



# Palliative Care in **Neurological Disease**

A team approach

Edited by  
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Penny McNamara  
Jane Seymour  
and Pam McClinton

Foreword by  
Roger Barker

# Palliative Care in Neurological Disease



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## A TEAM APPROACH

*Edited by*

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# Foreword

‘Palliative care is an important public health issue. It is concerned with the suffering, the dignity, the care needs and the quality of life of people at the end of their lives. It is also concerned with the care and support of their families and friends. This is by and large a neglected topic in Europe, but one that is relevant to everyone.’

(World Health Organization)

The perception and expectations in treating patients with long-term neurological disorders is changing. It has moved from an area of diagnosis and therapeutic nihilism to one of holistic practice and for those involved in this area of medical practice there is an increasing need to be a part of this transition. This book helps enormously in this respect.

Chronic long-term neurological disorders, especially those of neurodegenerative origin, tend to be managed by neurologists, old age psychiatrists and physicians involved with the care for the elderly, and in some cases by paediatric neurologists. Each of these disciplines has areas of expertise – the neurologists and psychiatrists in diagnosis and drug treatment; the care of the elderly physician with the management and social support of patients; and the paediatric neurologists with diagnosis and management including the family in those discussions. In addition, all of these disciplines refer, with little encouragement, to such relevant and helpful disciplines as physiotherapy, speech and language therapy and occupational therapy. However, as the disease progresses more input is required of a palliative nature. This may be within a respite or nursing home placement and the various specialists often feel this is not their responsibility, in part because they feel much less confident in this aspect of patient care. This is in contrast to other areas of medicine, most notably cancer, where palliative care is well established and factored early into the care package of patients. This point has been recently reinforced by Terry Pratchett, when writing about the future of his own case of Alzheimer’s disease.

All of the major neurodegenerative disorders of the central nervous system (CNS), such as Alzheimer's and Parkinson's disease, are currently incurable and will lead to death. This can greatly reduce the life expectancy of some patients especially those where the condition presents earlier (e.g. Huntington's disease) or progresses rapidly (e.g. motor neurone disease). Thus all of those who interact with such patients will at some point have to engage with end of life issues, however difficult this may seem. Indeed in the modern age there is almost a belief that death should be curable and that a failure to deliver on such a therapy is a failing of the medical profession, rather than an inevitable failure of the complex biological systems of our bodies and brain.

This book confronts and deals with these topics of palliative care and end of life issues in long-term neurological disorders and does so in a wonderfully helpful way. This involves not only a helpful discussion about the issues and how to approach them, but it also gets us to admit and accept that the optimal management of such patients involves being part of a team, each member of which brings their own area of unique expertise. Nowhere is this more pertinent than the period concluding life.

We can see end of life management as an acknowledgement of our failure and thus portray it as a negative experience that conveys hopelessness as we sign off the individual to the inevitability of death. However, what we often forget is that end of life issues will be played out in us all, and that there are many experts who can bring huge help to those at this stage of life, including all those suffering from their chronic degenerative neurological conditions. It can therefore be a very positive and helpful experience that many find extremely beneficial, and which many of us are rather ignorant about.

I remember my own inadequacies in trying to deal with cases of advanced juvenile Huntington's disease – in particular the problems of managing symptoms and problems in a one young individual, only to have my eyes opened by a palliative care consultant, who had been involved in a similar case for several years. Such was my level of naivety that I thought that such specialists only got involved when patients were transferred to hospices for the very end of life – namely the last few weeks.

Living with neurological disease is not easy, especially when it involves mental as well as physical problems. However, recognising how it will evolve and what the issues are is important in best managing patients and the families in which they are embedded. To avoid the palliative aspects of medical practice and end of life issues is not an option for those who see patients with these disorders. The numbers of such cases will increase as the population ages and the development of specialist clinics in which to manage them is to be applauded, but dealing with the disorder from diagnosis to death is necessary and does not just involve different drugs.

This book provides a unique insight into the very real challenges of palliative

care and end of life issues in patients with neurodegenerative disorders of the CNS, and I have found it a profoundly helpful read – not least in highlighting just how much I avoid these issues in my own practice, and how little I know about them.

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*June 2009*

# Preface

It is only in recent years that there has been serious attention paid to how a palliative care approach can be applied to people affected by conditions other than cancer, and to the specific challenges involved in palliative care delivery for distinct groups of patients. However, there is little empirical evidence identifying the palliative and end of life care needs of people and their families living with progressive long-term neurological conditions (PLTNCs) and how these can be addressed. Edited by a multidisciplinary team from Sue Ryder Care and the Sue Ryder Care Centre for Palliative and End of Life Studies at the University of Nottingham, and drawing on contributions from the experiences of doctors, nurses and the wider multidisciplinary team, this book aims to provide an accessible text for health and social care professionals caring for people with palliative and end of life care needs as a result of PLTNCs, focusing on the following four conditions: motor neurone disease (MND), multiple sclerosis (MS), Parkinson's disease (PD) and Huntington's disease (HD) and closely related disorders.

