

ALS Patient And Caregiver Resource Manual

My Dad and I learned about caregiving when we took care of my Mother as she progressed through each stage of ALS. I kept a journal of each situation and phase that she went through and wrote my first book, "A Beautiful Smile" within a year of her death. This second book, "A Caregivers Guide & Journal" will guide you through the day to day needs of a patient with ALS, as well as the caregiver's feeling and needs. The information provided along the way will be invaluable as you learn about the disease and how it affects each part of the body; where to ask for help, how to get the help needed and how to care for the patient and/or caregiver. This book is specific to the caregiver of ALS but will also be helpful for any situation pertaining to caregiving. The information in this book is first-hand knowledge of the caregiver's responsibilities, struggles, challenges, love and gratitude for someone taking over as a caregiver. The helpful information will give insight to: What ALS means, How to keep a journal, what to expect, how to inform the family, disability, Social Security, Medicare, Medicaid, Hospice, how to get the help you need, how to care for and comfort the patient. How to care for yourself. My wish is that you will learn about the disease and that the information will help you care for the one you love, and help you understand what you will go through as a caregiver. Take your time with the ones you love, cherish every minute, love them with all your heart and care for yourself along the way.

NORD Guide to Rare Disorders is a comprehensive, practical, authoritative guide to the diagnosis and management of more than 800 rare diseases. The diseases are discussed in a uniform, easy-to-follow format--a brief description, signs and symptoms, etiology, related

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disorders, epidemiology, standard treatment, investigational treatment, resources, and references. The book includes a complete directory of orphan drugs, a full-color atlas of visual diagnostic signs, and a Master Resource List of support groups and helpful organizations. An index of symptoms and key words offers physicians valuable assistance in finding the information they need quickly.

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

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the psychological aspects of ALS and their management, and incorporates chapters written by recognized scholars in their respective fields.

'The Loss of Sadness' argues that the increased prevalence of major depressive disorder is due not to a genuine rise in mental disease, as many claim, but to the way that normal human sadness has been 'pathologised' since 1980.

The Caregiver's Handbook is a definitive guide to caring for a sick or disabled person of any age. Whether it be adults looking after parents, partners looking after each other, parents looking after children, or young caregivers looking after their parents, the Caregiver's Handbook addresses both the needs of the caregiver, and person who needs care. The Caregiver's Handbook offers emotional support and practical advice on a wide range of topics, enabling individuals to provide the best care possible-whatever the requirements. Everyday concerns, including healthy eating, personal care, and rest and sleep, are addressed alongside topics such as safe movement and handling, choosing the right stability aids, or even how to maneuver a wheelchair for the first time. Features also include a look at how either at the needs of the caregiver, or how the requirement of specific conditions-such as dementia or physical impairment-can affect the way a task can be approached. The Caregiver's Handbook is a comprehensive, compassionate, and indispensable resource that all caregivers will want to have on hand at all times - it is essential reading for anyone caring for someone at home. This two-volume set constitutes the proceedings of the 13th International Conference on Universal Access in Human-Computer Interaction, UAHCI 2019, held as part of the 21st International Conference, HCI International 2019, which took place in Orlando, FL, USA, in July 2019. The total of 1274 papers and 209 posters included in the 35 HCII 2019 proceedings

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volumes was carefully reviewed and selected from 5029 submissions. UAHCI 2019 includes a total of 95 regular papers; they were organized in topical sections named: universal access theory, methods and tools; novel approaches to accessibility; universal access to learning and education; virtual and augmented reality in universal access; cognitive and learning disabilities; multimodal interaction; and assistive environments.

Kate has always adored her grandpa's storytelling - but lately he's been repeating the same stories again and again. One day, he even forgets Kate's name. Her mother's patient explanations open Kate's eyes to what so many of the elderly must confront: Alzheimer's disease and other forms of memory loss. Determined to support her grandfather, Kate explores ways to help him - and herself - cope by creating a photo album of their times together, memories that will remain in their hearts forever.

