and effective manner.

The doctor

Dr. Robert Twycross, Consultant Physician at Sir Michael Sobell House, Oxford, in describing the doctor's role in terminal care, said that he was a guinea-pig involved in a CUT - a Casualised Uncontrolled Trial. He was the first consultant to be appointed in his thirties, and the title of his autobiography would be "365 Bereavements a Year", which encapsulated his experience. He spoke of the negativity experienced towards death - the anger, frustration and grief - and ways of coping with that negativity. Evaporation and exercise were, for him, hardly ever enough, he said; there was inevitably also anger, expressed against colleagues, the family or God. There is an added stress for doctors working in terminal care in seeking to offer whole-person medicine. "We are all psycho-physicians", Dr. Twycross said, "involved with the psychological as well as the physical aspects of care".

Two breeds of hospice doctor are emerging, he continued: "remote control" and "hands on" - those who have to get in alongside other members of the team, and in the psycho-social systems as well. Hospice doctors are really coping with other doctors' failures, with the patients whose problems are so great that the GP cannot cope and refers them for hospice care. But the stress comes, Dr. Twycross commented, when you ask yourself: "Am I really there to care for other doctors' bosh-ups?". He quoted as a case history a 75-year-old lady diagnosed as having cancer of the pancreas, who was referred to Sobell House because her GP thought she was dying. She was found to be taking morphine for abdominal pain, with reflux colic and constipation. This was a typical bosh-up.

Dr. Twycross then introduced what he called the "mental fog factor", asking why care cuts off at this particular point. It could be because of an over-negative view of cancer, a personal fear of cancer, or simply existential anxiety (fear of one's own mortality). In order to come to grips with this, doctors and nurses will have to be better trained, and the role as a hospice doctor is therefore a combination of clinical work, teaching, training and research.

Turning to the needs of a teaching hospice, Dr. Twycross said that the current problems are a manpower shortage of properly trained doctors, and administrative indifference towards the need for proper training. He considered that hospice care is very definitely a specialty, and one which needs to defend itself, and he looked forward to seeing a national organisation such as a British Hospice Foundation being established.

The chaplain

The Rev. Peter Speck, chaplain at the Royal Free Hospital, London, began his talk by quoting some words of Dr. Twycross, who in 1980 wrote: "The control of chronic pain has as much to do with social, psychological, and spiritual support of the patient as it has to do with the chemicals ingested". This implied, he said, that if we are to come near to meeting the various needs of the dying person, we shall need to be flexible in our approach. This may mean there will be a variety of different people endeavouring to meet some of these needs, so good liaison between them is essential, and in this the priest/chaplain has a part to play.

Mr. Speck went on to distinguish between spiritual support and religious ministry. Spiritual support is concerned with ultimate issues and answering such questions as: "Why should this happen to me? Why now? What have I done to deserve this - it doesn't seem fair?", in the context of **Man's Search for Meaning** by Frankl, who said: "Man is not destroyed by suffering, he is destroyed by suffering without meaning." This requires a relationship of trust between the dying person and the chaplain.

Religious ministry is concerned with the practical expression of spirituality, in the way of seeing a priest, attending chapel, having time to meditate, receiving sacraments, etc. The chaplain's role, said Mr. Speck, was often restricted to that of dispenser of religious goodies, without forming a relationship with the patient or entering into any real dialogue. This makes it easier for staff as the priest does not get in their way, and easier for the priest who is feeling threatened by the dying, as he can hide behind the ritual.

Good pastoral care is concerned with discerning and holding together the religious and the spritual, and sharing some of the pastoral work with others. A priority for the chaplain, therefore, is the creation of a relationship of trust which allows for the expression of positive and negative feelings and fears.

