

TERMINAL CARE

How do we cope with death?

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SUMMARY. We hope that general practitioners will consider counselling their dying patients more actively, including those in hospital where terminal care may be poorly handled psychologically. This entails a major change in training which we hope is taking place through vocational training schemes. We feel a change in attitude to be necessary by many general practitioners who often deal with death by evasion and untruth.

*'One thing is certain, that Life flies;
One thing is certain, and the Rest is Lies;
The Flower that once has blown for ever dies.'*

Omar Khayyam

no way impose this upon his patient, but use his enlightenment to support and encourage the sufferer to face death in his own way.

General practitioners may expect 30 to 40 deaths in their practices a year (although in some areas considerably more), some of these being sudden deaths, but about half by extended illness—a disease process such as cancer which may take months or years from onset to death. Thus during a working life of about 35 years or more in general practice, we may expect to find ourselves dealing with many terminal illnesses, and ultimately probably our own. Amongst these terminal patients we include many who may be in hospital or terminal care homes, being convinced that these patients benefit from a continuing relationship with their family doctor until the end. Furthermore, their presence in these institutions may well reflect our own difficulties in dealing with this very problem. We feel the following stages to have been of importance in moulding our own attitudes.

1. As children

Initially perhaps, as children and adolescents, the foundation of our attitude to death was first laid. One hopes that many of the avoidances and prejudices of death ingrained in us by non-medical families have by now been cast aside, but since 'the child is father to the man', that could be too much to expect. Maybe those who have experienced death (either through their parent's occupation or through bereavement) have developed an earlier understanding; but, if traumatic, this experience may later prove to be an obstacle. On the other hand, it has been observed that the later in life bereavement is experienced for the first time, the more profound the response (Fox, 1975).

2. As medical students

As medical students, studying at what we fondly believed were the best teaching hospitals, the dilemma

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never occurred; death counselling and bereavement were not even on the curriculum. Patients never appeared to die in our idealized environment—one saw the occasional cachectic patient hidden behind screens; later one attended ‘interesting’ post-mortems on patients who had appeared as if by magic. Personal feelings never interfered and scientific knowledge was everything.

3. As house officers

Later came a period as newly qualified housemen. We worked long hours, gained much knowledge, but never quite knew what to do with the dying patient or his relatives. On the ward round it seemed the done thing to pass by the bed with a word and a joke, a whispered sentence of doom from the great consultant to his junior staff and on to the brighter prospect of a patient who was ‘being good’ by getting better. The patient was infantilized, did not usually ask embarrassing questions and, although he had probably overheard the sinister conversations at the foot of his bed, kept his peace until the end. We dreaded the painful conversation with the relatives, and thus avoided both them and the patient by being too busy, being called away, or just never getting round to it.

4. Crisis in the adult doctor

At some time the flood of harsh realities provokes a crisis in the doctor. It is then that he either has to reformulate his ideas of dealing with death or live out an unhappy career referring all his terminal cases to hospital or terminal care homes, and then ‘forgetting’ them (Freud, 1901). The doctor, after all, has been programmed by his training to be omnipotent and omniscient—in Berne’s concept to be ‘parent’ to his patient’s ‘child’ (Berne, 1966). Death and terminal disease disturb this relationship and render him impotent and useless.

5. Vocational training

Nowadays, fortunately, through schemes of vocational training for general practice, the doctor can be helped to take this step in the difficult road to establishing an adult-to-adult relationship with dying patients. The vocational trainee, who enters a year’s apprenticeship with a general-practitioner trainer, may well be intelligent and perceptive, but sometimes not yet mature enough to escape his programming as the omnipotent doctor. As a result, his way of dealing with the dying patient may be totally and brutally honest. He may, for instance, on entering the trainer’s practice, faithfully inform a patient of the presence of cancer, the hopelessness of the outlook, and the scientific projection of the expected life-span, then depart rejoicing in a job well done. This, to us, is as much a crime as that committed by some of our evasive and lying colleagues at the other end of the spectrum. (We use the word ‘lying’ advisedly. The *Concise Oxford Dictionary* states a lie to be an ‘intentional false statement’, to lie as to

‘speak falsely’, ‘deceive’.) Yet either way we do it for our greater comfort rather than the patients’.

