EDITORIAL

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Practical Neurology, 2004, 4, 318–321

After some 15 years working as a layman with neurological diseases, I was persuaded that it was a natural step to apply to the larger theatre of cancer the lessons I had painstakingly learned with the UK Multiple Sclerosis (MS) Society and earlier with the Motor Neurone Disease (MND) Association. Since the end of 2001 I have been working for Macmillan Cancer Relief, one of the three large cancer foundations in Britain – Cancer Research UK, the product of the merger of the Imperial Cancer Research Fund with the Cancer Research Campaign, Marie Curie Cancer Care and Macmillan Cancer Relief.

MEASURING THE DIFFERENCE

The contrast in sheer scale and complexity of the two fields in the UK alone is striking. One example is the size and longevity of the lay organizations: while the neurological charities were recognizable in their present form little more than 30 years ago, many of the cancer charities date from the first decades of the 20th century. This reflects a

Crossing the line – from neurology to cancer

wider difference. Simply, neurological disease is under-resourced and neglected by comparison with the cancers. Although I recognized things were constrained, I had not realized just how impoverished neurology is in Britain. Nor do I think most of my present colleagues fully realize this, so high are the fences between the disciplines and so narrow our focus.

The disparity could be calibrated by the relative number of specialist nurses supported from non-state resources, in other words the charities and the pharmaceutical industry. For neurological diseases they number perhaps 200, in the cancers – depending on how they are counted – 20 times as many. One of the few international indicators I have seen at first hand is the number and size of the international cancer conferences alone, by comparison with their neurological counterparts. They suggest an international population explosion of cancer clinicians.

The major cancer charities are either generalist (research or care) or site specific (breast,

prostate, bowel especially) while in neurology the charities have tended to crystallise into diagnostic groups: Parkinson's disease, muscular dystrophy, MND, MS, Alzheimer's, often reflecting the state of progress when they were founded. Over 840 cancer charities are registered with the Charity Commission for England, in addition to those too small or too transient to be recognized. For neurological disease, divide by 10. The combined income of the three largest UK cancer charities is over £500 million per annum, in neurological disease, less than 20% of this.

EVERYWHERE IS INDUSTRY

Another indicator of the difference between neurology and cancer is the prominence of the pharmaceutical industry. In cancer, a phenomenally profitable sector of medicine, the companies are visible at every turn, supporting workshops, conferences, study visits, clinical posts, training programmes, political lobbying and everything else that is not forbidden to

them. In neurology the codes of conduct separating the pharma companies from the charities and the professions are easier to sustain and (or perhaps *because*) there is little industry money available. In cancer the companies are everywhere. Relationships and influence are more intimate, and ethical conduct more at risk.

In the MS Society I had difficulty getting the attention of the pharma companies. In contrast, at an industry conference just before I changed jobs I was showered with business cards from companies, all of whom have since beaten a path to my door. Each year I receive three or more invitations from pharma companies to attend in an attractive part of the USA, at their expense, the premier international gathering, the American Society of Clinical Oncology. I refuse them all. If it's important enough to attend, it's important enough for my employer to pay for my attendance. The scale of the commercial interest in the cancer market is vast and it is clearly industry and health technologies that are in the driving seat in expanding the market still further, rather than disinterested research and care.

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WHY SO DIFFERENT?

Without a British Charcot to give them recognition, in the UK the neurological diseases have had widespread public recognition for only a few decades, while cancer has been a private and public nightmare throughout recorded history. The cancers are often all too visible and life-threatening. Until recently, neurological diseases were borne in private, marked by debility and degeneration rather than the drama of tumour. Fear of cancer is not to be underrated. I did not register its significance at the time, so I cannot now count the many people with MND or MS who told me about their anxiety and stress while waiting for a diagnosis of their baffling symptoms, then remarked what a relief it was to discover they did not have cancer!

The US 'war on cancer', based on the premise that the application of technology through un-

constrained private and public funds must eventually produce a solution, was influential in the UK and Europe too. The warlike metaphors have passed into the language as well as medical practice, with doctors' propensity to treat aggressively matched by an assumption on the part of many patients that treatment will continue to the end of their lives, even if it is unpleasant and ultimately ineffective. While there is some public recognition that many neurological diseases are incurable, this is not shared in cancer; 'While there's treatment there's hope' is a widespread opinion.

