As regards pain, as long as my mother was taking drugs orally that was all right—I could cope. But when it got to the stage that she could not keep anything down and we had to have injections it was terrifying a situation. I could not 'phone my G.P. at all hours of the night; there was no 24-hour service as far as I knew; and in fact I was often left in the middle of the night with my mother in absolute agony not knowing where to turn. I know now that there were places that could have helped me, but I did not at the time.

Treatment at St. Christopher's Hospice

Now after that tirade of criticism, which is obviously only about some aspects of it, may I say that in my husband's case everything was totally different. A month after my mother died I was told that my husband had cancer of the oesophagus and had about a year to live. I think possibly because of this, and it being the same hospital, they thought I needed a lot of help so I was referred to St. Christopher's Hospice. At first I regarded the idea with horror because I knew it was a terminal home and I hated the idea of my young husband being surrounded by dying people. I did not want him to know he was dying because, after a great deal of thought, I considered he was the sort of man who was probably better left in ignorance of that and I thought he would guess, being in this hospital. In fact (and this is very interesting) he never did. He gained nothing but inspiration and happiness from being in that hospital. He went in occasionally and then came home and I was helped at home.

The other marvellous thing that happened at St. Christopher's was the form of drug control. My husband and I went to the theatre two days before he died because his drugs were dosed in such a way that he never became a vegetable, and his life, even though he was consumed with the disease at the end, was always worth living. This I think is one of the biggest things against euthanasia because his life never became unbearable.

The hospital itself is architecturally a delight, which I think is also very important—and this is obviously something that Lord Aberdare ought to be thinking about. Most of our hospitals are really pretty sombre places and a lot of them should be rebuilt. The day-clinic was a joy to go to; it was like a social outing as opposed to those ghastly sessions at radiotherapy, where you are kept waiting for hours for transport and hours because the appointments have been over-booked. Believe me it is agony when somebody is undergoing radiotherapy—and all of you know the effect that has on you of total depression and vomiting and sickness—to have to go for a four-hour session for the sake of a five-minute treatment. That happens all the time. Now I do not know why—maybe it is a lack of organization, obviously it is understaffing, but it was a terrible problem. This never happened at St. Christopher's because presumably they have a large enough staff not to allow it to happen. Also I was taught with loving care to look after my husband and I think it was considered the more I could do for him the happier they were.

I must not go on about this because it is beginning to sound like a commercial for St. Christopher's and I know that Dr. Saunders and Sister McNulty are going to tell you about the professional aspects. But before they say anything I just want to tell you that for me and my husband their method was 100% successful. It was a totally different experience from that with my mother. I understand that there is an increase in the numbers of people dying in hospitals. I would think that if home assistance could be better organized this would not be the case. I do think that people would prefer that those they loved died with them—I certainly did. I think they needed my comfort, they needed my love—which I could not expect a detached medical person to give. But you do need help; believe me you do need help. It is the most frightening thing to be left on your own with this situation if you are not a professional. It would seem to me that it is necessary for some sort of corps to come into action as soon as somebody is pronounced incurable—a 24-hour service of G.P.s,

possibly retired G.P.s who work on a shift system, so that you could have somebody to come and give injections all night long and not feel that you are putting upon them. That is just a theory obviously, it is not my place to suggest that. But I do think people would prefer it if it were made possible.

Now over the last three years I have seen that death can be appalling. But I do believe that in nine times out of ten that is not necessary, and I hope with all my heart that this symposium is going to be one step in the direction of allowing all of us, and I do mean *us*, to die with dignity.

A Death in the Family: A Professional View

CICELY SAUNDERS

I once asked a man who knew he was dying what he looked for above all in the people round him, and he paused a moment and then he said, "For someone to look as if they are trying to understand me." He did not ask for success. He asked for the effort of trying. That is why we are all here today, and we have already been brought right into the centre of the situation of the patient who is dying and his family. We are beginning to try to understand, and I think I can best continue by sharing some of the things we have been trying to understand at St. Joseph's and St. Christopher's and other places as well. Above all we try to allow our patients to speak for themselves.

So often people are just not protected from the truth that you think you are protecting them from; they are left alone with it instead. I remember sitting down with one particular patient and saying, "How are you settling in?" He said, "I don't know if I have time. I think it's a little wooden box." He wanted to talk, and then he tucked it away again. On the record a few days later talking to one of the nurses, he said, "Of course it's just my rheumatism, I'm really not too worried."

The patient and his family are often separated by unshared knowledge. I remember one man talking with me about the 18 months after his first operation when he could not think what had happened to his marriage. There was some barrier between him and his wife, and he did not know what it was until eventually he had a recurrence and he tackled the doctors. The doctors, seeing the person, the man, behind the questions, then told him and he and his wife were able to share the trouble. And I remember asking him, "Back at the beginning, would you rather that you had been told more, or that your wife had been told less?" He said, "The second, but whatever had happened I would have wanted to share." They did come together, and they stayed together.

The Patient and His Pain

I have been asked to talk about the patient and his pain, and I think this is very important at this stage. If we are thinking of the things that separate the patient from those around him, certainly pain can be one of them. One patient on admittance, sitting bolt upright with tension, was separated from his wife with her terrible feelings of inadequacy as if by a solid wall. Home had become impossible just because of pain. By relieving that pain, we were able to bring them together, so that they were more together after he was admitted than they were when they were alone at home. More outpatient facilities so that this could happen at home are, I think, one of the most important developments just beginning in terminal care at the moment. For some patients, however, pain is something that is so all-embracing that it really cannot be coped with adequately all the time at home. Chronic pain is an apparently endless situation, whose meaning is really only one of threat. One patient

painted a vivid picture of this kind of pain, but after a short period, by control of infection and the use of steroids, pain was controlled. The point is that you can relieve pain so that a person is himself. To be able to go to the theatre two nights before you die is the kind of thing we should have as our aim, wherever it is possible.

