

# *Letter from . . . Chicago*

## Writing about dying

GEORGE DUNEA

Imagine yourself 50, famous, at the height of your career, about to go on a holiday to Puerto Rico, when you are suddenly seized with excruciating pain each time you try to empty your bladder. You decide to go on the trip anyway, but the pain persists and after a few days you have to return home to see your family doctor. He diagnoses prostatitis and prescribes a succession of urinary antiseptics, but your symptoms continue. At last the doctor palpates a small hard nodule in the prostate and sends you to see a urologist. The biopsy specimen shows adenocarcinoma; and the surgeon brusquely informs you in the presence of your wife that you need a radical prostatectomy and orchietomy; that you will be impotent and may become incontinent; and that, although his "opponents" will tell you that prostatectomy is not needed, it is the only known cure. You must, moreover, make up your mind immediately, because he can operate the day after tomorrow but must make arrangements to cancel his planned vacation.

### No peace of mind

"What is an orchi . . ." asks your wife in a small voice; he explains that it is excision of the testicles. You are shocked by his cold, impersonal, almost hostile approach and decide to seek further opinions. A second surgeon, equally reputable, suggests female hormones; a third, even more famous, thinks that you should do nothing. You hear about a specialist who has a linear accelerator with a powerful localised radioactive beam and you fly to California. But a lymphangiogram shows the cancer has spread to the lymph nodes. At long last you decide to get down to writing your book, for which all the research has already been done. Then bony metastases appear and you require stilboestrol, prednisone, powerful cytotoxic drugs. You have pain, oedema, you grow breasts, your appearance is at once bloated and wasted so that you no longer look like your former self, your liver grows large and painful, but you persevere and finish the book before the cancer affects every organ of your body and you lapse into coma and mercifully die.

This, in essence, is the subject of *The Final Battle*,<sup>1</sup> a collection of tapes and memoranda secretly recorded during his last illness by the late war correspondent and historian Cornelius Ryan, author of *The Longest Day* and *A Bridge too Far*. Posthumously edited by his wife Kathryn, and supplemented by notes she made during his illness, this is a powerful book, one that should be part of the curriculum of every doctor who treats human beings that worry and suffer.

We first meet Cornelius Ryan sitting in his favourite swivel chair in his studio, looking out on the garden and the distant hills that look uncommonly beautiful on that soft morning. For the first time he must acknowledge the distinct possibility that he

may be dying. Cancer, from now onwards, will be his constant companion; and he feels unbearably lonely for "a cancer patient's innermost agony is quite apart from the physical torment he endures and it cannot be fully revealed or candidly shared." Starting with the awful feeling that he is under a sentence of death, he successively feels apprehensive, frankly afraid, at times possessed by a terrible sense of injustice, condemned for a crime he did not commit. His mind sways from disbelief to fatalism, from anger to grief, to fear controllable during the day but not at night—eventually to resignation, as he is consumed by the cancer. Soon he will discover that hospitals are profoundly dehumanising and depersonalising. "You take off your clothes and you're in their hands, unable to decide when you come and go or to plan the next day yourself. You aren't a person any longer. You're a patient—without dignity or sense of self." Later he writes from his hospital bed, "Few nurses have time to care if you are lonely or apprehensive." Neither are the doctors all that might be expected. "That they did not give him peace of mind was not their fault," writes Kathryn Ryan; and no one can read the 450 pages of this man's ordeal without concluding that more needs to be done to comfort the patient afflicted with cancer and relieve his intolerable mental anguish.

Also struggling with cancer last year were several doctors who carefully recorded their experiences during the course of their final illness. Thus a 57-year-old paediatrician, Elliott Podoll, made videotape films recording his emotions during his 38-month battle with a malignant lymphoma. His feelings also ranged from early fear, anger, and depression, through a temporary period of profound immersion in his work, to a profound sense of helplessness and loss of control as the oncologists manipulated various chemotherapeutic regimens. During the final state of his illness he describes having the distinct impression that the Brompton mixture had dissected his head from the body—with the mind remaining clear and wondering whether there was any point in stretching out the period of dying, and whether it might not be better to be in a coma rather than watch the body being eaten by termite-like lymphoma cells. About the medical profession, the dying Dr Podoll did not wish to be derogatory, because he, too, thought they did as well as they could. Yet he wished they would soften their approach, establish a better relationship with their patients and a better way of communicating, concluding that he often felt things were out of his control.<sup>2</sup>

