Motor Neurone Disease A Family Affair

If you knew how it would end, could you find the courage to begin? When Alec asks Jess out, she knows it won't work. He may be charming and handsome, but Jess has rules. And the first? Don't fall in love. Jess has inherited Huntington's disease from the mother that she cares for. Falling in love would mean condemning someone to the heartbreak that she feels every day. Jess has learnt to keep everyone and everything at arm's length, but Alec is determined to break down her barriers. When she finally tells him why they have no future together, he proposes that they forget the future and live for the moment - for just one month. But as Jess begins to fall for Alec, she knows she has to end it. It's better that he is hurt now rather than heartbroken later, isn't it? An emotional, poignant but ultimately uplifting love story from the winner of the EHarmony Write Your Own Love Story Competition. Perfect for fans of The Man Who Didn't Call, In Five Years and PS I Love You.

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.

As end of life care is extended to more and more people it is increasingly important that people with progressive neurological disease are recognised as having particular issues as their disease progresses. This group of people with advancing motor neurone disease, multiple sclerosis, Parkinson’s disease, multiple systems atrophy, progressive supranuclear palsy, Huntington’s disease and other progressive neurological disease face increasing problems – with physical symptoms and psychosocial and spiritual issues for both themselves and their families and carers. This book encourages health and social care professionals to become closely involved in the care of these people and their families, so that advance care plans can be started and quality of life maintained. This book addresses the principles and practice of developing end of life care strategies for neurological disease, written with a clinical, multidisciplinary focus and illustrated with detailed case studies.

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.

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.

Dementia and Motor Neuron Disease is a single authoritative reference on the current understanding of frontotemporal dementia in amyotrophic lateral sclerosis (ALS). This comprehensive work is ideal for clinical and research groups focusing on dementia or ALS, as well as those working in the fields of neuroimaging and neuropsychology. Key topics covered include: • Frontotemporal dementia, including history, anatomy and impairment • Clinical phenomenology and treatment • Neuropathological, cognitive dysfunction and altered cognition spectrums • Neuroimaging • Molecular and cellular neuropathology • Genetics • Neurochemistry With contributions from international opinion leaders in dementia and motor neuron disease, this is a one-of-a-kind reference for established clinicians and researchers, as well as graduate students studying neurodegeneration.

Finding A Way will appeal to football fans, describing as it does the delights of playing the sport professionally, and sharing with the reader the secrets of the dressing room – and midfielder Len Johnrose’s candid opinions of the players and managers who populated his glory years. Yet this is much more than a footballing memoir, and the title refers to more than sporting endeavour. The book – full of humour – will also appeal to those who are fascinated by the human spirit and how it can vault the most intimidating barriers to happiness. ‘Finding a way’ has become Len’s mantra since his diagnosis with motor neurone disease (MND) in 2017, some years after his retirement from professional football, while he was working as a teacher and maintaining high standards of physical fitness through sport and gym. This cruel disease gradually removed all such activities from his life. Now it severely restricts his personal freedoms as his everyday movement became increasingly affected – the memoir was written using voice-recognition technology as Len can no longer control his hands. It’s been a long journey for Len since he played for Blackburn Rovers, Hartlepool, Bury, Burnley, Swansea City and Preston North End. Yet this quietly admirable man has found a way to overcome the unexpected challenges he’s faced off the field, and that brings its own satisfaction.

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.

The First Edition of InterViews has provided students and professionals in a wide variety of disciplines with the “whys” and “hows” of research interviewing, preparing students for learning interviewing by doing interviews and by studying examples of best practice. The thoroughly revised Second Edition retains its original seven-stage structure, continuing to focus on the practical, epistemological, and ethical issues involved with interviewing. Authors Steinar Kvale and Svend Brinkmann also include coverage of newer developments in qualitative interviewing, discussion of interviewing as a craft, and a new chapter on linguistic modes of interview analysis. Practical and conceptual assignments, as well as new “tool boxes,” provide students with the means to dig deeper into the material presented and achieve a more meaningful level of understanding. New to This Edition · Includes new developments in qualitative interviewing: New

materials cover narrative, discursive, and conversational analyses. · Presents interviewing as a social practice: Knowledge produced by interviewing is discussed as linguistic, conversational, narrative, relational, situated, and pragmatic. · Addresses a variety of interviews forms: In addition to harmonious, empathetic interviews, the authors also cover confrontational interviews. Intended Audience This text is ideal for both novice and experienced interview researchers as well as graduate students taking courses in qualitative and research methods in the social sciences and health sciences, particularly departments of Education, Nursing, Sociology, Psychology, and Communication. Praise for the previous edition: “I think this is one of the most in-depth treatments of the interview process that I have seen. The frank and realistic approach that the authors take to this topic is rather unique and will be very reassuring to researchers who are undertaking an interview study for the first time.” —Lisa M. Diamond, University of Utah

