Where to Die

Sir DAVID SMITHERS

For many years I was not aware that "terminal care" was a subject. It was not taught in medical school, though one might suppose that skill and experience were as necessary in the management of those who are dying as of those who are giving birth. I thought it was just what you did when there was nothing else to do. When I became a consultant, I had to practise terminal care and did it most imperfectly, with no guidance from my seniors; but with growing experience attained, I fear, at the cost of many patients who taught me all I knew of the subject until I met Cicely Saunders.

However, I started with one great advantage. I lived in the village where I was born (I still live there). Much can be learned from village life. It was said of my mother that no-one died in the village until she had been for a last visit—they waited. She was no grand lady who condescended, she went around the village on her bicycle. Conversation, chat, and gossip are an important part of country life. In a village everyone dies, it is normal practice, everyone knows about it—if not the post-mistress soon sees that you do—and someone goes in to help. In a block of flats in town somebody may die alone on the other side of a wall a few feet away from you and you may know nothing of it. Death does not seem to be such a part of life in big cities.

I start with these personal remarks because the first unconscious lesson I gave in terminal care had nothing to do with drugs and everything to do with talk. I made a rule for my registrars that if a decision had been taken that active treatment was no longer relevant to the real needs of a patient, then he had to be visited every day. I soon learned to do one ward round a week alone in the evening, to sit on beds, to listen, and to meet the family. The discussion of serious matters of life and death—be they explanations, reasons for hope, or the gradual understanding of approaching death, whether expressed or not—is much easier when your head is not high in the air above the patient and you are alone. This is when things that matter are said, sometimes not until the third or fourth visit. No-one who hasn't time for chat knows anything about terminal care, however brilliant a clinical pharmacologist he may be.

Contact with the Family

Meeting the family is essential. Relatives have to be prepared, they have to feel that everything has been done, not only by the doctors but by themselves. They have to be told how much they are doing to help, given jobs if necessary, exposed if possible to a period with the patient at home before re-admission, and committed to the task of terminal care themselves, with assurances all the time of backing from the hospital. Terminal care is not just something which hospitals take out of the hands of relatives for their relief.

I present these general observations because they seem to me to be by far the most important part of the subject before us today. What happens at the end depends on what has gone before. If the patient and his relatives have talked frankly and frequently to the doctor in charge, if the patient has been well but not overtreated, if confidence and respect have been established and the end prepared for, with the collaboration of the general practitioner and the help of the medical social worker, the real terminal phase is often brief and not too distressing. I have been by the bed with a wife while her husband died and then we have had a cup of tea together with Sister in mutual satisfaction with the way we managed things. I have also had less happy experiences. When things have been badly handled, tension, refusal to face facts, guilt, and pain can lead to troubles which do not cease with the patient's death. I believe that the need for experts in pain relief in the terminal stages of cancer varies directly with the way in which the patient had been

handled throughout his disease and that terminal pain is less often the result of an invasive cancer process than some suspect.

The proper place to die is at home, not too soon—but in time—and with as little discomfort and as much dignity as possible. All very well, you will say, but all too often that is not the way of it: 65% of cancer patients die in hospital; mental confusion, disturbed behaviour, and incontinence are troublesome and messy. Home care becomes increasingly difficult in the changing social conditions of today; there are housing estates which are almost empty of people in the daytime, when everyone goes to work to school, or to a creche, and the dying cannot be left alone. Home care demands sacrifice, too often from unmarried daughters, and a willing family doctor with home helps and social workers at his command—I mean at *his* command. If something called "administrative rationalization" or professional advantage is to be put before patient care and which is called a social "service" we really are in trouble. To divorce social workers from cancer hospitals or from general practice would be a disaster. The benefits of unified local authority social service departments may be great, mine I know is a limited view, but nothing will replace the medical social worker in my hospital who does a ward round with me and is our valued liaison officer between hospital, general practitioner, and local authority. If she becomes remote from the day to day work of the hospital the patients will be the ones to suffer.

Wanted, Better Facilities

We need more and better facilities for terminal care in hospital. I confess to a prejudice against isolated terminal care homes; not the few expert, specialist institutions for the really difficult problems, for research and development, for teaching us how to do things better, but for the general run. When you take on a cancer patient you take on his problems and his relations in collaboration with his family doctor. If he has to die in hospital it should be in your hospital, under your care, unless it is to his advantage to go elsewhere.

The bed problem in cancer wards is great already and is increased by doctors who telephone from other hospitals for urgent help about patients who have been under their care for months, usually with kind words about your reputation for working wonders. It is curious what a high incidence there is of such calls on a Friday.

There are, of course, brilliant and most valuable specialists who are just no good at terminal care; they really will not get any better. The danger is that they are often the ones who press for the appointment of psychiatrists to take over a duty which is rightly theirs. We do indeed need psychiatrists in cancer wards to give their expert advice and service and to deal with those who need psychotherapy but I vigorously deny that a psychiatrist is the best person to talk to seriously ill patients under someone else's care even though I have known them to do a wonderful job with patients who have been neglected by busy or inadequate specialists. Cicely Saunders, to whom we and our patients owe so much, has set a standard, pioneered, studied, and taught; her isolation has I believe made this possible but her teaching must be put back into the hospitals where the patients are. We should turn to her when beaten, not for every day. No rash of isolated terminal care homes inspired by her excellence and promoted by public pressure is required. Her influence needs to permeate every hospital where doctors can care for their patients as long as they are needed. In cancer this has become particularly important since we are steadily pushing back the time when active treatment becomes irrelevant. Many patients with multiple metastases are now being cured. Too many have been given up too soon or treated inadequately by the inexperienced in the past. Estimation of expected survival of patients with advanced cancer is difficult enough if you do nothing—with modern chemotherapy we are only just learning when such remarkable remissions may be obtained and we need more hospital beds to pursue this work.

