



OXFORD

Palliative Care in Amyotrophic Lateral Sclerosis

FROM DIAGNOSIS TO BEREAVEMENT

THIRD EDITION

EDITED BY

DAVID OLIVER | GIAN DOMENICO BORASIO | WENDY JOHNSTON

Palliative Care In Amyotrophic Lateral Sclerosis Motor Neurone Disease

**Robert H. Brown, Michael Swash, Piera
Pasinelli**



Palliative Care In Amyotrophic Lateral Sclerosis Motor Neurone Disease:

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 Amyotrophic Lateral Sclerosis or motor neurone disease is a rare disease but one 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 culminating in discussion of bereavement The experience of patients and families is considered and case studies are provided to show the practical application of the theoretical knowledge Different models of care are explored and this new edition utilises the increase in both the evidence base and available literature on the subject Additional chapters on nursing spiritual care decision making and ethical issues surrounding end of life care ensure that this new edition remains the essential guide to palliative care in ALS

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

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 *Palliative Care in Neurology, Volume II* Raymond Voltz, Marianne De Visser, David John Oliver, 2022-03-11

Supportive Care in Respiratory Disease Sam Ahmedzai, Martin F. Muers, 2005 Respiratory symptoms such as breathlessness and cough are common in patients with advancing and incurable disease For example cancer chronic cardiac and pulmonary disease progressive neuromuscular disorders and degenerative disorders all give rise to varying degrees of respiratory distress which adversely affects the patient's quality of life In recent years there has been significant growth into the palliation of respiratory symptoms leading to practical ways of giving relief in hospices hospitals and at home The book includes non malignant respiratory diseases such as tuberculosis in AIDS patients ventilator dependent patients and cystic fibrosis and focuses on aetiology and diagnosis and management emphasizing symptoms quality of life and psychosocial support The underlying theme of the book is the application of modern research based knowledge in a humane way for patients with advancing disease Aimed primarily at specialists in palliative care oncology and respiratory physicians doctors nurses physiotherapists and pharmacists will also be interested The book will appeal to those working in acute specialties such as cardiology or pulmonary medicine whose patients are not usually considered for palliative care but in whom relief of distressing respiratory problems could improve the quality of life

Neurological Disorders Thomas Brandt, 2003-01-03 This single volume reference covers the natural course treatment and management of all neurological diseases affecting the brain spinal cord nerves and muscles This comprehensive text reference seeks to assist physicians with treatment by providing an easy to use compendium covering the treatment and management of all neurological diseases along with details on the natural course of these diseases Organized for ease of use and quick reference each chapter presents a neurological disorder or key symptoms and systematically discusses the clinical syndrome and differential diagnosis natural course principles of therapy and practical management of each Covers wide range of neurological conditions and potential treatments including the evidence for and against each treatment Describes the spontaneous course of neurological diseases along with discussion of the management of different stages and variants of a disorder Presents special situations and exceptional cases in which alternative therapies should be considered

Palliative Care in Neurology Raymond Voltz, Marianne de Visser, David Oliver, 2020-03-10 Over the last 50 years palliative care has usually been associated with cancer patients but more recently there has been increased discussion of the role of palliative care for neurological patients In the past years neurology has moved from being a purely diagnostic area to a very therapeutically active one A further step

needs to be taken to modify the therapeutic activity from cure to care depending on the patient's disease trajectory Palliative care has been associated with care at the end of life whereas it may be appropriate earlier in the disease progression and will extend after death in the support of bereaved families The care of patients with neurological disease and their families will encompass the psychological spiritual and existential issues and neurologists and the teams in which they work should develop skills to consider all aspects of care in order to maximize the quality of life of all involved and enable patients to die peacefully

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

Neurology Charles Clarke, Robin Howard, Martin Rossor, Simon Shorvon, 2011-09-09 *Neurology A Queen Square Textbook* is a remarkable fusion of modern neuroscience with traditional neurology that will inform and intrigue trainee and experienced neurologists alike Modern neuroscience has penetrated exciting and diverse frontiers into the causes diagnosis and treatment of neurological disease Clinical neurology whilst greatly enhanced by dramatic advances in molecular biology genetics neurochemistry and physiology remains deeply rooted in practical traditions the history from the patient and the elicitation of physical signs Neurologists neuroscientists and neurosurgeons working at Queen Square and advised by an international editorial team have combined their expertise and experience to produce this unique text The synthesis of clinical neurology with translational research provides a fresh perspective which is Practical Multidisciplinary Translational Integrative The blend of new science and proven practice underpins this creative approach towards investigating and improving the care of patients suffering from neurological diseases About Queen Square The world renowned National Hospital for Neurology Neurosurgery and UCL Institute of Neurology based in Queen Square London have an international reputation for training research and patient care Research at both institutions leads developments in translational medicine that are transforming the treatment of neurological disease

