**Will NICE’s quality standard for multiple sclerosis improve care?**

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In January, NICE published new quality standard statements for the care of people with MS. This article describes the current management of multiple sclerosis in the UK, including the problems and challenges, and discusses whether the new NICE quality standard statements will address them.

NICE recently published its quality standard for multiple sclerosis (MS), which includes six quality statements (see Table 1). The statements are a set of evidence-based recommendations to the NHS in England and Wales on best practice for MS care. In response, the MS Society says: “For the first time, [the standard] will allow both CCGs and healthcare professionals to see clearly what level of service they are expected to provide for people living with MS.”

**The challenges**

MS is a major cause of long-term disability. It can be difficult to diagnose, there is no cure and treatment options are still limited. We are not doing very well in the UK; 25 per cent of people with MS see a GP more than four times (see Case study) before they get referred to a neurologist.

Without prompt referral and diagnosis, early treatment with disease-modifying therapy (DMT) is not possible. At the moment, 60 per cent of people in the UK with relapsing forms of MS who could be considered eligible for DMTs are not taking them and in a ranking of DMT prescription rates among European countries, the UK comes 25th out of 27.

But it is not all bleak; prompt treatment with DMT is increasing, and there are examples of excellent care in the NHS. The best care means having easy access to a skilled multidisciplinary team via a single point of contact and regular reviews with adequate resources. The real challenge in the UK is that access to the best kind of care is patchy and many people with MS do not get it. The NICE quality standard statements address these challenges. MS charities say the statements are good
But do not go far enough and that implementing and monitoring the standard will be key.

**What is MS?**
MS is an acquired, chronic, immune-mediated inflammatory condition of the CNS that affects brain and spinal cord. It commonly starts in a person’s late twenties, causes visual and sensory changes, weakness in the limbs, and gait, bladder and bowel problems. There may be partial recovery at the beginning but progressive disability is the norm. There are at least 100,000 people in the UK with MS and it is the commonest cause of serious physical disability in adults of working age.

**How is it diagnosed?**
For a diagnosis of MS, two distinct episodes of neurological dysfunction in the brain, spinal cord or optic nerve need to have occurred. An attack might go unnoticed by the patient but may leave residual subtle changes in vision, gait and reflexes. White women aged 20–40 years are most commonly affected but anyone can be. In Europe and the USA, MS affects 1 in 800 people, three times as many women as men and is the commonest cause of neurological disability in young adults. MRI of the brain is a sensitive but not very specific test. MRI of the spine is more specific. Management consists of treatment of the acute attack, prevention of future attacks by avoiding triggers, DMTs and symptomatic treatment such as pain control.

**What causes MS?**
MS is caused by demyelination in the CNS. Current thinking sees it as an autoimmune inflammatory and degenerative disease of white and grey CNS matter in a genetically susceptible person who has been exposed to environmental triggers. Research is currently focusing on genes in the human leukocyte antigen (HLA) and interleukin receptor-coding areas. Possible triggers could include viruses such as Epstein-Barr, toxins and vitamin D deficiency. Relapses could be triggered by surgery and infections.

The autoimmune model of MS suggests that a trigger such as infection activates T cells in the periphery. The T cells attach to receptors on endothelial cells and this interaction breaches the

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**Statement 1**
Adults with multiple sclerosis (MS) are given support at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis

**Statement 2**
Adults with MS are offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within six weeks of diagnosis

**Statement 3**
Adults with MS have a single point of contact who co-ordinates access to care from a multidisciplinary team with expertise in MS

**Statement 4**
Adults with MS who have problems with mobility or fatigue are offered support to remain physically active

**Statement 5**
Adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms

**Statement 6**
Adults with MS are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS

**Table 1. NICE quality standard for multiple sclerosis: quality statements**

but do not go far enough and that implementing and monitoring the standard will be key.
Types of MS
Relapsing-remitting MS (RRMS) is the commonest pattern. About 85 per cent of people with MS have this pattern when diagnosed. They have periods of remission, punctuated by relapses when symptoms are worse. Two-thirds of those with RRMS at the onset may go on to secondary progressive MS (SPMS). In SPMS, the disability gradually gets worse, no longer with the pattern of relapses. Up to 15 per cent of people have primary progressive MS (PPMS) in which symptoms develop gradually and get worse over time, with no initial pattern of relapses and remissions. A fourth pattern called relapsing-progressive MS (RPMS) was previously used but this term is no longer in general use.

