

### 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

aides from the local authority. The hospital had kept him in longer than perhaps might have been expected, and indeed they had said that they would be willing to re-admit. All these people were anxious and keen to help because of this old man's character. He was a fighter; and he was somebody that everybody admired and therefore wanted to help. However, at the time I am describing, over recent weeks his wife, his brothers and his sisters, and there was a great many of them, sons, daughters and even grandchildren began to converge on the little house, and what they did was steadily to dismiss the official helpers one by one. In the end all that were left in his particular circumstance were the general practitioner and the social worker. Finally only they continued to be allowed in, he to attend his dying patient and she to the swelling family, who were in fact conducting (and conducting is the word) the dying of their ancient head.

I think the family still let the social worker in and still continue to talk to her because she was felt by them to be allowing them to manage things themselves in their own way, and in fact this was also what this general practitioner was doing. During the last few days the family felt that the dying patient needed jellied eels and gin and they had these to hand, along with a good many other pretty unorthodox things. Afterwards it took some weeks for them gradually to move back into their previous daily routines. They continued to gather in the same small house and during the social worker's twice-weekly visits they told her and themselves, over and over again, all about this old man, and this was how they mourned him. And in fact it was a very long, full, and courageous life story that they told so vividly.

In a basement flat in another part of London a single woman in her 50th year sat by a gas fire in a rocking chair. The hospital had done all they could with surgery and radiotherapy, and now she was on the waiting list for a terminal home. Her general practitioner prescribed for her nagging pain. She could no longer work at her job as a supervisor in a big store. There were no more regular visits to the hospital, only the occasional ones to the surgery. Tired and worn out she potted about her flat and waited—for what? She had cared for her parents until they died; her two brothers and their families were living away and were busy getting on with their lives. Work friends called occasionally to encourage her, and neighbours shopped for her. Her social worker called too, and was in fact at this stage her only regular predictable visitor in what was a limbo before the acute stage of dying. That is in fact what they talked about, as well as her life and her hopes, her disappointments, her joys and regrets, and the uncertainty of the future. As she talked she rocked in her rocking chair, and it was as if she were rocking herself out of life. She came to remember a clergyman who had helped her as a young woman and she wondered if somebody like him could help again. The social worker was able to put her in touch with one, and when she went away into the terminal home he continued to visit her there.

My third situation was in the children's ward of the London teaching hospital—an 11-year-old girl who lingered for weeks with metastases in the lung; she was struggling for breath. She was the eldest of four and she had been ill on and off for over two years. Twice her mother had been in a psychiatric hospital with depression, and at the time I am speaking of she was in hospital again. The next two children were at home being looked after by good neighbours, and the youngest was staying with relatives. Their father continued to hold the family together. He went to work and spent much of the rest of his time travelling and visiting his wife and his daughter in their respective hospitals. He was at breaking point at this stage. At the time I describe his head was in his arms on the desk in the social worker's room and he wept, because his daughter was being comforted by a junior nurse reading to her her favourite parts of the New Testament. He, her father, had fled her bedside because he could not endure his feelings, and his feelings were very conflicted. They were of fury against the New Testament, and all that it stood for, which was also giving her comfort, and of despair that he could not do for her what that young nurse was doing by reading to her. His agony at that time was very great.

These three situations illustrate some of the essential tasks of the dying person and for those close to him. For the patient they are concerned with continuing to live while engaged in giving up life, and thus dying with human dignity. For relatives they are to carry on living by helping in the dying of someone close to them. Both are involved in an emotional and physical process of giving up, of letting go, of eventual separation and loss.

We professional helpers have to use our respective technical resources of knowledge, equipment, skill, and understanding to help the dying and those closest to them. I place ministers of religion among the professional helpers, because it seems to me

that their primary concern is the meaning and purpose of life and death.

