

Contents

Foreword [xiii]
Note on drugs and abbreviations [xvii]

Section I Palliative management [1]

1 Introduction to palliation [3]

- Palliation, palliative care and palliative management [3]
- ‘Hospice’ and palliation in advanced cancer [4]
- Palliative management in neurology: an increasingly recognized need [5]
- Different trajectories of care for cancer and neurological disease [6]
- Palliation and neuroscience [8]

2 Characteristics of palliation [12]

- It is patient-centred [12]
- It provides truthful information concerning disease status and prognosis [14]
- It offers support for family members [14]
- It maintains comprehensive care [16]
- It ensures continuity of care [16]
- It relies on teamwork and networking [17]
- It adjusts its approach in recognition of deterioration [18]
- It includes bereavement support [18]

3 Nodal points in decision-making [20]

- Introducing a palliative management approach [20]
- Introducing palliative interventions [21]
- Timing the onset of the terminal phase [22]
- Referral to a palliative care team [23]
- Writing a ‘do not resuscitate’ order [23]
- Introducing bereavement care [24]

viii Contents

- 4 Common deficiencies in palliative management [25]
 - Poor communication [25]
 - Rigid professional boundaries [29]
 - Ineffective networking [30]
 - Poorly developed teamwork [31]
 - Failure to maintain an accessible clinical record [32]
- 5 Common themes in palliation practice [33]
 - Holism [33]
 - Recording of observations [34]
 - Finding the best answer: innovation and experiment [36]
 - Appropriate therapy regimens [36]
 - Support of carers [37]
 - Working alongside complementary and alternative medicine [40]

Section II Major discomforts in advanced neurological illness [43]

- 1 Fatigue [45]
- 2 Problems with muscles and movement [47]
 - Weakness [47]
 - Disorders of muscle tone and contraction [49]
 - Seizures [55]
 - Involuntary movements [59]
 - Drug-induced movement disorders [61]
 - Syncope and falls [63]
- 3 Bulbar symptoms [65]
 - Impaired speech [65]
 - Dysphagia [65]
 - Fear of choking [68]
 - Drooling [68]
- 4 Respiratory symptoms [70]
 - Dyspnoea [70]
 - Hypoventilation [71]
 - Assisted ventilation [72]
 - Cough [74]
 - Retained secretions [75]
- 5 Gastrointestinal symptoms [77]
 - Dry mouth [77]
 - Candida infection [78]
 - Dysphagia [78]
 - Gastro-oesophageal reflux [78]

- Nausea and vomiting [79]
- Bowel dysfunction [82]
- Nutrition and hydration [86]
- 6 Urological symptoms [89]
 - Urinary retention [90]
 - Urgency and bladder spasm [91]
 - Urinary incontinence [92]
 - Sexual dysfunction [93]
- 7 Pain [95]
 - Types and mechanisms of pain [95]
 - The importance of early control of pain [96]
 - Pain in neurology [97]
 - Management of nociceptive pain [100]
 - Neuropathic pain [105]
 - Opioids in chronic pain [107]
 - Central pain [108]
 - Other strategies for difficult pain [109]
- 8 Cognitive, behavioural and psychological symptoms [111]
 - Cognitive impairment [111]
 - Delirium, agitation and restlessness [112]
 - Depression [114]
 - Anxiety [115]
 - Insomnia [116]
 - Grief and bereavement [118]
- 9 Miscellaneous symptoms [120]
 - Temperature control and pyrexia [120]
 - Sweating (hyperhidrosis) [120]
 - Pruritis [121]
 - Hiccups [122]
 - Headache [123]
- Section III Major neurological conditions requiring palliation [125]**
 - 1 Cerebrovascular disease: stroke [127]
 - Supportive phase [127]
 - The terminal phase [130]
 - 2 Demyelinating disease [132]
 - Supportive phase [133]
 - The terminal phase [139]

x Contents

- 3 Parkinson’s disease and related disorders [142]
 - The supportive phase [142]
 - The phase of transition [145]
 - The terminal phase [146]
- 4 Dementia [148]
 - Symptom management in dementia [149]
 - The terminal phase [152]
- 5 Amyotrophic lateral sclerosis (motor neurone disease) [155]
 - The palliative approach [155]
 - Telling the bad news of ALS [156]
 - Supportive phase [158]
 - The terminal phase [163]
- 6 Incurable Infections of the nervous system [166]
 - Rabies [166]
 - Creutzfeldt–Jakob disease [168]
 - HIV-acquired immunodeficiency syndrome [170]
 - The supportive phase of HIV infection [171]
 - The need for consistent supervision [173]
 - The terminal phase of HIV-AIDS [174]
- 7 Muscular dystrophy [178]
 - The supportive phase of care [178]
 - Transition to the terminal phase: the issue of ventilation [179]
- 8 Neuropathies [183]
- 9 Huntington’s disease [186]
 - Supportive care of Huntington’s disease [187]
 - The terminal phase [188]
- 10 Cerebral neoplasms [191]
 - The supportive phase [192]
 - The terminal phase [194]
- 11 Sequelae of traumatic brain injury [197]
 - The supportive phase [197]
 - The terminal phase [198]
- Section IV Ethical issues [201]**
 - 1 Consent and decision-making [203]
 - 2 Advance directives [205]

- 3 Proxy decision-making [207]
- 4 Ethical issues in states of disordered consciousness [209]
 - Coma [209]
 - Persistent vegetative state (PVS) [209]
 - Minimally conscious state (MCS) [212]
 - Locked-in syndrome (LIS) [212]
 - The management of PVS [214]
- 5 Terminal sedation [218]
- 6 Euthanasia [219]
- Section V Appendices [223]**
 - 1 Practical aspects of home care [225]
 - Necessary supports [225]
 - The home environment [226]
 - Education for home carers [227]
 - Common questions raised by home carers [227]
 - Advantages of home care [228]
 - The importance of a record in the home [228]
 - 2 Characteristics of an effective palliation service [230]
 - An accepted place in National Health Planning [230]
 - Palliation services are organized on a population basis [231]
 - Palliation teams are established and maintained [231]
 - Education for palliation is established [232]
 - 3 Suggested further reading [234]
 - General texts [234]
 - Web sites [235]
 - Journal articles [236]
 - 4 Medications referred to in the text [241]
 - Index* [253]