

Out of evil

Celebration. M Spufford. (Pp 126; £2.95 paperback.) London: Fount Paperbacks, 1989. ISBN 0-00-627449-8.



Celebration is a book essentially about courage. It is autobiographical, tracing the pilgrimage of a woman and her daughter who both suffer from incurable illnesses. Margaret Spufford is a doctor of letters of Cambridge University and a bye fellow of Newnham College. Her work as a seventeenth century historian is well known, but not so well known outside her own circle is that she has suffered severe pain from idiopathic osteoporosis for many years. Much of her time has been spent in hospital or lying immobilised at home in full length plasters. Despite that she has managed to continue her work, produce two children, and run a home. She pays tribute to her husband, who, she says, is "thankfully blessed with a loving tolerance and a strong sense of the ridiculous," without which they could not have survived.

The next crisis to strike came when their second child began to fail to thrive and was ultimately diagnosed as having cystinosis. Bridget lost a kidney from renal vein thrombosis, and her second kidney began to malfunction. Initially she was given four days to live, but when she survived that crisis the family was warned that she would die from renal failure in her teens. A transplant was not considered at that time because it would have been affected by disease. From this point the real purpose of the book emerges and the relevance of its title is discovered. Dr Spufford examines her own attitudes to the problem of suffering, particularly that of children; the ethical problems we have created with our own technology; and her deepening Christian faith, which has led her to become an oblate in a Benedictine order:

I needed to worship a Creator deeply involved in His universe, not a "mere" grower of trees bearing bruised blossoms and shrivelled flowers amongst the good fruit. The beginnings of an answer, not to the origin of this evil but to its possible transformation gradually came to me over the years of nursing my daughter. . . . I even know that my own utterly unwanted experience of physical pain and the emotional pain of nursing our daughter which were in themselves entirely evil, have enriched my own academic work in a way that was unplanned and unforeseen.

At one point when her pain was unbearable (she had suffered a jolt when being carried by two ambulance men) and when she couldn't control her screams, she found

That quite extraordinarily at that moment of unreachability, I had suddenly been aware even as I screamed of the presence of the Crucified. He did not cancel the moment or assuage it but was inside it.

The book is full of happy family anecdotes despite its underlying sombre theme and because of this is eminently readable. Dr Spufford has a gift of writing about things which sometimes "go too deep for words." So often one feels agreement with her analysis or definition, perhaps never having been able to express it before. Certainly, her warmth radiates from the book, reaches us, and draws us in to share with her the human condition. I found some of her observations about her daughter, however, almost too painful to bear. Bridget survived much longer than originally expected and received two transplants, but ultimately it was not her dreadful physical condition that made life miserable but her social isolation. We, as a society, rightly or wrongly have managed with advanced medical knowledge to keep people alive. Their physical state is given

great attention. As recent research has shown,¹ little or no provision is made for the mental and spiritual health and development of severely disabled young adults. One could argue that, unless they can go out and take their rightful place in the world around them, the morality of persevering with medical treatment is questionable. Perhaps a more positive attitude would be to insist on treatment and then join forces with those disabled people who have not yet been demoralised by the system and insist also on a fair share of everything that makes life worth living. Dr Spufford has, by her work, highlighted this great need. We must thank her for contributing such a valuable addition to medical literature. The book should take its place next to those of Cicely Saunders and Elizabeth Kübler-Ross in every practice or medical school library. Students, trainees, and indeed all who minister to the needs of the chronically ill should know this book and feel wiser and more humble for having read it. — JENNIFER GRAY, *general practitioner, Hall Green, Birmingham*

1 Harrison JF. *The young disabled adult*. London: Royal College of Physicians, 1986.

Quality counts

Disablement in the Community. Ed D L Patrick, H Peach. (Pp xvii+230; figs; £17.50 paperback.) Oxford: Oxford University Press, 1989. ISBN 0-19-261434-7.

Between 1977 and the mid-1980s a large multidisciplinary team in the department of community medicine at St Thomas's Hospital conducted a series of inter-related studies of disablement in Lambeth. These studies form the basis of this review of the information required to plan and provide community care for the disabled. By combining quantitative and qualitative methods the team considered both the needs of disabled adults (up to the age of 75, but excluding the mentally handicapped) and the services and support that they were receiving.

Measuring the prevalence of disability obviously depends critically on case definition. In Lambeth it was found that 15% of residents reported disability. Contrary to many people's perceptions, only a third of these disabilities were due to injuries, defects, or other physical problems. Sensory impairments (vision, hearing, etc) and neurological, cardiovascular, and respiratory diseases made up the majority of problems. Another wrong perception, that of the unchanging or deteriorating state of disabled people, was also exposed: a quarter of those followed up for two years reported improvements in their condition. In contrast, the authors are less encouraging about the scope of prevention. Apart from reductions in respiratory impairment by reducing smoking, in the incidence of stroke by detecting and treating people with hypertension, and in various symptoms by avoiding iatrogenic causes, they conclude that there is little scope for any appreciable change in the prevalence of disability. Indeed, with an aging population the opposite will occur.

Given the largely intractable nature of their impairments, how well are those with disabilities being helped? According to the surveys carried out in Lambeth 10 years ago, most disabled people were satisfied both with the medical treatment of their symptoms and with the provision of daily living aids. Underlying these results, however, was the finding that respondents had low expectations. Many were either unaware of what help was available or did not perceive any need for the services on offer. The picture that emerges is of a group who are proud, struggling to be self sufficient, and reluctant to make demands for themselves. Less than half of them thought that they should get more. Overall, the surveys show considerable contentment with provision of health and social services.