Mr. Speck went on to list some indicators of spiritual need and distress: (1) a break with religious/cultural ties; (2) a sense of meaninglessness or hopelessness; (3) remoteness of God and inability to trust; (4) concern with moral/ethical nature of treatment; (5) sense of guilt or shame; (6) intense suffering; (7) unresolved feelings about death; (8) anger towards God, religion, clergy. The response to them may take the form of sharing the pain and bewilderment of the dying person, or the form of specific religious ministry, such as Bible reading and prayer, baptism, reconciliation and the Sacrament of Penance, Holy Communion, marriage, commendatory prayers, Last Offices, and the funeral or memorial service.

In conclusion, Mr. Speck said the minister has three pastoral aims in meeting the needs of the dying: to reconcile, or re-establish any broken relationship that may be causing spiritual pain; to sustain the patient by the ministry of words and sacraments; to guide, as a companion who can journey with the dying person during this final part of his life. The hallmarks of this companionship are sensitivity and genuineness in care, coupled with an openness that will allow chaplains to work alongside other professionals without feeling threatened by their expertise.

The social worker

The final speaker was Miss Evangeline Rogers, social worker at Trinity Hospice, London, who began by asking the fundamental questions: why does a hospice employ a social worker, what does the social worker hope to achieve there, and is there any consensus and congruity of expectation about what the hospice wants from the social worker and what the social workers has to offer?

Social workers are often viewed, she continued, as the people who deal with problems, and there is a tendency to treat the social work department as a ragbag for all the problems that can't be dealt with elsewhere, even though the social worker is not always the person best qualified to cope. The problems of poverty, lack of or bad housing and insufficient material resources are seen as the social worker's particular province, yet in the hospice these are the least favoured, and this can engender frustration because the social worker cannot give direct help but must mobilise statutory or charitable resources. The frustration can lead to a questioning of the link that still exists between illness and poverty.

The financial problems that arise at a time of illness or death, Miss Rogers continued, are usually more related to years of poor family budgeting than to a single unpaid bill. The social worker must tackle the whole family problem, and try to move it on a bit. The family may be unable to face the fact that the main wage-earner is too ill to work, and the social worker must then help them to adjust to a sudden disastrous drop in income. She emphasised that social workers have to remember that everyone is a potential problem-solver, and concentrate on their strengths rather than their weaknesses. Their function is to demonstrate ways of problem-solving which people can subsequently use themselves.

Miss Rogers went on to point out that it can be difficult to believe that problems can be a positive means of growth, quoting an extract from **Life in the Snakepit** by Bette Howland to prove her point, in which the author wrote that life consists of obstacles to be overcome: there is always time to be served, or a debt to be paid. Social work is to do with all the pains and problems of living, and in the hospice setting especially of losing and loss, and helping relatives who react to loss with undue distress. Here the social worker has to stand back and look at the problem in the context of the whole family history in order to understand the causes of the deviant behaviour, and help the relatives to come to terms with their loss.

Sometimes the social worker can help the dying person to make sense of his whole life, settle unresolved conflicts, and pass some sort of judgment on the life that is coming to its close. The same skills can be employed as are used in child care: making a life-story book together, for example. Much of social work is to do with managing tricky transitions from one phase of life to another, and this can apply equally to the times of change within the hospice setting.

Any insights into problems the social worker may have must be shared with both the multidisciplinary team and the family or individual relative or friend, Miss Rogers continued. The best way of learning is by observing someone else carrying out a difficult task, and one of the most useful functions of the social worker is to act as a role model and provide active demonstrations. Social workers can show that it is possible to grasp nettles by grasping them, that it is possible to care by caring, and that limits can be set by setting them. The greater the risk, the greater the possible reward.

It is not easy, however, to share the most valuable insights with others - to hear one's words used and get no credit for them, Miss Rogers said. It can be hard being the only social worker in a sea of nurses and doctors, adhering to a particular view of a family in crisis, and taking the risk of doing something about it. It is also difficult when working single-handed to remain confident of an assessment, or to decide to change direction, without consultation or access to a peer group.

It is important for the social worker in the hospice setting, where everyone else is focussing on impending death and the impact of loss, to have a vision of what may ultimately grow out of this difficult time. Crises and problems are the seedbed from which real development takes place, and by trying to remove people's problems one is depriving them of a real chance to grow.

