



# Multiple sclerosis information

---

## for health and social care professionals

MS: an overview

Diagnosis

Types of MS

Prognosis

Clinical measures

A multidisciplinary approach to MS care

Self-management

Relapse and drug therapies

Relapse

Steroids

Disease modifying drug therapies

Symptoms, effects and management

Vision

Fatigue

Cognition

Depression

Women's health

Bladder

Bowel

Sexuality

Mobility

Spasticity

Tremor

Pain

Communication and swallowing

Pressure ulcers

Advanced MS

Complementary and alternative medicine

Index

### Advanced MS

Advanced stages of MS may require the expertise and input of palliative care services to achieve the best quality of life when the illness is limiting time left and needs are complex. It can integrate skilled multidisciplinary assessment and management of MS with appropriate support for the social, psychological and spiritual needs of someone with MS reaching the end of their life. It will support families or carers, many of whom have lived for many years with the consequence of MS. It can ensure those decisions and wishes about dignity in dying with MS, perhaps made whilst living with MS, are appropriately acted upon and any changes to those early choices are promptly recognised and care choices reviewed.

It is now accepted that palliative care provision should be available for all patients with life-limiting illnesses, regardless of diagnosis and should not be restricted to the last few days, weeks or months of life. Input for MS may be variable over a lengthy time span.

Those involved in the day to day care of someone with advanced MS will be involved in providing general palliative care. Specialist palliative care input should be considered where there is an expected lifespan of 6-12 months, intractable symptoms, complex psychosocial needs and when discussion or support is needed in advance care planning.

### Holistic assessment and support

MS is a variable condition with a wide spectrum of clinical presentations yet each individual's experience of MS is uniquely felt and influenced by many factors; individual coping mechanisms, past experiences and available support. The key to 'getting it right' for each individual is to listen to their narrative and know what matters to them in the moment and the time they perceive left to them. Holistic assessment identifies physical, emotional, social and spiritual needs, preferences or challenges. These are unlikely to be static or fixed.

The living end of MS has often been filled with uncertainty and unpredictability; the dying end may be no different.

As MS advances previous decisions may change and pro-active reassessment and review will be

required. This will avoid crisis led decision making and likely accompanying distress. Patients with advanced MS are housebound and assessment and review should be carried out in the patient's home or usual place of residence.

Spiritual needs are often overlooked, avoided or superficially addressed. Nearing the end of life and imminent death often triggers spiritual questions or fears and if unexplored can lead to significant distress.

### Symptom control

A survey of patients with advanced MS cited that on average patients experienced around nine different symptoms<sup>1</sup>. Pain, spasms and fatigue were the most common symptoms. Swallowing and communication problems, shortness of breath and nausea together with depression and cognitive impairment will also affect quality of life.

MS symptoms can become refractory to treatment, fluctuate in intensity or worsen with progression of MS. Symptoms may be:

- primary - a direct result of MS itself
- secondary - resulting from primary symptoms
- tertiary, arising from the social and psychochological problems of primary and secondary symptoms.

### Carer needs

Families and carers provide invaluable support for patients with advanced MS, but the role is demanding and can place carers under significant emotional and physical strain. Carer needs often go unrecognised. The families of people with MS may have experienced many years of living with the consequences of MS and they will have a range of responses, questions, anxieties and needs that must be addressed. It is important to provide both practical and emotional support for carers as well as to consider respite options for families.

### Estimating prognosis

Confident prognosis at any stage of MS is difficult and in advanced MS there is a risk of sudden deterioration and death from an infection<sup>2</sup>. Intimate knowledge of someone with MS will help to gauge the rate of clinical deterioration and possible time frames. A framework for end of life care in long term neurological disease, published by the National End of Life Care Programme, describes triggers that can help to identify when a patient may be approaching the end of life<sup>3</sup>:

- swallowing problems
- recurring infection
- marked decline in physical status
- first episode of aspiration pneumonia
- significantly worsening cognitive function
- weight loss
- significant complex symptoms.

Deterioration may extend over many years and death usually occurs from respiratory or other overwhelming infection.

### Planning for the future

People with MS should be afforded the right of self determination regarding their future care preferences or life-prolonging treatments. The initiation, pacing and any revisiting of any discussion about these choices must be led by the person with MS at a time they choose and it is critical to identify the cues they give. Some may fear that cognitive decline or communication impairment will prevent them articulating clearly their wishes at some point in the future. Some will not wish to enter into such a dialogue and prefer avoidance techniques.

Untreated depression and unidentified cognitive impairment in MS will negatively influence wishes and **must** be appropriately managed as part of the process of determining future directives.

The family and loved ones may also wish to be involved in discussion, but it may be that the person with MS wishes to have a private, confidential talk with a trusted other.