The training period offers enormous opportunities for the young doctor to deal with the changes in attitudes needed to deal with the dying patient, not least to learn humility and the contribution of the other members of the health care team. Trainers too can learn much from trainees, as in the case of one trainee dealing with a patient dying of cancer at the same time as his father was dying from the same condition, under the care of what appeared to be an evasive and untruthful family doctor. The trainee’s handling of the case with sensitivity, empathy and courage provided a great lesson to his trainer, whose support at a distance was needed for the former to deal with two complex interlocking family tragedies.

Managing patients

Having considered the ways in which our attitudes may have been reached, we now need to examine the way they may contribute to our better management of the dying patient. It is important also to realize the other factors which may influence our success or failure in doing so. Most important of these are the patient’s fears, anxieties, apprehension, irrational doubts, and shame. ‘How will I die?—Will it be painful?—Will I be dirty?—Will it hurt me—Will it hurt my relatives, my friends, my doctor?’ This latter question may seem strange, but we are convinced that it is through fear of hurting others that some terminal patients will avoid the communication with their loved ones (or even their doctors) that they so desperately need.

Thus the patient’s immediate family should not be excluded from the management of the case unless the patient expressly demands it. In particular we condemn the pernicious practice of telling the wife that her husband must not be told he is dying. This places an intolerable burden on her at a time when the relationship between the two needs to be at its strongest, without the artificial barriers that this instruction would impose.

On the other hand great pressures may be placed on the doctor by demands from the relatives that the patient should not be told of his condition. This, of course, leads to a similar barrier to the relationship between doctor and patient, and we try sympathetically, but firmly, to point out to the relatives that this decision must be left to us after assessing the patient’s own needs and insight. This requires careful and adequate counselling—time, tact, and team work. Sensitivity in relationships means listening, counselling, and follow-up—through those traumatic stages that lead to acceptance of approaching death and the grief that accompanies it (Parkes, 1974).

Grief

Grief itself is becoming a popular subject, quite rightly, in the lay press as the taboos of death and dying are slowly being dissolved. The concept of ‘anticipatory

'grief' has also been proposed as a kind of foreshortened spectrum of the feelings experienced by those close to the dying person, as they go through a process of 'disengagement' in preparing for his death.

Many of us, as friends or doctors of dying patients, have been through a minor form of anticipatory grief which makes the ultimate loss much less traumatic. One survey has suggested less depression in widows who were able to share their husbands' grief in preparation for bereavement (Parkes, 1972). One might similarly postulate that those dying husbands suffered less too, for the dying patient must experience anticipatory grief also—an aspect which is often ignored.

Depression

A true depressive illness is not uncommon in the dying patient. As in other cases of depression, pain may be felt more, especially in terminal patients who enter this phase and are not helped through it. In our experience, and that of many others, pain-killers may be needed in far smaller doses, if at all, in the terminal cancer patient who dies in the peaceful acceptance of his illness.

Some illustrations

Mrs M. H., one of a devoted couple in middle age, became jaundiced and was found to have an abdominal mass. After her first operation the pathologist reported carcinoma of the pancreas. The surgeon was 'unable' to see her after the operation as he had promised, but sent the ward sister along to tell her that another operation would be needed. The husband, however, saw the surgeon and put to him the list of questions that he and his wife had prepared. Later, while at home for a few days before the second operation, the couple came to one of us, who openly discussed the chances of curing her cancer. She went in for the second operation and on the night before told her husband 'remember, this isn't my illness, it's something that's happening to *us*'. He told us this with tears in his eyes as she lay in the intensive care unit recovering from a six-hour Whipple's operation, which we hope has cleared the growth. If the cancer recurs, our job and her last illness will be that much easier because of the groundwork already carried out.

