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## Informing the Public About Cancer

Most procedures for the early detection of cancer still require careful evaluation before they can be recommended for nation-wide population screening. The same is true of well-intentioned schemes to promote compulsory cancer education in schools.<sup>1</sup> Encouraging public demands for greater allocation of resources for cancer detection and propaganda could result in dilution of other parts of total community care. The Department of Health planners have the unenviable task of judging the extent to which reason must yield to uninformed public pressure goaded by the medical zealots of the day.

The public at large gathers its information about cancer from many sources in an entirely random fashion. Many people have knowledge of how a relative was affected by a particular form of the disease. Unhappily, the popular press tends to dwell on the more sensational aspects—the plight of young victims with leukaemia can always make the basis of a human-interest story. Apart from giving the public a somewhat warped view of cancer, such journalism is fairly harmless: but not so harmless was the role of the press in the build-up and perpetuation of the mystique and myths that surrounded the Issels clinic.<sup>2</sup> Without the interest of the newspapers it is very doubtful whether so many fruitless journeys would have been made in the hope of attaining cures beyond the powers of conventional medicine. Perhaps this was in part due to the low key in which the skills available now in our own hospitals are presented to the public.

In contrast, in the U.S.A. a very positive attitude is adopted towards progress in cancer treatment, and the Federal Government has put a great deal of money into the National Cancer Plan. Such a plan cannot survive without political backing, and its promoters have had to do a lot of fast talking to justify the expense and the methods chosen to distribute the money. This in turn has brought the whole affair to the attention of the more serious newspapers. At first the public imagination was caught by the excitement of the “conquest of cancer campaign” endorsed by President Nixon—when he was still riding high. A rosy picture was painted of the benefits that would come to mankind. Now the scene has changed, with the critics addressing both the scientifically minded public and the press science writers. Propaganda by vested interests makes the objectivity of the arguments difficult to assess; some are in the ring because they want to see more money diverted from

cancer into other aspects of biomedical science, while others are defending the policies of the cancer establishment—the National Cancer Institute or the American Cancer Society. The net result is that the American public is beginning to ask whether it has been promised too much and whether the claims for progress as the results of cancer research are too strong. Daniel Greenberg, a lay commentator whose exposé of American medical politics is familiar to readers of the *New England Journal of Medicine*, has raised serious doubts that the American people are being misled by unwarranted optimism about the progress in the treatment of cancer.<sup>3 4</sup> The *Washington Post*<sup>5</sup> has added its weight to this voice of dissent by reprinting his article, causing a sharp reaction from the establishment.<sup>6</sup> To appreciate this furore it must be understood that the National Cancer Plan had a budget of \$589 million in 1974 and its projected annual revenue increase will reach \$1421 million in 1980. For this amount of money, politicians and American tax payers want to see a real advance in the prevention, cure, and prolongation of survival in cancer—and positive evidence that the promises on which the programme was launched are being fulfilled.

In a small but important way this backlash of unfounded optimism is having its repercussions in Britain. The Cancer Research Campaign's posters appealing for donations, while preserving the eye-catching word “leukaemia,” have discreetly dropped the date when research is expected to conquer the disease; maybe the predicted target date was getting too close for comfort. Unlike the American Cancer Society, the British cancer charities devote very little of their effort towards cancer education except for support of the British Cancer Council.

It seems that, so long as the public are prepared to give money for cancer research without asking too many questions about how it is being spent, the administrators of the funds are in no hurry to promote cancer education. It is one of those causes in which the public generally seems to be content with eloquent rhetoric without questioning too often its validity or content. Yet the charities with their nationwide fund-raising advertising could do much to help get the important messages of cancer education across by discreet emphasis on those facts which it would be in the public's interest to know.

Those who propose to inform the public about cancer must

be cautious when making promises lest they turn out to be like those heard at election time and soon rescinded. Advances in the treatment of leukaemia and solid tumours in children, and a few tumours such as Hodgkin's disease in adults, cannot be used as a camouflage to draw over the mortality statistics (such as those for cancer of the lung, gastrointestinal tract, ovaries, and bladder) which have remained virtually unchanged since the advances attained 20 years ago as the result of improvements in anaesthesia and operative techniques. Our public face need not be too pessimistic, however, for about half of patients with some common tumours will survive for five years, lung cancer being a notable exception, and for many of them this survival to five years will be because they have been cured. This is something positive about cancer that the public should be told; maybe we should not over-stress the fact that it is not until some time has gone by that we can be sure that a cure has been achieved, for this only causes unnecessary anxiety.

To put too much stress on the details of any particular cancer in an education programme may do more harm than good. Levine<sup>7</sup> found that the fear of an illness was increased with the individual's knowledge of the disease. Cancer education programmes should be quite clear about the extent to which detailed information on normal and abnormal function of the body is germane to the message. Some groups need special advice—for example, on normal variations in the menopause and the indications for seeking medical advice. Here the audience is ideally composed of women in the relevant age range and the information is best given in the small group setting.<sup>8</sup> The special requirements for workers in potentially hazardous industries must not be overlooked, though as a rule management is all too aware of the problems once it has been warned by the Factory Inspectorate. But the unions sometimes seem more interested in compensation than in prevention, and workers may disregard preventive measures if they are inconvenient. The onus lies heaviest on the foremen and work supervisors; if they can be convinced the precautions are worthwhile then there is a reasonable chance they might be brought into force.

