Terminal care*

DAVID KYLE, M.A., M.B., B.Ch., L.M.S.S.A., F.R.C.G.P.

Brecon

I ONCE read somewhere that doctors tended to have patients more or less the same age as themselves, and I believe that this may be partly true. I am one of the older general practitioners in the area, and I have nearly 500 patients over 65 years old on my list, which gives me some qualification to speak on terminal care. None the less, before I was asked to take part in this symposium, I don't know that I had ever really thought of terminal care as a subject on its own, to be broken down and analyzed into its several components. It had just been part of the ordinary course of my professional life. Just as the care of babies led to the care of children, and the care of children to the care of young adults, so eventually by progression through the ages of man the care of old people led on to the care of terminal cases.

But as I began to think about it, I realized that over the years every doctor evolves his own particular way of dealing with a particular set of circumstances, even if this is not a conscious process. In a case of terminal care the relevant factors, *e.g.* the personality of the patient, the sort of family he has, the sort of house he lives in and other important data are all fed into his subconscious computer which bases its answer on its store of past experience, and almost automatically the future conduct of the case is planned. But the actual details will vary from doctor to doctor, depending on the sort of person he is, and two doctors may deal with the same situation differently, but equally well.

After this brief excursion into the perhaps not very profitable fields of philosophical speculation, it becomes necessary to provide a definition of terminal care. It can be defined as the care of those patients who are beyond cure and are expected to die within a few months, at the most a year. It applies therefore to chronic conditions, not to acute illness, and it is the chronicity which makes it so difficult to manage.

The cases concerned arel argely cases of malignant disease in all its manifestations, the later stages of cardiac and cerebrovascular disease, kidney diseases, neurological diseases, blood diseases and some forms of respiratory disease, though thank goodness the slow lingering death from tubercle, which was common when I started practice, is now hardly ever seen. Fortunately also diabetes and pernicious anaemia are no longer the slow killers that they used to be, not in my time as a doctor, but certainly in my memory as a child, and in the practice of my father. Not all those who require terminal care are old or even middle-aged. Some are in the prime of life, some may be children or young people such as the tragic cases of cirrhosis of the liver, leukaemia and systemic lupus erythematosus I have met in the last few years. Some may be babies or infants, with spina-bifida or other congenital diseases. Thus terminal care may be required at any age.

Who then is responsible for carrying it out? When the patient is at home, the family doctor is bound to be deeply involved. Whatever other help he may call on, he must be the leader of the team, for he is the only one to know all the background and all the personalities concerned.

*Being a contribution to a symposium on 'Management of Terminal Illness' on 8 November 1970 at the Postgraduate Centre, Nevill Hall Hospital, Abergavenny.

J. ROY. COLL. GEN. PRACTIT., 1971, 21, 382

The family is also deeply involved. In most instances, especially in the early days, it is one of the family who takes on the burden of caring for the patient. It may be a wife or husband, a sister or a daughter or a niece. Whoever it is, the doctor must watch the situation carefully so that he will be aware when the burden is becoming too heavy and the attendant is beginning to break under the strain. It is not easy for the family, day in day out, to put up with the vagaries of an ill person who may appear ungrateful in spite of every attention and may say the most outrageous and wounding things to those who care for him. The family find it difficult to believe that this is not malicious or deliberate. It is almost impossible for them to understand that the patient is not meaning to hurt them. It is essential that the doctor should explain the state of affairs and make them realize that this behaviour is the result of illness, and that when he behaves in this way the patient is really "not himself".

In almost every case the time will come when the family, however numerous and however co-operative, will begin to find that things are too much for them. If the strain is not relieved, the family will surely break under it. Long before this happens the district nurse will have been brought into the situation. In the early days she calls occasionally when she is "just passing the door", and in this way she will get to know the family and its ways. Then she will attend when she is wanted, to help with a bed-bath or give an enema, and later she will visit regularly. She will also provide a useful line of communication with the doctor and will let him know if he is wanted. The nurse, perhaps more than the doctor, will also be aware of what can be offered in the way of welfare and voluntary services. This may be in the form of mechanical aids, ranging from simple devices such as commodes and bed-rests to wheel-chairs, ripple-beds and hydraulic lifting-devices. There may be 'meals-on-wheels' available, a home-help may be needed for longer or shorter periods, and even financial help may be required and provided. In some rural areas not all these services may be provided but it is wonderful what can be achieved if the doctor is sufficiently informed and sufficiently tactful to find his way gently round bureaucratic obstacles. And if this fails he may be able to bull-doze his way through them.

In the older age-group the geriatrician can be of great help. Apart from clinical assistance on the medical aspects of the case, he may be able to provide some day care for suitable patients, together with physiotherapy or occupational therapy. This will provide a welcome break from the monotony of invalid life at home, and will relax the pressure on the family. In the same way intermittent inpatient care for a week or two at a time can sometimes be arranged, and this too is most valuable.

