

tion as an important aetiological factor in "sudden death in infancy".

V. REINICHE, Copenhagen, discussing an outbreak of ornithosis in a family who caught the disease from an infected parrot, showed the wide range of clinical features associated with the single infecting agent.

Professor N. GRIST, Glasgow, presented evidence to show the relative importance of virus infection in the aetiology of acute perimyocarditis. During epidemics of Coxsackie B virus infections, these agents were a frequent cause of this clinical condition.

H. PULLEN, Edinburgh, demonstrated from his experience of hospital cases the unduly high incidence of hypersensitivity to ampicillin in infectious mononucleosis.

Professor E. KLEMOLA and his colleagues presented further work on cytomegalovirus infection, which was a relatively frequent sequel to the establishment of extracorporeal circulation during open heart surgery in Helsinki.

Many of the other papers presented dealt with laboratory and epidemiological aspects of diseases. The value of the latter to the British observer was diminished by the lack of a firm understanding (even among the speakers) of the need to define the differences in the vastly different systems of medical care. The fourth conference in the series is to be held in Copenhagen in 1971: it is hoped that the organizers will pay attention to this and thereby enhance further the international goodwill and understanding which were the hallmark of this meeting.

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## **SYMPOSIUM REPORT**

### **THE MANAGEMENT OF THE DYING\***

**Dr B. Jolles** (*Consultant radiotherapist*) Chairman

The existentialists maintain that life may become more meaningful through man's knowledge of his own mortality. For the doctor and nurse the approaching end of life poses psychological problems which, apart from practical factors of immediate urgency concerning the welfare and physical comfort of the patient, loom large. The patient is often depressed by frequent and often prolonged hospitalization and bewildered and frightened by the institutional processes. He has to be reassured and his will to survive rekindled and reinforced by the degree of dependence and confidence which has to be built up on the part of the doctor, sometimes within a short period of time. The interpersonal relationship between doctor and patient is of great importance.

The importance of communication between doctor and patient, the survival of the illusion of one's immunity to death and his or her invol-

\*Abridged papers from a symposium held on 22 March 1967 at the Northampton General Hospital Postgraduate Centre.

nerability has to be kept in an equilibrium with the realistic acceptance of illness and its outcome. This can be achieved if a compassionate and enlightened approach is made to the patient and a bridge has been built between patient and doctor out of threads of compassion on one side and confidence on the other. It seems very important that:

(1) We do not tell the patient anything that will induce or increase his anxiety.

(2) That we do not allow that hope should ever die too far ahead of the patient.

The above two major commandments should, however, be viewed in the light of a further important dictum, that, at no stage of a serious illness the gravity of the situation should be minimized and the skill, intellect and the compassion of the doctor should all be directed towards the arrangement of the period before death in such a way that there should be no time left for the patient idly to await death.

Much has been written about officious striving in the treatment of malignant disease. The well-being of the patient should not be assessed in units of time of survival but consideration be given to what at best can be achieved in a particular disease in a particular stage of its advancement, its natural course and many other aspects of a practical, medical and psychological order. The drive to improve the figures in statistical reviews and survival rates should not let one forget that kindness and attention to the patient's well-being must always prevail.

As it has been very clearly demonstrated at the recent symposium on 'Ethics of medical progress' (1966), the actual determination of the time of death is not always easy. With the ever increasing power of medical science, not matched by an improved appreciation of moral values, the artificial prolongation of life in a body, not any more alive except for remnants of some physiological functions such as breathing and limited circulation, is sometimes ruthlessly pursued in order to delay the unavoidable.