The incredible book behind the primetime Channel 4 documentary, Peter: The Human Cyborg 'A remarkable account of what it means to be human and what technology can really achieve' Sunday Telegraph 'Peter's story is one of the most extraordinary you will ever hear. I urge people to read it' Stephen Fry 'A remarkable story . . . you're left desperate to take nothing for granted' Radio Times _____ Peter, a brilliant scientist, is told that he will lose everything he loves. His husband. His family. His friends. His ability to travel the world. All will be gone. But Peter will not give up. He vows that this will not be the end and instead seeks a completely new beginning . . . Peter has Motor Neurone Disease, a condition universally considered by doctors to be terminal. He is told it will destroy his nerve cells and that within about two years, it will take his life too. But, face-to-face with death, he decides there is another way. Using his background in science and technology, he navigates a new path, one that will enable him not just to survive, but to thrive. This is the astonishing true story about Peter Scott-Morgan: the first person to combine his very humanity with artificial intelligence and robotics to become a full Cyborg. His discovery means that his terminal diagnosis is negotiable, something that will rewrite the future. And change the world. By embracing love, life and hope rather than fear, tragedy and despair, he will become Peter 2.0. _____ 'Compelling . . . Scott-Morgan is a true one-off. It is in the telling of the love story, rather than the technical details of becoming a cyborg, that this book succeeds' The Times 'What's striking is Peter's constant optimism, bravery and his ability to find radical answers to problems that have confounded Britain's brightest minds' Daily Telegraph 'A soaring love story' Financial Times 'Fascinating and extremely moving' Sun

Jenifer Estess is a woman on the verge: She's about to launch her own company; she's looking buff and dating vigorously; she's driving in the fast lane -- with the top down. At the age of thirty-five, Jenifer dreams of falling in love and starting a family. Then she notices muscle twitches in her legs. Walking down a city block feels exhausting. At first, doctors write off Jenifer's symptoms to stress, but she is quickly diagnosed with ALS, a fatal brain disease that is absolutely untreatable. Max out your credit cards and see Paris, suggests one doctor. Instead of preparing to die, Jenifer gets busy. She dreams deeper, works harder, and loves endlessly. For Jenifer, being fatally ill is not about letting go. It's about holding on and reaching -- for family, friends, goals. Jenifer's girlhood pact with her sisters Valerie and Meredith -- nothing will ever break us apart -- guides them as Jenifer faces down one of the most devastating illnesses known to humankind. That same enduring pact inspires the creation of Project A.L.S., a movement started by the sisters that changes the way science and medicine approach research for ALS and the related diseases Parkinson's and Alzheimer's, and which has already raised more than $18 million. Will Project A.L.S. help scientists discover medicine in time for her? Jenifer answers these questions and others in this beautifully written and wholly inspiring memoir that celebrates a life fuelled by memory. Tales from the Bed forces us to reconsider society's notion of "having it all," and illustrates, more than anything, the importance of endurance, hope, and, most of all, love.

A Short History of Falling - like The Diving Bell and the Butterfly, and When Breath Becomes Air - is a searingly beautiful, profound and unforgettable memoir that finds light and even humour in the darkest of places. Now with a Foreword by Joe's widow, Gill Hammond We keep an old shoebox, Gill and I, nestled in a drawer in our room. It's filled with thirty-three birthday cards for our two young sons: one for every year I'll miss until they're twenty-one. I wrote them because, since the end of 2017, I've been living with - and dying from - motor neurone disease. This book is about the process of saying goodbye. To my body, as I journey from unexpected clumsiness to a wheelchair that resembles a spacecraft, with rods and pads and dials and bleeps. To this world, as I play less of a part in it and find myself floating off into unlighted territory. To Gill, my wife. To Tom and Jimmy. A Short History of Falling is about the sadness (and the anger, and the fear), but it's about what's beautiful too. It's about love and fatherhood, about the precious experience of observing my last moments with this body, surrounded by the people who matter most. It's about what it feels like to confront the fact that my family will persist through time with only a memory of me. In many ways, it has been the most amazing time of my life.

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.

How much more time do I have left? I fell for the second time yesterday. Am I deteriorating more quickly than I thought? I will have to be fed. I will have to be helped on the toilet. These thoughts churn in my mind. For the first time I have a genuine fear of what is to come. I've held it together until this point, but processing all the information about the future is too much. I can't stop the tears. How much longer will I still be able to walk? To speak? To act normally? It has been nearly eight years since I was diagnosed with Motor Neurone Disease (MND). When I started writing this book four years ago, I was full of anger, anxiety, fear and frustration. I have changed. It has been a journey of self-discovery, forgiveness of myself, as well as love and acceptance of others. This is my story about living with MND. But more than that, this is a book about hope, love, spiritual fulfilment, and the lessons I've learned on this journey.

