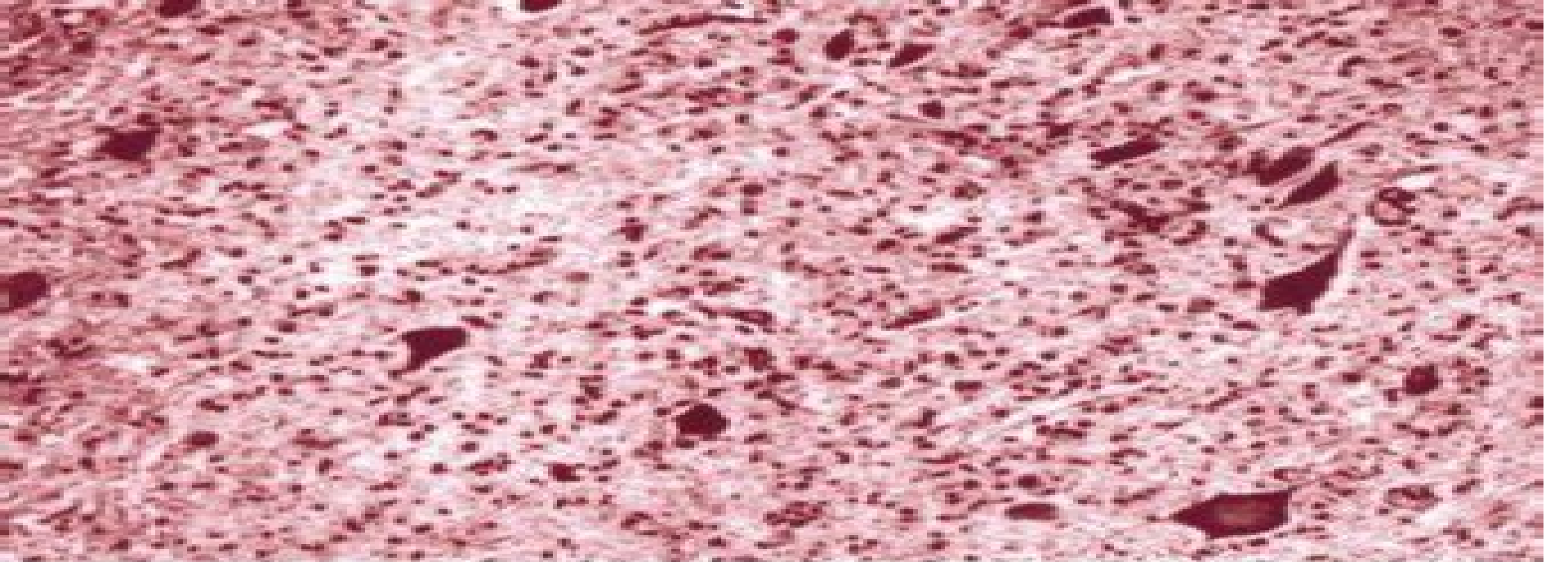


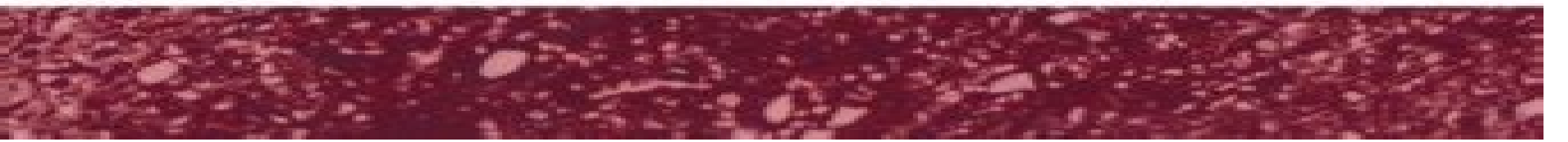


Palliative Care in Amyotrophic Lateral Sclerosis

FROM DIAGNOSIS TO BEREAVEMENT

second edition

EDITED BY DAVID OLIVER | GIAN DOMENICO BORASIO | DECLAN WALSH



Palliative Care In Amyotrophic Lateral Sclerosis

**David Oliver, Gian Domenico
Borasio, Declan Walsh**



Palliative Care In Amyotrophic Lateral Sclerosis:

Palliative Care in Amyotrophic Lateral Sclerosis (motor Neurone Disease) David Oliver, Gian Domenico Borasio, Declan Walsh, 2000 Although new treatments for amyotrophic lateral sclerosis motor neurone disease are being developed these at present offer only the potential to slow the disease process Therefore a palliative care approach to the care of the patient and their family is at the center of good clinical practice in ALS MND This book aims to provide an evidence based guide to the care of people with ALS MND including the control of symptoms the psychosocial care of patients and their families and care in bereavement The palliative care approach to the care of ALS MND is outlined and the role of the multidisciplinary team emphasized The international authorship are from many different disciplines and are all closely involved in the care of ALS patients giving a depth of practical knowledge and experience and allowing a comparison of the differences across cultures social circumstances health care systems and nations All contributors are clinicians involved in the care of people with ALS MND and they are able to provide clear guidelines of the care throughout the disease process from telling of the diagnosis to death The experience of patients and families are considered and case studies are provided to show the practical applications of the theoretical knowledge An evidence based approach grounded in day to day care of patients is used Different models of care are explored and the interaction of palliative care with other treatment regimes is addressed as the experience from the treatment of cancer has shown that there may easily be areas of conflict and confusion if there is a lack of clarity in the care provided for patients The book aims to provide a reference for all involved in the care of patients with ALS MND including neurologists general physicians rehabilitationists paramedical staff general family practitioners and specialist palliative care teams The care of a patient with ALS MND and their family is often a challenge but one all should take up so that patients can live life as fully as possible

Palliative Care in Amyotrophic Lateral Sclerosis David Oliver, Gian Domenico Borasio, Wendy Johnston, 2014-03-20 Amyotrophic Lateral Sclerosis ALS or motor neurone disease is a progressive neurodegenerative disease that can cause profound suffering for both the patient and their family Whilst new treatments for ALS are being developed these are not curative and offer only the potential to slow its progression Palliative care must therefore be integral to the clinical approach to the disease Palliative Care in Amyotrophic Lateral Sclerosis From diagnosis to bereavement reflects the wide scope of this care it must cover not just the terminal phase but support the patient and their family from the onset of the disease Both the multidisciplinary palliative care team and the neurology team are essential in providing a high standard of care and allowing quality of life both patient and carer to be maintained Clear guidelines are provided to address care throughout the disease process Control of symptoms is covered alongside the psychosocial care of patients and their families Case studies are used to emphasise the complexity of the care needs and involvement of the patient and family culminating in discussion of bereavement Different models of care are explored and this new edition utilizes the increase in both the evidence base and available literature on the subject New topics discussed include

complementary therapies personal and family experiences of ALS new genetics research and updated guidelines for patient care to ensure this new edition remains the essential guide to palliative care in ALS **Palliative Care in Amyotrophic**

Lateral Sclerosis David Oliver, Gian Domenico Borasio, Declan Walsh, 2006 This volume provides an evidence based guide to the care of people with ALS MND including the control of symptoms the psychosocial care of patients and their families and care in bereavement *Palliative Care in Amyotrophic Lateral Sclerosis* David Oliver, Gian Domenico Borasio, Wendy

Johnston, 2014 This volume provides an evidence based guide to the care of people with ALS MND including the control of symptoms the psychosocial care of patients and their families and care in bereavement **Amyotrophic Lateral Sclerosis**

Hiroshi Mitsumoto, 2012-12-10 Amyotrophic Lateral Sclerosis A Patient Care Guide for Clinicians is a practical reference for clinicians caring for ALS patients that brings together the collective wisdom of those at the forefront of patient oriented research and practice The book compiles recent findings of both evidence based and experience based research to provide clinicians with tools that improve quality and length of life for people with ALS To present a truly multidisciplinary approach to ALS this book mirrors the organization of a large clinic with separate departments working collaboratively It begins with a review of current understandings of ALS including diagnostic criteria genetic and sporadic subtypes epidemiology co morbidities and prognosis From there the book is divided into chapters that include neurological assessment nursing care and coordination speech and swallowing interventions nutrition and nutrition therapy physical therapy occupational therapy respiratory therapy assistive technology social work practice related to ALS and web based resources Each chapter is led by experts from that discipline who review evidence and experience based care options In addition the entire North American ALS Research Group ALSRG has had a chance to weigh in as well making this a unique and well rounded resource The book addresses everything from breaking the news of an ALS diagnosis to end of life care and bereavement By putting experts in conversation with each other both within and across individual disciplines Amyotrophic Lateral Sclerosis A Patient Care Guide for Clinicians provides comprehensive real world care information that can't be found anywhere else Amyotrophic Lateral Sclerosis features A practical reference for all members of the ALS care team covering everything from breaking the news to end of life care and bereavement Chapters that mirror the organization of large multi disciplinary ALS clinics and include pertinent information for each member of the care team Evidence and experience based findings provide current scientific and clinical consensus and a forum for real world care options *Amyotrophic Lateral Sclerosis* Francesco