Kevin and Jodi O'Donnell, were a young New Jersey couple busy raising a toddler and making plans for their future when they received life-altering news in 1995 that changed everything as they knew it. Kevin was only 30 years old when he was told that his health problems were the result of a rare, terminal disease called ALS (Amyotrophic Lateral Sclerosis), or Lou Gehrig's disease. Kevin and Jodi had not heard of ALS until then and had no idea how those three letters would challenge everything they thought to be certain. After more than 20 years of working with ALS families, Jodi realized that more information and better resources could be available to help families who are coming to grips with the

challenges of the disease and the caregiving responsibilities that are involved. In the Introduction to "Someone I Love Has ALS: A Family Caregiver's Guide," Jodi recounts the journey she took as a caregiver, advocate and writer and embraces and shares the lessons learned throughout the pages of this wonderful guide, "This guide was created by a variety of caregivers and professionals who have years of experience with various aspects of ALS. It was written by volunteers and experts who care about ALS and your journey. It is the resource that I wish we had received along with the shocking diagnosis." Although Kevin died of ALS in 2001 at the age 35, the disease never won the battle. ALS only strengthened Kevin and Jodi's love for God and each other and it created an even bigger purpose and plan: the creation of Hope Loves Company(r), the only non-profit whose mission is to support the children and grandchildren caregivers of PALS (people with ALS). "This book would have been a godsend for my family and me when my dad was diagnosed with ALS. We had no idea where to turn or what we were facing. We felt like we only had each other and no one else understood. I'm anxious to share this wonderful book with all of our newly diagnosed ALS families. Thank you Jodi, for always thinking of others and making a difference in the lives of ALS families. I am proud to be a part of this book and Camp HLC(r)" - Donna Dourney York, Founder of Hark, Inc. "This a terrific and helpful guide for

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caregivers and families of People ALS (PALS) from someone who has first-hand experience of caring for a person with ALS. Jodi O'Donnell- Ames has more than 20 years' experience fighting this horrific disease and truly cares about each and every person affected by ALS." - Lynne Brosch, nurse for several PALS

Explores the important emotional work accomplished in the final months of life and offers advice on dealing with doctors, talking with friends and relatives, and managing end-of-life care

Get everything you need to create and customize effective nursing care plans, now with evidence-based ICNP® diagnoses! Covering the most common medical-surgical nursing diagnoses and clinical problems, Gulanick & Myers' Nursing Care Plans: Diagnoses, Interventions, and Outcomes, 10th Edition features more than 200 care plans, each reflecting the latest evidence-based guidelines and national and international treatment protocols. It also features highlighted QSEN competencies and a clear differentiation of nursing and collaborative interventions. New to this edition are ICNP® diagnoses, care plans on LGBTQ health issues and on electrolytes and acid-base balance, and a new Online Care Planner that makes it easier than ever to customize care plans. Written by noted educators Meg Gulanick and Judith L. Myers, this #1 care planning book will help you learn to think like a nurse! 61 patient problem care plans include the most

common/important patient problems, providing the building blocks for you to create your own individualized care plans. 164 disorder care plans cover virtually every common medical-surgical condition, organized by body system. Patient problem care plan format includes a definition/explanation of the diagnosis, related factors, defining characteristics, expected outcomes, ongoing assessment, and therapeutic interventions. Disorder care plan format covers synonyms for the disorder (for ease in cross referencing), a definition, common related factors, defining characteristics, expected outcomes, ongoing assessment, and therapeutic interventions for each relevant nursing diagnosis. Prioritized care planning guidance internally organizes care plans from "actual" to "risk" diagnoses, from general to specific interventions, and from independent to collaborative/interprofessional interventions, to help you select the most important, priority interventions for your particular patients. NEW! Updated care plans are now based on the evidence-based, complete, and internationally accepted International Classification of Nursing Practice (ICNP®) nursing diagnoses. NEW! 19 all-new care plans are featured in this edition. NEW! Updated content throughout reflects the most current evidence-based practice and national and international guidelines. NEW! Online Care Planner on the Evolve website allows you to easily generate customized care plans based on

the book's content. NEW! Improved focus on core content includes several care plans that have been moved from the book's Evolve website.

Amyotrophic Lateral Sclerosis (ALS) Patient and Caregiver Resource Guide
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“Unsparring in her depiction of the disease’s harrowing effects, neuroscientist Genova also celebrates humanity.” —People “Sometimes it’s easier to tell truth in fiction...And she tells it with heart and hope.” —NPR “Her juxtaposition of scientific detail with compassionate, heartfelt storytelling is unparalleled.” —Bookreporter “Every Note Played will grip and gut you.” —The Boston Globe