If the final stage of the terminal illness is short, and without any unmanageable breakdown in the major functions of the patient, he may die peacefully at home in an atmosphere of love and affection, with his friends and family about him. In my early days in practice, now over 35 years ago, this was the common pattern, even when major problems such as incontinence and delirium occurred,—but the whole picture and pattern of life was different then. The better-off patients were able to afford private nurses, often both a day-nurse and a night-nurse, and such nurses were easily available from agencies and nursing co-operatives. The not so well-off patients relied partly on the family and partly on the services of reliable middle-aged women, often widows or spinsters living on a small income which they were glad to supplement by untrained though common-sense nursing. Every doctor knew the names of a number of these women and was glad to call upon their help in time of need. The pattern of the general practitioner's life was different as well. This was before the days of the NHS and the doctor depended for his income on the actual amount of work he did, not on the number of patients on his list. It was not unusual for him to have one or two terminal cases which he visited morning and evening every day. Most of those were private patients, as it was only those who were working and earning under £250 per year who were National Health Insurance

patients. Thus the economic motive reinforced the humanitarian motive and compensated for the extra work. I can remember one old retired bank manager, looked after by two devoted domestic servants, whom I visited every day for two whole years, and twice a day for the last few weeks of his life. These were still the days when the personality of the doctor was often therapeutically more potent than most of the drugs at his command.

Today, nurses are almost unobtainable, and cost the earth, and the sensible women have got whole-time jobs on a much more profitable basis. The home-help and the assistant nurses and the district nurse do their best, but they can only provide part-time care which is often not sufficient.

The time comes when many terminal cases, perhaps half of them, develop symptoms which make imperative their removal to an institution. Among these symptoms I would include faecal and urinary incontinence, severe dyspnoea, pain uncontrollable by oral analgesics, nocturnal delirium and confusion and very bad bed-sores. What are we to do with those cases? I think it is unlikely that a district general hospital would want them, and I do not consider that they should be asked to take them. This is no reflection on the humanity of the consultant or nursing staff, but rather an acceptance of the obvious fact that there is a waiting list for acute cases, and a bed is being wasted if the patient in it is beyond cure. The chronic sick geriatric hospital is more promising. but there are never enough beds, and it is easy to understand that the geriatrician does not want all his beds full of terminal cases. As a general hypothesis, it can be argued that one of the reasons a man becomes a consultant is that he tends to be more interested in diseases than in the people who have them. This is not meant to be in any way derogatory and you may think that there is no truth in it anyway. But I think you might agree that the consultant spends his life seeing the same diseases in different people, while the general practitioner spends his life seeing the same people with different diseases, and this must make a difference in his approach.

This leads to the obvious fact that the general-practitioner hospital, where it still exists, is of the greatest possible value for terminal cases when they can no longer be managed at home. It is easy to persuade the patient to go in, on the pretext of having an x-ray or carrying out some special tests. He does not mind going into his familiar cottage hospital where he may well have been before, where he will find friends and acquaintances on all sides. His own doctor will be looking after him, and his family and friends will be able to visit him regularly. It is easy by various excuses to draw out his stay as long as is required, until he no longer has the mental or physical energy to make any demands and unquestioningly accepts each day and what it brings. For those who cannot be nursed all the time at home this is undoubtedly the next best thing, and those of us who practise in Brecon are thankful that the facility is still ours.

When the patient is at home, the family doctor can do a great deal to help him and to maintain the morale of the family-circle. I am not now thinking of drug-treatment—in fact I do not propose to discuss this aspect at all. I think every doctor is familiar with the usual range of analgesics, tranquillizers, sedatives, hypnotics and their various combinations, and I think it would be a work of supererogation to go through them. There may be some new products unknown to me, and if so I look forward to hearing about them later. I would like rather to say a few words about the management of the case. It is important to do everything possible to ensure that the family are not overnervous or apprehensive. The doctor must make it clear by his general demeanour of quiet confidence that he is in control of the situation and that whatever emergency may arise the patient and his family can rely upon him to deal adequately with it. He must visit the home regularly, at first once or twice a week, and it is a great comfort to the family if he tells them when he is coming, but he must remember to keep his promise. As time goes by, he must visit more often, and in the later stages he must go every day,

even if it is only for a minute or two. The family must be kept informed as to how things are going and the probable future course must be discussed. All the ancillary services are brought into use and it must be made clear that they will not be left to cope alone in the event of any unexpected development, and if they want the doctor to come he will do so willingly. The doctor must be an integral part of the team and not just an onlooker on the sidelines.

The family must always be told exactly what is wrong and nothing must be withheld from them. But what the patient should be told is another matter. There are many who say that the patient should be told the truth about himself, and there are probably more who believe the opposite. I never tell a patient that he is going to die or that he has cancer. Sometimes the diagnosis or the prognosis is wrong—for instance in 1945 a patient of mine came home from hospital with a diagnosis of inoperable carcinoma of the stomach, confirmed by biopsy at laparotomy. Clinically the diagnosis was right too, but the man recovered and is now an active 83-year-old weighing over 12 stone.

