This slim, hardcover book is a collection of multi-authored chapters written by physicians and other healthcare professionals who clearly manage ALS patients on a daily basis. The title of the book may be a bit deceptive to some readers. Many of us, especially those west of the Atlantic, have understood ‘palliative’ to indicate terminal treatment of the dying patient, most commonly the patient with end-stage cancer. Thus, Palliative Care in ALS might have referred to the comfort care provided in a patient’s final days or weeks by a hospice facility. However, the editors of this book make it clear from the start that, to them, ‘palliative care’ is a term that encompasses the wide range of clinical management that begins when the diagnosis of ALS is first presented to the patient and family. Thus, there is an overview chapter on “Palliative Care”, and a later chapter, “End of Life Care in ALS”, which defines specific terminal management issues. The editors repeatedly emphasize the multidisciplinary team approach to ALS management, and offer this monograph as a reference to all healthcare professionals involved in ALS care.

Each of the eleven chapters, while loosely connected, can stand alone and be read separately. Five chapters are further divided into subchapters or appendices, each with separate authors. Despite the potential for multiple inconsistencies, missed cross-references, unequal prose, and topic overlap, this monograph on ALS has come through with flying colors. Minor problems and annoyances to the reader are overshadowed by an honest, refreshing, and down-to-earth approach to almost every facet of ALS management.

What distinguishes Palliative Care in ALS from other recent books is that it identifies the difficult management issues experienced by the medical professional ‘in the trenches’, and gives very specific guidance (with appropriate references and evidence-based data) to help that professional deal with each issue. For instance, in the second chapter, “Palliative Care”, David Oliver reviews reasons that patients may request euthanasia. Inordinate fear of pain and choking near death is a common reason, and can be dealt with by proper patient counseling. “Breaking the News”, a chapter by Borasio, Sloan, and Pongratz, is an excellent exposition on the what, when, and how of revealing the diagnosis and describing the disease during the patient’s initial visits. Issues important to discuss include the connection between disease onset and antecedent events such as surgery, the pros and cons of riluzole therapy, unconventional treatments, and referrals for expert second opinions. A more careful approach to the discussion should be made if ALS is only suspected, but the possibility of ALS should be mentioned. The authors provide specific suggestions on how to discover how much the patient wants to know about the disease. Even a “hierarchy of euphemisms” is provided to the reader whose difficult task is to explain, in a caring manner, that ALS is incurable and will continue to progress. An appendix to this chapter by Borasio and Voltz, based on their work on the topic, provides an ALS disease-specific advance directive in addition to important guidelines for end-of-life decisions. Their discussion about the benefits of advance directives is honest, and cites the literature to substantiate a warning that advance directives are not ‘the solution’ for achieving an improvement in the patient’s quality of life.

A major chunk of the book (at least 20%) is a single chapter on “The Control of Symptoms”, particularly dyspnea and dysphagia, with divided sections written by experienced clinicians. The discussion of tests to measure respiratory weakness was one of the few parts of the book with a heavier, more technical approach. Unfortunately, most of the tests described (such as sniff nasal pressure, trans-diaphragmatic pressure, and cervical magnetic stimulation) are not commonly used in routine clinical settings. The benefits, problems, and realities associated with non-invasive and tracheostomy ventilation are cogently presented. While patient ‘autonomy’ and ‘decision-making’ are clearly desirable in ventilator choices, the patient’s ability to pay may be just as important. Deborah Gelinas meticulously describes the elaborate preparations and training necessary to set up long-term tracheostomy ventilation at home.

One superb chapter, “Psychosocial Care” by Gallagher and Monroe, deals with a host of crucial management issues that are often not sufficiently addressed in the busy neurology clinic. The authors provide practical advice on assessing an individual patient without making stereotyped assumptions, maintaining hope, returning a sense of control to the patient, dealing with the patient’s denial, addressing spiritual concerns, dealing with needs of caregivers and children, and discussing intimacy and sexuality.

Chapter 6, “Multidisciplinary Care”, has some excellent
sections. The section on speech and language therapy by Scott and Foulsum provides a superb description of the multifaceted communication impairment in ALS. The authors state something which is not emphasized enough in books on ALS: there can be negative effects of the repetitive speech and mouth exercises commonly prescribed by therapists unfamiliar with this disease. The psychologist Jos Kerkvliet critically evaluates the early literature on the psychological impact of ALS in the patient, and finds it grossly wanting. This, he wisely notes, probably has resulted in an underestimate of the need for psychosocial intervention in this disease. The individuals of the ALS team can provide needed psychosocial support for patient and family. They must also meet regularly to coordinate care and to support each other in the face of the often complicated interactions with some ALS families.

There are some deficiencies in the book which call for improvement. Most of the authors are British or from the former British Commonwealth. Hence, some of the healthcare solutions offered are unachievable in non-British countries. A “specialist palliative care team”, as described in Chapter 2, does not usually exist in most American medical centers. The “seamless care” described between the general practitioner (GP), the ALS team, and the palliative care team is just not possible in our world of Health Maintenance Organizations (HMOs), where less care rather than more care is the rule. In the USA, the patient makes respiratory decisions with the help of the neurologist and the pulmonologist, and not with the palliative specialist.

A section on rehabilitation in Chapter 6 (“Multidisciplinary Care”) is more confusing than helpful. In a chapter that is seemingly discussing a well-run ALS team led by a neuromuscular specialist, this section describes yet a third team (in addition to the ALS team and the palliative-care team), the “rehabilitation consultant-led service”, staffed by, more or less, the same professionals found in the other previously described teams for patient care. The purported aims of such a rehabilitation service – supporting the patient both in outpatient and inpatient settings, linking with the neurologist, helping with research studies, supporting the patient’s GP – may be possible in the UK, but can rarely be fully or even partially attained by a rehabilitation service in the USA.

Chapter 7, “Models of Care”, purports “to show the diversity of care that may be offered within different cultures.” Separate essays from ALS specialists from the UK, the USA, Japan, the Netherlands, and South Africa are presented. While such a chapter has a great potential for educating an international readership, I believe more could have been written regarding the state of ALS care and management in each country. We are treated to the various goals and aspirations of the different national ALS/MND associations, but are told rather little about the current problems and realities in delivering ‘state of the art’ management in different parts of the world. A chapter such as this is a welcome addition to our knowledge, and I hope to see more in the future comparing the realities of care delivery across the globe.

Palliative Care in ALS, rather than simply giving an extended review of the ALS literature, provides both evidence-based knowledge and thoughtful insight about a field that often takes years to master. We, as ALS practitioners, know that there is presently no curative or restorative treatment. This leaves us with symptomatic or palliative therapy, and a certain urgency to provide this therapy when it can be effective. As a patient poignantly describes in a brief chapter of the book on personal experiences, “The main frustration with this disease seems to be that people often react too late to cope with my immediate needs...” Let us not react too late in providing palliative care for our patients.

Jerry Belsh MD
Neuromuscular and ALS Center
UMDNJ Robert Wood Johnson Medical School
New Brunswick, NJ, USA