The three clinical courses that MS can follow can only really be identified with the benefit of hindsight and so have questionable usefulness. A further category called clinically isolated syndrome (CIS) has more recently been added. CIS is also called a monosymptomatic demyelinating event and it may or may not develop into MS. MS is now also considered in terms of whether it follows an active or nonactive course, depending on clinical relapses, disease progression and new lesions on MRI.

RRMS shows the most inflammatory activity then early SPMS. PPMS is primarily degenerative rather than inflammatory. The DMTs work best against inflammation. Reducing inflammation is thought to reduce axon loss and so help prevent lasting disability.

Symptoms
Patients commonly have an episode of blurred vision in one eye with pain on moving the eye and an impaired ability to differentiate colours, especially red. They may also describe odd sensations, such as a patch of burning, wetness, tingling of half the body, band-like sensations or numbness. Other common symptoms are foot dragging, leg cramps, extreme fatigue, urinary and bowel disturbance, and loss of balance and co-ordination. Episodes may last more than 48 hours and are not associated with concurrent illness. Examination may show increased muscle tone and deep tendon reflexes.

Further complications of MS include urinary tract infections, osteoporosis, depression, visual impairment, poor mobility and cognitive impairment. Men may suffer from erectile dysfunction.

Investigations
Blood tests such as a full blood count, vitamin B12, thyroid function and other metabolic parameters should be normal. MRI of the brain may show hyperintensities in periventricular white matter. MRI of the spinal cord may show demyelinatin lesions, especially in the cervical spinal cord.

Case study
Lena is a 28-year-old woman who was diagnosed with MS three months ago. She says it was a real struggle to get a diagnosis: “About 18 months ago, I felt a bit unwell and my flatmate said I was dragging my foot. I assumed I’d overdone it in the gym and had a bit of a bug and within about three weeks I was basically back to normal. But I didn’t feel quite right. I went to my GP three or four times because I kept getting really tired and had tingling in weird places like my leg. I think my GP thought I was depressed and imagining it. I had lots of blood tests like for anaemia and thyroid function but they were all normal.

“My GP offered me counselling but I knew I wasn’t depressed, although I was getting more and more anxious about how I felt. A few months ago, I woke up one day and couldn’t see properly out of one eye. That’s when I went to my GP and demanded a referral. She sent me straight to casualty and I ended up seeing a neurologist and getting the diagnosis of MS. To be honest, by that stage it was a relief and they told me I had the type that means I can have treatment [relapsing-remitting MS]. Now I’m getting frustrated because they said I should start the treatment as quickly as possible but I have to be seen at the clinic first and the first appointment isn’t for another month. Whenever I ring up the number they give me, there’s always an ansaphone. Sometimes they ring me back, and sometimes they don’t.”

Other tests include examination of the cerebrospinal fluid (CSF) for oligoclonal IgG bands, asymmetrical prolonged conduction in evoked potentials and antiNMO antibody status in neuromyelitis optica (Devic’s syndrome).

Current treatments
The management of MS is based on lifestyle changes to limit relapses and disease progression, DMT to reduce the frequency and severity of relapses and managing symptoms.

Acute MS affecting function
In acute cases, treatment is with an intravenous steroid once a day for three days and then oral steroids. Severe or rapidly progressive disability may also benefit from plasma exchange.

RRMS
DMT is important for all patients with RRMS unless their disease course is very benign. First-line agents include interferon beta, glatiramer, teriflunomide and dimethyl fumarate. Other agents such as natalizumab are available for more aggressive disease. Fingolimod is used in highly active relapsing MS if interferon beta or glatiramer have not reduced the relapse rate. Specific symptoms require additional treatment. Fatigue may be helped...
by lifestyle advice including regular exercise, enough sleep, resistance training, yoga and relaxation. Drugs like modafinil and amantadine can help counter fatigue. Physiotherapy can help muscle spasticity and co-ordination problems. Sensory symptoms like pain may respond to gabapentin.

