Motor Neurone Disease A Family Affair

As end of life care is extended to more and more people it is increasingly important that people with progressive neurological disease are recognised a having particular issues as their disease progresses. This group of people with advancing motor neurone disease, multiple sclerosis, Parkinson's disea 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 soci 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 li 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.

The book aims to provide practical advice on the care of people with ALS/MND. The authors come from a wide spread of professional backgrounds an from countries across the world. The many different aspects of care are considered and the differing attitudes to care across the World are contrasted.

This is the story of my late wife Lydia and our family's journey with Motor Neurone Disease/Amyotrophic Lateral Scleroses (MND/ALS).Lydia presented symptoms in April 2009 and was diagnosed with MND in September 2009. She passed on 25 February 2011 and I dedicated myself since March 2011 honour her memory and raise awareness of this terrible dreaded disease. I spent 2 years and 7 months writing the book at night and weekends.MND is rare, terminal and untreatable and it was my mission to educate and inform Families with members who have been diagnosed with MND, Care Givers Medical Practitioners of our experience through the various phases of the disease. As the primary Care Giver I accumulated first-hand experience of th symptoms and symptomatic relief of MND and how to maintain the Patient's quality of life.It is also a personal and detailed journey of how my wife as t patient, suffered from the progressive ravages of the disease and how I as the husband and Care Giver, experienced the journey.The book is compose sections chronicling the journey from humble beginnings during the Apartheid Group Areas and Job Reservations eras through the difficulties of self-realisation, career development to financial stability only for the disease to strike and deprive us from enjoying the fruits of our labour.The first three sections maps the journey from humble beginnings to self-realisation.The fourth section maps our journey from April 2009 when she presented sympto diagnoses September 2009.The fifth section through to the seventh section maps our journey tracking the progressive degeneration month by month fr September 2009 to February 2011 when she passed on.The eighth section chronicles lessons learnt and my understanding and coming to terms with passing which I believe can offer comfort and coping mechanisms to the families left behind.I believe the fourth, fifth, sixth and seventh sections will be families, Care Givers and Medical Practitioners by describing the progressive degeneration phases and what to do to provide symptomatic relief.The eighth section offers insights from lessons learnt from the journey and will hopefully provide comfort and understanding for the families affected by MND/ALS.

Managing Chronic Illness at Home

A Guide for Patients and Families:Third Edition

Navigating Life with Amyotrophic Lateral Sclerosis

A Team Approach

Motor Neurone Disease

A Memoir

Motor neurone disease (MND) is a progressive condition that damages the nervous system, leaving muscles wasted and weak, and causing loss of mobility, and difficulties with speech, swallowing and breathing. MND tends to affect people over 40 and is most common between the ages of 50 and 70. There are about 5,000 people with MND at any one time in the UK. The cause remains a mystery and there is no cure. The third edition of this book, which sells primarily via the Motor Neurone Disease Association, gives a full update of treatments and resources available to help those diagnosed live life to the full. Topics include what the disease is, what the doctors will do, and how to cope with the difficulties. This new edition also examines the latest on benefits, and up to date thinking on drug trials. Dr David Oliver, a leading expert on MND, shows how to treat not just the physical effects but also the emotional ones for the whole family. Dr Oliver also explains the vital role of the Motor Neurone Disease Association.

In June 2011, Susan Spencer-Wendel was diagnosed with amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig ' s disease. It is a disease that systematically destroys the nerves that power muscles; Susan, forty-five years old and a mother of three, already walks with braces and is losing her ability to speak. Though Susan cannot stop the rapid decline of her body, she refuses to let her life stop before its time. Since her diagnosis, Susan has made sure that every day counts. She is more present than ever in her daily life, and ready to share her strength, determination and spirit. Susan ' s story began attracting interest when she published a piece in her local paper about a trip she took to see the northern lights following her diagnosis. But one of the most important adventures Susan planned took her to New York City with her fourteen-year-old daughter, Marina. Susan and Marina, both big fans of TLC ' s Say Yes to the Dress, visited Kleinfeld Bridal, where the two shared the experience of Marina ' s search for the perfect dress for the wedding Susan will never see. Until I Say Good-Bye is a truly magical story and so much more than one woman ' s " bucket list. " It ' s a celebration of life, a look into the face of death and an account of the effort we must make to show the people we love and care about how very much they mean to us.