So much pain can be relieved without resorting to analgesics. The doctor must sit and listen to the various facets of distress so that he may see whenever something specific or some new adjuvant can be introduced. Nor do we need to employ large doses if drugs are given regularly. The maximum doses needed by the majority of our patients are not high. Out of a total of 500 patients 428 were given diamorphine for control of pain. Only 19% ever needed more than 20 mg at a time.

Involving the Whole Family

If the patient has to come into hospital I do think it is of enormous importance that the family should feel as if they come in as a whole. Sometimes one enables people to meet again. One family I remember was reunited in this way. The sons met their father again, when at home they had been refusing to speak to him, resentful and uncomfortable with the illness of which they were so frightened: the fits, the strangeness. And in the hospital atmosphere the wife and the mother-in-law also began to be able to talk and work through some of their feelings. Rather later in this patient's illness, not very long before he died, he enjoyed the sort of visiting that one wants; like one's time together at home, the family just sitting reading the paper, the wife knitting, the informality and being relaxed. That wife was able to wash her husband and do a lot of things for him in the ward. We know something of this family and the stresses of their bereavement. The boys got very aggressive with each other. One thought he had a cerebral tumour and the mother, now a widow, had to call the doctor in the night. But now one is married, one is in the Air Force, and the third, having failed his O levels at the time of his father's illness, has taken them again and passed. As for the wife, she has been coming back to us as a volunteer.

Children should visit, should be involved, should be part of what is happening. But to do that we must be able to control pain; it must be the father they know. And in doing this we have to learn when to stop doing our prolongation and when we accept that this is a peaceful death and should be allowed to happen. It is far better to have a cup of tea on your last day than drips and tubes in every direction. And I think this cup of tea comes best of all from someone who has compassion, understanding, and practicality—someone who does add heart to skill and has a sense of meaning and assurance of another dimension in life. We should never impose our own beliefs and own feeling of meaning on to another person, but I am quite sure we could help produce a climate in which the patients can find their own meanings, and can find the quietness and dignity of death as it can be when it is a person not the apparatus around that is the centre of attention.

Finally, I remember a patient not with cancer but with motor neurone disease, a police sergeant who died aged 39 after 2 to 3 years of illness. I remember his saying at an early stage, "If I thought I'd ever be like that chap I'd do something to myself." But when he did reach the stage that he had been watching he found that, from inside, the situation was very different as long as he was not alone. We often discussed talks such as this and he once offered me a title, "Bringing-together Illness," in preference to the phrase "Catastrophic" or "Terminal" which I had been given. I said, "Do you always see this 'bringing-together' happen?" He said "Yes, I am a trained observer and I've been here for 18 months. Patient and family, patient and staff, patient and patient—yes it does happen." And he went on making this more true to himself up to the very end. I remem-

ber his saying, "I can't see round the next bend but I know it'll be all right." What we have to try to do, I think, is somehow to help the dying patient and his family in every possible way to find this kind of security. The world in which your own body is letting you down, and the world in which someone has left you, feels and sometimes is a very unsafe place. But this situation which cannot be changed can be transformed. The demands of the family are in many ways the same as those of the patient. They do not need just sympathy and sedatives, but something that was summed up for us for all time with for all with the words "Watch with Me." I think that phrase means listening without necessarily knowing the answers, and persevering with the practical, which includes developing skills. But above all it means do not forget to be simple; be prepared just to be there. We must somehow give everything that we can to these people that says "you matter because you are you," everything to enable the patient to live up until he dies, and the family to go on living afterwards.

St. Christopher's Hospice, London S.E.26

CICELY SAUNDERS, O.B.E., M.R.C.P., Medical Director

A Death in the Family: A Professional View

W. FERGUSON ANDERSON

The public require reassurance, in that people in general are worried about the process of dying. Individuals do not fear death but how they will die with the attendant problems. Cramond¹ believed that seriously ill patients did think of death as a possible outcome, often welcomed the chance to talk about their feelings, but were concerned mainly about the way in which dying would occur. In general people do not understand what goes on in a hospital—particularly when a person dies—and there is concern about the belief that old people are kept alive unnecessarily. Reassurance is therefore required that in fact old people are not kept alive, and the act of dying is not prolonged. The B.M.A. panel on euthanasia in 1970 felt that the argument that the elderly are kept alive by drugs had been grossly exaggerated and that old people benefited more from kindness, good nutrition, and good nursing.

In the hands of experienced doctors people towards the end of their lives are kept free from distressing symptoms such as thirst and from pain and discomfort. Much more explanation and communication with relatives as to what the present therapeutic regimen is about is necessary. The subcutaneous saline drip which is being given to alleviate symptoms of dry mouth and thirst is not prolonging the patient's life unnecessarily, but relieving uncomfortable and worrying symptoms. Though services for the elderly in hospital have improved and more consultant appointments have been made, it is still the young doctor, very often newly qualified, who is asked about the present condition of a very old person, usually supported by the experienced and well-trained sister. In our new planning we must try and provide time for the senior doctor to interview the relatives of those who are ill and need explanation and reassurance. Gibson² showed the great value and benefit when elderly people die in their own homes, and here again public reassurance is required that when the social circumstances permit domiciliary services should be adequate to enable the relatives to play a full part in the care of the dying patient without being pushed over the edge into breakdown. Lastly, our social conscience demands that when the general practitioner requires the admission of his dying patient to a hospital, accommodation of desirable amenity