The endeavour to prolong life at all costs has led, over the last few years, to a situation when consideration of medical advance often overrides moral and humanitarian precepts. The extent of the heartsearching scrutiny of what is being done in the field of transplantation and reanimation is a case in point. The scholastic hair-splitting of what are ordinary and what are extraordinary systems of prolonging life have brought in religious leaders to express an opinion that the physician is not obliged to give extraordinary treatment. In the words of the Pope:<sup>1</sup>

If the family tells the physician to stop the respirator and if the physician thinks that there is no hope of life being prolonged he can stop the respirator with a clear conscience.—The principle here is that of the double effect. Stopping the respirator does not cause death,—because death results from another cause, the disease or injury. From the theological point of view it is very important to differentiate between the action and the effect. The definition of death is a scientific definition, not a theological one, and theology is not concerned with this point. When the vital functions finally stop, then even if the organs are alive there is no longer life in the body. This is very important because it makes a clear distinction between vegetative life in the organs and superior life in the vital functions. The vegetative life is not considered to be life in the spiritual sense.

It is worthwhile to mention that in the Jewish Law<sup>2</sup> the removal of an

organ from a dying patient, even long after he has lapsed into a final coma, or suffered irreparable brain damage, cannot be sanctioned; so long as he lives his worth is exactly the same as of any other person being equally infinite. For the same reason any system of priorities based on the applicant's health or expectancy of life in admission for dialysis treatment could not be contemplated. Human life enjoys a supreme and intrinsic value unrelated to its state of health or social usefulness.

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Miss B. C. Field, S.R.N. (*Superintendent, Queen's Institute of District Nursing*)

For the purpose of this discussion, I have taken terminal care to mean the last few weeks of life.

District nurses, in their daily nursing routine are in close contact with the family and friends of the ailing patient, and become involved quite often in the emotional and distressing experience of death. The acute and chronic forms of all diseases are involved, and all ages affected; the very young to the adolescent—the young adult to the senior citizen. For each case different and difficult problems arise, but we find that it is usually the practical and social help that is most needed. To deal first then with practical help, there are several points to be considered.

(1) The sick-room furniture may need to be re-arranged. For example a feather bed may be removed and the patient must be told why this has been done. Various articles may be loaned to assist in the patient's comfort such as single hospital beds, sheets, heating apparatus.

(2) No hard and fast rule can be made about the position of the patient in terminal illness, the patient being allowed to find his own position of comfort. Our aim is to give as much relief as possible thus enabling him to enjoy his friends and family for as long as possible.

(3) At least twice daily nursing care and probably late night visits are given for injections such as morphia and pethidine. Bed sores can usually be avoided at the terminal stage of illness if particular care is taken of pressure areas. The relatives should be shown how to treat pressure areas, the patient encouraged to get up for short periods for as long as possible, and the hygiene of the sick-room impressed upon relatives.

(4) Suggestions should be made to the family that voluntary or paid help may assist them in caring for the patient. This may help to relieve them at night, enabling them to carry on the running of the house during the day. Sometimes we have to give advice about diet—light and easily digestible—so as to avoid flatulence. Action of the bowels arouses intense interest, both to an acutely ill patient and his relatives. Good fluid intake and suitable diet are important; strong purgatives should be avoided.

(5) The family must be prepared for the last few days of life and for the dramatic changes that are likely to occur—vomiting attacks, sudden haemorrhage—and they must know what to expect at the passing away of the patient, and what to do regarding the doctor, death certificate, notification of death and

contacting the undertaker. Under stress simple everyday things are often forgotten, so it is better to think ahead.

We should always bear in mind the religious faith of the patient and family—if they have any—and if necessary refer the family to a vicar. This aspect of terminal care becomes the clergyman's sphere.

The different ways we react to illness is so varied; people near death seem to me acutely aware of their surroundings and of people near them. Of course, the degree of closeness varies considerably in families and, even if well cared for, the patient can feel lonely and afraid and it is most important to see that he is made to feel part of the everyday social activities of the household. Confidence and moral support to both the patient and his family are so necessary. I feel that it is the process of dying that is feared more than actual death. The relatives are helped by being given small jobs to do.

Some patients appear to have no acute pain or discomfort and acquire an absolute calm, especially those who have a belief in God and the life hereafter. Others are in severe pain both mentally and physically. The control of pain is the doctor's province and we administer under his directions.