From neuroscientist and New York Times bestselling author of *Still Alice* comes a powerful exploration of regret, forgiveness, freedom, and what it means to be alive. An accomplished concert pianist, Richard received standing ovations from audiences all over the world in awe of his rare combination of emotional resonance and flawless technique. Every finger of his hands was a finely calibrated instrument, dancing across the keys and striking each note with exacting precision. That was eight months ago. Richard now has ALS, and his entire right arm is paralyzed. His fingers are impotent, still, devoid of possibility. The loss of his hand feels like a death, a loss of true love, a divorce—his divorce. He knows his left arm will go next. Three years ago, Karina removed their framed

wedding picture from the living room wall and hung a mirror there instead. But she still hasn't moved on. Karina is paralyzed by excuses and fear, stuck in an unfulfilling life as a piano teacher, afraid to pursue the path she abandoned as a young woman, blaming Richard and their failed marriage for all of it. When Richard becomes increasingly paralyzed and is no longer able to live on his own, Karina becomes his reluctant caretaker. As Richard's muscles, voice, and breath fade, both he and Karina try to reconcile their past before it's too late. Poignant and powerful, *Every Note Played* is a masterful exploration of redemption and what it means to find peace inside of forgiveness.

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. Eliot H. Dunsky, MD, is a retired physician who since his diagnosis in 2009 has been living with ALS, the complex, progressively debilitating disorder commonly known as Lou Gehrig's disease. Determined to maintain the best quality of life possible-for as long as possible-he extensively researched the condition and its management. As he immersed himself, talking to ALS patients and exploring emerging assistive technologies and aids, he realized that misunderstanding of this complicated disease was rife, preventing many from making the most of the precious years left. The result is this compilation of not only his personal experiences as his own condition advanced but also current research and links to additional specialized resources. Its aim is to help other patients learn to live with their diagnosis and navigate the day-to-day struggles associated with it. Appropriate symptom management can help fend off the devastating effects of

the disease for a longer period of time. ALS: An Orientation offers a practical guide for patients and their families on maximizing quality of life through strategic care and, importantly, coping with the emotional toll the disease can take. A terminal diagnosis simply means savoring to the fullest the life that is still possible.

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.

The author, Robert Rymore, had a good friend who was diagnosed with Lou Gehrig Disease. He wanted to be able to help her and decided to buy some books about the disease. To his disappointment there was a lack of good informative books available on the subject. He decided to investigate the subject thoroughly and write a book about it to be able to help others. He decided he would start talking to professionals - doctors, physical therapists, speech therapists and occupational therapists - to learn more. He quickly realized the information he was getting would be extremely valuable for other people with ALS and their loved ones. This book has been a labor of love, one born of necessity and certainly one that aims to help those with ALS, their families, and their friends. ALS symptoms, signs, stages, types, diagnosis, treatment, caregiver tips, aids and what to expect is all covered. Including chapters about financial considerations, famous people with Lou Gehrig Disease and resources. The book is written in an easy to read and understandable style and contains tips for caregivers.

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.

Amyotrophic Lateral Sclerosis: A Patient Care Guide for Clinicians is intended as

a practical reference for clinicians caring for ALS patients, and will bring together the collective wisdom of those at the forefront of patient-oriented research and practice. This will be an official project of the ALS Research Group (founded by Dr. Mitsumoto and currently headed by Dr. Bedlack), and provides both an evidence-based and experience-based guide to multidisciplinary ALS care. The book will begin with a brief review of current concepts of ALS including diagnostic criteria, genetic and sporadic subtypes, epidemiology, co-morbidities and prognosis. Individual chapters then tackle the gamut of specific issues that arise in caring for people with ALS, from breaking the news all the way through end-of-life care and bereavement. Amyotrophic Lateral Sclerosis: A Patient Care Guide for Clinicians is divided by disciplines, mirroring the way large multi-disciplinary ALS clinics operate and includes pertinent material for each member of the care team. Each section will have one primary author from that discipline (an expert ALSRG member), who will review the specific issues they have seen arise and review the evidence-based options presented for each issue. Each section will also have a group of secondary authors, other experts from the same discipline who offer counterpoints or other ideas about how to handle clinical problems (i.e. use of lipids and statins, screening for driving, etc.)—essentially what has or hasn't worked for them—thus capturing the variety of opinions across experts in the field

and providing real-world care information that isn't available or documented anywhere else.

