A first glance at terminal care

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IT is perhaps easy to rationalize the reasons for an interest in such a topic as terminal care. I believe both personal and professional considerations compel concern in this field. It is also true that until recently death has been a subject of taboo comparable to that of sex some years ago. However, this state of affairs is changing and an increasing number of workers are expressing growing interest. In fact, for anyone who turns up the literature there will appear a bewildering number of references; many of these are deeply philosophical or psychological in their orientation. Few of these papers originate from the sphere of general practice.

For some time I had considered the problem of a research project based on general practice. Much of what one reads in this sphere seems to me either trivial in its medical content or boringly arid in its array of analytical figures and tables. However, the subject of death can hardly be described as boring and carries profound implications both for the individual and those who care for him. It is an ever-recurring situation in any general practitioner's life: it is one we may seek to shun but it cannot be denied. Many of us may feel inadequate both in our emotional response and in our practical medical skill. It therefore occurred to me that here was a subject of many sides, worthy of investigation in the context of general practice and by a general practitioner. Following a little initial reading round the subject, I began to compile a questionnaire for completion by myself and possibly other interested practitioners, in order to delineate the manner of terminal care in general practice. The more I considered the problem the bigger it grew. I therefore determined on a wider approach to the subject which would bring me into contact with others experienced in this field. The award of the Upjohn Travelling Fellowship made this possible and I began my studies by spending a week at St Christopher's Hospice in Bromley, South London. I shall try to describe some of the facts and the multitude of impressions which come to mind from this period.

The hospice was opened in 1967. Its real beginning was long before in the mind of its medical director, Dr Cicely Saunders: years of purposeful planning and organizing intervened before her dream became a reality. The funds for its building were raised by private subscription, for the hospice operates outside the National Health Service. Many of its beds, however, are supported by a contractual agreement with the regional hospital board. In this way the general interest is served but independence in policy and emphasis is maintained. There are 54 beds, most of which are for terminally-ill patients with malignant disease past the phase of active treatment; there is in addition accommodation for 16 elderly people in a separate wing. The building itself is the most modern of its kind I have ever seen. It is designed with an eye to the function it has to serve in the nursing of sick people in such a way that their personal and social life may be encouraged. As for the nursing complement, one nurse to one patient is the aim. I understand this corresponds to the recommended establishment for an acute medical ward. Many of these nurses are part-timers: there is also a small army of voluntary helpers, many of whom have had relatives nursed in the hospice. At certain periods during the year a number of ordinands devote their time to St Christopher's.

J. ROY. COLL. GEN. PRACTIT., 1971, **21**, 387

In the course of one week I did not meet all the medical staff. During this time Dr Saunders was assisted in the clinical work by two other doctors on a part-time basis. The deputy medical director was away and also the doctor in charge of research. On certain days the hospital is visited by a psychiatrist and an anaesthetist with a special interest in the relief of pain. Any hierarchical approach to the clinical work appeared completely absent.

It is not for nothing that the hospice is called by the name of St Christopher, who carried his unique burden with increasing difficulty across a flood tide, finally to reach the opposite shore in safety. The hospice is openly a religious foundation though in no proselytizing sense. There is an official chaplain who spends a great deal of his time with the patients and with the staff. Clergymen of non-Anglican persuasion are frequent and welcome visitors. There is a regular pattern of religious observance centred on the simple but tasteful chapel: at certain times a bell sounds to summon those who wish and are able to attend service. Patients, staff, doctors and nurses may mingle in this observance. For those who carry the responsibility and experience the cost of helping these patients as they come and go, this part of the daily routine is crucial. Throughout the building, though not in the wards, one is reminded of the driving force behind this work by strikingly colourful examples of modern religious paintings.

What then are the aims of this foundation, drawing its strength from the ways of modern medicine and religious community? This is a difficult question to answer succinctly, for patients' needs and capacities differ. Perhaps the following quotation is somewhere near the mark. 'When life cannot be restored, then a man can accept the fact with a meaning that gives dignity to his life and purpose even to the process that is encroaching on his own vitality' (Bower 1964). Dignity is perhaps the key word and its restoration or preservation may be aided in various ways.