Almost similar sentiments arose from the videotaped interviews with 38-year-old David J Peters, who discovered a tumour in his right shoulder some nine months after he had begun practising dermatology in California. He lived for six years, and his perspective "from both ends of the stethoscope" encompasses a sense of isolation and loss of control over his own life, with "horribly bad" communication between doctors and the patient with terminal disease, and a terrible feeling of anguish and alienation when family, friends, and nurses began to avoid talking to the patient about his illness. Patients deplore corridor conferences between doctors and relatives, concluded Dr Peters;

they expect to be included in making decisions about their own lives; and they want their doctor not to abandon them, but to help them to die and to make dying easy when the time comes.<sup>3</sup>

### Will to live and know

Another doctor, Dr Douglas G Carroll, a sufferer from disseminated carcinoma of the colon, in a letter published posthumously in *Chicago Medicine*,<sup>4</sup> also emphasised the patients' need for concern and love—from wife, family, doctors, clergy, and friends—as well as deprecating the hurtful effects of people too careless or too busy to express sympathy or concern. Yet he thought that the response to dying cannot be categorised into a syndrome and that there are as many emotional reactions as there are people. Dr Carroll denied ever experiencing any of the reactions described by Dr Elizabeth Kübler-Ross. Instead, he maintained a feeling of detachment, as though he were one of his patients, with no regrets and no guilt feelings, even though "life is so beautiful that no one wants to leave it."<sup>5</sup>

Also possessed by a "very palpable desire to live" is psychologist Neil Fiore, PhD, who had a close scrape with death when an embryonal carcinoma of the testis metastasised to the lungs but then disappeared after a course of chemotherapy.<sup>5</sup> Although some of his psychological interpretations are open to question, his reactions to the discovery of cancer and his overall perspectives greatly resemble those of the other patients. They include early disbelief and distrust, leading to further consultations; a sense of loss of control and a wish to participate in decisions; a strong will to fight the cancer; a determination to become informed about his disease, treatment, and prognosis; and the need for a doctor who is infinitely patient and takes time to explain and answer questions.

Dr Fiore comes out in favour of a holistic approach, to provide comprehensive treatment and treat the mind as well as the body. He would like this accomplished by a specialised team of ancillary personnel and counsellors, who would help patients to understand and accept their disease, to assist them in making

decisions about alternative treatments, to adjust to functional losses, and to participate in further regimens. They would alleviate anxiety and tension about the results of tests, provide support during setbacks and periods of depression, help with rehabilitation, and enable patients to deal with the fear of recurrence. And, although most of this should fall within the province of the physician, doctors are often too busy to take time to listen and comfort. But, be that as it may, there is much to be said for the growing appreciation that the cancer patient needs more than chemotherapy and analgesia, especially in the final stages when he is all too often left isolated and surrounded by a conspiracy of silence.

Much credit for this renewed awareness of the needs of the dying patient goes to Dr Elizabeth Kübler-Ross, whose books emphasise, among other things, the successive stages of denial, rage, bargaining, and final acceptance, through which many patients progress during a fatal illness. Yet all this is not new, writes Ingrid Soudek in a recent review in which she points out that almost a century ago Leo Tolstoy had made the same clinical observation in *The Death of Ivan Ilych*.<sup>6</sup> Tolstoy, indeed, has his hero progress through exactly the same stages as described by Dr Kübler-Ross, and his anger drives his family and friends away from him. Rejected by his wife and daughter, abandoned by his friends, he finds solace only in the kindly ministrations of the faithful servant Gerasim; and only at the end does he discover that there is no fear because there is no death, which to the dying man was a matter of profound relief and joy.