The social worker's role is significant because it is less clearly defined, is more open and ambiguous, and so patients and relatives can use the social worker in a supplementary way to the professionals mainly concerned, usually the doctors and nurses and perhaps a minister of religion. The social worker focuses on the social and the personal characteristics of this particular patient and this particular family, trying to understand how the patient and his relatives are coping now in the light of their past life style. The social worker listens and observes and comments to try to gain this sort of understanding. As a result it becomes possible to work out with the patient what would help him day by day—things like practical services, aids, financial assistance, diversionary activities.

### Sorting Things Out

The kinds of things that a social worker (and not a social worker alone but others in the caring team) would give attention to are, what does the patient want to talk about, and when. It is a time of last chance to get things sorted out, to say goodbyes, however indirect or disguised they are. Some patients use a social worker as well as other helpers to review their past and to try to piece it together with what they presently experience: perhaps feelings of guilt, and of anger and sadness, disappointment about lost opportunities in life, and envy of others in good health with apparently a lot of life before them. The patient often talks to a social worker about when and how he will die, and what hopes and fears he has for himself after death and also for those he leaves behind. Sometimes the social worker may help patients and relatives to say some of these things to each other. Since the social worker will not usually be involved in physical and psychological help to the patient as death actually approaches, it may be easier for her to tolerate her own anxieties and to respond to those of the patient before the acute final stage. At that point she will concentrate her help upon the relatives as doctors, nurses, and minister focus on the patient.

And then what about helping the family? It can be very hard to carry on with life when someone close is approaching the end of theirs. One feels guilty. It is so poignant. Thus it may be difficult to attend to things like children's birthdays, starting at new schools or a new job, keeping wedding anniversaries, or the deeply felt private anniversaries of the significant times in the married life. The social worker helps the family to try to hold a balance between the continuing living events of daily life, and the preparation for the losing of the person who is going to die. After death medical and paramedical people usually withdraw except, of course, the general practitioner, who so often continues to attend to the physical symptoms of psychic distress. The social worker continues too, being well placed to help in the mourning process if the relatives, as so often happens, want to withdraw from hospitals and the staff who were associated with the acute traumatic stages of illness. If the social worker has done a reasonable job of helping relatives to manage the balance between living and letting go, then they will probably depend upon the social worker to help them through the mourning and all the subtle family readjustments associated with it. She should take months of time, and patience, on this painful but also comforting working-through.

A common fear of dying people and their relatives is that the health professions, and I include social workers among them, will not really care. Furthermore, I think there is a fear that the professionals will not really share the caring with each other. Although their traditions embrace caring till death, doctors and nurses are dedicated to the preservation of life. Social workers, too, are committed to help people live as fully as they can, and as yet social work has limited experience in helping the dying. Patients sense our fears and our helplessness in the face of death, and they rightly fear that we may be too afraid emotionally to enter into their situation. And so they may both fear and hope

that they will get instead false reassurance, jolly along, and attempts to disguise or divert them from reality. If this happens, and if it is all that happens, then it seems to me that they are being denied the opportunity and the responsibility to work at ending their life to the best of their ability. Surely to be offered this opportunity is the right of the human being.

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## Nurse Training

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I would like to quote from the Report of the Committee on Nursing.<sup>1</sup> "Most nursing in society is carried out within the family by non-professionals, by relatives and friends. This has always been the case. Yet such care, by its nature must be limited and will in large numbers of cases be quite inadequate." How then can we train nurses to support the patient in his home—the patient, his relatives, and all those non-professional sharers in this care? How can we achieve our aim to provide adequate, compassionate, and skilled care, when and where it is needed?

Those of us concerned with nurse training are conscious that community nursing experience must be included in basic nurse training, and that community nursing experience includes care of the dying. We must teach high standards of care, good quality care—but quality is not enough unless we also have quantity. On the whole our services are good; too often, however, they are patchy and inadequate. Fortunately—for us—many of the public are unaware of what we should be providing and, being unaware, make few demands on us. Thousands of people die, not as they would wish in the security and comfort of hospital or their own homes, but suddenly and violently. They do not have time to call on us for help. Thousands of others do need our help, and when they call are we prepared to answer? Are we equipped to take the strain of sustained action?