Although hospices are seen as "ideal" places, they are in reality full of crises and problems, and the staff have to come to terms with and admit that death is not always beautiful and dignified, but can be very destructive. The emotional problems that arise at this time have not yet received enough attention. Miss Rogers concluded by saying that if working in a hospice produces stress in staff, then facilitating growth must also arise from working in the hospice. Employing hospices should provide the opportunity, in the shape of time or persons, for the containment and exploration of potentially explosive emotions among staff, so that staff can in turn support patients and their families through difficult times.

QUESTION TIME

The morning session concluded with questions to the speakers. Dr. Gillian Ford, the Chairman, began by asking what the DHSS should be doing about a career structure and training syllabus for medical specialists in terminal care, and Dr. Twycross replied that although the Royal College of Physicians was not without blame in this respect, the DHSS must take the lead in breaking the deadlock that exists. The Chairman replied that it was a chicken-and-egg situation, because the DHSS had always regarded training matters as the province of the Royal Colleges, but if the Colleges did not think there was a need for special training they would not ask for

* Insert after .... with a section on terminal care - "**in which doctors were advised against going on to specialise in terminal care**" because of the psychological pressures ....

terminal care to be recognised as a specialty. Dame Cicely Saunders (St. Christopher's Hospice) added that it came back to a question of finance, but it was such an important topic all doctors should be discussing it. Dr. Richard Hillier (Countess Mountbatten House) said the problem was more complex. An inter-College group had recently produced a report on training in oncology with a section on terminal care * because the psychological pressures are too great for a young doctor. It was not only a matter of money, but also of manpower approval; realistic posts must be created. He drew attention to the formation of a new Association of Hospice Doctors, which would hold a meeting at the Catholic Chaplaincy in Birmingham on 25 October.

The Chairman then turned to the subject of nurse training and asked if there were enough places on the English National Board course on nursing care of the dying. Mrs. S. Hawkett (St. Christopher's Hospice) answered that there were 16 units throughout the United Kingdom which put on this course (No. 931) but the waiting lists were very long. St. Christopher's Hospice runs five courses a year, which are all fully booked. More encouragement was needed for units to put on courses, and there was also a need for more tutors for courses. Dr. Ian Capstick (St. Peter's Hospice) remarked that his hospice had obtained joint sponsorship for a course from the District Health Authority; this had been welcomed by the English National Board, and it was hoped to start the course in about six month's time.

The Chairman inquired about an advanced course in nursing care of the dying, and a delegate replied that the English National Board was looking into this possibility. The six week course was not sufficient for anyone wishing to specialise, so the Board was considering a course comprising three modules - symptom control, counselling, and management and teaching - which would last eight weeks. Another delegate added that her unit in Sheffield had been the only one to offer the six months course, but it had been dropped because a senior nurse could not be seconded to run the course because she could not be replaced for financial reasons. When the course was shortened to four months, there were no applicants. There was a demand for an advanced course, however.

