

# Home Care of Terminal Malignant Disease

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I have always believed that patients with a terminal illness should be cared for in their own homes, provided, of course, they have been thoroughly investigated and assessed in hospital before being transferred to domiciliary care.

There are two other qualifications: firstly, that home care is with the full agreement of the patient and his family, who should be completely aware of all that is implied, including the extra work and worry involved. Secondly, the total care of the patient should ideally be undertaken by a closely integrated domiciliary team. It is obvious that without the patient's consent and the family's co-operation home care would automatically break down. The scheme of care must be devised round the home and the family, who themselves form an integral part of the domiciliary team.

In the whole panorama of medical care no group of cases highlights the need for and the benefit to be derived from total care more than those dying of malignant disease; this applies particularly to the younger patients.

Within the National Health Service, moves were made in some areas as long as fourteen years ago to bring together family doctors, health visitors, and district nurses, all working within the same practice, and, therefore, all responsible for the same patients. Since then, this concept has spread to many areas, and where available, social workers and home helps have been drawn into the team. When such a group of people work together, an understanding is built up between them, each growing to recognise the role of the other in the total care of the patient and all knowing the patient for whom they are collectively responsible. It is remarkable how individuals become welded into a team, how well they are suited to undertake at short notice the total care of the patient, and how little it matters who is boss.

To this central core of workers must be added church workers of all denominations, the BRCS, the RWVS and helpful neighbours. The consultant in charge of the patient in hospital should also be recognised as a member of the team. He can be seen in the out-patients department or, better still, on a domiciliary visit to the patient's home.

This adds up to a formidable team which, at a moment's notice and from

the initial stage of diagnosis onwards, can cover the total care of the patient and not just the particular treatment of the cancer.

This sort of total care is not an idealistic dream but is in existence, and is effective. However, it is not always possible. In rural areas, doctors and nurses have always worked closely together but in urban areas, especially in the denser conurbations, such co-operation is difficult. Doctor, health visitor and nurse may not know each other, for they will rarely, if ever, meet on common ground, and it is inevitable that the thoughts of one will be unknown to the others and there will be no overall plan for the care of a particular patient. Even with the best intentions, this untidy and makeshift type of care deprives the patient of the total care he deserves and should have.

Given the necessity of total care of the patient by a group of people working together as partners, the policy of the team should be outlined.

To what policy or programme should the domiciliary team work?

In general, although a patient's cancer has been pronounced incurable, a positive programme of aggression towards the disease should be adopted. Until the actual stage of dying is reached the word 'can't' should not be allowed to enter either the patient's or the relatives' thoughts. The patient must see that the doctor, the health visitor, the nurse, and other helpers are interested and ready at all times with encouragement. Hope, even if it exists only in the patient's mind, must not be allowed to die an unworthy and untimely death.

I was interested to read in an article in *World Medicine* entitled 'Never Give Medicine to a Dying Man' by Dr Michael O'Donnell (1969) the following comment—

'My father, who knew a thing or two about realistic Medicine, used to say that patients didn't seek divinity in their doctors. All they wanted was optimism. Optimistic doctors, he pointed out, helped patients to fight against an inevitable decline in health. And the iller the patient, the more optimistic he liked his doctor to be—even if in the end the whole thing turned into a game in which both doctor and patient, although equally aware of impending tragedy, tried to outdo one another in euphoria.'

An active life must be encouraged, whether it be from a bed or a chair. The patient must do as much as possible for himself—dressing, bathing, feeding or working in the house or elsewhere. Apart from encouraging morale, this discourages contractures and stiffness of soft tissues, bedsores, and the like.

While encouraging the patient's independence the group of helpers must take particular care unobtrusively to shield the immediate family from as much mental and physical fatigue as possible. As the days go by the strain on them increases and if it should reach the point where they break down or

even unconsciously transfer some of their strain to the patient, home care will collapse. This applies particularly to homes where there are young people; there must be no gloom cast over the entire family and no persisting atmosphere of uneasy quiet in anticipation of approaching death. Here, the group can be of immense help, by example and by the maintenance of a positive and carefully arranged programme.

One of the first problems the family doctor has to face once the diagnosis is made is whether the patient should be told and, if so, when. It is essential for him to have a preliminary talk with relatives—preferably while the patient is still in hospital. Aided by his knowledge of the family, he can choose the best method of telling.

If the relatives are to be told the news by a hospital doctor this should not be left to a junior doctor or to the ward sister. In my view it is plainly the duty of the senior doctor in charge of the case. If the family doctor is not present at the time it is vital that he be given a clear idea of what has been said to the relatives and, even more important, how much, if anything, has been told the patient.

The question 'Should a doctor tell?' admits no easy answers. But the key figure in producing the answer in any particular case must be the family doctor. Ideally, it should be a joint effort between relatives, family doctor, and consultant.

