Palliative Neurology

Palliative care affirms the value of holistic support for persons facing death from advanced disease. Its concern embraces the physical, emotional and spiritual components of distress and suffering, and extends to family members, who experience great anxiety and often are forced to undertake a considerable burden of care. Increasingly the approach of palliative care is seen as relevant not only to terminal cancer but also to many other conditions that cannot be cured or lead to death. This handbook provides succinct and practical advice on the management of the major neurological disorders in both their supportive and terminal phases, recognizing that these conditions are increasing in prevalence in virtually every society along with a growing proportion of elderly persons. It demonstrates how the discomforts met with in dementia, stroke, Parkinson's disease, amyotrophic lateral sclerosis (ALS), Huntington's disease, muscular dystrophies and multiple sclerosis benefit also from a comprehensive approach to palliation by interdisciplinary teams.

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Show that you care

One thing I have learned is that the best thing that anyone can do for the dying (or bereaved) individual is to show that you care. … You don't even have to mention the problem at hand, just show the person that you are thinking about them and therefore are helping to shoulder their burden. As neurologists … we are obviously providing a lot of comfort for our patients just by seeing and talking to them, even in hopeless cases.

Spoken by distinguished neurologist P.G. McManis in the final weeks of his life, prior to his death from oesophageal cancer.
Quoted in obituary by C. Michel Harper. *Neurology* 2005; 64: 598–9.

Palliation in terminal illness

The work of providing palliation includes the attempt to understand the background of hopes and relationships and activities that have, in the past, motivated the one who now faces the loss of much that has constituted personal self-image and well-being. To help an individual hold on to qualities such as dignity, determination, courage, confidence and patience in the face of uncertainty and unpredictability, recurrent relapse or progressive deterioration is a core clinical responsibility; to recognize and encourage a patient's capacity for humour and love may bring more well-being than any number of interventions focused on specific symptoms.

Ian Maddocks

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Foreword

A scan through recent literature in the two fields of palliative medicine and neurology suggests little overlap in their clinical practice. In the three major palliative care journals published, respectively, in UK, Canada and USA, the primary focus is advanced cancer. Fewer than 5% of papers deal with non-cancer conditions, and most often these are respiratory, cardiac and renal diseases, with only ALS representing neurology care. Similarly, published texts and articles in neurology concern themselves primarily with diagnosis, investigation and active treatment of disease, and include relatively little about end-of-life care and effective symptom management in advanced disease.

A small number of exceptions exist. The publication in 2004 of the text '*Palliative Care and Neurology*', a multiple author work coordinated by neurologist Raymond Volz, reflected a new awareness among neurologists that their responsibility in clinical care ought to extend beyond the major hospital, and ensure effective support and symptom management in home and chronic care settings. A little earlier, in 2001, an issue of *Neurology Clinics* was devoted entirely to palliative care. Although selective in the number of conditions it addressed, it represented a new direction in the field.

There are readily discernible trends in modern neurology practice that will make it difficult for specialist neurologists to be active in promoting and engaging in the delivery of palliation support for persons affected by chronic neurological conditions. The number of those affected persons, especially among the aged, increases steadily, while the number of specialist neurologists is relatively small, and they are busy in office and hospital practice. The provision of palliation support is often necessarily prolonged and burdensome, and falls more on the larger number of general physicians, gerontologists, family physicians and the various paramedical professions. Increasingly, moreover, neurology divides into subspecialities, and in their more narrow areas of interest its practitioners are excited by new potentials for diagnosis and management, occasioned by innovative radiological and stem cell technologies and novel medications. All this makes training in palliative care (and even in general medicine and general neurology?), an option fewer trainee neurologists will see as necessary.

This text contends that the approach and skills of palliative care are relevant and readily transferable to incurable non-cancer conditions, whether for their terminal stages or during the period before the terminal phase is reached. Given the importance of such conditions in neurology, therefore, it behoves the specialist neurologist to accept a responsibility to know something of the new discipline of palliative care, and to be aware of what its approach and operation – palliation – can contribute to the quality of life of neurology patients. Neurologists should also understand how to engage and, if necessary, supervise the deployment of palliation team expertise for the benefit of both individual patients and attending family members.