A general practitioner then asked if there is any way of overcoming professional intransigence towards the whole concept of terminal care. Dr. Twycross replied that professional attitudes towards cancer must be changed, and a more positive approach taken towards rehabilitation and setting goals which would prolong and improve life. Another GP said that attitudes towards the whole concept of terminal care were entrenched, and excellent schemes had expired through hostility and lack of support. Dr. Peter Griffiths (Ty Olwen Hospice) agreed, saying that Macmillan systems of care in Wales had failed through lack of medical input as well as prejudice and ignorance in the community. Nurses were even suffering from physical and mental illness as a result of the stress of working in the "firing line". Medical interest and support should be identified first before putting a team into the community. Dr. Lamerton (St. Michael's Hospice) strongly supported this view, imploring delegates to look to their management structures. Dr. Hugh Ford remarked that two groups could be identified: those who are prepared to look at a new method of treatment, test its validity, and if it is proved take it on board; and those who wear blinkers and will not see. This applies to some young physicians and surgeons who say the whole subject of terminal care gives them the creeps, and they are unlikely to succumb even to Dr. Lamerton's powers of persuasion. Dr. Lamerton riposted that no patient is the exclusive property of one doctor, and added that there is no harm in poking fun when you encounter resistance - many doctors respond to this weapon. Miss H. Egerton (St. David's Foundation) said it was a question of personal relationships and selling your services in a pleasant way. She added that she was impressed by the standards of care on the part of GPs. Mrs. Angela Walton (Princess Alice Hospice) asked if there was something in the attitude of those concerned in terminal care which puts people off - over-enthusiasm perhaps. Possibly they don't appear to be quite normal. The Rev. Peter Speck said one must be careful in making assumptions about one's colleagues; antipathy can be guaranteed if working relationships are not well handled. Dr. R. Hillier commented that people should not worry too much about public relations. If they do their job well, the rest will follow. Dr. B.A. Jepson (St. Catherine's Hospice) supported this view, saying that as a new resource you have to tread very gently. To start with you are used as a garbage disposal unit, but if the job is done well the demands on your resources will change subtly, and often those who were the hardest to convince will in the end give most support.

UNIDISCIPLINARY DISCUSSION GROUPS

The afternoon session was devoted to discussion in unidisciplinary groups of the following questions:

General

(1) How is it possible to sustain our own professional position in provision of care for the terminally ill?

(2) Are we providing the service we say we provide?

(3) How is it possible to avoid professional isolation?

Nurses

(4) What is special about nursing skills for the terminally ill, as distinct from any other sort of nursing?

Doctors

(5) Is terminal care a specialty? Is forming a professional association a top priority? What can be done by hospice physicians about career structure and training?

Social Workers

(6) How do social workers set boundaries for their own work with the terminally ill and their families?

Chaplains

(7) What do chaplains feel about professionals and others trespassing on their" patch"? What more can or should be done to reach a structured approach to spiritual pain?

Administrators

(8) What has the Association of Hospice Administrators to offer the movement as a whole?

The delegates were divided into three groups of nurses, and one group of each of the other disciplines.

The first nursing group to report had concentrated on Question 2, and considered they were not providing the service they would like to provide because caseloads were too heavy, due to the fact that it was difficult to refuse any patient referred to them. They had discussed ways of lightening their workload, including using volunteers, but agreed these would have to be carefully selected and properly trained. An immediate goal must be establishing criteria for referral as another way of relieving the pressure of work. They came to the conclusion, however, that specialist nurses in terminal care have a great deal to offer, and they should have confidence in themselves and in the service they provide.

The second nursing group first considered the stresses of working in isolation (Question 3), and suggested that support could come informally, from colleagues, or from team meetings. Letting off steam at home is helpful, as is having a sense of humour and religious faith. Contact with other groups and attending conferences is a useful opportunity for sharing problems. It is important, they agreed, not to appoint someone to this job who is likely to give way under the stress of working in isolation.

This group took Question 1 in two parts: sustaining their position with their own nursing colleagues, and with colleagues in other disciplines. Nursing colleagues who expect too much can present a threat; so can economic factors, when the service is regarded as the icing on the cake and is therefore vulnerable to financial cuts. A possible solution is to have managers with some understanding of the specialist role; another is to group nurses in connected specialties (such as stoma care, oncology and terminal care) together, into a team large enough to warrant having its own manager. It would be an advantage if home care, hospice, and hopsital services were more closely integrated. It would also be helpful to have a clearer definition of the specialist role, as confusion and ignorance about it is rife. Macmillan Nurses are unhappy about some of their publicity, as they do not want to be seen as "special" or better than other nurses. Specialist nurses should not be upset if all dying patients are not referred to them; other nurses can often manage these patients quite well. But there is often a problem when roles overlap, or are blurred.