As he grappled to come to terms with the diagnosis of a physically crippling disease, his body swiftly declined until he was finally completely paralysed with no voice. But his mind remained untouched. He was trapped within his body. Imagine being delivered a death sentence. You are told you have an incurable, fatal disease. Everything you understand about your life is turned upside-down. Your mind is forced to deal with the consequences. How would you view your time? It would all feel like a horrible dream. This, though, is no dream. This is just where the nightmare begins. The Silent Scream: Living with the Beast is the story of a fit, healthy man who is suddenly struck down. A man dedicated and passionate about nature, forced to suffer at its hands in isolation as he journeys through the last months of his life. It is the dramatised true story of the silent and savage journey of the author ' s father and their

family, battling against Motor Neurone Disease. Using the backdrop of nature in this book, written by the author but read through the eyes of her father, the vileness of this disease is magnified. Inspired by the work of Mervyn Peake, William Golding and Peter Ackroyd, The Silent Scream will appeal to anyone who enjoys short stories and true life events. " This is the abrupt end to my father ' s life. It is also a testament to the love my parents had for each other as they tried to fight ' the Beast ' together until he finally had to let go. As I witnessed the fear and pain that he suffered as he fought to come to terms with his reality, I made a commitment to write about his experience, " the author comments on her inspiration behind The Silent Scream.

Amyotrophic Lateral Sclerosis and the Frontotemporal Dementias

A Life with Stephen

Palliative Care in Neurological Disease

Living With Motor Neurone Disease

Living with Motor Neurone Disease

The Silent Scream

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 ALS.

Our understanding of the pathology of amyotrophic lateral sclerosis is a continuously changing field. New hypotheses are generated with each new discovery; they are abandoned to be reanalyzed after some time under the light of new observations. This book present a series of reviews from experts in different aspects of the disease focus on these hypotheses. There are also a few review chapters providing clear examples of these new observations that make the field to reanalyze previous conclusions.

In 2001 Peter Anderson was 37 and had the perfect life: very much in love and recently married with an infant daughter he adored; an intelligent and sensitive man working a job he loved as a popular secondary school teacher and a talented sportsman training

for a marathon... The bubble was about to burst. Peter was diagnosed with Motor Neurone Disease (MND), a physically crippling disease that destroys nerve cells controlling muscular movement. He was told that over time his body would cease to function - yet his mind, his memory and his feelings would be untouched by the disease. His life expectancy was two years. Incredibly, eleven years on, despite Peter's body wasting away, his mind remains as it has always been: strong and vibrant, intelligent, enquiring, touched with gentle humour. Silent Body - Vibrant Mind has been written with often unimaginable physical difficulty. An unforgettable story about what matters in life.

Expert And Practical Advice

Palliative Care in Amyotrophic Lateral Sclerosis (motor Neurone Disease)

A Practical Manual

Communicating with Children When a Parent is at the End of Life

Living with the Beast

ScholarlyBrief

"This essential guide is packed full of information about Motor Neurone Disease (MND) and how to deal with it. The book provides up-to-date information on a range of topics from diagnosis and treatment to adapting to life with MND including mobility, feelings, relationships, and much more. The authors address the physical and emotional upheaval for the person with MND and for the whole family, offering positive help and advice." - back cover.

Paper presented at the National Conference of the Motor Neurone Disease Association of New Zealand, 1995.

ALS, also known as Lou Gehrig's disease, cannot be cured but it can be treated. A great deal can be done to treat the symptoms of ALS, to improve an individual's quality of life, and to help families, caregivers, and loved ones to cope with the disease. This extensively revised and rewritten new edition of the bestselling Amyotrophic Lateral Sclerosis: A Guide For Patients and Families addresses all of those needs, and brings up-to-date important information to those living with the reality of ALS. The book is completely revised throughout and contains NEW information on: Recently developed approaches to treating ALS symptoms Use of non-invasive ventilators Multidisciplinary team care New guidelines being developed by the American Academy of Neurology for patients with ALS The use of riluzole (Rilutek) to treat ALS Amyotrophic Lateral Sclerosis covers every aspect of the management of ALS, from clinical features of the disease, to diagnosis, to an overview of symptom management. Major sections deal with medical and rehabilitative management, living with ALS, managing advanced disease, end-of-life issues, and resources that can provide support and assistance in this time of need.