Pagnini, Zachary Simmons, 2018-02-16 Amyotrophic Lateral Sclerosis ALS is a devastating neurodegenerative disorder with a progressive and fatal course with no known medical therapies that can reverse the disease or halt its progression Palliative care is the mainstay of disease management aimed at maximizing Quality Of Life QOL for the patient and caregiver Clinicians caring for patients with ALS need to understand complex psychological issues in the patient and caregiver including depression anxiety hopelessness and wish for hastened death physician assisted suicide They also need to confront the

psychological implications of rapidly advancing genetic research the impact of cognitive and behavioural dysfunction in a sizable minority of ALS patients and caregiver burnout Healthcare providers can optimize care by better understanding not only these factors but by learning how to facilitate their management with problem solving coping techniques and with psychologically based approaches such as mindfulness and other non pharmacological approaches aimed at maximizing QOL Amyotrophic Lateral Sclerosis Understanding and Optimizing Quality of Life and Psychological Well Being provides a detailed review and evaluation of ALS presented in a comprehensive and integrated fashion The book achieves this through detailed and up to date information about the current state of knowledge in this field It also offers new insights regarding future directions for research This book will provide clinicians with a comprehensive description of the psychological aspects of ALS and their management and incorporates chapters written by recognized scholars in their respective fields **Stepping into Palliative Care** Jo Cooper,2017-11-22 The second edition of this highly successful text has been greatly expanded and updated and is now available in two companion volumes Stepping into Palliative Care 2 focuses on symptom management emergencies bereavement and spirituality This practical guide with numerous examples illustrations and thorough references includes boxes tables figures self assessment questions points for reflection and case studies to aid comprehension The clear layout and straightforward approach is ideal for all those working in community care including nurses nursing students doctors and social workers and those already involved to some extent in palliative care

Amyotrophic Lateral Sclerosis, Second Edition Robert H. Brown,Michael Swash,Piera Pasinelli,2021-12-24 Amyotrophic lateral sclerosis or motor neurone disease is one of the most debilitating and devastating of the neurological diseases The only comprehensive textbook available on the topic this completely reorganized and expanded new edition examines all aspects of ALS from pathology to patient care and provides the reader with a ready reference to help with the difficulties encountered in patient diagnosis and treatment Undoubtedly an important work in the field this book will be of great interest to clinical neurologists and trainees and to all those concerned with the care of people with ALS *Palliative Care in Japan for Individuals with Amyotrophic Lateral Sclerosis* Mitsuko Ushikubo,2017 Palliative care has not been focused on noncancer yet Amyotrophic lateral sclerosis ALS is a fatal rapid progressive and intractable neurodegenerative disease Individuals with advanced ALS cannot perform activities of daily living by themselves but their mental awareness remains clear Individuals with ALS experience various pain soon after diagnosis and a multidisciplinary team approach is needed because their pain can become complicated Caring for individuals with ALS needs to both start and end with palliative care in the physical psychological social and spiritual aspects The Japanese Ministry of Health Labour and Welfare enacted the Principles of Policy for Rare and Intractable Diseases nanbyo which were the first set of such principles to be established in the world This chapter describes the palliative care in Japan from the perspectives of nursing and nanbyo measures Also three unique characteristics of ALS care in Japan are mentioned the high level of disagreement between patients and family the high rate

of ventilator use compared with Western countries and the low consumption of morphine Healthcare practitioners need to apply the notion of the total pain to provide palliative care to individuals with ALS and acknowledge the challenges of providing timely symptomatic management