Information about specific forms of cancer as they affect particular individuals is a daily requirement for the relatives of cancer patients; their interest is real and anxious. The task is often easiest when the eventual outcome is predictable, and it is a delicate point of judgement what to say when the prognosis is uncertain. It is unlikely that a reference bureau on cancer would be able to deal with the specific needs of giving the appropriate answers to questions put by a patient's relatives. Opinions vary on just how much the patients themselves should be told; circumstances differ so much from one patient to another that generalizations are impracticable. If anything, we in Britain err on the side of reticence that may result in the patient becoming isolated from his relatives by a conspiracy of silence. However, to swing over to a "brutally frank" style of doctor-patient relationship (as seems at first sight to be demanded by some of the protocols of American cancer chemotherapy trials) would require the patient to have been conditioned by several years' living in the U.S.A. for it to produce reassurance and not acute anxiety.

## Penicillamine: More Lessons from Experience

When in 1973 we reviewed<sup>1</sup> the place of penicillamine in the treatment of rheumatoid arthritis the drug was new to most rheumatologists. Those who began to prescribe it did so with the caution due to a drug which has so many similarities, both therapeutic and toxic, to gold; and as a result, despite a high withdrawal rate because of drug intolerance, there have been very few deaths attributable to penicillamine. This drug is now being prescribed more widely, and non-rheumatologists may not all be aware of the precautions which have been developed<sup>2</sup> by hard won experience. Penicillamine treatment was the subject of a well-attended workshop and an unofficial colloquium at the VIII European Rheumatology Congress in Helsinki in early June. What further lessons are to be learnt about management from the experience reported there? The most important have to do with dosage. The trial which showed the activity of penicillamine in advanced and recalcitrant rheumatoid arthritis<sup>3</sup> had used two-weekly increments of 250 mg up to maintenance doses of 1000-1500 mg daily, and that was the regimen<sup>1</sup> recommended in 1973. No drug can restore a ruined joint, and some rheumatologists have been using penicillamine at an earlier stage with good effect and at maintenance doses of 500-750 mg daily, with increments at four-week intervals from a starting dose of 250 mg. These lower doses have cut down intolerance to the drug without noticeably reducing its benefits.<sup>4-6</sup> A few patients respond well to as little as 250 mg daily; some need as much as 2000 mg. Thus the policy of gradually increasing the dose from small beginnings, originally advocated by Jaffe<sup>7</sup> as a means of diminishing early intolerance, also enables the clinician to work up to the optimum maintenance dose for each patient, this being the least amount that appears to be bringing about a remission. Response to penicillamine is delayed for several weeks, so that the rate of increase of dose must be slow even if this somewhat lengthens the latent period of therapeutic effect—during which other treatments must be kept up.

The rule that the starting dose of penicillamine should be 250 mg daily or less is absolute, because a few patients react even to this dose by high fever, acute dermatitis, persistent vomiting, thrombocytopenia, or neutropenia. Violent reactions like these preclude further use of the drug by such hypersensitive patients. The blood changes occur quite unpredictably, but if detected promptly they respond rapidly to withdrawal of penicillamine, without other treatment; if ignored they can be fatal. Platelet and white cell counts must be carried out every 7-14 days for the first few weeks and monthly counts, continued indefinitely, are obligatory in maintenance therapy. Disturbing reports have recently been received about patients who have died when these basic precautions were omitted.

Thrombocytes are now often counted by machines. Occasionally, because of some clumping, a falsely low count may be recorded, and a visual check should always be made before the decision to withdraw penicillamine is taken. The incidence of severe and early haematological disturbances and other side effects has been much reduced by the adoption of lower dose regimens,<sup>8</sup> but one characteristic penicillamine reaction, proteinuria, has not. At some stage after the first few months of treatment almost one-third of patients taking penicillamine for rheumatoid arthritis or cystinuria (but not Wilson's disease) excrete protein in their urine. When this increases

<sup>1</sup> *The Times*, 10 May 1975, p. 5.

<sup>2</sup> J. Issels, *Cancer, a Second Opinion*. London, Hodder and Stoughton, 1975.

<sup>3</sup> Greenberg, D. S., *Columbia University Journalism Review*, 1975.

<sup>4</sup> Greenberg, D. S., *New England Journal of Medicine*, 1975, 292, 707.

<sup>5</sup> *Washington Post*, 19 January 1975.

<sup>6</sup> Davis, A. C., *Columbia Journalism Review*, March/April 1975, p. 61.

<sup>7</sup> Levine, G. N., *Journal of Health and Human Behaviour*, 1962, 3, 30.

<sup>8</sup> Knoopf, A., *Changes in Opinion after 7 Years of Public Education in Lancaster*, 1974, Manchester Regional Committee on Cancer.