



Guidance

Fatigue Management for People with Multiple Sclerosis

Second edition

Sarah Harrison



**College of
Occupational
Therapists**

Specialist Section

**Neurological
Practice**

First published in Great Britain in 2004 by the National Association of Neurological Occupational Therapists (NANOT) (now known as the College of Occupational Therapists Specialist Section – Neurological Practice) as *Fatigue management for occupational therapists*.

Second edition published in 2007 by The College of Occupational Therapists, 106–114 Borough High Street, Southwark, London SE1 1LB

www.cot.org.uk

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Category: Guidance

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Typeset by Servis Filmsetting Ltd, Manchester

Printed and bound in Great Britain

ISBN 978-1-905944-03-3

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Preface

Fatigue requires multidisciplinary assessment and management, as laid out by both the *National Institute for Clinical Excellence (NICE) Guidelines for multiple sclerosis* (2003) and the *National Service Framework (NSF) for long term conditions* (Department of Health 2005).

The original publication, *Fatigue management for occupational therapists*, published in 2004, was developed in response to the increasing and urgent demands of occupational therapists working in neurology. Practitioners were seeking specific guidance to the clinical application of energy conservation strategies and fatigue management in multiple sclerosis (MS). This project became the focus of the Chronic Progressive Disease Forum, a subgroup of the National Association of Neurological Occupational Therapists (NANOT), a specialist section of the College of Occupational Therapists. The demand from occupational therapists has been very high, reflecting the increasing recognition among health professionals of the value of occupational therapy in the management of fatigue.

This second edition is a revision of the original work. Various chapters have been rewritten and updated to include recent evidence. The aim of this publication is to provide occupational therapists with the theoretical background and evidence base for fatigue management as well as to give practical guidance and resources to be used for implementing a fatigue management programme.

While it is hoped that aspects of this guidance will be valuable to all members of the team, it should be noted that this programme has been written from an occupational therapy perspective and is designed to meet the immediate demand of occupational therapists in this field, in both community-based and inpatient rehabilitation settings. It is not recommended for use in acute, ward-based settings or following new diagnosis. Potential referrers include neurologists, general practitioners, physiotherapists and MS specialist nurses.

This programme should not be administered in isolation. Fatigue management is indicated following a comprehensive assessment of occupational performance, when 'fatigue' is identified as a major barrier to function. While this edition may be occupational therapy specific, future editions are likely to be the result of collaboration among all disciplines, reflecting the increasing evidence base for joint working in fatigue management.

This edition is divided into two parts. In Section 1, the first chapter consists of a literature review, covering evidence and theories related to the physiology of fatigue that is specific to MS. Other, secondary factors, which contribute to the experience of fatigue in general, are also considered in some depth. Chapter 3 provides an overview of treatment approaches for MS fatigue, while Chapter 4 focuses on occupational therapy and fatigue management programmes. Existing evidence for this approach is presented. Chapter 5 addresses the issues of assessment and measurement in both the clinical and

research settings, while providing a summary of the most frequently used scales and questionnaires.

The remaining chapters focus on the clinical application of fatigue management programmes. Chapter 6 lays out the basic content of a fatigue programme and discusses the relative merits of group and individual programmes. Finally, Chapter 7 uses a real example to highlight the relationship between fatigue and activity and the complex psychological issues that this can present. This case report lays out the steps involved in the implementation of an individual fatigue management programme. It attempts to demonstrate the clinical reasoning process that shapes both the direction of treatment and clinical decisions. The case report highlights the role of occupational therapy beyond purely the communication of energy conservation strategies.

Section 2, *The fatigue management workbook*, was developed originally at the National Hospital for Neurology and Neurosurgery and is referenced by Bowcher and May 1998. It has been updated and adapted and is designed for reproduction; a CD-ROM is provided for this purpose. It is best used in conjunction with an occupational therapy or multidisciplinary education programme for fatigue management rather than distribution in isolation.

Much of the text is based on work written by Sarah Harrison in part fulfilment of an Msc in Neurorehabilitation. Her dissertation examined the efficacy of an individual fatigue management programme for people with MS. A full copy of this is held in the theses collection at the College of Occupational Therapists' library in London.

Sarah Harrison is now working independently and is in the process of developing a series of professional courses with Therapy Services at the National Hospital for Neurology and Neurosurgery in London to supplement this work.

Catherine Sykes worked with Nicki Ward (MS specialist nurse) in the development of a *Multidisciplinary fatigue management manual*, published by Biogen Idec. She has contributed to the NICE guidelines for the management of MS as well as MS Society information booklets on fatigue.