Watchful waiting, the first line of many neurological interventions, is uncommon in cancer: treat immediately, with the biggest weapons in the armamentarium is the usual starting point. Treatments with the aim of cure have been used in cancers from the earliest times: attempts to cut out or poison tumours were joined a century ago by radiotherapy, later by chemotherapy and now by biotechnology and genetics. Though few are genuinely curative, and there has been only modest treatment progress in the last generation, months or sometimes years of remission have been won and the public knows this. By contrast, although the tradition of treatment in neurology in continental Europe was somewhat more active than in the UK, there have been few interventions that showed much promise, until recent advances in the treatment of stroke, epilepsy and the neurodegenerations.

Because the cancers are so visibly dangerous, as well as frequently disabling or disfiguring, it has been relatively easy to arouse public and political support for action. As life expectancy in the West has risen over the last century, so the incidence and prevalence of cancers and resulting mortality have also risen. Life expectancy for the wealthy has risen faster than for the poor and the cancer risk from 'improved' lifestyle has also increased. It is not surprising that the economically and politically powerful have thrown their weight behind this 'war on cancer'. The neurological diseases have been harder to differentiate in the public mind, their effects less conspicuous and treatment less heroic. There has been a powerful strand in cancer of claiming each small step as a famous victory, with the result that in the media and the public mind things are much more optimistic than in reality.

BIGGEST NOT NECESSARILY BEST

Neurology has some things in its favour, not least that its delayed growth coincided with the rise of consumerism. Whereas in the can-

cers there has been a tendency for the voice of patients and carers to be swamped by that of the professions, at least in UK neurology there is growing recognition of the power of professionals and patients speaking with a common voice. The cancer interests could learn much from neurology: involvement of patients and their carers in all aspects of the disease course, engagement of people affected by the diseases in the treatment and management of their own disease, patient involvement in research about matters that concern them directly, the development of specific professional roles with a remit of patient support, and the intimate connection between research and care. The lesson that allocation of resources is in every sense a political matter rather than the result of the inherent virtue of the case has not been lost in neurology. There is a new political sophistication which is greater than that in cancer.

Conversely, there are many innovations in cancer treatment and services from which neurology would do well to learn. Its hallmark now is collaboration, not only between clinicians but between professions, so that multidisciplinary meetings to consider patients' treatment and progress are the norm, not the exception. Patients have benefited from the appointment of specialist clinical leaders, the extensive development of palliative and terminal care and management, reduction of waiting times through inventive process management, recognition that the grievous nature of the diseases requires special techniques of technology appraisal, and the rapid development of clinical genetics services and genetic research.

In spite of the disparity in scale, there are similar factors restricting development in both fields in the UK: a shortage of clinicians and other professionals, under investment in imaging and related technologies. With age as the major risk factor for both types of disorder, the impending bulge of ageing makes a surge of age-related neurological disease almost inevitable. With growing public awareness and the beginnings of effective treatment and prevention, it is reasonable to suppose that neurological disease could catch the imagination of public and politicians alike. Many of the basic discoveries in neuroscience have derived from research driven by cancer, immunology and genetics conspicuous among them.

GROWING TOGETHER?

'Epidemic' is a word usually applied to infec-

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tious disease, but the estimated growth rates of neurological, cancer and other age-related disorders, coupled with increased survival resulting from improved care justify its use. In future, increasing numbers of people will not suffer from cancer, stroke or diabetes, but all three and several other disorders too. Treating each of these separately will inevitably produce poorer outcomes and dissatisfaction for patients and carers. Certainly they require distinct clinical skills, but from the patient's or carer's perspective it doesn't matter much what causes pain, breathlessness, anorexia and fatigue. What matters is that the symptoms are treated effectively and sympathetically.

What does not yet exist are orderly mechanisms of knowledge transfer, so that stroke services in the UK have barely benefited from the lessons of best practice in cancer care. Palliative care, though it has equal importance for cancers and neurological disease, is dominated by cancer and remains inaccessible to most patients with non-cancer diseases. For the UK, the *Guidance on Supportive and Palliative Care* published by the National Institute of Clinical Excellence (NICE) in early 2004 has the potential to change all this. For the first time, the practice of this aspect of cancer care is in the spotlight and there is every reason to suppose that, for other diseases, professionals and patients will ask why similar standards should not apply equally. It would be a worthwhile endeavour to make this the growing point between the two fields. Improving the management of complex and distressing symptoms at the end of life, or at any stage during the disease trajectory, would be a goal of immeasurable benefit to patients, their carers and professionals alike.