But this is not the reason that I do not tell my patients the whole truth. My reason is that if you deprive a sick man of hope you deprive him of all he has. You can admit the gravity of the situation, but you must also admit a ray of hope. Only twice in 35 years (on both occasions because a large sum of money was involved and certain dispositions had to be made) have I told a patient that he had cancer and would soon die. The effect was quite shocking. In each case the patient almost literally turned his face to the wall, became depressed and morose and spent his last few weeks in an agony of self-pity to the anguish and distress of the family. Where hope is not denied, it is still possible to rationalize new developments and prescribe symptomatic treatment with some show of reality. In this way it is possible to preserve some sort of a basis, even if a fictional one, for the conduct of life from day to day as long as it continues. As the end approaches sensibilities are less acute and death in most cases comes peacefully without realization of its coming. In some cases an unexpected episode will happily supervene, while in others the process of dying may seem interminable, and these are the most difficult to manage.

It is in these cases, and in others where there are persistent and distressing symptoms, that one wonders if there is not some justification for hastening the end. I do not mean legalized euthanasia—I think that is too great an assumption of responsibility for any doctor either alone or as one of a committee. Where the symptoms warrant it, an adequate dose of an effective drug must be given, even if it means that the patient's life may be shortened. But where death is lingering only, and without distress, I cannot in good conscience find any reason to intervene.

A similar problem arises over the treatment of an intercurrent illness such as a respiratory infection. Is it justifiable to use antibiotics? Is it justifiable *not* to use antibiotics? No general advice can be given. It depends on the patient, the family and on other individual factors. And what about doing investigations like intravenous pyelographies and barium-meals? In most cases I think not, as for instance when not long ago I turned down a suggestion that I should do an IVP and a micturating cystogram in an old lady of 93 with a chronic urinary infection. On the other hand the family doctor must beware of assuming that an elderly patient is not worth treating. If he hesitates too long he may have on his hands a terminal case which should never have become one.

No discussion on terminal care can avoid consideration of the part played by religion. The man who believes that there is a God, and that he has a soul which is separate from his body and that all life does not end with death is I think much better equipped to endure a long terminal illness. And I believe that there are more of them than one realizes, people who may never go to church, yet have an inner strength to support them.

By contrast with this private religion, organized religion has much less impact now than in previous generations. In our care of terminal cases I do not feel we get much help from ministers of religion either in the Established Church or among the non-conformists. Perhaps it is our own fault—perhaps we should make it our business to tell the minister concerned when we think help is needed. And yet a minister who is in touch with his people should know when they are in trouble and need his help. The Church of Rome is an outstanding exception. The priest is in the house as often or more often than the doctor and is a welcome visitor who provides real comfort. I am sure a liaison with the Church is something we should think about.

One final word, as a general practitioner, on terminal care. There is a school of thought (to which I do not subscribe) which considers that general practice is a specialty. That this is a contradiction in terms, like saying "black is white", nobody really seems to have noticed. However, in one small corner of general practice, I think (I hope without presumption) that the general practitioner may have some claim to be a specialist, and that is in the field of terminal care.

The other speakers tonight will be looking at the problem from a different standpoint, and may disagree with everything I have said. In a talk such as this, based on my own thoughts and ideas and constructed in isolation without argument or interruption, it is inevitable that some of my hobby-horses should take me for a ride. Sometimes they may have got out of control, but I hope they have not trodden too heavily upon anyone's toes. If they have, I offer my apologies in advance.

Anglo-Canadian exchange in general practice: Canadian view of British general practice: British view of Canadian general practice

A British and a Canadian general practitioner give their impressions of "the other side" following a five month exchange of practices between a Teesside and a Burlington (Ontario) group practice.

The Canadian practitioner (GPS) was favourably impressed by the premises, organization and research opportunities of general practice in Britain and also, perhaps surprisingly, by the system of remuneration and the status of the doctor in the eyes of his patient. He missed the hospital facilities of Canada and felt that the British doctors overdid home visits many of which were unnecessary and a response to demand rather than need. Certificates of unfitness for work were often requested on meagre grounds—"It is my impression that the employee, certainly in the Teesside area, tends to claim sick benefits for the most trivial of reasons".

The British doctor (GNM) found that general practice organization fell behind that of Britain. The Canadian practice of doing frequent overhauls and checkups on fit patients was tedious and clinically unrewarding. The system of payment discouraged any delegation of work to auxiliary staff. The hospital privileges allowed to general practitioners in Canada were a definite advance in patient care over the British system, although the advantages of this could be overstressed. The relative absence of certification was a great boon and Canadian workers tended to continue at work through minor illnesses. Postgraduate education for general practitioners was largely hospital-orientated. The patient–doctor relationship was generally not as happy as in the United Kingdom.

G. N. MARSH, G. P. SWEENY. *British Medical Journal.* 1971. **I**, 336–341.