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

J. McTRUSTY

I would like to quote from the Report of the Committee on Nursing.¹ "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.

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

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Continuity of Care

B. J. McNULTY

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

system and the patients are sure of getting a nurse whom they know, and this is of enormous importance in the lessening of anxiety to relatives. This surety of always being able to talk to someone you know gives confidence to the family, and this confidence prevents abuse of the system. We had expected that perhaps people would ring up unnecessarily in the night but it has not proved so. Our staff comprised two full-time State-registered nurses, now expanded to three, and one part-time nursing auxiliary. In addition a part-time social worker, occupational therapist, and physiotherapist have always been available for help and advice, together with the Hospice medical staff, who can be consulted at any time.

Liaison Service

The value of this liaison service between the Hospice and the community can be gauged, firstly, by the welcome and relief expressed by patients and their families; they frequently say, "I feel so much safer now, I feel I am not alone now." Secondly, through the use of the clinic made by district nurses, who appreciate having someone to talk things over with. Thirdly, by the increasing number of general practitioners referring patients directly to the outpatient clinic because, they say, "You have so much more experience in these matters." This is not that they abandon their interest in the patient by any means but they have recognized that we have something to offer in teamwork with them, and perhaps I might say for emphasis that I worked with about 600 general practitioners. Fourthly, by the number of hospital medical social workers who ask for domiciliary support for a patient who wants or has to be discharged from an acute ward until he requires terminal care.

The most important factors contributing to the success of this hospital-based domiciliary service are the continuity of care and the good communication existing between the treating hospital, the general practitioner, and the Hospice—together with adequate assistance and support in the home. Without this the whole thing falls. Now continuity of care involves the supervision of the patient by someone familiar with the treatment and the drugs used in the control of his symptoms. How often does one hear the fear expressed by a patient that the new doctor may not know what pills the patient has been on, or that he cannot take such and such a drug?

The custom of bringing patients back to the treating hospital for follow-up appointments when no further active treatment is considered is well meant but misplaced. A dying patient finds such visits exhausting; he does not always see the same doctor and continuity of care becomes progressively less. And I think if we are honest we will say that we see this very frequently. The reason for the follow-up appointment is so that the patient should not feel abandoned. But if a consultant can refer his patients to a unit such as ours, there is no sense of abandonment, only one of progression from one caring unit to another, and because the patient lives in our locality his general practitioner will be known to us personally and our communication with him will be direct and specific. But communication with the general practitioner is not always very easy particularly after hours (that is, after 7 pm and at weekends) and in this I speak with sad experience. Again the night-call system used by many London practices whereby a mobile doctor can be directed through a central bureau to an emergency is the bare fulfilment of an obligation, not I submit good medical care. The patient and his family feel abandoned by the doctor whom they know.

Night nurses are in short supply and although most areas have some form of night nursing service frequently this offers no more than a late night visit for injections and "tucking down." The Marie Curie Memorial Foundation gives grants to local authorities to be used at their discretion for the employment of night nurses for patients suffering from cancer. This system operates well in some areas, but less than well in others. Nursing aids urgently needed for the dying are not always as readily available as they should be. Domestic help is woefully

inadequate, particularly for lack of funds but also for lack of people. The burden of the care of a dying patient at home is heavy, especially for the elderly—who do not easily accept a stranger into the home.

The financial problems in nursing a dying patient at home are considerable. Invalid diet means higher food bills. There are numerous chemist's items, increased heating costs, and loss of wages, either those of the patient, or of the relative who has to give up work to nurse him. Supplementary Benefits, National Society for Cancer Relief grants, rent rebates, Income Tax relief, and the Attendance Allowance need either a declaration of resources—which many people are unwilling to give—or the fulfilment of certain strict requirements. Methods of applying for such aid are often so complicated and cumbersome that the relative feels unable to cope.

Re-housing or minor structural repairs may make all the difference to a patient being able to stay at home, and die at home if he so wishes. But the machinery for obtaining these is geared to the healthy with time to spare. The deliberations of the various committees involved can be so protracted as to be useless or too late for the dying.

Better liaison between hospital and community is very much part of our present thinking. The experiment in which I have participated during these past three years has shown how close this liaison can be, how greatly the patient benefits from such a liaison—and what satisfaction it can bring to all who participate.

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MRS. B. J. McNULTY, S.R.N., Sister in Charge, Outpatient Clinic and Home Care Programme

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Local Government Services

W. MITCHELL

It is better to die living than to live dying. Thus the needs of the dying are very much those of the living, and every resource should be made available to all who want to die in their own homes. Idealistic I may be, but we must strive towards it; otherwise apathy will allow a less ideal situation to prevail.

Although I do not live directly in the area of which St. Christopher's is the centre, I am in the area that their arms stretch out to. So I am very well pleased that if ever I am in the position of needing help I know where to go. There are centres where such excellent care is not given. There is, for example, much criticism of domiciliary care, understandable because from area to area it varies tremendously. The National Council for the Single Woman and her Dependent did a survey some time ago which showed up just these variations. I thought originally, when I sat down to write this, that in 1974 when the reorganization of the health services takes place these problems will be cured. Unfortunately a lot of dying people are going to need the support of the domiciliary team before that date, and proposals must be made for a reliable service after that date.

Domiciliary Team

I see the organizational domiciliary team as Cogwheel Care of the Dying. Various disciplines participate. There must be a drive wheel to set the train of cogs in motion. The cogs as I see them are initially the hospital, nursing, and medical social work team—they know the present and future needs of the patient. The local health authorities have the facilities to provide for certain of the needs. The G.P. provides medical care and support for the family and the social workers and the voluntary services play a