Regarding Question 4, this group agreed they have no special nursing skills; but they do have more time and a better environment in which to care for patients, and a more understanding management to help them develop their skills. They did not see themselves, or wish to be seen as a panacea for all ills; they merely wanted to be seen in the context of the other nursing services available.

The third group of nurses took Question 1 first, suggesting that in order to sustain their professional position operational policies shuld be written down and passed on to the community services, to avoid the smudging of roles between the specialist nurse and other members of the team. Boundaries must be set by an objective outsider, as a nurse cannot refuse to take cases. The nurse should take evidence with her when suggesting to GPs new or different medication for symptom control.

Answering Question 3, many members of this group did not feel isolated, but all were agreed that local meetings and conferences which allowed time for discussion are helpful. Managers sometimes do not understand the need to get away for study days, so there is consequently a lack of financial support.

Considering Question 4, the group thought their own expectations of their specialist skills is very high, but there must sometimes be compromise if standards cannot be attained. They thought their skills must be evaluated by proper research. They were sure the hospice movement had given them special nursing skills to offer: acting as role models for students, involving the patient's family, giving control back to the patient and family rather than allowing the system to take control, the use of time, the value placed on honesty, building up relationships with patients, and not seeing death as a failure. The ability to be self-reflective, which requires emotional maturity, is important.

The doctors' group took Question 3 first, saying that professional isolation varies according to geographical distribution and age group. Younger doctors worry about "burn-out", getting into a rut, or drowning in a sea of marshmallow love. The importance of working in a team emerged continually in their discussion. Regular study leave, sabbaticals, teaching and research, learning to integrate with other colleagues, even retiring at the age of 51, were all advocated.

On question 5, the medical group agreed that terminal care is definitely a specialty. It is important to achieve recognition within the profession, and this could be done by trying to establish an inter-College committee with oncologists, and by forming a professional association of hospice doctors, so that the specialty could speak with one voice. The work should then continue to be a challenge.

The social workers' group started with Question 2, agreeing that they are providing the service they thought they should be providing, but being unsure if other disciplines realise what it is! They thought they were quite good at dealing with practical matters such as benefits, but this is only a minor part of the service. Social work skills include counselling and support before and after bereavement, as well as selecting and interpreting what is happening with patients and their families. It is more important that social workers should be seen as patients' advocates, defending their right to self-determination. There is too much pressure on them to achieve a "perfect" death, but they have the right to refuse medication, to die on their own at home, to have a "good enough" death. Social workers also facilitate, liaise and teach.

Turning to Question 6, the group spokesman said social workers do not always set boundaries, because it is difficult to say "no" when social work is not appropriate. Screening procedures are sometimes used to find those most likely to need counselling in bereavement. It is important, however, to set limits in order to avoid "care overkill", and it is often easier for an outside supervisor to do this.

On Questions 1 and 3, the group thought they needed an affirmation of the social work role in order to sustain their professional positon, and to combat the effects of working in isolation, and this they get from their peers. But it is only in the context of the multidisciplinary team that their role could be evaluated and proved. The group asked if social workers are valued for themselves as people or for the skills they offer. Is their contribution to team discussions taken into account, or does the doctor make the final decisions? One of the great strengths of the hospice movement is the emphasis on the team approach. Social workers welcome the chance to work in the multidisciplinary team, but are not sure if they are valued: only other team members could tell them this.

The chaplains' group took Question 3 first, saying that most clergy do not feel alone because of their faith; loneliness is not a threat to them as they know they will have to work in isolation and their faith sustains them.

On Question 7 the group thought that some people with a smattering of religious knowledge do often pontificate, which could be regarded as a trespass and be difficult to cope with. However, a sense of trust comes from the multidisciplinary team and chaplains have to earn this trust and their place in the team. The group did not believe there is a structured approach to spiritual pain; no two people are alike and each one must be approached individually. It is important to be able to direct anger so that resolution can follow, and memories must also be healed. It is difficult to come to terms with the concept that death is a healing process, but when people are horizontal they tend to think vertically: sensitivity grows. The group wondered how other professions recognise spiritual pain.

