

From the start, distinguished physicians and surgeons were appointed to visit the hospital, though it was not expected that patients would be cured. At first there was little specialisation but in 1934 the need for a neurologist was recognised. James Collier was appointed but died soon after and was followed by Derek Denny-Brown, later professor of neurology at Harvard University. The hospital expanded as the decades passed, but its functions remained largely unchanged until the late 20th century when a blossoming of interest in more active approaches to the management of disability added the need for a commitment to research.

It is hard to imagine a greater contrast than between the hospital 25 years ago and today. Then, most patients were still resident and had little prospect of leaving. Now, there are units for profound brain injury (persistent vegetative state), neurobehavioural disorders (including Huntington's disease), respiratory paralysis and disability management. A Transitional Living Unit for patients, their carers and families aims at eventual return to the community. There are units for biomedical engineering and electronic assistive technology. There is rehabilitation for severe stroke, and routine rehabilitation is provided on a daily basis for the local community. A recent development has been the formation of a virtual Institute for Complex Neurodisability which through international collaborations provides an authoritative guide to best practice in neuro-rehabilitation and disseminates its approach through courses and learning programmes.

Making extensive use of the archives, Gordon Cook has documented the origins, growth and development of the hospital, revealing along the way something of the changing attitudes of society towards illness and disability and the responses to them over the past 150 years.

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Reference

- 1 Dickens C. *Household words* 1850.

Palliative neurology

Edited by Ian Maddocks, Bruce Brew, Heather Waddy, Ian Williams. Cambridge University Press, New York 2005. 276pp. \$55.

People in the advanced stages of long-term neurological conditions need high quality palliative care services.¹ For this to happen, models of care have to be further developed and resourced, and symptom management needs to advance through education and collaboration between specialist neurologists and palliative care providers. This book fills a gap in the literature by presenting an overview of current knowledge and practice, and the steps necessary for service development. It is intended for an international audience of health professionals and managers caring for those with advanced neurological conditions, particularly those in primary care and the whole range of medical specialties.

Easy to read, it does not make for easy reading. Those with advanced neurological conditions face challenges in every aspect of their lives. Many face the gradual onset of conditions which may take

some time to diagnose, and then follow a chronic course of increasing disability and progressive losses. Key relationships, employment, independence, and one's very sense of self may be threatened. Many symptoms, such as weakness and fatigue, are not amenable to quick and ready remedies and require management by multiprofessional teams with specialist skills – the availability of which is patchy. Facilities for respite and nursing care for more dependent patients may be inadequate, particularly for younger patients.

The range of life-threatening neurological conditions are covered, from the more frequent such as cerebrovascular disease and dementia, to relatively rare infections and inherited conditions. A key challenge facing the provision of palliative care for this group of patients and their carers is the relative infrequency with which most health professionals encounter many neurological conditions. A primary healthcare team may only care for a patient with motor neurone disease or primary brain tumour once in many years. Few health professionals outside specialist neurological centres will care for sufficient patients to develop the necessary palliative care expertise, and dedicated community services for this group are also rare. Educational resources, such as this book, are desperately needed.

The book is well structured into five sections. Policymakers and service managers would be advised to read from start to finish. Clinicians are more likely to dip in and out. Sections one and three, on the principles of palliative management, and the medical background to major neurological conditions requiring palliation, assume little or no prior knowledge. These sections clearly present the principles of palliative care and the necessary context for decision-making. The importance of recognising transition points as illnesses progress, and deciding when to adopt a more palliative approach, is stressed: 'Now comes a time...to cease striving for function, and focus on whatever brings pleasure or relief'. It is acknowledged that such transition points, for example in Parkinson's disease, may be hard to spot. The predictability of disease progression encourages future care planning, particularly where progressive cognitive impairment is a feature. Such discussions are hard, and the communication section provides valuable pointers on how to manage uncertainty and to maintain realistic hope where possible. Family and carers face huge hurdles, and careful attention is paid to their needs, throughout the illness and into the bereavement period.

Section two, on major discomforts in advanced neurological disease, draws together both specialist palliative care and neurological practice and promises to be informative for all, regardless of background. It is encouraging to see what can be achieved by true multiprofessional care, vital for assessment, treatment and future care planning.

The fourth section on ethical issues is a little disappointing. The major ethical questions are outlined, but not explored in depth. This lack of specificity may be due to the international perspective, as the interpretation and expression of ethics into law varies widely between countries. An alternative explanation is that the subject matter – including consent and decision-making, advance directives, proxy decision-making, ethical issues in states of disordered consciousness, terminal sedation and euthanasia – is simply too wide and important to be covered in one short chapter.

The final section provides checklists for service delivery and further resources and references. Advice covering practical aspects of

home care is disarmingly simple, and yet may easily be overlooked. It is these aspects of care which can make such a difference to success of care at home, and quality of life. Characteristics of an effective palliation service are summarised, and offer a framework for service review.

This is a book whose time has come. It is well written, intensely practical and largely free of jargon. It is refreshing that it does not preach, and provides practical pointers for the way forward. Sufficient information is provided to support shared decision-making with patients and their carers by specialists and non-specialists alike. The take home message is that the care of this group of patients has been patchy and fragmented and that we can do better:

The model of care being proposed is subversive, in that it refuses to recognise some of the boundaries within health care that have formerly separated hospital from home, doctor from nurse, specialist from generalist, modern medicine from traditional and alternative practice.

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Reference

- 1 Department of Health. *National Service Framework for long term (neurological) conditions*. www.dh.gov.uk/policyandguidance/healthandsocialcare/topics/longtermconditions/fs/en (accessed 4 July 2006).