

### 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."

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## 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.

### Community Services Upgraded

Over the past few years—and gathering momentum from year to year—there seems to have been a tendency to upgrade the services available to patients within the community outside the hospital. In addition, there has been talk of functional and administrative unity so that the Health Service, both within and outside hospitals, can become one entity. In an increasing number of areas nurses, health visitors, and G.P.s have been coming together to work as a team in caring for the same patients. Each, in so doing, has got to know the patient, to understand each other's point of view and each other's role in the concept of total care. With this team work, domiciliary consultations between hospital doctors and G.P.s in the patient's home and open access to x-ray and laboratory facilities we can see gradually emerging a reshaped Health Service in which those who can be cared for at home are able to stay there and those who require specialist investigation and treatment can still be admitted to hospital.

All this fits in with the current thinking on domiciliary care and functional unity and the benefits from this could be staggering: to the patient, total care as something to be expected as a right in his own community; to the G.P., the home nurse, and the health visitor, a greater fulfilment and satisfaction in their professional work; to the hospital, more beds for those whose need is vital, the possibility of getting patients out of hospital as easily as they can be admitted, of hospital beds being used and not misused, and specialist care being conserved and not allowed to spill over on to patients who could equally well be treated at home.

One item stands in the way of success. It is not possible to care for the patient if one cannot care for the home in which the patient lives. (It seems to be impossible for politicians to understand this.) Home helps have been separated from the Health Service and considered of such low priority and of such little importance in the total scheme of care that they have been handed over to another service. The day must come when they are upgraded, given a uniform and a car and the role in care that they deserve and must have.

In consequence of this those of us who believe in total care and try to practise it are finding the burden of it becoming as difficult as we can take; this is a bitter thought when one accepts that it could have been made so much easier by just the attachment of one home help to each total care group.

### Positive Programme

The programme for each patient is basically the same; a positive one based on hope and on an aggressive attitude to the disease. Hope, even if it exists only in the patient's mind, must never be allowed to die. An active life must be encouraged for as long as possible—from a bed or a chair. The patient must continue to do all he can for himself or herself. Unobtrusively the immediate family must be shielded from as much physical and mental fatigue as is possible. This applies particularly to homes in which there are young people. There must be no gloom cast over the whole family.

With each visit the doctor must expect the situation to have changed. Between them the nurse and the doctor must try to anticipate the next stage in the illness—above all they must be able to meet at frequent intervals to discuss the case and its treatment. If the help the Social Services can offer in providing a home help is too limited, then help must be obtained from friends and neighbours, the Women's Royal Voluntary Service, with Meals on Wheels and the church, so that as much as possible of the weight of cleaning, cooking, and shopping is taken off the family. It is ideal if the consultant who looked after the patient in hospital can be asked to visit the home from time to time (as a member of the team) to help in assessing the condition of the patient and to advise in the progress of treatment.

The problem of telling or not telling the patient is one which can be solved in each particular case only by a consideration of many factors. In spite of what has been said and written on this subject it is an immensely difficult one. It may suddenly and unexpectedly confront the doctor, the nurse, or the relatives at any stage in the illness and each must be prepared with an answer. It is ideal if all the members of the team have decided on the answer before the need to give it arises. If this is not possible, everyone should know what has been said so that all can be in agreement—at least in front of the patient.

### Break-down of Care

I have spoken of home care breaking down. This can happen and must be accepted when it does. A home is particularly at risk, for example, when there are too many helpers involved, some of whom may be inexperienced. One or two words wrongly used at the wrong time can be all that is necessary to cause a break in care. One must remember how very necessary it is for the doctor and the priest visiting any patient to be on the same wavelength.

The final difficulty is of over-involvement. If at any time the member of a group feels that he or she should withdraw from the case there should be no argument. This particularly applies when the patient is young or a helper inexperienced.

A stage will eventually be reached when active treatment is over and there is little else to do but sit at the bedside and wait. This is a very delicate and difficult moment in care and we all know that it may be prolonged for days. Each succeeding hour may have to be explained to relatives. Nursing may have to be augmented so that it is continuous throughout the day and night and the reliance on the British Red Cross Society, the Marie Curie Foundation, Friends in Need, and other helpers will be stretched sometimes almost beyond its limits. I accept, too, that to be successful total care may well entail using the organizational capabilities of the group practice staff to the full—and in this sense they also are members of the team, answering repeated calls for substitutes or reinforcements and scouring the neighbourhood by telephone or visits until the need has been satisfied.

This all amounts to an exercise in care which can be simple or may be exceedingly complicated. Once initiated there is no turning back except through admission to hospital. A decision must soon be made whether this sort of community care is what Government and people envisage as part of the new Health Service. If not, I submit that the treatment of the dying—as opposed to the total care of those with a terminal illness—must in every case be accepted as the responsibility of the hospital service. To my mind this would be an unpardonable insult to the family doctor and the community health care team.

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## The Social Worker's Role

M. P. DANIEL

I should like to start by describing three situations which seem to me to illustrate some of the tasks and some of the problems for the dying person and those close to him.

The first situation is in a small top front room in the East End of London, where an old man over weeks inched his way towards death. There had been many helpers and a great many offers of help. There had been a home help, a district nurse, meals on wheels, nursing