One Blink at a Time is Ismail and Cheryl Tsieprati's story of living with ALS (Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's Disease) for more than 30 years. One Blink at a Time is upbeat, inspiring and full of optimism as Ismail and Cheryl recount in alternating chapters how they deal with their daily challenges. Although ALS has stolen Ismail's ability to move, speak, even to breathe on his own, it has not taken away his determination to live a happy and productive life. Ismail spelled out his chapters using eye blinks, letter by letter, word by word. Cheryl and Ismail's distinctive voices add to the impact of this exceptional book. Full of practical advice from training caregivers to preparing for emergencies to surviving the hospital, the book also includes an extensive glossary and resources for anyone dealing with ALS and other disabling conditions. But above all else, One Blink at a Time is an inspiring love story. Ismail and Cheryl are as devoted to one another today as they were the day they were married nearly 50 years ago.

Includes Vital Information on Frontotemporal Dementia (FTD)Foreword by John Q. Trojanowski, MD, PhD, Director, Alzheimer's Disease Center, University of Pennsylvania HospitalAlthough the public most often associates dementia with

Alzheimer's disease, the medical profession now distinguishes various types of other dementias. This book is the first comprehensive guide dealing with frontotemporal dementia (FTD), one of the largest groups of non-Alzheimer's dementias. The contributors are either specialists in their fields or have exceptional hands-on experience with FTD sufferers. Beginning with a focus on the medical facts, the first part defines and explores FTD as an illness distinct from Alzheimer's disease. Also considered are clinical and medical care issues and practices, as well as such topics as finding a medical team and rehabilitation interventions. The next section on managing care examines the daily care routine including exercise, socialization, adapting the home environment, and behavioral issues. In the following section on caregiver resources, the contributors identify professional and government assistance programs along with private resources and legal options. This newly revised edition follows recent worldwide collaboration in research and provides the most current medical information available, a better understanding of the different classifications of FTD, and more clarity regarding the role of genetics. A completely new chapter 5 enlightens the reader about the various drugs that are now being used with FTD patients and also delves into a number of nonmedical options. The wealth of information offered in these pages will help both healthcare professionals and caregivers of

someone suffering from frontotemporal dementia. Lisa Radin and her son, Gary Radin, provided complete care for father and husband Neil Radin over a four-year period. Based on this firsthand experience with a devastating illness, they compiled this collection of expert articles on FTD by medical specialists, healthcare professionals, and fellow caregivers. Gary and Lisa founded in 1998 the Neil L. Radin Caregivers Relief Foundation and were both involved in planning and coordinating the Multidisciplinary Conference on Picks Disease & Frontotemporal Dementia held in May 1999 in Philadelphia; the proceedings of this conference were published in *Neurology*. Lisa also provided organizational support for the Frontotemporal Dementia and Pick's Disease Criteria Conference held at the National Institutes of Health in July 2000 in Bethesda, MD.

Family caregiving affects millions of Americans every day, in all walks of life. At least 17.7 million individuals in the United States are caregivers of an older adult with a health or functional limitation. The nation's family caregivers provide the lion's share of long-term care for our older adult population. They are also central to older adults' access to and receipt of health care and community-based social services. Yet the need to recognize and support caregivers is among the least appreciated challenges facing the aging U.S. population. *Families Caring for an Aging America* examines the prevalence and nature of family caregiving of older

adults and the available evidence on the effectiveness of programs, supports, and other interventions designed to support family caregivers. This report also assesses and recommends policies to address the needs of family caregivers and to minimize the barriers that they encounter in trying to meet the needs of older adults.

Sarah has a problem. Every year she and her father march in the Fourth of July Parade. This year is different. Sarah's daddy is sick and can no longer walk. To make matters worse, he relies on a wheelchair, an UGLY wheelchair. Sarah has to decide whether she will listen to her pride and break a father-daughter tradition or listen to her heart and embrace a new one. Through her compassion, Sarah learns not only to accept her father's new wheelchair, but his disability as well. The Stars That Shine is a lovely tribute to all children who live with a disabled or terminally ill parent. Enclosed are resources for ALS patients, their caregivers and children. Although this story is about ALS, the message resonates with all families who live with similar challenges.