After-care Home

In June 1971 the medical social workers in my hospital and I put a proposal to our Board of Governors for the establishment of what we called an "after-care home." It was to be part of the hospital and to fill the gap that exists in our bed provision. We have a fine variety of progressive care units, from a hostel built into the structure of the hospital, through normal wards to sterile nursing units, of which we have the largest concentration in the country. But we lack beds for short-term care—one or two days, for patients having chemotherapy—and have few beds for long-term, usually terminal, care, where we need to keep the patient in, or in and out, perhaps for three to six months. We thought that these needs could best be met together since there are certain disadvantages in a single purpose block, if that purpose is too clearly seen to be for the care of the dying. The extra beds which we proposed would be a good deal cheaper to run than those in the rest of the hospital, would reduce our cost per bed, and would enable us to use the beds we have far more efficiently than we are able to do at present. It is our great regret that money for this project has not yet been found.

We need to create more terminal care facilities in those hospitals where many cancer patients are dealt with so that we may increase their opportunities for continuing care and patients may be seen through by the people they know and trust. Let us then take this matter more seriously, for the provision of these services is grossly inadequate and we all expect to need them one day, except Sam Snead, who asked why he went on playing golf for money at his age and told "You can't take it with you" replied: "But I'm not going."

Royal Marsden Hospital and Institute of Cancer Research
Sir DAVID SMITHERS, M.D., F.R.C.P., Director of Radiotherapy
Department

Supporting the Patient in the Home

RONALD GIBSON

"Please don't let me go to hospital, doctor." I wonder how many times the family doctor hears those words in his professional life. Strangely enough, he does not construe them as meaning that the hospital is a terrible place, or that the people working in it are ogres: what the patient is saying is that at this delicate and critical stage in his life he wants to be surrounded by his own walls, to be in his own bed, and to have his own family with him. He has enough to contend with already, without having to learn about hospital life and routine and visiting hours. Dying in itself demands enough of him in terms of mental and physical endurance. He is asking that he should not have to cope with more than these.

He is thinking too, maybe (as we, indeed, should be thinking) that the test of the Health Service and of those who work in it is not only how best to prevent illness and to keep people alive and healthy, but also how to let them die with dignity and in peace. Strangely enough, though it is not for us to tell him, this latter is probably the greatest challenge of all.

I believe that when patients ask to die at home it is our task—all of us together—to see if this can be made possible. It should be easy enough, with so many of us involved. Why, then, is it a challenge?

Lack of Understanding

I think, firstly, because so few of us understand death and the process of dying. We are never taught about death when we are

students. We have done what we can to keep this patient alive—now we can do no more, so he is going to die; and why is it called "death" anyway? It is merely an end to a body and a brain which has worn itself out or is too wracked with disease to be able to function any longer. We cannot even define death; we are finding it increasingly difficult to be sure at what precise moment it actually happens. And, perhaps most significant of all, we have not realized that death is itself amenable to treatment.

Secondly, it is a challenge for the very reason that it is so difficult to treat. It is, perhaps, instinctive for a general practitioner when he knows that his patient is dying, to ask for admission to hospital. The alternative, to a busy man, may involve domiciliary consultations and a succession of visits spreading over weeks and even months. It will also mean overcoming innumerable obstacles and difficulties in an effort to bring into the picture all those who, at any rate on paper, are available to help. Every visit has to be mentally prepared for and the routine of treatment constantly varied. These and other considerations (not the least of which may be that he himself believes that a patient's death in hospital is more to be desired than at home) causes him not to accept the challenge of caring for the dying himself. All this patient now has to do is to die, which is as simple as it is inevitable and can as equally well happen in a hospital bed as at home.

Some of us deny this thesis. Many patients dread it. I have heard it said that there is a trend away from home terminal care towards the hospital. Fortunately this view is based on statistics so that I can happily disbelieve it and continue to rely on my own observations.

Death in the Young

Thirdly, the process of dying is a challenge because it does not occur—as we so naturally tend to think—only among the elderly who, as it were, give themselves up to their Maker with some relief; or among the late middle-aged with inoperable cancer. Let me be trite and remind us that young people can die. It is with them that it is at its most formidable and agonizing and it is in coping with them that we face the greatest challenge.

Home care cannot and indeed should not be attempted unless certain criteria have been satisfied. It is one of the hazards of home care that it can break down irretrievably if the foundation on which it has been built is found to be insubstantial, and if it breaks down the resulting trauma can be far worse than if it had never been attempted at all.

Possibly and preferably, then, an initial period of diagnosis and assessment in hospital; then an assurance that home care is accepted by both patient and relatives. This is particularly important because the family represents a vital part of the domiciliary team—they must be fully brought into the picture and made aware of the amount of extra work and worry that may be involved. Next, there must have been full liaison between hospital and G.P., not only so that each knows what the other is about, but so that each knows what the patient has been told and each can express a view on the feasibility or advisability of home care. Finally, the G.P. must be recognized as a fully fledged member of a domiciliary team, each member of which knows the patient, the patient's illness, their own particular role in the pattern of care, and has an understanding of and sympathy with the programme.

No-one must think I am suggesting that terminal care should always take place in the home. I must also make it clear that I am talking of the total care of the whole patient and not just a narrow treatment of the disease—a progress, in fact, from family doctoring to family care. And family care means what it says: care not only of the patient but something which overflows on to relatives—particularly young relatives—so that any signs of stress can be recognized at an early stage when they can be dealt with (even if this means asking for a hospital bed for the patient for a week or two) and not left until home care becomes no longer viable.