Letter from . . . Chicago

Death with dignity

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In recent years a succession of writers has lamented that a society which has the highest standard of living should also have the lowest standard of dying. Death, they maintain, has replaced sex as the most unmentionable taboo, and the act of dying has become lonely, mechanical, dehumanised, and at times gruesome.[1] Some have referred to the "obscenity of modern dying," exemplified by an impersonal object lying naked and exposed on a wooden board in an intensive care unit.[2] To some extent, however, a revulsion has taken place against this state of affairs, and old values seem to be reemerging under new formulations or even slogans. Of these, "death with dignity" is currently the most popular—with patients, house staff, and the news media.

Quite recently, after prolonged private discussions with the new intern, a patient with alcoholic cirrhosis and advancing hepatic failure announced that he wanted no further treatment and that he wished to "die with dignity." At about the same time the newspapers reported from California how a patient with diabetic nephropathy and chronic renal failure used a similar formulation when he declared his intention to discontinue chronic dialysis. Within the last year several states have considered "death with dignity" bills which would allow patients to draw up wills renouncing the use of heroic or extraordinary means to support life. In Tennessee a group of citizens has formed an organisation to establish a person's right to a merciful death. And in the same spirit a leading commentary in the *Journal of the American Medical Association* described how in August 1974, in a remote cottage on the island of Maui, Charles A Lindbergh peacefully set out upon his last journey in a living museum of tropical foliage and wildlife, overlooking the sea he loved.[3]

The trend is timely enough; the theme, however, is an old one. "We must leave the earth," wrote Kazantzakis, "not like scourged, tearful slaves, but like kings who rise from table with no further wants, after having eaten and drunk to the full." It is a theme expounded in its various aspects by Socrates "true philosophers make dying their profession"; by the peripatetics "the good man should flee life when his misfortunes are too great"; by the elder Pliny "life is not so desirable a thing as to be protracted at any cost"; by Seneca "the wise man lives as long as he should, not as long as he can"; by Epitectus, by Plutarch, and by many other ancient writers; echoed by Montaigne "the only learning I look for is that which . . . teaches me how to die well and to live well"; and by Nietzsche "would that there came preachers of quick death . . . but I only hear slow death preached."

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Intensive care units

What is new and characteristic of our times, however, is that technology has blurred the dividing line between this life and the next, and in the process has brought into being an intermediary state, the intensive care unit. In these efficient but in some ways macabre places, life merges into death, consciousness into unconsciousness, and the difference is frequently hard to tell, especially with the increasing practice of intubating patients for the sake of their blood gases. As a case in point, a patient with stroke and malignant hypertension, intubated because of earlier respiratory difficulties, was found with eyes wildly rolling about and was deemed unconscious; but when after a heated debate the tube was removed, he complained that he was hungry. In a related incident a middle-aged professor described waking up after triple coronary surgery and finding himself catheterised, in restraints, and unable to protest when someone tried to pass a stomach tube past his deviated nasal septum. What must have been five minutes seemed to him eternity as he tried to explain that he would like to pass the tube himself but could not make himself understood.

Yet, since "the long habit of living indisposeth us for dying," the intensive care unit must remain a necessary though disagreeable corollary of the triumphs of modern science. The practice of keeping unconcious patients alive for prolonged periods of time is, however, much more questionable. The longest record seems to have been established in Tarpon Springs, Florida, where a mother has nursed her unconscious daughter for 34 years, feeding her through a tube and turning her hourly to avoid bedsores. The widely publicised case of Karen Ann Quinlan, however, assumes greater significance, because medicine, the law, and modern respirator technology have conspired to keep a hopelessly brain-damaged young woman in a state of suspended animation and to establish a precedent requiring that "life" be maintained at all costs and by "extraordinary means."

The Quinlan case

Miss Quinlan, once an attractive and athletic young woman, became unconscious in April 1975, perhaps from a mixture of alcohol and tranquilisers, perhaps from a head injury, possibly from foul play. Since then she has remained totally paralysed and lies curled up in a fetal position in a New Jersey hospital bed, totally dependent for life on a respirator, but with the electroencephalogram still showing minimal signs of brain activity. Her parents have pleaded with the court to "show compassion" and appoint them legal guardians of their adult daughter for the sole purpose of turning off the respirator and allow her to "die with grace and dignity." The family's priest echoed the parents' views. The doctors, however, refused to disconnect the respirator. During the trial the prosecutor for the county stated that stopping the support would be regarded as homicide; an attorney appointed by the court to represent Miss

Quinlan—because she could not speak for herself—likened the suit of the Nazi atrocities and gas chambers of the second world war; but a neurologist described Miss Quinlan's condition as worse than any comatose patient he had ever seen and called keeping her alive "a waste"; and a newspaper reported that Miss Quinlan's hospital bills of $425 a day had already exceeded $100 000 and that the cost was being borne by the taxpayers. Yet hundreds of letters were received, mostly urging that Miss Quinlan be kept alive in hope of a medical miracle. And while physicians expressed regret that the case had been moved out of the customary medical channels into the courts, legal experts predicted that the judge had no option but to rule against the parents.

The judge agonised over the decision but confirmed the worst expectations. Refusing to distinguish between ordinary and extraordinary means of supporting life, he denied the parents' request and ruled that discontinuing cardiorespiratory support was a medical decision, while at the same time warning doctors that the court would not authorise that Miss Quinlan's life be taken from her. There is a presumption, said the judge, that one chooses to go on living, and since Miss Quinlan was not brain-dead, the law precluded her removal from the respirator. Reaction to the trial has been mostly unfavourable, and a widespread feeling prevails that an already difficult situation has been made impossible for the doctor, and that the law should never have been brought into such a case. Society is now committed to support by extraordinary means a potentially unlimited number of patients who have practically no chances of survival, an expensive sacrifice on the altar of technology and one which society cannot well afford.

