

# Palliative Care in Amyotrophic Lateral Sclerosis

FROM DIAGNOSIS TO BEREAVEMENT

THIRD EDITION

EDITED BY
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Palliative Care in Amyotrophic Lateral Sclerosis David Oliver, Gian Domenico Borasio, Wendy Johnston, 2014-03-20 Amytrophic 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 Amyotrophic Lateral Sclerosis David Oliver (FRCGP.), Gian Domenico palliative care in ALS 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 (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 and 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 systmes 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 Amyotrophic Lateral Sclerosis Francesco Pagnini, Zachary Simmons, 2018-02-09 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 OOL 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 Public Policy in ALS/MND Care Robert H. Blank, Jerome E. Kurent, David Oliver, 2020-11-27 This book focuses on the public policy and political ethical dimensions of ALS MND across a wide selection of countries and argues for the need of a multidisciplinary and international approach Policy issues addressed include adequacy of funding for research and care payment policy and regulatory functions of public and private insurers long term services and caregiver support public health and prevention efforts access to genetic testing and assisted technologies ensuring a competent and adequate workforce especially for hands on caregivers and the challenging issues of providing palliative and hospice care for ALS MND patients advance directives and assisted suicide that face policy makers in all political jurisdictions **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 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 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 frombreaking 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 End of Life Care in Neurological Disease David Oliver, 2012-11-27 As end of life care is extended to more and more people it is increasingly important that people with progressive neurological disease are recognised as having particular issues as their disease progresses This group of people with advancing motor neurone disease multiple sclerosis Parkinson s disease multiple systems atrophy progressive supranuclear palsy Huntington s disease and other progressive neurological disease face increasing problems with physical symptoms and psychosocial and spiritual issues for both themselves and their families and carers This book encourages health and social care professionals to become closely involved in the care of these people and their families so that advance care plans can be started and quality of life maintained This book addresses the principles and practice of developing end of life care strategies for neurological disease written with a clinical multidisciplinary focus and illustrated with detailed case studies **Post-Polio Syndrome:** Background, Management and Treatment, An Issue of Physical Medicine and Rehabilitation Clinics of North America, E-Book Darren Rosenberg, Craig Rovito, 2021-07-01 Approx 240 pages **Physical Management for** Neurological Conditions E-Book Sheila Lennon, Gita Ramdharry, Geert Verheyden, 2018-07-28 The second edition of the Neurological Physiotherapy Pocketbook is the only book for physiotherapists that provides essential evidence based information in a unique and easy to use format applicable to clinical settings Written by new international editors and contributors this pocketbook provides quick and easy access to essential clinical information Comprehensive and handy reference on physical management and movement limitations suitable to any health care context and environment Use of eclectic approach which focuses on selecting the appropriate evidence based tools to assess and treat neurological conditions without subscribing to any specific treatment approaches International case studies are presented to provide worldwide scientific evidence Fully revised by international contributors with the inclusion of 8 new chapters covering Common impairments Inherited neurological disorders Complex case management Virtual reality and interactive gaming technologies

Advocacy in Neurology Wolfgang Grisold, Walter Struhal, Thomas Grisold, 2019-02-07 Advocacy is a broad term that covers activities aimed at increasing attention awareness information nursing treatment and support to improve the outcome of patients These actions can be focused directly towards patients or indirectly via third parties Although advocacy is present in all medical specialties neurology in particular finds itself in need of strong advocacy tools as the diagnosis treatment long term care and associated resource and social issues have become increasingly complex While some physicians implicitly or explicitly act as advocates there is a lack of holistic research in order to clarify the meaning of advocacy along with concrete methods and strategies Advocacy in Neurology provides an integrated approach to the concept of advocacy in neurology Structured in five sections the book begins by explaining the term advocacy in general before elaborating on the areas of interest within neurology The text goes on to offer concrete strategies and tools for clinicians to deploy advocacy in their

daily work and then discusses specific neurological diseases to point out and explain where advocacy is or could be beneficial. The book ends with an outlook presentation of results and an ending conclusion Advocacy in Neurology offers a practical perspective on advocacy activities in neurology aiming to show when and why they are important for neurology

Essentials of Neuroanesthesia Hemanshu Prabhakar, 2017-03-24 Essentials of Neuroanesthesia offers useful insights on the anesthetic management of neurosurgical and neurologic patients This book covers all topics related to neuroanesthesia providing essential knowledge on the brain and spinal cord Sections include chapters on anatomy physiology and pharmacology along with specific chapters related to various neurosurgical and neurological problems and their anesthetic management This book provides an understanding of related issues such as palliative care evidence based practice of neuroanesthesia sterilization techniques biostatistics and ethical issues and is useful for trainees clinicians and researchers in the fields of neurosurgery neurocritical care neuroanesthesia and neurology Offers useful insights on the anesthetic management of neurosurgical and neurologic patients Discusses related issues such as palliative care evidence based practice of neuroanesthesia sterilization techniques biostatistics and ethical issues Useful for trainees clinicians and researchers in the fields of neurosurgery neurocritical care neuroanesthesia and neurology Palliative Care within Mental Health David B. Cooper, Jo Cooper, 2018-10-10 Palliative Care Within Mental Health Ethical Practice explores the comprehensive concerns and dilemmas that occur surrounding people experiencing mental health problems and disorders Working beyond narrow stereotypical definitions of palliative care as restricted to terminal cancer patients this balanced and thought provoking volume examines the many interrelated issues that face the individual families and caregivers setting the groundwork for improved ethical relationships and interventions Chapters by experts and experienced practitioners detail the challenges concerns and best practices for ethical care and responses in a variety of individual and treatment contexts This is an essential and thoughtful new resource for all those involved in the fast developing field of palliative mental health

