

NICE Guideline for the management of multiple sclerosis in primary and secondary care

November 26th was a landmark for people with MS: it saw the publication of the MS Clinical Guideline.

If neurology has in the past been described as the Cinderella of the NHS, then MS could be the Cinderella of neurology. For years people with MS have watched services improve for those with other chronic conditions, when government has set them as priorities, with cancer and heart disease as prime examples.

Whilst the Department of Health Risk-sharing Scheme has given access to the disease-modifying drug therapies, only approximately 10% of the estimated total MS population of 85,000 are eligible, and for the 90% - which includes some of those most severely affected - specialist services may be either unavailable, inaccessible or both.

For this reason, the MS Guideline offers a real opportunity for improving services for the whole range of people affected by the condition, whether undergoing diagnosis or living with severe disability.

The Guideline makes six key recommendations:

1. Specialised services

Specialist neurological and neurological rehabilitation services should be available to every person with MS when they need them. This is usually when they develop any new symptom, sign, limitation on activities, or other problem, or when their circumstances change.

2. Rapid diagnosis

An individual who is suspected of having MS should be referred to a specialist neurology service, and seen rapidly within an audited time. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed (also rapidly within an audited time).

N.B. The Guideline Development Group debated the meaning of the word 'rapidly'. In this context, it is taken to mean that the exact time will vary according to clinical need but should be, in the opinion of the development group, no longer than 6 weeks from referral to being seen by a neurologist, and a further 6 weeks until any necessary investigations are completed.

3. Seamless service

Every health commissioning organisation should ensure that all organisations in a local health area 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.

4. A responsive service

All services and service personnel within the health sector

should recognise - and respond to - the varying and unique needs and expectations of each person with MS. The person with MS should be involved actively, in all decisions and actions.

5. Sensitive but thorough problem assessment

Health service professionals 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 or reduced bladder control.

6. Self referral after discharge

Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate.

The Guideline is evidence-based where robust evidence exists. Where it does not, the recommendations were based on the expert opinion of the Consensus Reference Group, comprising multi-disciplinary MS specialists and representatives of people with MS.

In addition to these key recommendations, the Guideline offers guidance on diagnosis, assessment and treatment of specific symptoms.

Importantly too, the "full" version, to be published in January 2004, contains the evidence base, a valuable resource to clinicians and researchers in its own right. This includes 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.

Notwithstanding the acknowledged current shortage of specialist health professionals, the Guideline Development Group are optimistic about the achievability of these recommendations. They feel that many tangible improvements can be made without additional resources - and made quickly - through reconfiguration of services, through better understanding by health professionals of the range of patients' needs and through a more flexible and patient-centred approach.

- Copies of the NICE Clinical Guideline can be obtained from the NHS Response Line 0870 1555 455 quoting reference no N0366.
- The full guideline is produced by the National Chronic Conditions Collaborating Centre and will be available in January 2004 from their website www.rcplondon.ac.uk.



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MOVEMENT DISORDER & SPASTICITY MEETINGS

Modern Management of Spasticity

Friday February 27th, 2004; Plymouth

Advanced Management of Spasticity in the CP Child & Adult

Thursday 26th February, 2004; Edinburgh

Each meeting is available to interested specialists at all levels, whether consultant, junior or specialist nurse.

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