### References

- 1 Ryan C, Ryan KM. *A private battle*. New York: Simon and Schuster, 1979.
- 2 Dunlop B. He let the world watch him die. *Chicago Tribune* 1979 July 29.
- 3 Lewis R. MD-cancer patient describes his "two careers." *AMA News* 1979 Oct 5:3.
- 4 Carroll DG. What's dying like. *Chicago Medicine* 1979;82:333.
- 5 Fiore N. Fighting cancer—one patient's perspective. *N Engl J Med* 1979;300:284-9.
- 6 Soudek IH. Waiting for the end. *Pharos* 1979 Summer:9-13.

*The first triple immunisation injection was given into the left deltoid of a 3-month-old baby just over three weeks ago. The baby now has a firm swelling with an inflammatory lump on the skin that looks about to discharge pus. Minor local reactions causing a small, deeply placed nodule are common, but I have not encountered such an unpleasant reaction. Is this an infection or is it a local reaction to one of the constituents in the triple vaccine? If so which one should we leave out next time?*

A small nodule remaining for some weeks after a DPT injection is common and harmless. It is just possible that a low-grade infection has been introduced but it seems unlikely three weeks after the injection. I have twice seen alarming, blue, indurated non-discharging inflammatory reactions after DPT, suggesting to me something like an Arthus reaction, and I have not dared to give another DPT (+ polio)—so that I gave DT (+ polio) alone. If there is doubt, as I think that there must be, I would regrettably advise you to give DT (+ polio) alone next time.

*A seaman with a head injury was transported from his ship to hospital by helicopter. Although conscious when lifted into the aircraft, he had three grand mal seizures after being in the aircraft for 10 minutes. He was lying in a position where he was looking at the rotors through a window. Could this stimulus have provoked the convulsion? Is this a recognised hazard of transporting patients with head injuries or other casualties in helicopters?*

The head injury was the most likely cause of the seizures: at least 5% of patients with head injury suffer one or more seizures, and seizures are most common in the first 24 hours after injury.<sup>1</sup> Daylight interrupted by helicopter rotors does, however, precipitate tonic clonic convulsions,<sup>2</sup> and the frequency of the flicker produced by the rotors is usually close to that optimal for the induction of paroxysmal EEG activity in photosensitive patients.<sup>3</sup> About 5% of patients with long-

standing epilepsy are photosensitive.<sup>4</sup> There are unfortunately, no data available for assessing the way in which the epileptogenic effects of flicker and head injury may summate. If, as is usually the case, the patient lies in a semi-prone position within the body of the aircraft direct sunlight can be avoided. Furthermore, the effects of reflected intermittent light may be minimised by placing the patient's head on one side, with one eye partially covered by the pillow. Monocular occlusion greatly reduces the convulsive effects of intermittent light.<sup>4</sup> It is not, incidentally, sufficient protection for the patient's eyes to remain closed in the presence of flickering light because the light diffuses through the eyelids.

- 1 Jennett B. *Epilepsy after non-missile head injuries*. 2nd ed. London: Heinemann, 1975.
- 2 Hobbs G. Strobe-effect-induced seizures in flight. *Approach* 1978;23:22-3.
- 3 Johnson LC. Flicker as a helicopter pilot problem. *Aerospace Med* 1963;34:306-10.
- 4 Jeavons PM, Harding GFA. *Photosensitive epilepsy*. London: Heinemann, 1975.

*I am medical adviser to a factory where a cream liquid soap is to be introduced for use by all workers. The soap contains, among other ingredients, coconut diethanolamide, monethanolamine alkyl sulphate, and sodium dodecyl benzene sulphonate. Are these substances free from the danger of skin hazards?*

Coconut diethanolamide is used as a hard surface cleanser and thickening detergent in some washing up liquids, but is mainly found in shampoos and bubble baths. Monoethanolamine alkyl sulphate was widely used in detergents in the past but is now used chiefly in shampoos and hand cleansers. Sodium dodecyl benzene sulphonate (Sodium Dobs) is probably the most universally used detergent in family wash powders. All of these substances if applied neat to the skin will cause irritant dermatitis but when used in the correct percentages—for instance, 2-3% for coconut diethanolamide—have proved relatively harmless, although this does not exclude the possibility of the occasional allergic reaction developing in a few individuals.