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 to 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 very rare, terminal and untreatable and it was my mission to educate and inform Families with members who have been diagnosed with MND, Care Givers and Medical Practitioners of our experience through the various phases of the disease. As the primary Care Giver I accumulated first-hand experience of the 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 the patient, suffered from the progressive ravages of the disease and how I as the husband and Care Giver, experienced the journey.The book is composed of 8 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 symptoms to diagnoses September 2009.The fifth section through to the seventh section maps our journey tracking the progressive degeneration month by month from September 2009 to February 2011 when she passed on.The eighth section chronicles lessons learnt and my understanding and coming to terms with Lydia's 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 benefit 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.

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.

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.

Here is the first book to provide a comprehensive overview of the clinical, pathological, and research aspects of motor neuron disease (MND). The text contains all essential features of the anatomy, physiology, pharmacology and toxicology of the motor system, a full description of MND and its variants, as well as historical developments and a review of the current concepts and controversies. This book comes at a time of increasing interest in neurodegenerative disorders and MND in particular. It will prove a key reference book with an integrated overview of the field, and will be indispensable to practicing neurologists, researchers, and all those with an interest in MND.

Finding A Way is much more than a footballing memoir, and the title refers to more than sporting endeavour. The book – full of humour – will also appeal to those who are fascinated by the human spirit and how it can vault the most intimidating barriers to happiness.

Motor Neurone DiseaseA Family AffairSPCK

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

Dedicated to our readers, we include novel information (not reported in IntechOpen’s books before) about new contributions of aberrant astrocytes to MND damage and death in the SOD1G93A rat experimental model of ALS; novel genetic studies on ALS; an update of the structural and functional consequences of the spinal muscular atrophy-linked mutations of the survival motor neuron protein; stem cell therapy for MND; and the novel treatment for SMA and ALS in the introductory chapter. This book contains selected peer-reviewed chapters written by international researchers. In this publication, the readers will find a compilation of state-of-the-art reviews about etiology, therapies, investigations, the molecular basis of disease progression and clinical manifestations, and the genetic familial ALS, as well as novel therapeutic modalities. We look forward with confidence and pride to the remarkable role that this book will play for a new vision and mission.

The extraordinary, life-affirming autobiography of DODDIE WEIR OBE Rugby legend and MND campaigner Doddie Weir has always lived life to the full. On the pitch, Doddie's irresistible talent took him to the heart of every team he graced, and brought him 61 caps for his national side. He won fans all over the world with his sportsmanship, humour and boundless energy – especially when on the charge 'like a mad giraffe'. Then, in June 2017, Doddie made the announcement that he had been diagnosed with MND. With no cure and almost no treatment of any sort available, Doddie set out to do what he could to change that, tackling the issue head on with his trademark positivity and good humour. Since then, his MY NAME'5 DODDIE Foundation has raised and pledged millions towards research into this dreadful condition and his tireless campaigning has transcended the world of sport. MY NAME'5 DODDIE is a humbling, courageous and very funny celebration of a remarkable man. And with a brand new update, this is an absolute must-read – rugby fan or not. 'Lucid, brave, and full of the wit and character that makes him the legend he is' – RORY BREMNER

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.

THE NEW YORK TIMES BESTSELLER What would you do with one last year? Susan Spencer-Wendel was determined to laugh instead of cry. In June 2011, Susan Spencer-Wendel learned she had amyotrophic lateral sclerosis (ALS) - Lou Gehrig's disease - an irreversible condition that systematically destroys the nerves that power the muscles. She was 44-years-old, with three young children, and she had only one year of health remaining. She decided to live that year with joy. She left her job as a journalist and spent time with her family. She built a meeting place for friends in her backyard. And she took seven trips with the seven most important people in her life. As her health declined, Susan journeyed to the Yukon, Hungary, the Bahamas, and Cyprus. She went to the beach with her sons and to Kleinfeld's bridal shop in New York City with her teenage daughter, Marina, for a glimpse of the wedding she would never attend. She also wrote this book. No longer able to walk or even lift her arms, she tapped it out letter by letter on her iPhone using only her right thumb, the last finger still working. And yet Until I Say Good-Bye is not angry or bitter. It is sad in parts - how could it not be? - but it is filled with Susan's optimism, joie de vivre and sens of humour. It is a book that, like Susan, will make everyone smile. From a hilarious family Christmas disaster to the decrepit monastery in eastern Cyprus where she rediscovered her heritage, Until I Say Good-Bye is Susan Spencer-Wendel's unforgettable gift to her loved ones and to us: a record of their final experiences together and a reminder that every day is better when it is lived with joy.

