TERMINAL CARE UNITS

ERIC WILKES, *M.B.E.*, M.R.C.P., D.Obst.R.C.O.G.
Baslow, Derbyshire

THE main purpose of terminal care units is to convoy over their last months the dying who cannot be looked after at home and yet do not need the expensive facilities of an acute hospital bed. The social, economic and medical factors influencing admission to such units or to hospital are not clearly understood, but the homes specializing in the care of the dying in various parts of the country are working under such pressure that their value needs no further demonstration. In an area where there is no terminal care unit a recent survey found that over ten per cent of cases of malignant disease dying at home were thought by the general practitioner to merit admission and 14 per cent of the cases were being looked after by relatives themselves over 70 years of age. The organization and problems of terminal care units thus seemed worth a brief survey.

Nursing staff

The main problem facing the terminal care unit is the provision of skilled nursing in a leisurely, homely atmosphere. Although the gay thoughtlessness of young nurses can prove at times of immense value to the dying, it is better on the whole to have more mature nurses, who stay on more permanently and cope better. Nowadays the married part-time nurse or sister carries a major share of the burden. The shortage of suitable nursing staff is the predominant and over-riding factor. However little we may like it, the interests of our patients must come second to the recruitment—and holding—of nursing staff; therefore, all units must be sited near major centres of population. This is also desirable because dying patients may love a nice view but they love even more the frequent and easy visiting by relatives, the sight of crowds and shops and even the drink at the local pub or the flutter at the betting shop. The lovely, isolated country house given over for a peppercorn rent to charitable purposes is not really suitable. Even now specially designed homes are being built at great expense and with great determination in areas so far removed from the towns they hope to serve that nursing

recruitment will always be difficult and unsatisfactory, and they will never function at maximum efficiency. They will also have trouble getting good domestic staff. And yet in London the competition for nurses is so intense that devoted members of a Catholic nursing order can be seen working side by side with Agency nurses who are not always suitable, who do not stay long, who cost some 18 guineas a week, but without whom the unit would have ground to a halt.

It is natural that many nurses should not be attracted to terminal care. A young student nurse alone on duty with three deaths to cope with is not likely to recommend this to her friends. It is also not surprising that some sincere and devoted nurses are not always very successful at this line of work. The slower pace of nursing will, however, suit the older nurse, she will be less bewildered since she has not to deal with a whole range of new and unfamiliar drugs introduced since her training days, and because so much of the work is good old-fashioned nursing it is at her that recruitment for these units should be mainly directed.

General lay-out

A proportion of patients are distressing to the others and must be given a single room. Those about to die should also be allotted a single room. To have all patients in single wards is impractical for it is too wasteful of nursing time. A small ward of four beds or less is too closed a community to tolerate easily the death of one of its members. A ward of six or eight beds is more suitable. Less than a 25-bedded unit is uneconomical. More than 50 beds can produce a busy impersonal atmosphere too like the hospital. Four or five eight-bedded wards should be almost right plus 20 per cent single rooms in addition. There should be two female beds to one male, and sleeping accommodation for one or two relatives.

It may be possible to have movable partitions so that patients can sleep separately but be pushed easily into day-rooms for social life together. Day-rooms are essential and should have the routine comforts of the living room—wireless, television, papers and books, tobacco and sweets, and comfortable chairs. Old people pottering out into the garden to look for the tortoise or the cat do not need much physiotherapy but gentle physiotherapy there must be, even if it amounts to little more than massaging swollen limbs and helping patients to walk. Occupational therapy too should be sited near the day-room.

Sterilizers, ample linen cupboards, and bathroom accommodation for the disabled and weak must be provided. In several homes there is an enormous waste of staff time and energy because there is no lift. Some homes have been awaiting their lift for nearly 20 years.

The food must be good and kitchen facilities must be modern and labour-saving. The elaborate concealment of ward wash-basins in one new home rang false and seemed likely to impair ward efficiency; but the idea that these homes should not be slavishly modelled on the nineteenth century hospital ward is certainly sound enough. Although gadgets are no substitute for nursing, hydraulic hoists, electric ripple-beds and modern intercommunication and monitoring systems will save both labour and hardship. The mortuary must be discreetly sited.

There must be ample changing-room accommodation with lockers and lavatories for the increasing proportion of part-time staff. At the moment this is usually an unattractive and inadequate afterthought, although unused accommodation for residential staff who do not exist lies empty upstairs because the architects were wrongly briefed.

Costing and finance

Most of the homes visited were supported by private charity but even these had a proportion of their beds that could be filled by patients paid for by the National Health Service on a contractual basis. Although some of these private funds were hard-pressed there seemed to be no evidence that medical care suffered from any vicious shortage of funds. The institutions that were part of the National Health Service seemed no better off than those privately owned, nor was there much sign that National Health Service institutions could more easily obtain expensive equipment.

It seemed to cost, variably and approximately, rather more than £20 to keep a patient for a week. About two-thirds of this will be for staff salaries, and principal items in the remaining third will be something like £2 10s. 0d. for food, £1 for heat, light and fuel, and 12s. for laundry, per patient per week. These figures are perpetually going up and £25 per patient per week will now be a more realistic figure.

A converted house is obviously less convenient and cheap to run —for example, one old house costs £3,000 to redecorate every three years—but conversion is not cheap. If it is done fairly lavishly it will cost rather more than £2,000 per bed. A new home can be built for £3,000 per bed. These costs should be compared with the £40 needed to keep a patient for a week in the fully equipped hospital bed that would now cost about £10,000 to build.