In their advanced stages people with PLTNCs present a range of problems which may make both care delivery and advance planning for care in the last stages of life both complex and challenging: ethically, practically and clinically. This is due to the range of physical, cognitive and emotional problems that people experience as they approach the end of their lives, as well as challenges relating to communication, decision making about nutrition and technologies of life support, and family care.

Contributors to this book recognise that people may require intensive input from rehabilitation and therapy teams at the same time as complex symptom management and supportive non clinical care. However, given that palliative care needs among people with PLTNCs may be present from diagnosis, it is the integration of palliative care and neurological expertise which is the focus of this book.

We recognise the complex issues of care coordination, communication and the need for team working when caring for people with PLTNCs and aim to provide an accessible and relevant overview of how a palliative care approach



can enhance the experience of giving and receiving care for those affected by PLTNCs.

We hope that those reading this book will be inspired to seek out ways to address such complex issues and be encouraged to build bridges between palliative and neurological care to enable people with PLTNCs to live with the best quality of life for as long as possible.

**Judi Byrne**  
**Penny McNamara**  
**Jane Seymour**  
**Pam McClinton**  
*June 2009*

## **PALLIATIVE CARE IN NEUROLOGICAL DISEASE**

Sue Ryder Care is a national charity providing compassionate health and social care to people across the UK.

We provide three types of health and social care: homecare, palliative and end of life, and neurological care. Our homecare supports people needing support and their families. Our palliative care ensures people receive compassionate, timely and expert support at all stages of illness and our neurological care provides services for complex late stage conditions when people can no longer be cared for at home.

For information about our work contact: 0845 050 1953 or email: [info@suerydercare.org](mailto:info@suerydercare.org)

## About the editors

**Judi Byrne** has a wide level of experience and knowledge of operational management within the NHS, charity and commercial environment. Her work on developing palliative care pathways for cancer patients has led to a focus on the issues and challenges in providing care for everyone at the end of life, not just those with a cancer diagnosis. Currently she leads on the national PINC Care at the End of Life programme for Sue Ryder Care, which has been recognised in the NHS National End of Life Care Strategy as an example of good practice.

**Penny McNamara** is a consultant in palliative medicine at St John's Hospice Sue Ryder Care and Bedford NHS Trust. She spent much of her early medical training in the South Thames region, before moving to East Anglia when her husband took up his consultant post in anaesthesia at Bedford Hospital. She became interested in medical ethics at medical school and completed her thesis for her MSc around the issues of rationing as applied to palliative care. She contributed to the ethics chapter in the *Oxford Handbook of Palliative Care* and has published work on management of malignant ascites and fractured neck of femurs in patients with advanced malignancy.

She is currently the Programme Director for SpR training in Palliative Medicine in the Eastern Deanery and chairs the development group.

**Jane Seymour** is head of the Sue Ryder Care Centre in Palliative and End of Life Studies at the University of Nottingham. She has a nursing and social science background and has been a researcher and teacher in palliative and end of life care since 1994, following a career in clinical nursing. Jane's current research interests focus primarily on the development of palliative care beyond cancer care, advance care planning, older people's experiences of end of life care and public and professional education in these areas. She has published widely in the nursing, social science and palliative care press on these themes.

**Pam McClinton** qualified as a Registered Nurse and worked as a staff nurse and ward sister before moving to work in the community and complete further training to be a district nurse. It was while working as a district nurse that her interest in palliative care developed and she progressed to become a Community Macmillan Nurse. Her interest and expertise in palliative care continued as she chaired the Royal College of Nursing Palliative Nurses Forum and also worked as a Macmillan Lecturer at the Centre for Cancer and Palliative Care Studies based at the Royal Marsden Hospital. Recently she has been part of the National Audit Office expert panel on end of life care.

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# Progressive neurological conditions: epidemiological and clinical picture

**Francesca Crawley**

There are many different progressive long-term neurological conditions (PLTNCs). This chapter focuses on multiple sclerosis (MS) and Parkinson's disease (PD), which are two of the more common conditions, and on motor neurone disease (MND) and Huntington's disease (HD), which are much rarer. In the UK, each general practitioner will have an average of three people with MS on their case load, but only a one in ten chance of a patient with MND.

Reference is made in this chapter to the 'incidence' and the 'prevalence' of each disease. The 'incidence' is the number of new cases of the disease developing in a year and the 'prevalence' is the number of patients with that disease at any point in time.

## **MULTIPLE SCLEROSIS**

### **Epidemiology of MS**

Multiple sclerosis (MS) is the most common central nervous system disease to affect young adults. It is more common in women than in men (2:1). Disease onset is generally in the third or fourth decade of life.

There is no database of patients with MS in the UK. We base our estimate of the total number of individuals with the disease on local population studies, extrapolated to include the whole country. By using these estimates, there are thought to be about 85 000 people with MS in the UK. Worldwide the prevalence is thought to be around 2 500 000. In the UK we think that about 2500 people are diagnosed with MS each year.<sup>1</sup>

People with MS are not distributed evenly throughout the world. The prevalence of the disease increases as you travel further away (north or south) from the equator. For example, in the UK, this means that there are more people with