As far as social help is concerned we can sometimes obtain extra money for nourishment, heating apparatus, bedding, and so on through National Assistance, British Legion, The Marie Curie Cancer Foundation Fund, W.R.V.S., social welfare and other local voluntary bodies.

**Dr C. P. Elliott-Binns** (*General practitioner, Northampton*)

A houseman has little training in how to manage the dying and their relatives and one of my earliest memories after qualification is being told, rather unfairly, by my registrar to explain to a husband that his wife was dying of leukaemia. I recall the embarrassment and back-peddling so that the poor man hardly understood what I was talking about. Strangely enough, although the pathological diagnosis appeared clear-cut the patient recovered and her blood picture became normal. I still occasionally see the husband in the town on his bicycle and understandably he gives me a sour look.

So, like all inadequate lecturers, I have to fall back on medical literature, and with the help of the College of General Practitioners was able to obtain a large number of articles and books on the subject. Most of these tended to be philosophical in outlook, only a few scientific, and some like the recent article by Yudkin a happy blend of the two. This talk then is a review of the literature with a few of my own ideas thrown in for good measure.

Yudkin, writing on "Children and death",<sup>7</sup> pointed out the tremendous change in attitude over the last 100 years. The Victorian child had death in his prayers and in his precepts, and it was sex that was taboo, death freely discussed. The modern child knows more details of his origin in this life than his departure. The death-bed scene was a reality, with the patient aware of what was going on and the relatives, including children,

sitting or kneeling round the bed. Children were often expected to see the dead body to say goodbye. Now, in our country at any rate, this is not the case although in the States the attitude is sometimes bizarre. I recently talked to a curate who was invited to a funeral party in the U.S.A. and was surprised to find the dead body seated fully-dressed in a chair, while the mourners walked about drinking cocktails and eating sandwiches.

Because of this taboo children often have a lively fear of death, and Yudkin describes how this can induce a definite syndrome of unexpected antagonism to doctors and nurses and lack of interest in what is going on. The fear is based on phantasy, e.g. being shut up in a black box, and the child must be encouraged to express his fears. Of course, the same applies to adults. Yudkin complains that death in a ward is handled in an ugly and obscene way with whispering and scuffling, and there is a lot of truth in this. He also complains that treatment is often continued too long and quotes "No one nowadays is allowed to die without being cured".

Gibson<sup>2</sup> points out an odd thing about death, namely that it does not follow the law of dissolution of Hughlings Jackson, i.e. the higher centres going first, as in anaesthesia. The patient may remain clear-headed to the very end, unless the disease itself predisposes to coma. I am sure we all can remember interesting conversations with patients who were pulseless and near death.

One of the most famous examples was that of King George V who conducted his last Council meeting whilst dying. Although he was too weak to sign his name he behaved with charm and wit. Another king, Charles II, retained his sense of humour to the end and apologized for being an unconscionable time adying. Famous last words are fascinating but sometimes one wonders if they are what was actually said or what people considered should have been said. History books for example give the dying words of William Pitt the Younger as "Oh my country, how I leave my country". Another version given by the Oxford *Dictionary of quotations* is "I think I could eat one of Bellamy's meat pies".

What does it feel like to die? William Hunter said "If I had the strength to hold a pen I would say how easy and pleasant a thing it is to die". Professor Joseph Barcroft once nearly committed unintentional suicide in a freezing experiment and described the freedom from pain and discomfort and a feeling of bliss. This is largely confirmed by those who have been drowned and later resuscitated.

Hinton<sup>3</sup> writing on "Distress in dying" collected statistics on the subject. He noted that 13 per cent of dying patients have moderate or severe pain, while seven per cent experience other unpleasant symptoms such as nausea or dyspnoea. These symptoms are more difficult to control than pain, and the patients who suffer most are those who die in heart, kidney or lung failure rather than in such diseases as cancer. Mental confusion is shown by 40 per cent and two thirds are unconscious six hours before death.

Anxiety and depression are both common. The chief worries are "Will I die?" "Will I suffer?" "Who will look after me?" and "How will my family manage?" To these one might add "Will I be a bother to other people?"