Give your students a complete guide to community health nursing! Community/Public Health Nursing, 7th Edition provides a unique, upstream preventive focus and a strong social justice approach, all in a concise, easy-to-read text. Covering the nurses' role in promoting community health, it shows how students can take an active role in social action and health policy – emphasizing society's responsibility to protect all human life and ensuring that diverse and vulnerable populations have their basic health needs met. Clinical examples and photo novellas show how nursing concepts apply to the real world. Written by community health

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nursing experts Mary A. Nies and Melanie McEwen, this book describes the issues and responsibilities of today's community and public health nurse. UNIQUE! A 'social justice' approach promotes health for all people, including vulnerable populations. UNIQUE! 'Upstream' preventive focus addresses factors that are the precursors to poor health in the community, addressing potential health problems before they occur. Case Studies present the theory, concepts, and application of the nursing process in practical and manageable examples. UNIQUE! Photo novellas use photographs to tell stories showing real-life clinical scenarios and applications of important community health nursing roles. Application of the nursing process at the individual, family, and aggregate levels highlights the community perspective in all health situations Clinical examples offer snippets of real-life client situations. Theoretical frameworks common to nursing and public health aid in the application of familiar and new theory bases to problems and challenges in the community. Healthy People 2020 boxes include the most current national health care objectives. Research Highlights boxes show the application of research studies to the practice of community nursing. Ethical Insights boxes highlight ethical issues and concerns that the community/public health nurse may encounter. Objectives, key terms, and chapter outlines at the beginning of every chapter introduce important concepts and terminology. NEW AND UNIQUE! A Veterans Health chapter presents situations and considerations unique to the care of veterans. NEW! Genetics in Public Health boxes reflect increasing scientific evidence supporting the health benefits of using genetic tests and family health history to guide public health interventions. NEW! Active Learning boxes test your knowledge of the content you've just read, helping provide clinical application and knowledge retention.

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The management of chronic diseases is one of the tasks of all members of the health team, and different models need to be applied in the practice of chronic care management. One of these models is home care services. There are two main sections in this book. In the first part of the section, the concept of caregiving and care at home is explained. In the second part, the responsibilities of caregivers at home and the responsibilities of caregivers of people who have health problems that occur during different periods of life are discussed. In the second section, the problems of caregivers are also included. I would like to think that what is quoted in this book, which contains examples from different cultures of the world for home care approaches, will contribute to the development of home care services. This book is presented to all health professionals working in the field of health services as well as health politics professionals and students trained in these areas.

Abstract: Amyotrophic Lateral Sclerosis (ALS) is a complex terminal diagnosis that carries an enormous burden for the patient and their caregiver. This qualitative study examined the strengths, challenges, and quality of life of ALS caregivers. Fifteen caregivers for someone who has been diagnosed with ALS and is living in the home participated in this study. Topics that were explored included the role of the caregiver, experiences with community based resources, support systems, strengths and challenges, living arrangements, end-of-life decision making, and recommendations to service providers. The results facilitate the understanding of the lives, experiences of services, and suggestions for service change among people who are affected by an ALS diagnosis. The implications of this study assist social workers and other health care professionals in designing programs, policies, and interventions that act to better reach the needs of caregivers who are supporting someone that has been

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diagnosed with ALS through the progression of the disease process.

Above all, Phyllis Langton's memoir, *Last Flight Out: Living, Loving & Leaving*, is a passionate love story, one that deepens as she and her husband George Thomas live their way into the experience of ALS, its unremitting losses and its surprising gifts, with dignity, keen humor, a fighter pilot's courage and a nurse's unsentimental pragmatism. "I know what's going to be on my death certificate. That's more than you can say," George tells her after receiving his diagnosis. How they are going to live the time that remains to them as a couple is also not in question, for they are equally committed to savoring every minute, respecting George Thomas's choices about what makes for a meaningful life, a meaningful death. Supporting her husband's wishes is a moral as well as emotional choice on Langton's part, and definitely not always an easy one. As a medical sociologist, she invites her readers into an open discussion of some of these choices through a thoughtful discussion guide. "Phyllis Langton has had as illustrious a career as anyone in academia, but she has taken infinite pains now to write a different kind of book. Her story of her husband's life with and death from ALS (Lou Gehrig's disease) yields many a valuable lesson. . . . Here love and mortality, laughter and sorrow are all but inseparable, and their inseparability may help lessen a reader's fear of death and dying. Anyone who enjoys a deeply moving story will want to read this wondrous, indispensable book, and anybody who faces adversity, that is to say, everybody will need to read it," Jeffery Paine, author of *Father India*, *Re-enchantment*, *Adventures with the Buddha*, and *Tales of Wonder*. "Who would have thought that disease can be a page-turner? But Phyllis Langton's bittersweet memoir of her fighter-pilot husband's last years shows that a good marriage can be as joyous in sickness as it is in health," Mark Weston, author of *Giants of Japan*. "In my 28 years as a