The third edition of this best-selling text guides students and researchers through the process of doing qualitative research, clearly explaining how different theoretical approaches inform what you do in practice. The text bridges the gap between ‘cookbook’ and more abstract approaches to qualitative research, by posing ‘difficult questions' that researchers should be asking themselves . The book invites researchers to engage in a creative and critical practice in how they draw insights, interpret a range of types of data and craft knowledge from qualitative research. Fully revised and updated, with three new chapters, this edition: · Covers the full research process, with new material on analysing and interpreting data and research ethics · Engages with exciting new developments in the field through challenging qualitative researchers to be creative with how they research and with what they find. · Examines the potential of qualitatively-led approaches to mixed methods, and their implications for research design, research practice and the production of convincing arguments. A theoretically engaged, grounded approach to qualitative researching, this remains the ideal text to guide students to become thoughtful, creative and effective qualitative researchers.

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.

Motor Neurone Disease is one of the most difficult conditions to manage medically and socially. A disease which leads to the loss of control of most muscle systems of the body, it has no known cause and no cure. For this reason, clinicians have traditionally been reluctant to reveal the diagnosis to sufferers or their families and the condition has become known as one of the best kept secrets of medical practice. However in recent years a number of organizations have set up to support sufferers and their families and consequently, the public profile of the condition has changed dramatically. Motor Neurone Disease provides an extremely helpful guide to the medical facts relating to the condition and considers the psycho-social effects on sufferers and those who care for them. It will be essential reading for doctors, nurses, social workers, physio-, speech and occupational therapists as well as all those suffering from Motor Neurone Disease, their families and carers.

'If you are hungry for truth and beauty, read this book' Roisin Ingle, The Irish Times 'A demonstration of a will to live that is breathtaking ... a work of documentary poetry ... an extraordinary read' The Herald 'An unforgettable read about what it means to be alive' Woman's Way 'The world "inspirational" is over-used, but if ever a book deserved this epithet, this is it' Sunday Independent 'Sparsely and beautifully written .. the human spirit and will to live shines out of these pages' Irish Independent A No.1 bestseller, It's Not Yet Dark is an unforgettable book about relationships and family, about what connects and separates us as people and, ultimately, about what it means to be alive. In 2008, Simon Fitzmaurice was diagnosed with Motor Neurone Disease (mnd). He was given four years to live. In 2010, in a state of lung-function collapse, Simon knew with crystal clarity that now was not his time to die. Against all prevailing medical opinion, he chose to ventilate in order to stay alive. Here, the young filmmaker, a husband and father of five small children draws us deeply into his inner world. Written using an eye-gaze computer and told in simply expressed and beautifully stark prose, the result is an astonishing journey into a life which, though brutally compromised, is lived more fully and in the moment than most, revealing at its core the power of love its most potent.

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.

‘I Found My Tribe is inspiring, humbling and a picture of what love really looks like’ Marian Keyes 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. Ruth’s tribe are her lively children and her filmmaker husband, Simon, who has Motor Neurone Disease 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. ‘Fitzmaurice tells her story in sparkling prose that is as sinewy as her new sea-strengthened body, and as admirable and boundless as her spirit’, Sunday Times ‘Uplifting and life-affirming’ Stylist

"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.

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.

The Instant #1 Sunday Times Bestseller The inspirational memoir from rugby league legend Rob Burrow on his extraordinary career and his battle with motor neurone disease. ‘A pocket rocket of a player and a giant of a character . . . He is one in a million and his story is truly inspirational’ – Clare Balding ‘I’m not giving in until my last breath’ – Rob Burrow Rob Burrow is one of the greatest rugby league players of all time. And the most inspirational. As a boy, Rob was told he was too small to play the sport. Even when he made his debut for Leeds Rhinos, people wrote him off as a novelty. But Rob never stopped proving people wrong. During his time at Leeds, for whom he played almost 500 games, he won eight Super League Grand Finals, two Challenge Cups and three World Club Challenges. He also played for his country in two World Cups. In December 2019, Rob was diagnosed with motor neurone disease, a rare degenerative condition, and given a couple of years to live. He was only 37, not long retired and had three young children. When he went public with the devastating news, the outpouring of affection and support was extraordinary. When it became clear that Rob was going to fight it all the way, sympathy turned to awe. This is the story of a tiny kid who adored rugby league but never should have made it – and ended up in the Leeds hall of fame. It's the story of a man who resolved to turn a terrible predicament into something positive – when he could have thrown the towel in. It's about the power of love, between Rob and his childhood sweetheart Lindsey; and of friendship, between Rob and his faithful team mates. Far more than a sports memoir, Too Many Reasons to Live is a story of boundless courage and infinite kindness.

Volume of accessible essays exploring women's varied responses to medical technology.

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.