Depression is less common than anxiety, although seven out of 100 dying patients are potentially suicidal and wish to end their lives prematurely. Although the aged are more aware of the likelihood of death they tend to have less mental distress. In practice the important point is that the morale of the dying patient depends largely on two factors:

- (1) Freedom from discomfort.
- (2) Sympathy of relatives and attendants.

How can distress of the dying be dealt with? Because hope of cure is abandoned the patient himself must not be abandoned, and his symptoms must be treated energetically. Pain in particular should be relieved even if the dose of drugs has to exceed what would normally be given.

Anxiety and depression should also be treated with tranquilizers, sedatives or antidepressants, but only if there is a real indication for this. One should not assume that all dying patients are anxious or depressed and make them drowsy or stupid with drugs when they would wish to be clear-headed.

It is as equally important to give the patient a chance to talk about his worries. I am not one who believes in telling a patient categorically that he is going to die, because it is almost impossible to assess the effect of such knowledge. I always prefer to leave an escape-route which the patient can use if he wishes. Often the patient knows he is dying and the doctor knows he knows but there is a collusion of silence and it is usually better so. But this does not mean that the patient should be prevented from discussing his worries. Often we brush him aside by saying "Don't be silly, old chap, you're not going to die". This does not deceive the patient but is often used by the doctor or nurse to avoid their responsibility in this matter.

The doctor must also show consideration to the relatives and give treatment where it is necessary. If the wife complains of headaches or pains in the chest while looking after her dying husband, do not ignore her. It is a cry for help and the help must be given.

When the patient has reached the stage of actual dying there are certain points to be observed, and these are taken mostly from the works of Cecily Saunders<sup>5</sup> who qualified both as a nurse and a doctor.

(1) Patients prefer to be propped up to see what's going on, although the neck should not be flexed, with the chin on the chest.

(2) Fading vision is distressing. The room should therefore be well lit and the curtains open.

(3) The death rattle, distressing to patient and relatives alike, can sometimes be relieved with an injection of atropine.

(4) Thirst occurs after pain sensation has gone. The lips and mouth should be kept moist even when the patient appears unconscious. One of the last words of Christ on the cross was "I thirst", and he was offered vinegar on a sponge.

(5) The dying patient tends to feel hot rather than cold. He should be lightly dressed and the room should have cool fresh air. Often you see a dying man fumbling to undo his pyjama jacket, and a relative or nurse doing it up again because they think he may "catch cold" or even die "improperly dressed".

(6) Hearing is the last sense to go. If possible someone he loves should be by his bed talking to him quietly as he dies, because this will be his last memory.

For this reason also it is important that a priest should be present if possible.

(7) Dying is probably not of itself unpleasant and may even be ennobling.

We do not understand its significance and therefore the process should not be blanketed unnecessarily with drugs. The patient should not die on a wave of morphia unless there is good reason. We live in an age of unbelief, which, I think, history will judge to be an abnormal age due largely to superficial ideas of science and psychology. But even the most cynical or materialistic of us is not justified in assuming that because the human cerebral cortex is only capable of interpreting and analysing a simple four-dimensional world this proves that no other level of existence is possible. One could imagine an earth-worm, only aware of the soil through which it burrows and the soil passing through its intestines, having grave doubts as to the existence of such things as music and mathematics. It may well be that in the context of the Universe as a whole the human cortex is only ranked a little above the ganglia of the earth-worm.

This is a common meeting-point for mathematician, physicists, theologians and poets such as T. S. Eliot, and we should have grown out of the age when only scientific knowledge was considered genuine. A master of Balliol College was reputed to have said, "What I don't know isn't knowledge", and this is an out-of-date attitude.

Professor Worcester<sup>6</sup> of Harvard summed all this up in the following sentence:

"Whatever the doctor's personal views about the possibility of life after death he should act in the presence of the dying as if he believed in it."

