Personal View

These personal opinions are based on two and a half years as medical director of a home "for those for whom curative treatment is unlikely to be of any further avail." That expression is the result of much thought and not just an attempt to evade the use of the words "terminal care." We must not avoid the issues at stake, from the point of view of either the patient, or his relatives. But the only certainty in medicine is its uncertainty, and this applies particularly in the prognosis of "terminal" illness. Constantly I see patients whose relatives have been told by a doctor "he can only live three months at the most" and that was over two years ago. What unnecessary anxiety has been caused, especially as the end of the forecast period draws to a close.

My basic criterion in talking to patients and their relatives is that we must always be truthful within the limits of the patient's ability to understand. When giving a prognosis, why not say, "It is always impossible to look into the future; fortunately, we cannot. How worrying it would be if we could. So in your case, let us take it a month (or week, or day) at a time, and be grateful for what time you have. This we will make as comfortable and happy as possible."

And we can all quote cases in which, in spite of an apparently firm diagnosis, the prognosis has been proved incorrect. One of our early patients was sent to us from hospital with a diagnosis of carcinomatosis abdominis, though admittedly there had been no laparotomy. She had had a paracentesis twice. With reasonable care (she was 75 years old) her condition improved and she could go home. Some months later, a routine follow-up inquiry showed that she had been readmitted to hospital and a simple ovarian cyst removed. Incidentally, at any time we have 10 to 12 patients who have improved sufficiently with proper medical and nursing care to return home and be with their families, knowing that they can return to us at any time.

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What then should a patient be told about his diagnosis, and what should the relatives be told? I am convinced that both must be told the same. To tell the wife that her husband is dying but that he must not be told, imposes an extra, intolerable burden on an already anxious relative. I see this daily, and I also see daily the relief which comes to that family when no longer is there an artificial barrier between its members. One patient used the expression to me "you can have no idea what a relief it is to have the barrier of doubt removed." In our work we can get very close to our patients and their relatives, chiefly because we always have (or make) the time to sit and listen. From carefully kept records I know that over 95% of patients have a pretty accurate idea of the general nature of their illness. This is gleaned from the general chatter which goes on in hospitals, chiefly among patients. You cannot send a patient to the radiotherapy department these days without them having a very shrewd idea of what it is all about.

My biggest problem at the moment is dealing with the patient who has been told by the hospital consultant, "It was only a simple ulcer and I have taken it all away. You will have no further trouble" or "It was just an appendix abscess, which will soon heal up." One, admittedly rather intelligent, patient told the ward sister after such a remark, "I could tell by the look on his face that the poor man just didn't know what to say. I feel really sorry for him." The general practitioners who have to care for these patients when they leave hospital, also tell me how difficult it is to help patients who have been told such absurdities. If only the consultant would leave a small loop-hole—"I think I was able to get it all away and we hope you will now get better." This at least gives those who will have the ultimate care of the patient a position in which to manoeuvre.

I write as a retired hospital consultant, so I do appreciate present day pressures. When I visit a patient before admission to our home it often takes me over an hour to get a real rapport with the family—in some cases it takes us several weeks in the home. It would be difficult for the consultant to find time to do this, but I would ask that others who can should be asked to make this contact. I now lecture to the nurses regularly during their training, and also on their postgraduate study days, and I find that they are much closer to their patients than the doctors are and they could, if backed by the consultant, be of tremendous help. Hospital residents should also be helped to deal with patients and relatives. How often was I asked when still in hospital work, "Isn't there something we can do for Mrs. Smith?" My reply, "Yes, help her to die decently and with dignity," was met with an incredulous look and the further remark, "No, I mean isn't there something we can *do* for her?" The most personal of my opinions I have left till last, but to me it is the most important. Many good articles are written these days on the medical, nursing, and social care of these patients. The subject has even been given time on television—the highest accolade. And yet every article I have read stops short of the aspect that really matters. How can one help people to face the most frightening of all experiences—the experience of the unknown—unless one has a real positive hope to offer. I was frightened recently when told that at a teaching hospital patients with fear of death were being referred to the psychiatrist. That really would frighten me. I accept unreservedly that one must never enter uninvited into a patient's inner thoughts. But from my personal experience, one will be invited, if the patient knows he will not be brushed off, or smothered with religious clichés. Man is more than an intellectual animal, he has a spiritual side. To quote Arnold Toynbee, "A human being is endowed with some God-like spiritual and intellectual capacities. He has the power to commune and co-operate with the spiritual presence behind the phenomenon of the universe. By comparison with our physical stamina, our spiritual and intellectual capacities are collossal. There is only this misfit—why and what is death." There is a sure and certain answer which we celebrate each Easter.

A final thought from William Burke—"the only thing necessary for the triumph of evil, is for good men to do nothing." Isn't it time the medical curriculum did something?

F. R. GUSTERSON

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