Oxford Handbook of Palliative Care Max Watson, Stephen Ward, Nandini Vallath, Jo Wells, Rachel Campbell, 2019-09-12 The *Oxford Handbook of Palliative Care* returns for a third edition maintaining the concise yet comprehensive format suited to the busy practitioner for quick access to key information and fully updated to reflect changes in the palliative care landscape Featuring an increased emphasis on

non malignant diseases such as dementia this authoritative text combines evidence based care with the bedside experience of experienced palliative care professionals to give the reader a complete overview of the physical emotional and spiritual aspects of care for the end of life patient Symptom management is covered in detail with updated formulary tables and syringe driver protocols and a new chapter on international perspectives to broaden the reader's perception of methods for delivering end of life care The third edition of the Oxford Handbook of Palliative Care is the essential companion for all of those working with adults children and families with palliative care needs in both hospital and community settings The following correction has been made online and will be included in the first reprint Readers can get in touch with us directly using the contact details on the back of the book or at our online form via the address below with questions or comments <https://global.oup.com/academic/category/medicine-and-health> Chapter 5 Page 109 The dose for Hyoscine butylbromide sc has been amended in line with NICE guidance <https://bnf.nice.org.uk/drug/hyoscine-butylbromide.html> 20 120 mg 4 hourly has been corrected to 20 80mg 4 hourly *Oxford Textbook of Palliative Medicine* Geoffrey W. C. Hanks, 2011-07-21

Emphasising the multi disciplinary nature of palliative care the fourth edition of this text also looks at the individual professional roles that contribute to the best quality palliative care *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 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 *Integrated Palliative Care of Respiratory Disease* Stephen J. Bourke, Tim Peel, 2019-07-22 The second edition of this book brings together the knowledge skills and attitudes of specialists in both respiratory and palliative medicine to focus on the palliative care of patients with respiratory diseases It deals not only with end of life care but also with symptom control and supportive care to

improve the quality of life of those living their lives with advanced progressive lung disease Integrated Palliative Care of Respiratory Disease builds on the previous edition introducing new models of care for patients with advanced lung disease These models emphasize the introduction of palliative and supportive care at an earlier stage in the disease and running disease modifying and palliative treatments in parallel There is a new chapter on the role of palliative care in lung transplantation The book highlights significant new research into key respiratory diseases and some on going controversies about issues such as best models of care for different diseases and advance care planning This book is an invaluable reference for doctors trainees and clinical nurse specialists in respiratory and palliative medicine and is of interest to anyone who wishes to gain a better understanding of the complex nature of palliative care in respiratory disease Textbook of Palliative Care Roderick Duncan MacLeod, Lieve Van den Block, 2025-02-25 This second edition provides the most up to date information on all aspects of palliative care including recent developments including COVID 19 global policies service provision symptom management professional aspects organization of services palliative care for specific populations palliative care emergencies ethical issues in palliative care research in palliative care public health approaches and financial aspects of care This new Textbook of Palliative Care remains a unique comprehensive clinically relevant and state of the art book aimed at advancing palliative care as a science a clinical practice and as an art Palliative care has been part of healthcare for over fifty years but it still needs to be explained to many Healthcare education and training has been slow to recognize the vital importance of ensuring that all practitioners have a good understanding of what is involved in the care of people with serious or advanced illnesses and their families However the science of palliative care is advancing and this new edition will contribute to a better understanding This new edition offers 86 updated or new chapters out of 108 written by experts in their given fields providing up to date information on a wide range of topics of relevance to those providing care towards the end of life no matter what the disease may be We present a global perspective on contemporary and classic issues in palliative care with authors from a wide range of disciplines involved in this essential aspect of care The Textbook includes sections addressing aspects such as symptom management and care provision organization of care in different settings care in specific disease groups palliative care emergencies ethics public health approaches and research in palliative care This new Textbook will be of value to practitioners in all disciplines and professions where the care of people approaching death is important specialists as well as non specialists in any setting where people with serious advanced illnesses are residing It is also an important resource for researchers policy and decision makers at national or regional levels Neither the science nor the art of palliative care will stand still so the Editors and contributors from all over the world aim to keep this Textbook updated so that the reader can find new evidence and approaches to care **Motor Neurone Disease**, 2024-05-29 International Review in Neurobiology serial highlights new advances in the field with this new volume presenting interesting chapters Each chapter is written by an international board of authors Provides the authority and

expertise of leading contributors from an international board of authors Presents the latest release in International Review on Neurobiology series Updated release includes the latest information on Motor Neuron Disease Neurodegenerative Disorders as Systemic Diseases Keiji Wada,2015-10-21 This book sheds new light on neurodegenerative disorders as systemic diseases Classically neuronal cell death was a hallmark of such disorders However it has become evident that neural dysfunction is more important in the pathophysiology of neurodegenerative disorders More recently the prionoid spreading hypothesis of disease causing molecules has attracted a great deal of attention Therapeutic strategies thus must be reconsidered in the light that neurodegenerative disorders are indeed systemic diseases The first part of this book introduces the concept of neurodegeneration in biology and pathophysiology The second part focuses on clinical evaluation and biomarkers from the perspective of this new concept while the third summarizes the risk factors of neurodegeneration The fourth part of this work indicates future directions of treatment and the final part discusses health promotion for prevention and quality of life This book will be of interest to both researchers and medical personnel and provides a fresh approach to neurodegenerative diseases paving the way to new research and improved quality of health care for patients

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

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

The Enigmatic Realm of **Palliative Care In Amyotrophic Lateral Sclerosis Motor Neurone Disease**: Unleashing the Language is Inner Magic

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