Mr J.C., aged 65, came to one of us having coughed up blood. His obvious concern was shared and an urgent chest x-ray arranged, which showed possible lung cancer. Seen again, the need for further follow-up was explained and his feelings about knowing the diagnosis were sounded. His remark was 'I want to know everything', and this was entered in the notes. He then saw a chest physician, who referred him to a thoracic surgeon, who took a biopsy. The diagnosis was lung cancer and it was considered inoperable. Deep x-ray therapy was given by a further specialist. After all this he returned. 'What did the specialists say?' we asked. 'Nothing', he replied. This was in fact quite true, the last specialist having apparently avoided seeing him

after the final treatment. (This is not necessarily meant as a criticism.)

He received the news of his lung cancer philosophically and shared our hope that the x-ray treatment would prove effective in holding off the tumour. This session proceeded to a discussion of how best he might deal with this illness with his wife, who had herself had cancerophobia for years. Haematuria, jaundice, and haemoptysis occurred over the ensuing months. The fact that these were indicative of his approaching death was never denied, and at times he discussed his illness in a warm and even humorous way. The excellent relationship was maintained to the end, his wife being involved in all final decisions. Unfortunately he died in hospital after brief admission for a palliative pleural tap. To date, the wife's grief reaction has not been as severe as might have been expected if she had been unprepared.

Emotional aspects

How do we cope with death? The patient with feelings of anger, remorse, fear, jealousy, nostalgia and depression; the doctor all too often with avoidance, denial, evasion and lies; the relative often with a complex mixture of all these. We as doctors collude in playing the part of 'the honest liar in the face of death'. It is not good enough—although, in mitigation, we are merely reflecting the attitudes of the society in which we live.

The following was written by a dying patient (Twycross, 1975).

'I huddle warm inside my corner bed
Watching the other patients sipping tea.
I wonder why I'm so long getting well
And why it is no one will talk to me.

The nurses are so kind—they brush my hair
On days I feel too ill to read or sew.
I smile and chat, trying not to show my fear,
They cannot tell me what I want to know.

The visitors come in. I see their eyes
Become embarrassed as they pass my bed.
'What lovely flowers' they say, then hurry on
In case their faces show what can't be said.

The chaplain passes on his weekly round
With friendly smile and calm, untroubled brow.
He speaks with deep sincerity of Life.
I'd like to speak of Death, but don't know how.

The surgeon comes, with silent retinue,
Mutters to Sister, deaf to my silent plea.
I want to tell this dread I feel inside,
But they are all too kind to talk to me.'

Anon.

Isn't this just the patient who should be visited by the family doctor, who has probably known her and her family for years? We feel it is his place to visit such patients and counsel them in the hospital. We general practitioners don't do it because we are afraid of 'in-

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terferring', creating resentment and, inevitably, anger among some of the staff who often feel the family doctor should only visit 'socially' and not intervene in the management of their patient. We also don't do it because of our anxiety and inadequacy in dealing with death.

Let us hope that we will all—nurses, general practitioners, hospital doctors, relatives and friends—be able to work together as a team to help such patients. However, we general practitioners will need courage to learn how to counsel them; one hopes we will be able to draw from our experience of dealing with terminal patients allowed to die at home—often the ideal environment for the final illness.

There is one final question. Is the patient who seems *not* to want to know the truth the very one we should be working with towards acceptance? Or should we perhaps respect his wishes and let sleeping dogs lie? The answer eludes us, and no doubt always will.

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Addendum

The Editor of the *Journal of the Royal College of General Practitioners* acknowledges with thanks the permission of the Christian Medical Fellowship to reproduce a poem by an anonymous patient from *The Dying Patient* by R. G. Twycross.

Cost of the NHS

Figures showing the total cost of the NHS in Great Britain in the period from 1950 to the end of the current financial year were given in the House of Commons by Dr David Owen, Minister of State for Health, as follows:

	£ million
1950-51	472
1955-56	617
1960-61	924
1965-66	1,326
1970-71	2,093
1975-76	5,458
1976-77 (estimated)	5,637

Reference

The Family Practitioner Services (1976) 3, 198.