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 **Cumulated Index Medicus** ,2000

Oxford Textbook of Palliative Nursing Betty R. Ferrell, Nessa Coyle, Judith A. Paice, 2015 The Oxford Textbook of Palliative Nursing is the definitive text on nursing care of the seriously ill and dying It is a comprehensive work addressing all aspects of palliative care including physical psychological social and spiritual needs The text is written by leaders in the field and

includes an impressive section on international palliative care Each chapter includes case examples and a strong evidence base to support the highest quality of care The book is rich with tables and figures offering practical resources for clinical practice across all settings of care and encompassing all ages from pediatrics to geriatrics **Handbook of Physical** Medicine and Rehabilitation Marlis Gonzalez-Fernandez, Stephen Schaaf, 2021-08-30 Handbook of Physical Medicine and Rehabilitation is a concise but broad reference dedicated to the day to day needs of those in physiatric practice including trainees and other clinicians faced with rehabilitation problems Contributors from leading rehabilitation programs and centers come together in this unique handbook to provide expert guidance into management techniques for a variety of diagnoses and clinical problems Structured in its approach and focused on clinical care delivery this essential resource is designed to help practitioners navigate the PM R landscape with insight into conditions and issues encountered in everyday practice regardless of setting Designed for on the go reference chapters are organized within sections from A to Z beginning with management by diagnosis to address topics spanning the spectrum of practice from amputations and prosthetics cardiac rehabilitation multiple sclerosis and stroke to traumatic brain injury plus more A dedicated section focusing on musculoskeletal management of common injuries throughout the body is followed by reviewing management for a range of problems including but not limited to anxiety bladder and bowel fatigue infections pain management and seizures A final section evaluates diagnostics modalities equipment and technology to explore topics of EEG EMG neuropsychological evaluation tracheostomy and more Throughout chapters feature core definitions for the disorder or problem its etiology and pathophysiology diagnostic approaches treatment methods functional prognosis and outcomes and suggested order sets in a systematic manner for targeted access Complete with flow charts diagrams and tables Handbook of Physical Medicine and Rehabilitation is the essential manual to all topics PM R Key Features Addresses management by diagnosis and problem for the full range of physiatric conditions and injuries Portable size and format for quick point of care problem solving Provides inpatient rehabilitation and outpatient clinic order sets for the most common diagnoses Loaded with need to know assessment and rating scales practice guidelines and more Ethics in Palliative Care Robert C. Macauley MD,2018-03-01 This is a comprehensive analysis of ethical topics in palliative care combining clinical experience and philosophical rigor A broad array of topics are explored from historical legal clinical and ethical perspectives offering both the seasoned clinician and interested lay reader a thorough examination of the complex ethical issues facing patients suffering from life threatening illness Palliative Care Nursing Deborah Witt Sherman, 2010 This textbook has introduced concepts and methods of education which help to move palliative nursing forward as an evidenced based practice of whole person care Betty Ferrell PhD FAAN Research Scientist From the Foreword In this comprehensive textbook on palliative care nursing editors Marianne Matzo and Deborah Witt Sherman succeed in bringing together the heart of nursing and the true meaning of palliative care with the most current evidence based practice GeriPal Palliative care is a philosophy of caregiving that

integrates disease modification with supportive compassionate therapies for patients at the end of life Palliative care nurses are responsible for alleviating pain and other physical symptoms along with satisfying the emotional social cultural and spiritual needs of patients who are facing life threatening illness This third edition of Palliative Care Nursing provides more comprehensive newly updated content knowledge attitudes skills and cutting edge teaching and learning strategies to achieve the AACN End of Life nursing competencies providing a lifespan approach Now in its third edition this book continues to emphasize the value of complementary holistic modalities in promoting health wholeness and wellness even as death approaches Key topics discussed Ethical aspects of palliative care Legal aspects of end of life decision making Loss suffering grief and bereavement on the part of patients and their families Symptom specific nursing management of pain anxiety depression fatigue malnutrition and dehydration all common to palliative care How to communicate with the seriously ill and dying patients their families and their health care providers Disease specific aspects of palliative care for those battling cancer heart disease lung disease HIV AIDS end stage renal and liver disease neurological and other disorders

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