The administrators' group began with Question 2, saying that of course they thought they were providing a good service - there was really no question to answer! However, the position of the administrator in the health service is a sensitive one, and in the hospice setting is difficult to define. Is fund-raising part of his role, or should this be the function of the figurehead? Most administrators would like to feel they are in the "front-line" although they are not directly involved in patient care. They have a problem in sustaining their position because of the aura surrounding them as a "back-door support". They felt that in order to improve their position they should look at management structures to gain a place in the multidisciplinary team.

The group spokesman told the meeting that the Association of Hospice Administrators had been formed after a conference at which many had found they had common problems although they came from many different backgrounds - accountancy, personnel management, the law, the Services, and the NHS. This new association should provide to hospice administrators the sort of service which would in turn enable them to provide a better service to patients, by improving efficiency and relationships and offering a wider range of practical support and information.

CONCLUSIONS

The Chairman summed up the conference by picking out points which had arisen as groups reported back on this discussion. There was general agreement that we were providing the service we say we provide, but that we have to beware of being swamped and of being all things to all men. Various support mechanisms had been identified by different groups including team working, meetings, conferences and generally sharing with colleagues informally or in formal associations of the same discipline. One group, the Chaplains, had emphasised that aloneness could be a source of strength. The maintenance of professional standards was helped by devising operational policies and agreeing them with other staff as well as making sure that training and experience are both right for the degree of responsibility shouldered. Boundaries could be set by acknowledging limits, accepting that not all terminally ill patients need to be referred for special care, giving control back to families and not sighing for the impossible. The value of professional associations in maintaining standards and in giving back to the Hospice movement had been acknowledged. The Chaplain's group had emphasised the importance of earning trust from patients and other members of staff and had reminded the conference that, while there was general acceptance of the importance of spiritual pain we know little about it.

The Chairman said that conferences such as this are an important source of information and support for thsoe engaged in terminal care and thanked Mr. Graham Cannon, Director of the King's Fund Centre, on behalf of all the delegates for the valuable opportunity to meet and discuss their problems and priorities.

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King Edward's Hospital Fund for London

KING'S FUND CENTRE

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PROFESSIONAL PRIORITIES AND PROBLEMS IN TERMINAL CARE

Thursday, 4 July, 1985

CHAIRMAN: **Dr. Gillian Ford**, CB,
Director of Studies - St. Christopher's Hospice

PROGRAMME

10.00	REGISTRATION and COFFEE
10.30	Setting the scene
10.45	**Sister Jo Hockley**, St. Bartholomew's Hospital **Mrs. Pam Spearing**, Newcastle upon Tyne
11.00	**Dr. Robert Twycross**, The Churchill Hospital, Oxford
11.15	**The Reverend Peter Speck**, The Royal Free Hospital
11.30	**Miss Evangeline Rogers**, Trinity Hospice, SW4
11.45	DISCUSSION
12.30	LUNCH
1.45	Discussion in groups - unidisciplinary: TO IDENTIFY FROM THE STANDPOINT OF OUR PROFESSION THE PRIORITIES WHICH WE THINK SHOULD BE OBSERVED IN PROVIDING HIGH QUALITY CARE FOR PATIENTS.
3.00	TEA
3.15	Report back
4.30	Summing up - coordinating the whole - where do we go from here.

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King Edward's Hospital Fund for London

PROFESSIONAL PRIORITIES AND PROBLEMS IN TERMINAL CARE

Thursday, 4 July, 1985

List of those invited to attend.