Motor Neuron Disease

The Contribution of ANG and CHMP2B to Motor Neurone Disease Pathogenesis

Assessment and Management

The Client and Family with MND

Palliative Care in Amyotrophic Lateral Sclerosis

The National Institute of Neurological Diseases and Stroke

Written and designed to provide comprehensive, easily accessible advice for all healthcare professionals involved in the care of patients with this challenging condition, this book addresses the entire care pathway from presentation to diagnosis

to symptom management and end of life issues.
This text shows how much can be done to help someone with motor neurone disease live their life to the full. Oliver spells out what the disease is, what doctors will do and how to cope with the difficulties. This new edition also gives a full update of treatments and resources available.
Motor neurone disease (MND) is the third most common adult-onset neurodegenerative disorder. It is relentlessly progressive and universally fatal, usually as a result of respiratory failure. In 3-5% of MND cases overt dementia is present, however, subtle impairment to cognitive function is present in up to 50% of sufferers. In approximately 10% of MND cases there is a clear pattern of inheritance, however, genetic causes are believed to make a substantial contribution to apparently 'sporadic' disease. Mutations in ANG were first identified in a large cohort of MND cases from several diverse geographical regions, four of the patients suffered from familial disease, whereas the remaining 11 had no family history of MND. A mutation in CHMP2B was originally identified in a Danish pedigree with autosomal dominant FTD, which was subsequently followed by the identification of missense mutations in two, unrelated, patients with familial MND, one of whom also showed features ofFTD. The initial aim of the present study was to determine whether mutations in ANG and CHMP2B contribute to MND pathogenesis by mutation screening a large cohort of MND patients for whom serial clinical details were available. Neuropathological tissue was available for a proportion of these cases. Sequencing of ANG revealed a mutation in one case diagnosed with an early-onset, classical amyotrophic lateral sclerosis (ALS) phenotype, who showed rapid deterioration and characteristic ALS neuropathology. Four cases carrying 3 missense mutations in CHIvfP2B, including one novel mutation, p. Thrl04Asn, \vere identified. Only 1 case had a family history of MND, the remaining 3 were affected by apparently sporadic disease. In all 4 cases analysis of clinical and neuropathological data was consistent \vith a diagnosis of the progressive muscular atrophy (PMA) variant of MND. To analyse the affect of mutant CHMP2B on the transcriptional response, gene expression profiling was performed on RNA extracted from motor neurones (MNs) from CHMP2B cases and controls. Significant changes in the expression of genes from multiple pathways were identified, including: axon guidance; actin cytoskeleton regulation and SNARE interactions in vesicular transport; cell cycle; apoptosis; mTOR signalling and autophagy regulation; MAPK signalling; calcium signalling and Wnt signalling. The alterations to these pathways were predicted to result in: disassembly of cell structure; increased calcium concentration in the ER lumen; decrease in the availability of A TP; downregulation of the classical and p38 MAPK signalling pathways; reduction in autophagy initiation and a global repression of translation. Finally, to determine the effect of CHMP2B mutations on cellular phenotypes, HEK- 293 cells were transiently-transfected. This demonstrated that mutant CHMP2B expression resulted in the formation of large cytoplasmic vacuoles and aberrant lysosomal localisation.
Silent Body, Vibrant Mind
From Diagnosis to Bereavement
I Found My Tribe

A Complete Guide

Music to Move the Stars

Motor Neuron Disease in Adults reviews new information as it applies to all aspects of motor neuron disease (ALS, PLS, PMA). The choice of articles is for those that use evidence-based methods to ensure that the new information is solid and advances the topic or issue. The book can be used by anyone who provides any type of care to ALS patients. In particular, neurologists will find the latest information on diagnosis and management, as well as new information on genetics and frontotemporal lobe involvement. Allied health providers will find useful information for their discipline. Patients will also find both specific and general information to help understand what they are experiencing and how to help manage their symptoms.