The calibre of the staff will vary as much as the buildings and this will affect running costs. A proportion of 3.5 to 4 patients to each nurse was said by one home to be adequate and by another to be not enough. If the domestic staff are a loyal team who will re-

arrange their own duties to cover a colleague's absence, less need be spent on temporary assistance.

The more successful homes were not necessarily the best equipped but they had a good atmosphere and very often had kept the same domestic staff with which they had started years before.

Some criticisms and difficulties

Some consultants—perhaps even one in three—feel a distaste for terminal care units. Most of these consultants have little knowledge or experience of this branch of medicine but it would be idle to say that they exaggerate the difficulties or that this distaste is restricted to those who are especially ignorant of the problems of terminal care. One doctor who had spent nearly ten years looking after terminal cancers still doubts whether the special unit is the best way of dealing with this need. The bereavements experienced by the survivors in a ward and their refusal or inability to talk about the recently dead indicate clearly the grief and tragedy of their situation.

To dilute terminal cases with other types of patient seems surprisingly unpopular with doctors, though it is done routinely, especially in cottage hospitals. It is said that only one in six of these mixed cases should be terminal if the atmosphere is to be relaxed and morale unaffected. This seems a low proportion.

Rather bitter things were said at the way occasionally patients were admitted in a moribund state and died only hours later. This was sometimes an honest mistake, sometimes it was ascribed to the desperate shortage of beds (the hospitals were apparently more often guilty of this than the general practitioners) and sometimes it was due to a basic misunderstanding of the role of the unit. It is especially important to the religious institutions that they should have some opportunity to cater for the spiritual welfare of their patients. It is rarely easy to build up this relationship in days and sometimes it takes months.

Sometimes hospital staff or relatives lied about the purpose of the terminal care unit in an unintelligent way so that patients arrived expecting some miraculous new treatment. This only made it difficult for everyone. It would be better to talk of a home where there is peace and quiet and time to build up strength for the next stage of therapy. It is thus highly desirable that the hospital from which the patient has been discharged should maintain some—even tenuous—contact with him. A spurious outpatient appointment for six months later is better than frank neglect and dismissal.

The medical officers to the homes were often interested general practitioners. The standard of their work was variable but high, but there was a tendency for the homes to operate *in vacuo*, in a profes-

sional isolation rather characteristic of general practice. This carries with it the danger of a lack of critical reappraisal of problems, the danger of the unit being a garage for the dying well equipped with bedpans but with little knowledge of modern palliative techniques such as intrathecal phenol and where drugs even as reasonably straightforward as, for example, cyclophosphamide would only rarely be used. There are two possible ways of dealing with this. One is to allow other interested local practitioners access to the beds for their dying patients and although most homes consider it their job to admit cases direct from the general practitioners, in no case did I see the practitioner continue to care for his patient after admission. The other way is to have the terminal care unit integrated with a radiotherapy unit. Nothing is more demoralizing for patients and staff than to admit patients to a ward for treatment where the failures of that treatment are all too evident: so most radiotherapists are enthusiastic supporters of the terminal care unit concept and would gladly help by doing rounds with the medical officer for discussion of difficult cases. This, or course, is already being done in some places.

Chronic cases

Although many of the patients are old, the staff seemed agreed that their work should not be classed as part of geriatrics, since many of their more serious problems were wholly unsuitable for the geriatric ward.

However, with modern palliative techniques the methods for dealing with the chronic sick must be an integral part of the terminal care unit's stock-in-trade.

A small percentage of patients—often breast cancers—improve enough to return home for a while. It should be possible to send suitable patients home for a few weeks and then have them back again before home facilities are overstretched or they are too ill to move easily. This would help morale tremendously. Some units are also holding patients convalescing from radiotherapy and although these do not mix with the terminal care cases at least it gives something of a break to the nursing staff, while saving radiotherapy beds and improving liaison with the elusive world outside.

Conclusion

As the shortage of doctors and nurses becomes increasingly felt so we shall have less time for the dying. The difficulties are great, but in an ageing community and in an era of deteriorating nursing standards it seems that homes for the dying, now so under-capitalized, will be needed in future even more than they are today, and

that the obvious disadvantages resulting from the collecting together of cases at present incurable will be, by force of circumstance, acceptable to us.

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Appointment systems in general practice. (Do patients like them, and how do they affect work load?) J. S. K. STEVENSON, M.B., CH.B., D.OBST. R.C.O.G. *Brit. med. J.* 1966. **2**, 515.

A three doctor partnership with 5,800 patients started an appointment system in January 1962. After two years they found that the number of home visits had increased and considered cancelling the scheme.

However, after merging with a neighbouring practice, engaging extra ancillary help and reorganizing the consulting hours to cover a greater portion of the day, five doctors, now with 9,200 patients were able to show a reduction in home visits and in total work load per doctor. Re-visits in particular were drastically reduced.

In Dr Stevenson's opinion, to work such a system efficiently, the patient must regard himself as being attached to the group as a whole rather than to a specific doctor. He goes on, " I firmly believe that the development of general practice in this country has suffered immeasurably from the profession's reluctance to burn the effigy of the frock-coated personal medical attendant. He is the anachronism of present-day general medical practice."