Mrs. A. Armitage	Coordinator	Home Hospice Support, Norfolk	E
Dr. P. Atkins	Medical Director	St. Barnabas Hospice	A
Mrs. W.A. Auston	Sister	Greenwich Support Team	D
Mrs. P. Bailey	Medical Social Worker	Doncaster Royal Infirmary	E
Dr. R.C.H. Baxter	Consultant	Greenwich Support Team	A
Mrs. P. Birtwistle	Matron	St. Ann's Hospice	D
Miss S. Brooks	Senior Nurse	Greenwich Support Team	D
Reverend P. Brothwell	Chaplain	St. Giles Hospice	LT
Mrs. Y. Bryan	Home Care Sister	North Humberside Hospice Trust	D
Mrs. M. Buckley	Macmillan Sister	Ogwr Health Authority	D
Miss B.W. Burford	Clinical Nurse Specialist	Brompton Hospital	D
Mrs. G. Campbell	Sister	Doncaster Royal Infirmary	D
Mr. W.G. Cannon	**Director**	**King's Fund Centre**	
Dr. I. Capstick	Medical Director	St. Peter's Hospice	A
Mrs. S. Castle	Clinical Teacher	Pilgrim's Hospice	D
Mrs. D. Cawkwell	Social Worker (Planner)	West Sussex Social Services	E
Miss M. Cockburn	Matron	St. Lukes Nursing Home	D
Mr. J. Collins	Macmillan Nurse	Monkgate Health Centre	D
Mrs. M. Cree	Macmillan Nurse	Paul Bevan Foundation	D
Miss A. Cunningham	Social Worker	St. Gemma's Hospice	E
Mrs. R. Delamore	Voluntary Help Coordinator	St. Ann's Hospice	E
Mr. D. Denny	Administrator	Thames Valley Hospice	WGC
Mr. S.J. Dunlop	Hospital Secretary	Hospital of St. John and St. Elizabeth	WGC
Miss H. Egerton	Director of Nursing Services	St. David's Foundation	D
Deaconess G. Evans	Chaplain's Assistant	Royal Free Hospital	LT
Mrs. S. Evans	Macmillan Nurse	Paul Bevan Foundation	D
Dr. Gillian Ford	**Director of Studies**	**St. Christopher's Hospice**	A
Dr. Hugh Ford	GP	Heacham Group, Norfolk	A
Mrs. B. Gale	Macmillan Nurse	Central Clinic, Colchester	D
Miss L. Gibb	Support Team Sister	St. Thomas's Hospital	D
Mrs. C. Gilraine	Macmillan Nurse	Winchester	D
Dr. P. Griffiths	Medical Director	Ty Olwen Hospice	A
Mrs. B. Hall	Senior Nurse (District)	Easington, Co. Durham	D
Sister M. Handy	Sister	St. Christopher's Hospice	B
Miss G. Hambling	Macmillan Nurse	Hastings	B
Mrs. R. Harrington	Macmillan Sister	Ogwr Health Authority	B
Mrs. J. Hartley	Administrator	The Care Foundation	WGC
Mrs. R. Hatlane	SRN	Royal Marsden Hospital	B
Mrs. S. Hawkett	Nurse Tutor	St. Christopher's Hospice	C
Mr. F. Hill	Bursar	St. Christopher's Hospice	WGC
Dr. R. Hillier	Medical Director	Countess Mountbatten House	A
Sister Jo Hockley	**Terminal Care Liaison**	**St. Bartholomew's Hospital**	C
Dr. T.S. Hughes	Anaesthetist	Doncaster Royal Infirmary	A
Mrs. V. Hunkin	Macmillan Nurse	Truro	C
Dr. T.J. Hunt	Medical Director	Arthur Rank House	A
Mrs. J.E. Hunter	Macmillan Nurse	Southend General Hospital	B
Dr. B.A. Jepson	Medical Director	St. Catherine's Hospice	A
Dr. S. Kirkham	Medical Director	Pilgrim's Hospice	A
Dr. R. Lamerton	Medical Director	St. Michael's Hospice	A
Dr. J.O. Laws	Chairman, Medical and Nursing Committee	The Shropshire Hospice	WGC