Catherine and her colleagues at University Hospital Birmingham NHS Foundation Trust (UHB) are seeking funding for a multi-centre research trial to evaluate a multidisciplinary fatigue management group programme.



Multiple Sclerosis Society

Foreword

The MS Society, on behalf of people with MS, welcomes this document as an enormously helpful contribution to the understanding of fatigue and MS and the development of strategies for managing it. Fatigue is the most common symptom of MS. It blights the lives of around 85 per cent of people with MS. It impacts significantly on their daily lives, making all their other symptoms much harder to deal with. It prevents the individual from having a sense of control over his/her condition, and decreases his/her sense of wellbeing. It is a major contributing factor for many people with MS in their decision to give up working, a decision which in turn impacts on their financial independence and can lead to feelings of further debilitation.

Fatigue is difficult to treat, particularly as there is no diagnostic test, and also because clinicians and people with MS do not share a common language to describe the problem. This leads to huge frustration on both sides, which can result in clinicians abandoning their patients, while people with MS often resort to alternative treatments, of doubtful quality.

Despite years of investigation, the basis of MS-related fatigue remains obscure. The MS Society of Great Britain and Northern Ireland recently consulted its members about their priorities for research, and the resounding consensus was that fatigue research – understanding its biological basis and finding treatment strategies for dealing with it – is a top priority.

This publication, which updates *Fatigue management for occupational therapists* (2004), is a welcome development from the College. Fatigue in MS is complex in nature and requires a complex response. The contribution of occupational therapy is key, and much valued by people with MS. This publication will also help inform neurologists, general practitioners, physiotherapists and nurses, who all will welcome further insights into the physiology of fatigue, as well as evidence-based strategies for fatigue management. Section 2 of this guidance, *The fatigue management workbook*, is available as a CD-ROM and is a valuable tool.

Sharon Haffenden
Director of Research and Services
MS Society

Acknowledgements

The author would like to thank:

Catherine Sykes for her significant contribution to the development of this guidance; Sharon Haffenden, the MS Society's Director of Research and Services for the foreword.

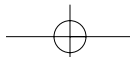
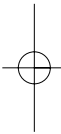
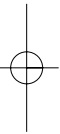
Also: Dr Diane Cox – Reader in Occupational Therapy; Lynn Lamont – MS Specialist Occupational Therapist; Christine Jones – Chief Executive of the MS Trust.

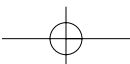
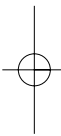
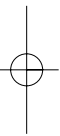
Members of the NANOT Chronic Progressive Disease Forum: Frances Beavis, Sarah Broughton, Kate Heward, Miranda Pink, Carole Shaw, Jo Sills, Clare Stuttaford.

Susan Hourihan and Pip Wilford, Clinical Specialist Occupational Therapists, and the National Hospital for Neurology and Neurosurgery for permission to use the information included in *The fatigue management workbook*.

The author also wishes to acknowledge the original work compiled in 1995 by Amanda Lake and to thank the following for their contribution to the further development and revision of the information in Section 2: Heidi Bowcher, Shelley Garrett, Claire Leadbetter, Carrie Lumsden, Siobain Maguire, Miriam May, Jane Streeter.

Section 1: Understanding and treating fatigue in multiple sclerosis





1 Introduction

Multiple sclerosis is a disease of the auto immune system, the cause of which remains unknown. It is recognised as one of the most prolific of all chronic progressive neurological diseases, affecting 1 in 800 of the population in the United Kingdom, with a lifetime risk of 1 in 400 (Macdonald et al 2000; Compston and Coles 2002). It is characterised by random lesions throughout the white matter, which interfere with nerve conduction and lead to a spectrum of disabling symptoms including weakness, spasms, ataxia, reduced balance, bladder and bowel dysfunction, fatigue, mood disturbance, cognitive and perceptual deficits (Crayton et al 2004). The impact of multiple sclerosis on society is great. Statistically women are twice as likely as men to develop the disease, with onset usually between puberty and 60 years, peaking in the 30s and 40s. Thus, this aggressive and unpredictable neuro-degenerative disease affects a population typically at the height of their domestic and working lives (Aronson et al 1996; Grima et al 2000).

Although marked progress has been made in the development of disease modifying therapies (DMT) aimed at reducing relapse rate, for many, symptom management remains crucial to the ongoing participation in daily life (Kesselring and Beer 2005).