I can remember shortly after the war seeing a film of *Wuthering Heights*. It was not in my opinion a very good film because it tried to improve on a book which could not be improved on. It annoyed me that when Catherine was dying (in the film), she asked Heathcliff to carry her to the window. Although this struck me as being 'corny' it was probably psychologically correct since what Catherine wished for was the fresh air, bright light, the touch and voice of the one person she really cared for and to die looking at the moors she loved so well.

To summarize then—the act of dying is important in itself just as is the act of birth. It is the duty of the doctor to control physical and mental distress but to refrain from stupefying the patient with drugs unnecessarily. Since no one understands death the doctor should show humility in this matter and recognize the importance of the priest and of the relatives in the care of the dying patient.

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**Rev A. Bransby** (*Hospital chaplain*)

It is necessary and vitally important that the word 'care' should be emphasized in this involvement in which we are called to enter. One remembers the story of the professor of medicine who told his audience he "wished at some time to be permitted to address them on this very theme—but, of course, would be under a handicap of not being able to speak from experience". This dilemma constitutes much of the real problem as we consider the care of the dying. It has been very realistically said that "dying is an art—like everything else". It is because of this that a ministry to the dying ought not to be viewed in isolation; the act of dying ought not to be separated from the act of living since it is a continuation of the whole process of life. Yet there are problems of which we are only too well aware.

Our concern, therefore, is a mutual one—not so much of the 'patient' because he or she may be in the process of dying, but of the 'person' in order that the potential may become actual where the person matters.

On the other hand, when faced with this problem C. S. Lewis said "It is hard to have patience with people who say—there is no death, or—death doesn't matter. Whatever *is* matters".

We may be living in a society which prides itself on its self-sufficiency and in a world of many advances, yet it may well be we must be prepared to relearn the whole business. There are certain facts about this which affect us all, of that I am quite certain. Obviously, in consideration of care for the dying certain words come almost spontaneously to our minds. On the one hand, fear, loneliness, separation, and, on the other hand, peace, acceptance. Sometimes we avoid the words death and dying; instead we speak of passing away and falling asleep. In times of war we refer to people being called to higher service. Yet by so doing, it is possible to beg the real question. There is so much to break down and to build up. One recalls Tolstoy's *The death of Ivan Ilych* and how he experienced torment of mind because of the attitude of those about him, who were so casual, not caring—not feeling for him. It is this which is so important from the spiritual angle to all who are engaged in the care of the dying. Their work will overlap and spiritual work is not necessarily confined to the priest, chaplain or minister. This is precisely where we all become involved.

From my own point of view our work can be and should be far more effective, because of what we are, rather than what we may say. It is in this sense we speak of a pastoral care. What must be cultivated is manner and presence and it is the exercise of these which should bring calm and serenity. There has been much criticism of the parsonic voice, no doubt justifiably. If the voice must be used, and no doubt it must be, then there shall be quietness and confidence, avoiding above all any impression of 'over-busyness'. It is this particular person that counts. It is an art to sit or stand quietly by the patient, with an attentive ear. Whatever may be our definition of prayer—a release of spiritual power, contact with a higher order, in touch with God—this in itself can never replace that fact that the minister must be prepared to enter the valley with the person. A



relationship must be established by what he is. This may mean sharing unresolved problems and conflicting emotions. Oft-times it can be comparatively easy to hide behind outward things, even prayer and sacrament, and yet remain aloof. A relationship which means anything cannot be forced; it must be shared, and because of this it does need some regularity with the same degree of interest throughout. This is important in any kind of spiritual ministry. When this practice is applied in care for the dying it must be sustained for some considerable time. Only close contact will establish whether they want or need to be enlightened. The truth is conveyed not only in words—if people ask for spiritual help they will only ask where they have discovered care, kindness and love. However, one cannot take away all hope of recovery and leave people without light. One of the old Scottish divines defined peace as “the possession of adequate resources”. These resources are in God, and this exercise of pastoral duty must never fail in this respect. C. S. Lewis records that his wife said “not to me—but to the chaplain—I am at peace with God”. Co-operation at every level in our care must seek to establish just that.

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