But to what extent should we believe this encouraging though unlikely finding? The answer lies towards the end of the book in a chapter describing the only qualitative study undertaken by the

team. As such it is an elegant example of the value of this kind of work and illustrates the limitations of quantitative approaches. Interviews with 24 people with rheumatoid arthritis disclosed widespread and serious criticism of the way services are organised and delivered. Few were content and many were engaged in long arduous struggles to obtain help. The arrangements are seen by those using them to be unacceptable, inefficient, inflexible, and unresponsive to their needs. The dangers of community care are clearly spelt out:

We have long recognised that institutional care dehumanises and depersonalises by making the individual subordinate to a system that meets the needs of the organisation, not the recipient. The same is true of community services, which also limit independence, constrain choice, and deprive the individual of dignity.

Given that considerable discontent with current provision exists, what should be done to improve the lot of disabled people? The key debate revolves around whether to provide financial assistance or services. In Lambeth three quarters of respondents favoured cash rather than services. This is clearly consistent with the current government's commitment to increasing consumer power through the market. These studies suggest that a shift from service provision to financial assistance may well find favour with the recipients.—NICK BLACK, senior lecturer in health services research, London School of Hygiene and Tropical Medicine

Authors galore

Renal Pathology with Clinical and Functional Correlations. Ed C C Tisher, B M Brenner. (Pp xxxiv+1598; figs; £120 two volume set.) Philadelphia: Lippincott, 1989. Distributed by Gower Medical. ISBN 0-397-50779-8.

For many years now pundits have been proclaiming the imminent demise of the textbook and its replacement by electronic information systems, but the publishers' lists continue to bulge with new offerings.

As knowledge expands it is, alas, becoming rarer to find a subject

that can be covered adequately by a single person, and with a wide ranging subject such as renal pathology the need for multiple authorship is understandable. It was, however, a surprise to read the roll call of contributors recruited by Professors Brenner and Tischer: to produce the 51 chapters the services of no fewer than 101 contributors have been used.

Most of these are from North American centres, though more than a dozen are from elsewhere. Many of the authors will be well known to practising nephrologists and pathologists (sometimes from their contributions to other textbooks).

Almost all the chapters seem to cover their subject thoroughly, though there is considerable variation in the extent of referencing. In some cases it is so comprehensive as to be daunting—for instance, there are more than 1000 references on minimal change glomerulonephritis. In most contributions references go up to 1986—no mean feat given the number of authors, though this means that at publication the book is about two years out of date.

The book will be valuable to the nephrologist or postgraduate nephrologist who is beginning to feel that the third edition of Heptinstall is getting a little bit out of date. There are, however, some irritations. Some of the authors show a rather parochial North American attitude in their descriptions of disease patterns and in referencing. Some seem to have bulked out their contributions with superfluous illustrations (not always of the finest quality), and this reinforces an impression that the allocation of space has not always been accurately done. The multiplicity of authors and the inevitable overlap mean that conflicting views are offered on the same subject: the inevitable hobby horses are sometimes ridden a little too vigorously. In some chapters the descriptions of pathology flit between human and experimental animals and between different animals in a way that could be confusing.

Whether these cavils are seen as important or are regarded as mere nit picking will depend on the temperament of the purchaser. I missed the balance and editorial assurance that I found in Heptinstall's third edition (and hope will be retained in the subsequent edition), but undoubtedly this book is well produced, good value for money, and provides extensive coverage of the subject.—D J EVANS, professor of histopathology, St Mary's Hospital Medical School, London

NOTED

HIV Infection: Teaching Slides. W Holmes, F Savage. In sets of 24 colour slides, with literature: HIVc—clinical manifestations; HIVe—prevention and counselling; HIVv—virology and transmission. Cost of each set inclusive of surface postage to any destination: self mounting £3.50+VAT; mounted £4.90+VAT; mounted in plastic file or file bar £9.80+VAT. Airmail postage plus 60p per set of 24 slides. Available from Teaching Aids at Low Cost, PO Box 49, St Albans, Hertfordshire AL1 4AX.

These slide sets were obviously designed with the Third World very much in mind, and there are excellent clear illustrations detailing the clinical definitions of AIDS and the physical signs. A simple view of

the virology of human immunodeficiency virus and its likely transmission is provided, and there is a series of attractive and simple slides discussing possible methods of prevention, both for doctors and for patients. Perhaps more emphasis should be given to condoms and the avoidance of other venereal diseases, but this is compensated for by the clear advice given on counselling and the likely reaction of a patient to news of the diagnosis.

The slides could also prove valuable in schools, for the teaching of preclinical medical students, and for paramedical staff. Each set comes with an excellent bibliography and a commentary for those lecturers whose detailed knowledge of AIDS is limited.

The Education of People with Profound and Multiple Handicaps: Resource Materials for Staff Training. J Sebba. (Pp x+160; figs; £16.95 paperback.) Manchester: Manchester University Press, 1989, in association with the British Institute of Mental Handicap. ISBN 0-7190-2596-6.

Aimed at improving professionals' understanding of the special needs of people with profound and multiple handicaps, the manual is directed particularly at nurses, teachers, and physiotherapists, though it may also be helpful to doctors concerned in organising medical care for such patients. There is a well presented section on assessment, and the section on teaching, which advocates some helpful methods, is a useful source of reference. Nursing students would gain valuable skills by working through the practical exercises.

Although the manual is designed as a package for a five day intensive course, with current lack of resources staff are unlikely to be able to go on such courses, and it would be valuable if the authors could adapt it for in house, in service learning by incorporating more practical exercises and making the tutor's notes available in a separate booklet with more detailed information.