Living with Motor Neurone Disease: A complete guide is designed to guide the reader through this complex progressive neurological condition that attacks the motor neurones, or nerves, in the brain and spinal cord. This means that messages gradually stop reaching the muscles, which leads to weakness and wasting. Motor Neurone Disease can affect the everyday things that we take for granted. A diagnosis of MND can be frightening and overwhelming. Good quality information and support from people who understand MND is vital at this time. Living with Motor Neurone Disease is written by many of the most distinguished Irish experts on MND, bringing safe, reliable, practical information and reassurance to everyone affected by Motor Neurone Disease. Having accurate information and timely access to the best available services including doctors, neurologists, MND outreach nurses and local community healthcare professionals makes all the difference when it comes to a person's journey with MND. This is a step-by-step guide for everyone which explains what MND is; how it is diagnosed; how it affects the individual and the family; the psychological dimensions of the condition; the caregiver experience; living with the condition and facing the future; how to talk to children and adolescents; how to tell family and friends; how to adapt working conditions and home life; and it describes all the supports; medical, psychological technological and practical to cope with the daily impact of living with MND. In summary, it is an invaluable resource to inform, educate prepare and signpost people toward practical everyday supports and clinical expertise. Living with Motor Neurone Disease: A complete guide is a must-read for professionals; for doctors, nurses, educationalists, for psychologists, systemic family therapists and psychotherapists, those working in human resources and everyone who needs to understand the condition when they encounter it.

Anyone interested in ALS/MND-physician, patient, or healthcare policy director -should read this book and learn from it. -Walter G. Bradley D.M., F.R.C.P., Professor and Chairman Emeritus, Miller School of Medicine, University of Miami, USA "This book illustrates the inequities in the accessibility of quality neurological care existing globally and which forms a major target for redress by the World Federation of Neurology and the World Health Organisation." -William M Carroll

AM, MBBS, MD, FRACP, FRCP(E), President, World Federation of Neurology 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. Robert H. Blank, PhD, (University of Maryland) is an adjunct Professor of Political Science at the University of Canterbury in Christchurch, New Zealand. He has been a frequent guest professor at Aarhus University in Denmark and at National Taiwan University in Taipei, Taiwan, and a Research Scholar at New College Florida. Jerome E. Kurent received his MD from the University of Cincinnati College of Medicine and completed residencies in Neurology and Internal Medicine at the Johns Hopkins Hospital. He completed fellowships in neuromuscular diseases and electromyography at the National Institutes of Health, followed by a Geriatrics Medicine fellowship at Harvard where he also received his MPH. Dr. Kurent joined the Medical University of South Carolina faculty in 1984, and is Professor of Neurology, Medicine and Psychiatry and Behavioral Sciences. David Oliver, MD., recently retired as Consultant Physician in Palliative Medicine at the Wisdom Hospice in Rochester, Kent where he developed an integrated service over 32 years. He is an Honorary Professor at the Tizard Centre at the University of Kent, where he supervises students and is involved in research

A Handbook for People Whose Arms and Hands Don'T Work Anymore

Motor Neuron Disease: New Insights for the Healthcare Professional: 2013 Edition

The 'at Your Fingertips' Guide

Motor Neurone Disease - Essentials: Expert and Practical Advice

Motor Neuron Disease in Adults

The Management of Motor Neurone Disease

Motor neurone disease (MND) is a neurodegenerative condition that affects the brain and spinal cord. MND is characterised by the degeneration of primarily motor neurones, leading to muscle weakness. The presentation of the disease varies and can be as muscle weakness, wasting, cramps and stiffness of arms and/or legs, problems with speech and/or swallowing or, more rarely, with breathing problems. Whichever area the disease starts, as the disease progresses the pattern of signs and symptoms becomes similar, with increasing muscle weakness in the person's arms and legs, problems swallowing and communicating and weakness of the muscles used for breathing, which ultimately leads to death. Most people die within 2-3 years of developing symptoms, but 25% are alive at 5 years and 5-10% at 10 years. The most common type of MND is amyotrophic lateral sclerosis (ALS). There are rarer forms of MND such as progressive muscular atrophy and primary lateral sclerosis, which may have a slower rate of progression. Every