Patients are admitted either from home or another hospital. Once admitted there is no question that they cannot stay for the rest of their life, although by mutual consent a temporary home discharge may be arranged. Otherwise the hospice is 'home'. Physical pain is one of the most pressing symptoms, and without relief life that remains is intolerable. 'Nor is a man exclusively concerned with the isolated feeling of pain but with his general state, with the fact that he must endure it: he becomes preoccupied with the disorganization of his inner functions and his inability to work and to think' (Buytendijk 1961). The medical staff respond to this situation by the early and adequate prescription of analgesia, particularly of diamorphine administered in a variant of the well-known Brompton mixture. Dosage of diamorphine may rise to 30 mg four or five times a day at carefully chosen intervals. Pain is anticipated and distress avoided. Nausea and vomiting are perhaps as distressing and phenothiazine antiemetics such as prochlorperazine (Stemetil) and promazine (Sparine) or the antihistamine cyclizine are administered with the analgesic. Breathlessness is not such a common problem in the hospice but when it occurs no consideration of theoretical pharmacology would prevent the use of diamorphine to relieve the great distress dyspnoea will cause. The use of local or intrathecal nerve block by injection has a definite, if limited, place in the therapeutic practice.

These are not curative procedures but careful attention to detail of dose and administration will greatly relieve the patient. With symptoms largely controlled, the patient regains an interest in his life and may turn to those other environmental factors which will help to restore his dignity. I have mentioned the tasteful planning of the hospice. There is relative privacy with four beds to a bay: the windows are large and there are many little corners in which a patient can sit to watch the world outside, the trees, the tennis courts and the passers-by. Life is not far away. For those confined to bed, a modern manual unit gives access to the nursing staff by press button, to the radio and television sound track head-phone and to meetings and services held on the ground

floor of the hospice. Relatives are welcomed to the wards at almost any time. Patients may be taken to the communal sitting room to meet their relatives and particularly their young children. They may also be taken into the garden at the rear of the hospice to enjoy the open air, the flowers and the fascination of the fishpond. It was perhaps in this setting that the community and life of the hospice was so well summed up. Here were seen patients for whom in terms of time and opportunity, life seemed to have little to offer: near them played the children of the playgroup, the existence of which enabled their mothers to work in the hospice. Old ladies from the old people's wing would be in evidence, as also members of staff taking a short break from work. This scene is symbolic of the fact that patients are not set apart and that the wall behind which so often doctors, nurses and relatives place the dying, here does not exist.

Among themselves, those patients who are able, may take part in social events. Both staff and patients participate with great enjoyment. I saw a recital of 'The Sound of Music' on gramophone records played in honour of a patient's birthday. On another occasion an old lady celebrated her ninetieth year. I believe participation was in no way forced, although I felt particularly for the women these occasions were most popular. Birthdays, flowers, hair-dos, knitting and many other feminine interests help to maintain morale and involvement in living. Perhaps the men are at a disadvantage here. As a group their interests are probably less uniform and inevitably that spontaneous bond of common interest is absent which exists between female patients and nurses. No doubt nurses of the opposite sex develop a way of supporting male patients during terminal care but this was less obvious to me than those ready-made ties, which were apparent between women in what is after all a predominantly female hospice. The chaplain ran a discussion group for some of the men. Unfortunately I was not able to attend one of these meetings, since the group had been temporarily abandoned due to several deaths in a short period. I gather that discussion covered any subject apart from religion and politics and that women were excluded. As far as they are able, patients are therefore helped to express their individual character and live in community with the nurses, their fellows and their families.

If patients at St Christopher's approach their end with dignity, are they also able to do so with insight and courage? Le Shan (1969) writes: 'The ideal of the full rich self, the development of one's own being in one's own special way, the freedom to be oneself fully without fear—this is a goal acceptable to our Zeitgeist and worth fighting and suffering for. It is literally a goal worth living for. Patients once they grasp this goal, seem to find it.' Is this more true amongst those who die at St Christopher's than for those who die elsewhere? I think it would be impossible to answer this question on grounds other than those of personal impression. Nor is a week's attachment long enough to enter the contracting world of these patients. Certainly in a few instances as a complete stranger I was soon told by the patient what he expected to be the outcome of the illness. More often I felt either he had little insight or had brought down a shutter between himself and reality. The experience of those who knew the patients intimately was, I think, different. In a significant number it was possible, without premature removal of hope for recovery, to bring the individual to share his fears with staff and relatives and to accept that life was drawing to a close. To help towards this end the working of the staff was impressive, as were the methods of support of the staff in their endeavours.