The doctor is confronted with a diversity of situations or personalities. The preliminary consultation with the patient's family may have clearly directed the doctor to the approach he should make and, as a general rule, this family decision is helpful and clear. On the other hand, the advice or instructions given by the family may be completely contrary to the doctor's own convictions in the particular case; they may, for example, be based on religious convictions, cowardice, indifference, or a completely unintelligent approach to the disease and its prognosis. Worst of all, the family may give no advice at all; with pathetic trust, they may say 'We leave it to you, doctor—we are sure you know best.' This means that the doctor is left on his own and must, with the help of his team, make his own decision and possibly risk breaking up the last weeks or months of happiness in a family and losing the confidence of his patient.

I have read that the doctor's decision must be based on factors including the intelligence, social status, Christian faith, and personality of the patient. He is, presumably, to allot marks for each and, according to the result, tell or not tell. A family doctor of only one year's experience would discard this method with no more than a single thought.

I have known the most intelligent patients from the top shelf of our social

cupboard who appear to remain in complete ignorance of their disability, and I have never known whether this ignorance was real or simulated in order to save embarrassment or unhappiness to their family and their doctor. Then there is humility, which causes a patient to accept the disease without question. Fear seen in the eyes of a patient is a sufficient reason for not delving into details of an illness, and a cheerful buoyant attitude which implies 'Tell me, doctor, I can take it', may, in fact, conceal a dread of being told. On the other hand, truculence and even animosity call for action, for they bring with them mental unrest to the patient and unhappiness to the family. For these patients the doctor should enlist the help of the consultant originally concerned and, round the bedside, the full story can be told and the patient reassured that everything humanly possible has been and is being done for him. The need for a patient to bring his personal and family affairs up to date and the attitude of his employers must be considered. The age of a patient must also influence the doctor; an elderly patient may expect to die, a child certainly will not.

To tell or not to tell the patient that he has incurable cancer is part of the treatment of his illness; as some patients with pain require sedatives and others will not, so some patients with advanced cancer will require to be told and others will not. No rigid rule can be applied, and it would be a dreadful thing for any textbook to dictate to a doctor that part of the treatment is telling every patient of his diagnosis.

I may have been fortunate in my contact with this type of case, but except in a bare minority of cases, I have not been troubled with this problem. I believe it exists only on paper. There comes a time when it is apparent without words that the patient has accepted a hopeless situation. From then on, all concerned may find it easier to play a gentle game of 'make-believe'. With compassion, sympathy, and understanding the patient, his family, and his doctor, can go along together day by day, accepting and explaining each situation as it arises until the time arrives when no further earthly care is needed. But I would qualify this by saying once again that inherent in this concept is the necessity for frequent visits from the doctor, for full co-operation from the nursing services, and for a positive attitude of encouragement from all those surrounding the patient.

Now I must speak of euthanasia—if only to discuss it in a few words. No problem of patient care needs interference by statute. I could not imagine the indignity to all concerned of withdrawing from a patient's bedside while papers are signed and witnessed giving me permission to use some drug in lethal doses to terminate the life under my care. This is solely a matter between patient and doctor.

When the final stages of the illness approach, skilful manipulation involves an almost unconscious preparation for each visit so that awkward questions can be anticipated, new situations or symptoms countered, gaps filled, and comfort boosted. All these can run together so smoothly that they will go unnoticed by patient and relatives, which is as it should be. Yet at any stage, one tiny item may catch the doctor or any member of the team unawares so that control of the situation is lost, confidence slips, and ensuing visits may be dreaded or even resented. The mental strain on the doctor in coping with this type of patient is severe.

Just as in hospital the role of the specialist gradually gives way to that of the family doctor, so as the disease progresses the work of the doctor in the home becomes subservient to that of the nurse. Any doctor who has watched his patient progress through an incurable illness with the loving care of nurses who have been with him from the stage of diagnosis until the moment of death knows how fortunate is such a patient and how privileged the doctor. The doctor cannot judge from his short time with the patient, or from the inevitably emotional comment of relations, how his treatment of pain, anxiety, or any other symptom is succeeding or failing. He must rely absolutely on the word of the nurse. In these last days the nurse must lead the team of helpers. Pride has no place in terminal care if this is to be successful.

It must not be forgotten that the care of a patient with an incurable illness can be carefully and gently pursued in hospital or in a nursing home. It may be that the patient and his relatives would prefer this. All that is missing in such cases is the patient's own home and bed.

There is a risk that those who care for these patients may become too involved, and find it difficult to accept the inevitable. Over-involvement should be avoided, and if at any stage a member of the 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 reasonably inexperienced.

In every case the stage is reached when there is little more to do but wait. When the help that man can give has been exhausted, all that is left is the hope of a merciful death, but there is no need for us to deny ourselves the comfort of having helped a patient to close his life in this world with as much reassurance, peace, and dignity as it is possible for man to devise.

*This article is based on a paper read at the Conference on the Treatment of Malignant Disease held at the Royal College of Physicians in July 1970.*