person with MND has an individual progression of the disease. About 10-15% of people with MND will show signs of frontotemporal dementia, which causes cognitive dysfunction and issues with decision-making. A further 35% of people with MND show signs of mild cognitive change, which may affect their ability to make decisions and plan ahead. MND is a disorder which can affect adults of any age. However, incidence is highest in people aged 55-79; onset below the age of 40 years is uncommon. There are approximately 4,000 people living with MND in England and Wales at any one time. The cause of MND is unknown. About 5-10% of people with MND have a family history of the disease and several abnormal genes have been identified. As there is no cure for MND, care focuses on maintaining functional ability and enabling people with MND and their family members to live life as fully as possible. Early diagnosis, without delay after investigation, may be helpful as it allows for the provision of medication and aids, as well as for communication about the disease and advance care planning to be undertaken appropriately. Care of people with MND varies across England and Wales, with MND multidisciplinary team clinics and networks providing coordinated multidisciplinary care. However, some people with MND are left isolated and their care is less than ideal. This guideline aims to consider the clinical- and cost-effectiveness evidence for the care of people with MND from the time of diagnosis, including communication of the diagnosis. It covers monitoring of disease progression, management of symptoms (in particular muscle weakness, excess secretions, breathing and nutrition problems), ongoing support and services, mobility, emotional and psychological changes, and preparation for end of life. Particular emphasis is placed on determining the best way to organise the care and management of people with MND.

This book summarizes the advances in our understanding of amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD), as well as the potential relationship between the two.

Navigating Life with Amyotrophic Lateral Sclerosis provides accessible, comprehensive, and up-to-date information about the challenges patients, family members, and caregivers face when confronted by ALS, a disease that affects approximately 5,600 Americans every year, with as many as 30,000 people managing the disease at any given time. ALS is a difficult disease for the patient and is also challenging for the caregiver and family as there are many questions, issues relating to care, and problems to manage. This guide covers all aspects of managing ALS, from the onset of symptoms, diagnosis, treatments, and coping strategies, to the use of home health care or hospice, and new research in the field. The book also sheds lights on difficult topics, such as end-of-life care and managing legal affairs. Navigating Life with Amyotrophic Lateral Sclerosis is unique because it covers two perspectives: one author is a neurologist with 30 years of experience treating ALS patients, and the other author experienced first-hand the issues in providing care for a parent with ALS. Formatted in a question-and-answer style, peppered throughout with patient stories, and with sections devoted to family members and caregivers, this compassionate resource provides guidance to those seeking to understand how to live with this disease.

Interpreting the Meaning of Existence for the Person with Motor Neurone Disease, and Their Family Carer(s).

Can't Scratch That Itch

Current Advances in Amyotrophic Lateral Sclerosis

Caring for the Dying Patient and the Family

A Family Affair

Public Policy in ALS/MND Care

Tim, I just finished reading your book. I teared up 3 times and laughed twice. You have done an amazing job! I was thinking to myself how you and Karen are handling all of the changes with such grace. The two of you are such an amazing team and have developed such strong

communication skills- you two could probably host a course for other married couples. Another poignant moment for me was on the page where you wrote We also informed our family that we had the disease that did not have a cure... I think the we in that statement is so true. . . . your book- have you anticipated how you will share it? You may want to consider both the MDA and ALSA (ALS Association) as outlets to share your story and tips. I also think you should pass this along to some of your neurology providers. I think your Prologue is an exceptional teaching tool for medical professionals. I still cant stop thinking about how you continually think about your blessings- I am going to tear up again and I am not a crier! I thank you for allowing yourself to be vulnerable and sharing your experiences. You are lucky to have found Karen, and she is lucky to have found you. Amy Callan, OTR, DOT | Outpatient Occupational Therapy Supervisor

The particular needs of people with progressive long-term neurological conditions - including Parkinson's Disease, Motor Neurone Disease (MND), Multiple Sclerosis (MS) and Huntington's disease - may make care delivery and planning the last stages of life.

This Essentials guide is packed full of information about motor neurone disease (MND) and how to deal with it. It provides up-to-date information on a range of topics from diagnosis and treatment to adapting to life with MND, including mobility, feelings, relationships and much more. It addresses the physical and emotional upheaval for the person with MND and for the whole family, offering positive help and advice and providing: Medically accurate information about living with MND; Advice on finding the right care and treatment throughout the progression of the disease; Detailed advice about activities of daily living, including difficulties with bladder and bowel function; Practical information about employment, benefits, how to adapt the home and the care services that are available.

Unending Work and Care

A Community Nursing Perspective

Lydia

Motor Neurone Disease Essentials

A Guide for Family and Friends

Amyotrophic Lateral Sclerosis. "How Can I Help?"