The usual formal relations of nursing and medical staff with the patients and each other were absent. After a report on each patient by the sister, the doctor makes her round in isolation. Doctor and patient face each other on a personal basis and in privacy. In this situation confidences may grow and hidden fears and questionings may come to the surface. To be a spectator at this type of ward round will interrupt the rapport which develops between doctor and patient, just as a psychiatric consultation would be disturbed. The doctors, however, have no privileged access and any nurse who

deals with patients in whatever way is encouraged to help them to express their thoughts and feelings. The senior nursing staff are particularly skilled in this work of looking for physical, mental or spiritual disharmony. Remarks or attitudes of particular significance would be recorded in the notes which are kept in common by medical and nursing staff. Whenever requested, the priest or minister will become a further member of this group trying to sustain the patient though his last illness. Certain patients are visited by the psychiatrist. It is hoped to bring help to each individual at whatever level his belief or needs require.

There is however great cost in this work to those who do it. Many of the patients stay for weeks or months. Inevitably the staff come to regard them as friends so that a series of bereavements is inevitable. To support the staff and to increase their own insight, group and staff meetings take place at which these matters are explored. It is clear however that the religious convictions of many of the staff are more fundamental. The regular services and sacraments which are unobtrusively celebrated in the chapel, provide a sheet anchor to their lives and invest their work with a more than human significance. They see themselves as followers of St Christopher helping their patients through the final storm of life to an immortal shore.

St Christopher's does not regard itself as a self-contained community: it is increasingly looking outside for support and interest. Already a hundred or so volunteers frequently come into the hospice to perform duties for the patients and help them in other ways. Many of these volunteers have had relatives who have passed through the hospice. An experienced ward sister of St Christopher's with extensive district nursing experience may visit the homes of those who are possible candidates for admission: in performing these visits she aims not only to make a social assessment but to give patient and family some of those skills in listening which are the mark of St Christopher's. A recently established clinic will see those patients who need and are able to come up. In this way the patient becomes familiar with the ways of the hospice and the right time for admission can be selected.

There are plans for further extension of the work of St Christopher's. A neighbouring site has already been acquired and in the not-too-distant future construction of new buildings will enable the research and teaching of the hospice greatly to expand. Already research and teaching are in progress but the new facilities will further extend the influence the hospice has established in focusing attention on the final phase of life. For those who are called to this work it is an exciting future.

During a week's attachment, a visiting family doctor sees many of the problems he has met before either in his own hospital or in the home. It is particularly in the latter setting that his skills of care should be developed. Perhaps an initial reaction is to regard the need for such a hospice as St Christopher's as a recognition of one's own failure adequately to support a patient within the context of his own home and family. Whatever the extenuating circumstances, I suspect in a proportion of cases this may well be true. Had the doctor had greater insight, skill in the use of drugs, more co-operation with nurses and more time, he would probably have been able to care for his patients at home and helped them through the terminal phase of life in that place where they most wanted to be. However, as family doctors we must not romanticize family life. There are other forms of community which may have their own attractions. We may recall the tensions and difficulties in child rearing which the close knit family unit may engender; too often we see the seeds of neurosis sown amongst a proportion of those children brought to the family physician. Some have advocated upbringing in the communal setting of the kibbutz to eliminate these stresses. Perhaps there is a parallel here for the final phase of life. When a member of a family is dying, the tensions and stresses set up by this painful spectacle may be too great to be contained under the one roof. In such a

situation the large family of St Christopher's, the therapeutic community, may well disperse so much of the stress that patient and relatives can come together again. Were such hospices available universally for our patients, I think this type of situation could be the main indication for their use. Their existence should encourage rather than deter us from increasing our skills in this field.

St Christopher's is extending its care into the homes of patients, particularly through the agency of the hospice-based visitor. Is there perhaps a potential problem in this arrangement? Practices are undoubtedly becoming better organized with the direct attachment of district nurses and health visitors to doctors in groups of increasing size. Improved communications have, in my experience, encouraged continuing home care where previously the doctor, in real or imagined isolation, might well have passed on the problem to another colleague. A regrettable absentee in my experience is this close working arrangement has been the mental welfare officer: I find he tends to regard himself as a hospital-based worker and he does not participate in the discussion and endeavour of a group general practice within the community. A phone call which usually interrupts the work of consultation, is no substitute for a direct meeting. I feel a medicosocial worker based on such a hospice as St Christopher's should be responsive, as its domiciliary visiting and support expands, to the changing pattern of general practice. Obviously, direct attachment is neither possible nor necessary but a relationship more akin to that of our district nurses than to that of the mental welfare officers is highly desirable. She would be a welcome visitor in a group practice and a further encouragement to their development.