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healthcare chaplain I have observed the journey toward death Phyllis Langton portrays in *Last Flight Out*. But I am a professional who only sees those brief moments I am at the hospital or nursing home bedside or visiting in someone's home. Langton invites us into her life with her husband George as he moves through increasing disability to his final breaths. It is moving and, in my view, honest," Chaplain Hank Dunn, author of *Hard Choices for Loving People*. "I couldn't put *Last Flight Out* down. . . . What an incredible message to read especially with a disease that takes and takes," Sharon J. Matland, R.N., M.B.A.--V.P. Patient Services, ALS Association Phyllis A. Langton, Ph.D., R.N., Professor Emerita, Sociology, George Washington University, is the author of numerous scholarly articles and books. *Last Flight Out* is her first memoir.

Willard and Spackman's *Occupational Therapy, Twelfth Edition*, continues in the tradition of excellent coverage of critical concepts and practices that have long made this text the leading resource for Occupational Therapy students. Students using this text will learn how to apply client-centered, occupational, evidence based approach across the full spectrum of practice settings. Peppered with first-person narratives, which offer a unique perspective on the lives of those living with disease, this new edition has been fully updated with a visually enticing full color design, and even more photos and illustrations. Vital pedagogical features, including case studies, Practice Dilemmas, and Provocative questions, help position students in the real-world of occupational therapy practice to help prepare them to react appropriately.

You Don't Have to Do It Alone Whether you're prepared for it or not, chances are you'll take on the role of caregiver when a family member or friend is affected by a serious illness or injury, or when you find your elderly parent needs help. As you'll soon discover, the range of tasks and

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responsibilities involved are overwhelming. Share The Care offers a sensible and loving solution: a unique group approach that can turn a circle of ordinary people into a powerful caregiving team. Share The Care shows you how to: Create a caregiver "family" from friends, real family members, neighbors, coworkers, and acquaintances. Hold a meeting to organize your group, and introduce members to the Share The Care systems that guarantee every job will be done and no one person will have to do too much. Discover the hidden talents within the group, make the most of their resources, cope with group issues, and stay together in the face of adversity. Included here are valuable guidelines, compassionate suggestions, and a simple-to-use workbook section that together offer support to free the patient from worry and the caregivers from burnout. Share The Care offers friends and family the best answer ever to the frequently asked question "What can I do?"

Kevin and Jodi O'Donnell, were a young New Jersey couple busy raising a toddler and making plans for their future when they received life-altering news in 1995 that changed everything as they knew it. Kevin was only 30 years old when he was told that his health problems were the result of a rare, terminal disease called ALS (Amyotrophic Lateral Sclerosis), or Lou Gehrig's disease. Kevin and Jodi had not heard of ALS until then and had no idea how those three letters would challenge everything they thought to be certain. After more than 20 years of working with ALS families, Jodi realized that more information and better resources could be available to help families who are coming to grips with the

challenges of the disease and the caregiving responsibilities that are involved. In the Introduction to "Someone I Love Has ALS: A Family Caregiver's Guide," Jodi recounts the journey she took as a caregiver, advocate and writer and embraces and shares the lessons learned throughout the pages of this wonderful guide, "This guide was created by a variety of caregivers and professionals who have years of experience with various aspects of ALS. It was written by volunteers and experts who care about ALS and your journey. It is the resource that I wish we had received along with the shocking diagnosis." Although Kevin died of ALS in 2001 at the age 35, the disease never won the battle. ALS only strengthened Kevin and Jodi's love for God and each other and it created an even bigger purpose and plan: the creation of Hope Loves Company(r), the only non-profit whose mission is to support the children and grandchildren caregivers of PALS (people with ALS).

2010 had been a very good year for Bruce H. Kramer. But what began as a floppy foot and leg weakness led to a shattering diagnosis: he had amyotrophic lateral sclerosis. ALS is a cruel, unrelenting neurodegenerative disease where the body's muscles slowly weaken, including those used to move, swallow, talk, and ultimately breathe. There is no cure; ALS is a death sentence. When death is a constant companion, sitting too closely beside you at the dinner table, coloring