The potential readership for this text includes all members of such teams – all the professional categories that contribute to care for such persons.

Neurodegenerative conditions are not generally well understood by the lay public, yet families necessarily undertake a major responsibility for care, often over a prolonged period. Family carers of patients may also find this text useful, whether for negotiating care options with professional staff or for advocacy with community resources or employers.

The emphasis is on the maintenance of comfort and function in the face of physical and mental deterioration; the neurological conditions are arranged with relatively brief introductions, giving emphasis to the management of major symptoms. The attitude to be encouraged is one of helping persons live their lives as normally as possible rather than becoming the subjects of 'treatment'.

The plan to write this small text arose from contact with colleagues at Mie University Hospital, Tsu City, in Japan. In that Prefecture, there is a higher incidence of amyotrophic lateral sclerosis (also called motor neurone disease) than in most other parts of the world. Neurologists there, especially Dr Yugo Narita, Dr Norikazu Kawada and their chief, Prof. Shigeki Kuzuhara, encouraged me write to about palliation in neurology, with a view to having the text translated to Japanese. I am grateful to them for this encouragement and support.

As principal author, I must accept responsibility for any errors or deficiencies. Coming to this theme as a palliative care physician based in Adelaide, Australia, I am ignorant concerning specialist neurology. The faults you find here are mine. But I acknowledge with gratitude the advice and the contribution of my consultant fellow–authors who represent a

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spectrum of neurological practice: Prof. Bruce Brew, Chairman of Neurology at St Vincent's Hospital, Sydney; Dr Heather Waddy, neurologist in private consulting practice in Adelaide and Dr Ian Williams, a consultant neurologist with a particular interest in people affected by chronic neurological conditions and their support in community settings in the UK. Diana Maddocks provided consistent support, critical review and meticulous proof reading.

Ian Maddocks
Adelaide, Australia
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Note on drugs and abbreviations

The drugs listed throughout the text, and their formulations, are mainly those currently available in Australia, with a few additions drawn from English texts. Due to the variation in drug company names, generic names are used. The doses suggested are for adults.

There are many medications available for the management of symptoms in neurological practice, and frequently several will be suggested as alternatives for treating a particular discomfort. An important part of the practice of palliation is the recognition of individual patient variation, and of the fact that rarely will one medication be satisfactory for assisting comfort in all the patients who have a common symptom.

Each physician will have favourite choices, but each should also be prepared to change and to experiment with possible alternatives.

Symptoms are often multiple, and the list of medications for any patient may be long. While every clinician wishes to avoid unnecessary prescribing and to avoid polypharmacy, it is inevitable that many individuals in the advanced and terminal stages of a neurological illness will be receiving, at the one time, medications for pain, nausea, constipation, anxiety and depression, muscle dysfunction and sleeplessness. Swallowing is often impaired, and formulations that are available for parenteral use, and particularly for S/C injection in the home via an indwelling cannula, assume a special importance.

Where a drug is listed, its various formulations are appended with reference to the dose and type of each.

Using morphine as an example:

- *morphine 1, 2, 5 and 10 mg/ml susp*. indicates that liquid preparations of morphine are available as 1 mg/ml, 2 mg/ml, 5 mg/ml and 10 mg/ml;
- *morphine 5, 10 and 15 mg tab*. 10–20 mg 4 hourly prn indicates the several strengths of immediate release morphine that are available, and the dose range 10–20 mg is suggested for a particular use;

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- *morphine 5, 10, 15 and 30 mg/ml inj. (sulphate); 120 mg/1.5 ml (tartrate).* 20–500 mg by S/C infusion per 24 h. Indicates various ampoules available for parenteral use, and the range of doses that may be necessary when using a 24 h S/C infusion.

CR or SR: controlled- or sustained-release formulation; bd: twice daily; tds: three times a day; qid: four times a day; prn: as required; cap.: capsule; inj.: injection; supp.: suppository; S/C: subcutaneous route; I-V: intravenous route.