Within the hospice group discussion both supports and enlightens all members of the staff. It is clear that already the demands for teaching are mounting. With the completion of new building in the future, family doctors who work in the neighbourhood should perhaps be drawn into the teaching and general life of the hospice. The idea of group discussion is not new to general practitioners and particularly in the London area quite a number of doctors have become familiar with the type of seminar run at the Tavistock Clinic. In the setting of St Christopher's on-going groups of general practitioners could well learn much for the benefit of their patients from their own reactions to death and bereavement.

The student and young doctor are inclined to undervalue nursing care. Perhaps because nursing training is intellectually less taxing, the attitude that someone 'is only a nurse' is all too prevalent. How misguided this attitude is I came to realize as I have admitted more and more elderly and terminal patients to our general-practitioner hospital beds. Nursing care is all-important to these people, often beyond the benefits of scientific medicine. This knowledge was further reinforced by the attachment of our two district nurses and employment of our own practice nurse. A maternal dimension was added to the more objective type of care which male doctors on the whole will be able to give to their patients. There is a real similarity between the patient-centred conversation which now dominates our practice coffee break and the intimate concern of the staff at St Christopher's. In a place such as St Christopher's, when active dynamic treatment is past, the feminine, maternal rôle becomes predominant with its accent on caring and attention to intimate detail. We may wonder whether as new hospices open throughout the country they will become a woman's preserve. Among women one sees quite often a strong desire to run or help in child welfare or Family Planning Association clinics. Terminal care may also attract this type of enthusiasm, as both the staffing structure and the army of predominantly female volunteers at St Christopher's may suggest.

What are the aspects of practical management to be learnt by the general-practitioner observer in St Christopher's? The first is to use early a small range of drugs, particularly heroin for pain, in sufficient doses to allay discomfort and to allow the patient to retain his full individuality. The second is to find the ability to listen to the patient often without

knowing the answers. In this relationship we may sometimes help the patient to make a success of his life during his final illness, according to his own personality and outlook. On occasion we may be able to feel that: 'There is a way of winning by losing, a way of victory in defeat which we are going to discover' (van der Post *A Bar of a Shadow*).

What of personal feelings in undertaking an attachment of this kind? We may feel a certain sense of foreboding in spite of our familiarity with death in the home and in hospital, in leaving behind the outside world and entering an institution where death is said to be the preoccupation of staff and patients. Perhaps we share in small degree the feelings of patients who discover they are to enter a place of terminal care. However, much of this oppression is dispelled by the intrinsic interest of the subject, the healthy and animated staff and helpers and the patients themselves, who in their extremity remain real people. Is it possible to do this work without creating an emotional barrier around ourselves? For many this would be inevitable but I had the impression that even senior members of the medical and nursing staff frequently continued to suffer in their patient's death. Psychological and religious insight, however, protected them from permanent distress. For myself I found return to the varying triviality and severity of illness in general practice a welcome contrast.

There are a number of other terminal hospices and houses in the country. The Marie Curie Foundation runs a dozen homes for patients with cancer. There are others besides and it appears there is a movement springing up for the building of more such institutions, often outside the National Health Service which has not been able to meet this need. Those involved in planning are turning to St Christopher's for advice.

The preceding remarks have been an attempt to describe my personal, subjective impression of a most remarkable hospice. I can only describe it as a work of art. It was conceived in the mind of one individual: it is now a reality. Its medium is neither in words nor music nor painting nor architecture, though all these forms play a part. Its essence is a community of differing needs and talents, for which the symbol of St Christopher aptly signifies the nature of the weighty burden which its members, each in his or her own individuality, carry together.

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Clinical research in general practice

"I must take this opportunity to suggest that general practice research at the moment is too much concerned with medical and practice organization. I am not decrying this sort of study and some excellent work has been done. But what has become of clinical research? Why are we general practitioners much keener to look for links between appointment systems and the mean consulting time than we are to look for genetical markers in spina bifida, asthma, or congenital pyloric stenosis? There is, of course, room for both types of research in general practice, but the prevailing fashion for organizational research has produced an imbalance. We should surely concentrate on trying to solve more of the clinical problems, which can be solved only from general practice, and worry less about such questions as the optimum floor area of a consulting room—consulting rooms have four walls and four walls limit the horizon".

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