

## **PRESS RELEASE**

### **New guidelines for the NHS on the management of multiple sclerosis in primary and secondary care set to improve services for patients**

The National Institute for Clinical Excellence (NICE) and the National Collaborating Centre for Chronic Conditions (NCC CC) have today issued a clinical guideline for the NHS in England and Wales on the management of multiple sclerosis (MS). The guideline represents a significant driver for change in an area of healthcare that has not, until now, benefited from the application of a consistent and coherent national approach.

Multiple sclerosis (MS) is a chronic disabling neurological disease. Damage to the nervous system caused by MS may lead to a large number of symptoms that can differ greatly between patients and which have an adverse and sometimes debilitating impact on the quality of life of people with MS and their families. It is estimated that around 63,000 people in England and Wales have MS and it is the most common cause of neurological disability in the young.

The guideline focuses on the quality and configuration of services for people with MS and their carers, emphasising the need for flexible services across primary, secondary, tertiary care and social care, that can properly address the whole range of needs a person with MS may encounter during the often protracted course of the disease. Priorities for implementation highlighted in the guideline are:

- Making specialist neurological and neurological rehabilitation services available to every person with MS, when they need them.
- Ensuring that a person who is suspected of having MS is referred to a specialist neurology service and seen rapidly within an audited time, and the person is seen again after all investigations necessary to confirm or refute a diagnosis of MS are completed (also rapidly within an audited time).

- All organisations within a local health area should agree and publish protocols for sharing and transferring responsibility for, and information about people with MS so as to make the service seamless from the individual's perspective
- The person with MS should be actively involved in all decisions and actions taken concerning the management of their condition, if they wish, and all services and people employed within the health sector should recognise and respond to the varying and unique needs and expectations of each person with MS.
- Health service workers in regular contact with people with MS should consider in a systematic way whether the person with MS has a 'hidden' problem contributing to their clinical situation, such as fatigue, depression, cognitive impairment, impaired sexual function and reduced bladder control.
- Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed how to make contact with these services when they aren't under regular treatment or review. They should also be given guidance on when such contact is appropriate.

The guideline also makes recommendations on the diagnosis and treatment of specific impairments (including fatigue, bladder and bowel problems, spasticity, pain, visual problems, depression and anxiety, speech difficulties and sexual dysfunction) which can continue throughout the life of a person with MS and which are therefore, for many people with the condition, the most important aspects of managing it.

**Andrew Dillon, Chief Executive and executive lead for the guideline,** said: "This guideline makes important recommendations for improving the care of people with MS. It represents a catalyst for change and will inform a more joined-up approach to service delivery."

**Mike O'Donovan, chief executive of the Multiple Sclerosis Society,** said, Tens of thousands of people with multiple sclerosis currently face a lottery of health care. Long waits for diagnosis are frequently followed by repeated struggles to access the treatments they need at the time they need them.

“The new guideline is the most far-reaching step ever taken towards better management of one of the most common, complex and unpredictable neurological conditions. It provides a stimulus for action which can make a real difference to the quality of life of people affected by this dreadful disease. The MS Society is committed to working with the NHS to see the opportunity for better care for people with MS is fully grasped.”

**Christine Jones, Chief Executive of the MS Trust** says, “The MS Trust welcomed the opportunity to participate in the development of a clinical guideline for MS. The fact that I was the only person on the development group with MS, was a heavy responsibility. I am hugely grateful to the many people with MS who provided feedback on the drafts as they emerged. In my view, thanks to this input, the guideline reflects a much better understanding of the reality of living with MS and a clearer picture of the services we actually need.

“The introduction of a benchmark for good practice in the NHS is a positive step forward. From now on, local service providers will be monitored and measured against the new standards. It’s up to all of us to ensure that the standards of good practice which the guidelines advocate are really met – and where this is not the case, to work with the NHS to achieve them. Now the real work begins.”

The National Collaborating Centre for Chronic Conditions (NCC CC), based at the Royal College of Physicians, has developed the guideline on behalf of NICE. The NCC CC follows international standards of guideline development. They established a group consisting of representatives of people with MS, health professionals and health service researchers which reviewed the published clinical research alongside current clinical practice and the experience of people with MS and their carers, together with the feedback they received from two rounds of widespread consultation. In addition, the NCC CC formed a Consensus Reference Group (CRG) to support the development of the guideline. The group used formal consensus techniques in their consideration of areas where there was insufficient evidence or disagreement over the interpretation of the evidence.

The full guideline, from which the NICE guideline is derived, is produced by the NCC CC and will be available in January 2004 from the NCC CC website at

<http://www.rcplondon.ac.uk/pubs/books/chf/> or from the NICE website ([www.nice.org.uk](http://www.nice.org.uk)). The full guideline will include information on how the evidence was collected, reviewed and assessed, a description of how the recommendations were formulated and graded and full reference details of the literature in the evidence base.

**Ends**

## **Notes to Editors**

### **About NICE**

1. NICE is part of the NHS. It is the independent organisation responsible for providing national guidance on treatments and care for those using the NHS in England and Wales. Its guidance is for healthcare professionals and patients and their carers to help them make decisions about treatment and healthcare. For further information about NICE you can visit [www.nice.org.uk](http://www.nice.org.uk).
2. NICE produces guidance in three areas of health:
  - the use of new and existing medicines and treatments within the NHS in England and Wales – technology appraisals
  - the appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales – clinical guidelines.
  - whether interventional procedures used for diagnosis or treatment are safe enough and work well enough for routine use– interventional procedures.
3. NICE also funds three enquiries that undertake research into the way patients are treated to identify ways of improving the quality of care (the investigations are known as confidential enquiries).
4. NICE guidance and recommendations are prepared by independent groups that include professionals working in the NHS and people who are familiar with the issues affecting patients and carers.

### **About clinical guidelines**

5. Clinical guidelines are recommendations on the appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales. They sit alongside, but do not replace, the knowledge and skills of experienced health professionals.
6. NICE clinical guidelines are developed by independent groups - National Collaborating Centres - that include healthcare professionals working in the NHS, patients and people who are familiar with the issues affecting patients and carers. Professional and patient/carer groups whose members are likely to be affected by the guideline are able to submit information and comment on the recommendations before they are finalised.
7. For details of NICE clinical guidelines currently in development, log on to the website at <http://www.nice.org.uk/catcg1.asp?c=20055>.

### **About the MS guideline**

8. The National Collaborating Centre for chronic Conditions is based at the Royal College of Physicians. The following partners have member status on the partners board of the centre:
  - Royal Pharmaceutical Society of Great Britain
  - Royal College of Nursing
  - Clinical Effectiveness Forum for Allied Health Professionals
  - Royal College of Surgeons of England
  - Royal College of General Practitioners
  - Royal College of Physicians of London
  - NHS Confederation
  - Royal College of Physicians Patient and Carer Liaison Committee
  - National Institute for Clinical Excellence
  
9. Local health communities should review their existing service provision for people who have MS against this guideline as they begin the development of their Local Delivery Plans. The review should consider the resources required to implement fully the recommendations set out in Section 1 of the guideline, the people and processes involved, and the timeline over which full implementation is envisaged.