The judge's decision will be subject to an appeal. For the time being, however, Karen Quinlan, described at the trial as an emaciated shadow of a human being, is not allowed to die, and, like Edgar Poe's hypnotised Mr Waldemar, she must continue her unnatural life.

The thin line

Meanwhile, on the basis of interviews with hundreds of patients declared legally dead and then revived, Dr Kübler-Ross has further blurred the already attenuated dividing line between this world and the next. In a recent address she related how patients described they were floating a few feet above their bodies watching the resuscitation efforts, and how they could accurately describe the scene, the details of what was said, and the comings and goings of the observers. "They have a fabulous feeling of peace and wholeness. . . . People who are blind can see, paraplegics have legs that they can move. They have no pain, no fear, no anxiety. . . . In fact it is such a beautiful experience that many resent being brought back to their physical body."

It is also reported that Dr Kübler-Ross said that almost all patients described being greeted by someone who had died before. She told her audience, which gave her a standing ovation at the conclusion of her talk, that she now knew beyond doubt that life existed after death, and that "it is a good feeling to be able to say after many years that people do not die. If you love somebody, tell them now before it is too late." But, while metaphysics may forever remain divided between things everybody knows and things nobody will ever know, problems of a more terrestial nature have arisen, and they concern the high costs of funerals. It appears that the "American way of death" has become far too expensive, and the nation's 22 000 undertakers have been censured by the Federal Trade Commission for a wide variety of abuses. These include overcharging for flowers, pallbearers, cemetery services, fees for clergymen, and death notices in newspapers; also double billing for the same services when two separate companies were concerned.

Among other practices referred to by the commission as "exploitative, unfair, and deceptive" were false claims about legal requirements for expensive coffins and burial vaults; misrepresentations about the need for embalming and using a coffin before cremations; false claims about watertight coffins; picking up and embalming bodies without permission ("body snatching"); and the free use of scorn and of phrases such as "welfare funeral" to increase the price. The disclosures provoked a flood of letters and further complaints. "There may be a few who are honourable," wrote one woman, "but for the most part they are vultures." It is expected that new regulations will be issued shortly to protect the public against unscrupulous practices. Yet in a world where, like the very act of dying, much that once was simple has become increasingly complicated, the modern funeral remains a far cry from what Sir Thomas Browne described as "sober obsequies, wherein few could be so mean as not to provide wood, pitch, a mourner, and an Urne."

References

[1] Kübler-Ross, E, *On Death and Dying*, London, Macmillan, 1969.
[2] Paton, A, *British Medical Journal*, 1969, **3**, 591.
[3] Howell, N M, *Journal of the American Medical Association*, 1975, **232**, 715.

What is the treatment for Eales's disease of the eye? Has urokinase any role in its management?

The poor results of treating Eales's disease with systemic corticosteroids are not surprising in the light of the minimal signs of a true inflammation found in this condition. They compare unfavourably with those recently reported[1] where photocoagulation was used in many patients to destroy microaneurysms and new vessel complexes, thereby eliminating potential sources of bleeding. This would appear to be the treatment of choice at present. The role of urokinase in clearing vitreous haemorrhage in preparation for other measures such as light coagulation remains obscure. Successful experience has been reported in small series of patients,[2 3] but without controlled trials it is difficult to assess the efficacy of any measure in a condition which is apt to improve or worsen suddenly.

[1] Spitznas, M, Meyer-Schwickerath, G, and Stephan, B, *Midland Medical Review*, 1974, vol 10 No 1, 99.
[2] Dugmore, W N, and Raichand, M, *American Journal of Ophthalmology*, 1973, **75**, 779.
[3] Forrester, J, and Williamson, J, *Lancet*, 1973, **2**, 179.

A single healthy girl in her early twenties taking a combined oestrogen/progestogen oral contraceptive notices slight galactorrhoea during her pill-free days of the cycle. How best should one advise her with regard to continuing an oral contraceptive?

Although uncommon, it is well known that galactorrhoea may be associated with using oral contraceptives. The exact incidence has not been determined, because it is not always looked for and the amount of milk secreted is variable. In all cases fully investigated there has been an increase in the serum prolactin concentration, and in some there has been evidence of a pituitary tumour or one has developed apparently at a later date. An excellent review article[1] on pathological galactorrhoea lists phenothiazines, rauwolfia alkaloids, imipramine, and oral contraceptives as being associated with galactorrhoea, and it is also seen in hypothalamic disorders, pituitary tumours, hypothyroidism, and trauma to the chest wall. Galactorrhoea is often associated with amenorrhoea. This latter symptom may be obscured by continuing oral contraception. A possible course would be to stop the pill, use some other form of contraception, and see what happens to the periods. Because of the known association with a pituitary tumour every effort should be made to decide whether one is present or not. This demands high-level endocrine and neurological investigation. It may seem that this is taking a steam-hammer to crack a nut, but galactorrhoea may be of serious significance for the patient herself and for her fertility.

[1] Dewhurst, C J, in *Year Book of Obstetrics and Gynaecology*, ed J P Greenhill, p 193. Chicago, Year Book Medical Publication, 1973.