Palliative Care in Neurology Raymond Voltz, 2004 Palliative care is the duty of every neurologist however to date this has not been a standard feature of neurological practice or training This book helps define a new field namely palliative care in neurology It brings together all necessary information for neurologists caring for a patient with advance disease Palliative care is an approach to the management of patients with life threatening illness that attempts to enhance comfort relieve psychosocial and spiritual distress assure respect for decision making provide support for the family and prepare the patient and family for the end of life This unique book covers each of the many dimensions of palliative care as they relate to patients with advanced neurological disorders Basic principles of palliative care and specific ethical issues such as euthanasia food and hydration and advance directives are covered The needs of populations with specific neurological disorders are described and the management of symptoms that are common to all is explored in detail Each chapter introduces its topic using a case report that may be used directly for teaching purposes The authors have put together an invaluable resource which lays the foundation for further research in the field

Amyotrophic Lateral Sclerosis Martin Henrik Maurer, 2012-01-20 Though considerable amount of research both pre clinical and clinical has been conducted during recent years Amyotrophic Lateral Sclerosis ALS remains one of the mysterious diseases of the 21st century Great efforts have been made to develop pathophysiological models and to clarify the underlying pathology and with novel instruments in genetics and transgenic techniques the aim for finding a durable cure comes into scope On the other hand most pharmacological trials failed to show a benefit for ALS patients In this book the reader will find a compilation of state of the art reviews about the etiology epidemiology and pathophysiology of ALS the molecular basis of disease progression and clinical manifestations the genetics familial ALS as well as novel diagnostic criteria in the field of electrophysiology An overview over all relevant pharmacological trials in ALS patients is also included while the book concludes with a discussion on current advances and future trends in ALS research

Respiratory Management of ALS: Amyotrophic Lateral Sclerosis Lee Guion, 2010-10-25 The Respiratory Management of Motor Neuron Disease brings together the latest research expert opinions and treatment options for respiratory symptom management It provides a detailed step by step approach to assessment of upper and lower airway structures and how motor neuron loss impairs function Treatment options emphasize symptom management and enhanced quality of life Palliative care end of life decision making and long term mechanical ventilation in patients with MND ALS are included This textbook encourages critical thinking through 1 inclusion of researchable questions at the end of chapters and 2 discussion of different approaches to patient assessment and symptom management when medical evidence is lacking Students will be encouraged to use their understanding of anatomy physiology pharmacology lung expansion and secretion mobilization techniques to review support or challenge current

practices in MND ALS Respiratory therapy students respiratory care practitioners nurses in neurology clinics primary care physicians and pulmonologists whose practice includes patients with motor neuron disease will all benefit from the detailed review of bulbar and thoracic muscles loss of function and treatment recommendations Psychological Issues in Amyotrophic Lateral Sclerosis Francesco Pagnini, Gianluca Castelnuovo, 2016-03-02 Amyotrophic lateral sclerosis is a fatal and progressive disease characterized by progressive muscles weakness with consequent loss of physical capacities Patients become relentlessly immobile and in the late stages of the disease develop a locked in state in which only residual muscular movement is possible but the intellect and the personality usually remain unimpaired At now there is no cure for ALS The psychological impact of the disease is huge on both patients and caregivers Aim of the present Research Topic is to collect new evidence about quality of life depression anxiety pain spiritual and existential issues hope and hopelessness in the ALS field with attention to both patients and their caregivers Emphasis will be provided to the investigation of psychological support and the possible role of psychologists in this challenging field Keywords Amyotrophic Lateral Sclerosis Health Psychology Clinical Psychology Motor Neuron Disorder Quality of Life Subtopics The subtopics to be covered in the Research Topic include but not limited to 1 Assessment of psychological variables in ALS 2 Quality of life during the course of the illness 3 Impact of technological assistance to illness wheelchairs NIV 4 Interfaces among biological psychosocial and social factors 5 Psychological and psychotherapeutic interventions 6 Couple and family relationships 7 Research methodology measurement and statistics 8 Cultural and social features of ALS 9 Professional issues including training and supervision 10 Implications of research findings for health related policy Physical Management in Neurological Rehabilitation Maria Stokes, 2004 Building upon the success of the first edition of this popular book the new edition of Physical Management in Neurological Rehabilitation has been completely up dated and revised to reflect changes in practice today The authors consider the theoretical basis and scientific evidence of effective treatment taking a multidisciplinary problem solving approach to patient management which involves patients and carers in goal setting and decision making Book jacket