Father Paul Lewis	Chaplain	St. Christopher's Hospice	LT
Mrs. M. Mather	Home Care Sister	North Humberside Hospice Trust	B
Miss M. McCallum	Deputy Matron	St. Columba's Hospice	B
Mrs. M. McGovern	Home Care Sister	Jersey Hospice Care	B
Dr. M.A. McKenna	M.D. Macmillan Service	King Edward VII Hospital	A
Mrs. I.T. Morley	District Nursing Sister	Jersey D.N. Association	B
Mrs. C. Murphy	Macmillan Staff Nurse	Maelor General Hospital	B
Mrs. A. Nash	Senior Nurse	Dorothy House Foundation	B
Miss F. Neve	Senior Staff Nurse	The Cromwell Hospital	B
Miss M. O'Grady	Community Liaison Nurse	Hospital of St. John and St. Elizabeth	B
Miss B. O'Hara Murray	Macmillan Support Team	Hither Green Hospital	B
Dr. D. Oliver	Medical Director	Wisdom Hospice	A
Mrs. S.E. Oliver	Senior Social Worker	Christchurch Hospital	E
Ms. L. Percival	Senior Social Worker	Greenwich Support Team	E
Miss T.M. Percy	Course Teacher	King Edward VII Hospital	B
Mrs. G. Petrie	Domiciliary Nursing Services	Marie Curie Memorial Foundation	B
Miss M.E. Phillips	Senior Ward Sister	Singleton Hospital	B
Dr. F.J. Powell	Clinical Assistant	Salisbury Hospice	A
Mr. P.H. Powley	Consultant Surgeon	Princess Margaret Hospital	A
Miss J.O. Reeves	Matron	St. John's Hospice	B
Mrs. V. Ridgeway	Psychologist	The Cromwell Hospital	E
Dr. A.P. Riley	Medical Director	Hayward House	A
Dr. P. Roberts	Consultant Physician	Thames Valley Hospice	A
Miss E. Rogers	**Social Worker**	**Trinity Hospice**	**E**
Sister M. Rosarii	Ward Sister	Hospital of St. John and St. Elizabeth	C
Miss M. Rouse	Macmillan Nurse	Basingstoke General Hospital	C
Mr. W.R.E. Rowland	Administrator	St. Francis Hospice	WGC
Dame Cicely Saunders	**Medical Director**	**St. Christopher's Hospice**	**A**
Mrs. M.G. Skelton	Macmillan Nurse	Burlington Road Clinic	C
Miss M. Sloan	Matron	St. Gemma's Hospice	C
Dr. A.M. Smith	Medical Director	St. Francis Hospice	A
Mrs. Pam Spearing	**Macmillan Nurse**	**Newcastle upon Tyne**	**C**
Reverend P. Speck	**Chaplain**	**Royal Free Hospital**	**LT**
Miss E. Specterman	Coordinator	Southend Terminal Care Support Team	E
Mrs. B. Stuttle	Assistant Director of Nursing Services	Southend H.A.	C
Miss E.A. Swarbrick	Matron	St. Catherine's Hospice	C
Reverend K. Tailby	Spiritual Adviser	Southend Terminal Care Support Team	LT
Miss W. Taylor	Sister	The Leicestershire Hospice	C
Miss M. Terry	Sister	St. Helena's Hospice	C
Dr. Robert Twycross	**Medical Director**	**Churchill Hospital**	**A**
Miss S. Walker	Sister	St. Nicholas Hospice	C
Mrs. A. Walton	Nursing Director	Princess Alice Hospice	C
Dr. J.R. Wedley	Consultant Anaesthetist	Guy's Hospital	A
Mrs. P. Willcock	Social Worker	St. Francis Hospice	E
Mrs. D. Willton	Macmillan Nurse	Hastings	C
Miss S. Wimbles	Matron	Torbay and South Devon Hospice	C
Mrs. L. Woods	Medical Social Worker	St. Benedict Hospice	E
Mrs. H. Wyeth	Staff Nurse	St. Barnabas Hospice	C
Ms. Pat Young	**Rapporteur**		