Each of the four UK nations has statutory guidance on safeguarding the wishes of people with mental capacity and those who do not have mental capacity and it is a duty of care for health care professionals to understand and follow the appropriate guidance (Figure 1).

### The dying phase

MS is not in itself a terminal condition; the vast majority of people with MS live their normal life span and die of conditions completely unrelated to MS. In one study, death occurred as a consequence of the

<b>Figure 1</b>
<b>England and Wales</b>
Mental Capacity Act 2005 <sup>4</sup>
<b>Scotland</b>
Adults with Incapacity (Scotland) Act 2000 <sup>5</sup>
<b>Northern Ireland</b>
Currently no primary legislation Mental Capacity Bill in preparation (Oct 2011)

secondary complications of chronic disease, such as pneumonia and septicaemia, in 50% of people with advanced MS<sup>2</sup>. The proportion of deaths due to stroke, myocardial infarctions and malignancies was similar to the general population.

Recognising and acknowledging that someone with MS has finally reached the dying phase of life can be a challenge. Many features of progressing MS such as increasing weakness, deteriorating functional ability, difficulty in swallowing and cognitive impairments can also be features of imminent death in terminal disease.

As a life is ending for someone with MS information must be shared with the patient and the family and checked for understanding. They may have become accustomed to symptoms fluctuating in intensity and may not have insight into the significance or finality of change. They may have lived with change or progression for many years. They may need reassurance that ceasing to eat and drink is a normal part of the dying process and not the cause of deterioration.

Intrusive or uncomfortable MS symptoms together with other common end stage symptoms must continue to be pro-actively managed. Key drug interventions are likely to include the following medications or their equivalents:

Midazolam	agitation/ muscle relaxation
Hysocine butylbromide	respiratory secretions
Diamorphine	pain

Recognised tools are available to facilitate the assessment and management of patients at the end of life. With appropriate training, tools such as the Liverpool Care Pathway for the Dying Patient have been shown to improve the quality of care provided to dying patients<sup>6</sup>. The pathway helps ensure key needs are regularly assessed including areas which are often overlooked such as spiritual and psychosocial needs as well as guiding professionals with appropriate anticipatory prescribing.

### References

1. Higginson IJ, Hart S, Silber E, et al. Symptom prevalence and severity in people severely affected by multiple sclerosis. *J Palliat Care* 2006;22(3):158-65.
2. Sadvnick AD, Eisen J, Ebers GC, et al. Cause of death in patients attending multiple sclerosis clinics. *Neurology* 1991;41(8):1193-6.
3. National Council for Palliative Care, Neurological Alliance, National End of Life Care Programme. Improving end of life care in long term neurological conditions: a framework for implementation. London; National End of Life Care Programme; 2010.
4. Department for Constitutional Affairs. Mental Capacity Act 2005 code of practice. London: The Stationery Office; 2007.
5. Scottish Government. Adults with Incapacity (Scotland) Act 2000: A short guide to the Act. Scottish Government: Edinburgh; 2008.
6. Marie Curie Palliative Care Institute Liverpool. The Liverpool Care Pathway for the Dying Patient. Liverpool: Marie Curie Palliative Care Institute Liverpool; 2010.

### Further resources

Department of Health. End of Life Care Strategy: promoting high quality care for all adults at the end of life. London: Department of Health; 2008.

NHS End of Life Care Programme. Capacity, care planning and advance care planning in life limiting illness. A guide for health and social care staff. London: Department of Health; 2011.

MS Society. MS and palliative care: a guide for health and social care professionals. London: MS Society; 2006.

Dying Matters - [www.dyingmatters.org](http://www.dyingmatters.org). [Accessed Sept 2011]

Brown JB, Sutton L. A neurological care pathway for meeting the palliative care needs of people with life-limiting neurological conditions. *Int J Palliat Nurs* 2009;15(3):120-7.

We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

## MS Trust information service

### Helping you find the information you need

The MS Trust offers a wide range of publications, including a newsletter for health and social care professionals Way Ahead and the MS Information Update, which provides an ongoing update on research and developments in MS management.

For a full list of MS Trust publications, to sign up for Way Ahead and much more visit our website at [www.mstrust.org.uk](http://www.mstrust.org.uk)



Freephone 0800 032 3839 (Lines are open Monday - Friday 9am-5pm)

email [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

write MS Trust  
Spirella Building  
Letchworth Garden City  
SG6 4ET



This publication will be reviewed in three years

MS Trust  
Multiple sclerosis information for health and social care professionals. Fourth edition.  
ISBN 1-904 156-24-X  
© 2011 Multiple Sclerosis Trust

Registered charity no. 1088353

All rights reserved. No part of this book may be produced, stored in a retrieval system or transmitted in any form by any means, electronic, electrostatic, magnetic tape, mechanical, photocopying, recording or otherwise without written permission of the publisher.