your thoughts and feelings and words, your outlook on life is utterly transformed. The perspective and insights offered in *We Know How This Ends* reveal this daily reality and inspire a way forward for anyone who has suffered major loss and for anyone who surely will. Rather than wallowing in sadness and bitterness, anger and denial, Kramer accepted the crushing diagnosis. The educator and musician recognized that if he wanted a meaningful life, embracing his imminent death was his only viable option. His decision was the foundation for profound, personal reflection and growth, even as his body weakened, and inspired Kramer to share and teach the lessons he was learning from ALS about how to live as fully as possible, even in the midst of devastating grief. At the same time Kramer was diagnosed, broadcast journalist Cathy Wurzer was struggling with her own losses, especially the slow descent of her father into the bewildering world of dementia. Mutual friends put this unlikely pair—journalist and educator—together, and the serendipitous result has been a series of remarkable broadcast conversations, a deep friendship, and now this book. Written with wisdom, genuine humor, and down-to-earth observations, *We Know How This Ends* is far more than a memoir. It is a dignified, courageous, and unflinching look at how acceptance of loss and inevitable death can lead us all to a more meaningful and fulfilling life.

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.

A practical handbook for women confronting the problems of caring for an aging parent explains how to deal with the changing parent/child roles, foster aging

parents' independence, get help from other family members, find time for oneself, and balance work, family, and caregiving responsibilities. Original.

Background: Amyotrophic Lateral Sclerosis (ALS), an incurable motor neuron disease, primarily affects those between the ages of 60-79, and sees an approximate post-diagnosis life-expectancy of only 2-5 years. The condition has an unpredictable but ultimately terminal trajectory that poses a number of challenges for patients, caregivers and healthcare providers. One of these major challenges is the need to make sure that patients' quality-of-life is as high as possible throughout the disease course. Many factors have been shown to influence quality-of-life, including patients and caregivers' ability to cope and adapt to the changes associated with the disease. There is some evidence to suggest that the manner in which healthcare providers present the information and empathize with their patients' thereafter, in addition to patients' initial reactions to hearing their diagnosis, may hold some predictive value or have an impact on subsequent coping-related outcomes. But still, our knowledge regarding the relational, communicational and psychodynamic forces that occur within the process of diagnostic disclosure is relatively limited. Therefore, further investigation of patients and caregivers' experiences in the conversations surrounding their ALS diagnosis is necessary to enhance guidelines and

practices towards improved coping and quality-of-life support for people living with ALS. Objectives: The purpose of this study was to explore the experiences of persons living with ALS in diagnosis and disclosure, with specific attention paid to their experiences in hearing their diagnosis, and their preferences for care and coping support. The perspectives of those living with the disease and those of their caregivers were considered. Methods: Data were collected from a sample of 18 people consisting of persons with ALS/ PLS (n = 9), family caregivers (n = 7), a professional caregiver (n = 1), and one past caregiver (n = 1). Data were collected during individual (n = 5), dyad (n = 8) and group (n = 9) interviews that were conducted using interview guides comprised of a series of open-ended questions related to the study's research questions. The interviews were audio-recorded and transcribed verbatim. A thematic analysis of the acquired data was conducted using methods outlined by Braun & Clarke (2006) in order to establish major themes. Coding was done using NVivo 11 software. Results: The data revealed six major themes that specifically relate to the ALS diagnosis process, eight themes relating to the diagnostic disclosure process, and eight themes pertaining to the coping process. Three major themes were established with regards to participants' desired experiences for support in their coping: hope stimulating conversations and activities, ongoing information provision aimed at

curbing uncertainty, and independence, autonomy, lifestyle and normalcy supported throughout the disease course. Significance: This project serves as an initial step in bridging the relevant gaps in our knowledge and understanding toward improved patient-centred care practices in diagnosis, disclosure, care and coping support for persons with ALS. There is also potential for the project's findings to guide practice and policy developments to benefit the care of persons with other illnesses characterized by short and unpredictable trajectories. Focusing on research designs for projects that collect both qualitative and quantitative data, this practical book discusses strategies for bringing qualitative and quantitative methods together so that their combined strengths accomplish more than is possible with a single method. The approach is broadly interdisciplinary, reflecting the interest in mixed methods research of social scientists from anthropology, communication, criminal justice, education, evaluation, nursing, organizational behavior, psychology, political science, public administration, public health, sociology, social work, and urban studies. In contrast to an "anything goes" approach or a naïve hope that "two methods are better than one," the author argues that projects using mixed methods must pay even more attention to research design than single method approaches. The book's practical emphasis on mixed methods makes it useful both to active

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researchers and to students who intend to pursue such a career.

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