### Rights, Duties, and Responsibilities

We have no right to force our services on unwilling recipients, but we have a duty to make known what we can offer, and we have a responsibility to make ourselves available, confident that what we offer will be acceptable.

These are three points I would emphasize in nurse training. Firstly, the right attitudes of the nurse to the patient and to the rest of the team; proper use of skilled and unskilled members of the team; compassion and skill; kindness and efficiency. Secondly, acceptable care should be planned with relatives, telling them what to expect and how to cope with each situation. They must be confident that the care the patient is to receive will be as skilled and efficient as that provided in hospital. Preparing the relatives as well as the patient is one of the most important things in management of the dying. The third point to stress is availability—assuring the family of continued support, being available and reliable, and, should the burden of this care prove too great, being able to promise a bed in hospital, if only for a short time.

In a recent study I did of the care of the dying, out of 500 patients nursed at home through terminal illness to death their approximate age was 74 years, and males and females were almost equally divided. Of the total 51 were in their 90th year, 198 were in their 80s, 127 were in their 70s, 70 were in their 60s, 34 were in their 50s, 15 were in their 40s, 14 were in their 30s, and 5 were under 10 years. In 19 of these cases a hospital bed had been requested and was not available. Of the total, 97

cases had been visited for a few days only (these were strokes and coronaries). In 169 cases no other services were involved and in 37 cases the district nurse felt she had not been called in early enough. This study is hardly completed and its results will be used for teaching purposes. Nevertheless, basic and postbasic training are not enough: nurses need ongoing support and constant stimulation. More research is needed, and nurse administrators should know the needs of their communities and should use their nursing staff wisely.

<sup>1</sup> *Report of the Committee on Senior Nursing Staff Structure*. London, H.M.S.O., 1966.

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## Continuity of Care

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During the past three years my work has been the care and supervision at home of patients who are discharged from, or awaiting admission to, the wards of St. Christopher's Hospice. My task was to maintain continuity of care by linking up with the general practitioner and the domiciliary services; to keep continued contact with discharged patients; and to get to know the ones who would one day need admission. Later the work was expanded to include an advisory service to family doctors and district nurses on all aspects of the management of terminal illness, with advice, support, and encouragement to patients and their relatives.

The observations made in this paper are based on work with 784 patients for the period October 1969—October 1972. The work was originally a research and development project supported by the Department of Health, but from April of this year it was funded through the regional board. Of these 784 patients, 132 were discharged from the Hospice wards, some more than once. Originally they had not been expected to live, some of them not more than eight days, but improvement in their condition and control of their symptoms made discharge possible. Although a number were well enough to be up and about, many were in need of constant nursing care, and some were bed-ridden—but in spite of this they were able to be discharged home. Close supervision of the outpatient clinic and the assurance of instant re-admission if it became necessary were vital factors in the success of their care at home. Of the remaining patients, 420 were referred by general practitioners, 198 by hospital medical social workers for home support, and 70 by district nurses for advice; 36 were referred direct by their families as the result of word-of-mouth recommendation from friends.

During these three years 86 of the 784 patients were able to die at home by their own wish, many without having been admitted at all. Their drug requirements were assessed and monitored by the clinic medical and nursing staff, in close co-operation with the general practitioner. The average length of time for a patient to remain at home is about three months, though there are variables from 24 hours to four years. Because a high proportion of patients were able to go home for quite long periods, we could make best possible use of our available beds; we do have only 54, but can support at home between 70 and 80 patients.

Frequent domiciliary visits were made by nurse clinicians, with occasional medical visits for consultation if necessary, outpatient clinic sessions with the doctor taking place at regular intervals. In the past 12 months, 1,915 home visits were made, and 51 clinic sessions were held. We operate a 24-hour call