A transformative, euphoric memoir about finding solace in the unexpected for readers of H is for Hawk, It ’ s Not Yet Dark, and When Breath Becomes Air. Ruth ’ s tribe are her lively children and her filmmaker and author husband Simon Fitzmaurice who has ALS and can only communicate with his eyes. Ruth ’ s other "tribe" are the friends who gather at the cove in Greystones, Co. Wicklow, and regularly throw themselves into the freezing cold water, just for kicks. The Tragic Wives ’ Swimming Club, as they jokingly call themselves, meet to cope with the extreme challenges life puts in their way, not to mention the monster waves rolling over the horizon. Swimming is just one of the daily coping strategies as Ruth fights to preserve the strong but now silent connection with her husband. As she tells the story of their marriage, from diagnosis to their long-standing precarious situation, Ruth also charts her passion for swimming in the wild Irish Sea--culminating in a midnight swim under the full moon on her wedding anniversary. An invocation to all of us to love as hard as we can, and live even harder, I Found My Tribe is an urgent and uplifting letter to a husband, family, friends, the natural world, and the brightness of life.

Motor Neuron Disease: New Insights for the Healthcare Professional: 2013 Edition is a ScholarlyBrief™ that delivers timely, authoritative, comprehensive, and specialized information about Diagnosis and Screening in a concise format. The editors have built Motor Neuron Disease: New Insights for the Healthcare Professional: 2013 Edition on the vast information databases of ScholarlyNews.™ You can expect the information about Diagnosis and Screening in this book to

be deeper than what you can access anywhere else, as well as consistently reliable, authoritative, informed, and relevant. The content of Motor Neuron Disease: New Insights for the Healthcare Professional: 2013 Edition has been produced by the world ' s leading scientists, engineers, analysts, research institutions, and companies. All of the content is from peer-reviewed sources, and all of it is written, assembled, and edited by the editors at ScholarlyEditions™ and available exclusively from us. You now have a source you can cite with authority, confidence, and credibility. More information is available at http://www.ScholarlyEditions.com/.

This book provides a theoretical framework based on humanism, philosophy and the principles of palliative care, from which to address assessment and treatment planning throughout the progression of the disease from time of diagnosis, during terminal care and bereavement.

Amyotrophic Lateral Sclerosis

Novel Aspects on Motor Neuron Disease

Until I Say Good-Bye

End of Life Care in Neurological Disease

An International Perspective

Motor Neurone DiseaseA Family AffairSheldon Press

When a parent is nearing the end of life, children can feel like their world has been turned upside down, and they are often scared and confused about what is happening. Sensitive and clear communication with children is vital to help them understand and cope with their parent's illness. This accessible book demonstrates how to support children through effective and sensitive communication, covering types of communication, language, information sharing, and overcoming common barriers. Developing confidence and skills such as talking, listening, giving children a voice and breaking bad news is also covered. The author outlines the concept of a 'communication continuum' which can be used to assess how much a child knows or understands about their parent's illness and how much they would like to know. The book contains a wealth of practical strategies and ideas, as well as case vignettes, practice tips and reflective exercises. This is an essential resource for anyone working with or supporting a child whose parent is at the end of life, including palliative care workers, nurses, social workers, teachers and counsellors.

This third edition of a popular textbook has been completely revised by the joint editors, Janet Moscrop and Joy Robbins. As in previous editions, the focus is on the person dying at home, in residential care or in hospital and the emphasis is on teamwork in caring for the individual and their relatives and friends. Experts in all aspects of care have contributed to this complete revision of the previous text and each chapter is written by a different member of the multiprofessional team. The chapter on the terminal care of people suffering from AIDS has been enlarged and consideration is also given to care of those in the term inal stages of other non-malignant diseases. Other new material includes chapters on complementary therapy, the use of the day centre, the value of volunteers, diversional therapy and

respite care. The chapter on bereavement covers many aspects of grief and loss and there is a sensitive approach to the need for supporting staff in this spe cialized work. Consideration is also given to the needs of dying and griev ing people from differing ethnic backgrounds with varying cultural expectations in a pluralistic society. The third edition offers a broad overview of the support given to the dying person and the carers by medical and nursing staff, physiothera pists, pharmacists, social workers, the chaplaincy and members of the pastoral care team. Students of all these disciplines should find this book both readable and informative.