Ethical Issues in Neurology James L. Bernat, 2008 Written by an eminent authority from the American Academy of Neurology's Committee on Ethics Law and Humanities this book is an excellent text for all clinicians interested in ethical decision making The book features outstanding presentations on dying and palliative care physician assisted suicide and voluntary active euthanasia medical futility and the relationship between ethics and the law New chapters in this edition discuss how clinicians resolve ethical dilemmas in practice and explore ethical issues in neuroscience research Other highlights include updated material on palliative sedation advance directives ICU withdrawal of life sustaining therapy gene therapy the very low birth weight premature infant the developmentally disabled patient informed consent organizational ethics brain death controversies and fMRI and PET studies relating to persistent vegetative state **Neuropalliative Care**, 2022-08-31 Neuropalliative Care Part One Volume 190 covers a type of care that is given when there is no cure for the

neurological disorder and the patient is in distress It provides a scholarly background of neuropalliative care from historic underpinnings to its practice in various geographical regions along with best practices for specific neurological disorders It covers the work of multi or interdisciplinary teams whose care is intended to make the patient as comfortable as possible and includes partners and families in treatment plans Summarizes research in neuropalliative care Identifies current practices in different geographic regions Provides best practices for specific neurological disorders and patient populations Includes advanced care planning

Neurodegenerative Disorders Orla Hardiman, Colin P. Doherty, 2011-06-15 *Neurodegenerative Disorders* provides an accessible guide to the commonest neurodegenerative diseases outlining the main clinical features treatment options and outcomes of the conditions most frequently encountered in clinical practice Beginning with an overview of the general principles that underlie degeneration and the contribution of established and new diagnostics techniques the book goes on to describe the most common neurodegenerative conditions including Alzheimer Disease Dementia and Cerebrovascular Disease Parkinson s Disease Fronto Temporal Dementia Amyotrophic Lateral Sclerosis Huntington s Disease Parkinsonism Plus syndromes and Prion Diseases Final chapters cover important management issues including the use of palliative care strategies advance directives and competence Written by experts in the field internationally *Neurodegenerative Disorders* is a practical guide for clinicians that will be indispensable for the management of these conditions

Palliative Care in Neurology, Volume II Raymond Voltz, Marianne De Visser, David John Oliver, 2022-03-11 *Neurology Update* Huw Morris, 2016-07-14 This is a companion to the highly successful GP Quiz Book 1 It enables interactive learning and rapid identification of new areas of knowledge Questions and answers on a range of disease management topics are covered with material sourced from the British Medical Journal and the British Journal of General Practice The practical application of research findings and advisory statements is unique in presenting both fact and authoritative opinion The book includes questions model answers and references for each question for those who wish to study that topic in more detail It can stimulate discussion for individuals or those in a group setting Students and all professionals working in healthcare will find it essential reading and reference

Amyotrophic Lateral Sclerosis Deborah Gelinas, Robert G. Miller, Patricia O'Connor, 2004-10-01 ALS is not a curable disease but it is a treatable one Treatments are now available that can make a major difference in prolonging life and enhancing the quality of life for people with the disease and there are treatments for many of the symptoms of ALS that can help ease its burden Multidisciplinary teams in specialized ALS centers are providing top quality care and comprehensive rehabilitation for persons with ALS In spite of the progressive nature of this disease and its clear tendency to shorten life the momentum of research in this disease is expanding dramatically and numerous clinical trials are testing promising new therapies Our understanding of the basic causes of ALS is expanding gradually The substantial resources of patient advocacy groups such as the Amyotrophic Lateral Sclerosis Association and Muscular Dystrophy Association provide tremendous help and support for people with ALS and

their families Although the diagnosis of ALS can initially be devastating the vast majority of people discovering new courage from within to battle this disease and live life with vigor and enthusiasm The information in this book will prove useful to people with ALS and their families both in managing the disease and living within its limitations

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