**Treatment efficacy**

The approach to RRMS management is changing. Early diagnosis and treatment with DMT is considered important in preventing disability, even if there are few clinical symptoms. Importantly, this really only holds true for MS characterised by relapses, according to the Association of British Neurologists’ (ABN) revised (2015) guidelines. They say: “The implication of current research is that no disease-modifying treatment is effective, or indicated, in patients with established progressive MS in the absence of relapses.”

The ABN revised guidelines say that all the licensed DMTs for MS reduce relapse rate and MRI lesion accumulation in RRMS to varying extents. Direct comparison is tricky because head-to-head trials are lacking and there are lots of confounding factors. However, the authors of the guidelines broadly group the seven available treatments into: drugs of moderate efficacy (average relapse reduction in the 30–50 per cent range): interferon beta, glatiramer, teriflunomide, dimethyl fumarate and fingolimod; and drugs of high efficacy (average relapse reduction substantially more than 50 per cent): alemtuzumab and natalizumab. The authors note that the side-effect profiles also vary a great deal.

**Emerging treatments**

Immunosuppression followed by stem cell transplantation (‘bone marrow transplant’) is currently being trialled for MS. The monoclonal antibodies rituximab, ocrelizumab and daclizumab are also undergoing trials, though the latter is associated with liver and skin reactions. Laquinimod is an oral quinoline that reduces inflammatory cells in the CNS and has shown promising results in RRMS. Firategrast is an oral drug also showing promising results in treating RRMS. Vaccine trials to treat MS are currently underway. Deep brain stimulation has been evaluated, but results are variable. Medical marijuana has shown promise in reducing spasticity, pain and spasms in clinical trials.

**Follow up**

Patients need to be seen by a neurologist or member of an MS team, both during and after a relapse. Otherwise, if stable, they can be seen every 6–12 months unless a change of medication is required. Further monitoring depends on which DMTs are being used. The frequency of MRIs depends on the progression of the disease and frequency of relapse. Diabetes, hypothyroidism, low vitamin D and low vitamin B12 levels are all more common in people with MS and may contribute to fatigue so should be monitored regularly.

**Predicting outcome**

It is notoriously difficult to predict the prognosis in people with MS. Some people do very well with few relapses and little progression whereas others become rapidly disabled within a few years. In the past, women and those with sensory symptoms or optic neuritis had better prognosis and those with frequent relapses and motor or cerebellar symptoms did worse. Nowadays, having more MRI lesions at the onset of the disease seems to predict a worse outcome, especially in cognitive function.

**The NICE quality standards for MS**

NICE quality standards are sets of prioritised statements designed to drive measurable quality improvements. They are derived from best available evidence and are developed by NICE in collaboration with health and social care professionals, their partners and service users (patients).

The quality standard for MS covers the diagnosis and management of MS in adults aged 18 years and over. The standard is needed because NICE recognises that “MS can lead to a high level

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**1MSg campaign**

http://www.1msg.co.uk

To encourage people with MS to ensure they are making informed decisions about their disease management based on the latest facts and information. Supported by Biogen

**Neuro-Compass**

https://www.neuro-compass.education/en-gb/home/

A medical education resource developed by healthcare professionals for healthcare professionals who manage people with MS

**Multiple Sclerosis Society UK**

https://www.mssociety.org.uk

A campaigning charity that funds research, runs local groups and provides information on MS

**MS Trust**

https://www.mstrust.org.uk

A campaigning charity and source of information on MS

**NHS Choices**

http://www.nhs.uk/Conditions/Multiple-sclerosis/Pages/Introduction.aspx

Reliable, evidence-based information for patients

**Apps**

http://www.healthline.com/health/multiple-sclerosis/top-iphone-android-apps#2

A range of commercial iPhone and Android apps for multiple sclerosis. Variable reliability and value. NHS Innovation Accelerator (https://www.england.nhs.uk/ourwork/innovation/nia) is working to develop and evaluate evidence-based apps and tools

**Box. New sources of online information on MS**
of disability with considerable personal, social and economic consequences.” The diagnosis has a significant impact on an individual’s ability to work, their quality of life and has consequences for their family.

Through the six quality statements (see Table 1), the quality standard is expected to improve the following outcomes:

• The patient experience of diagnosis and support
• Frequency and severity of relapse
• Number of emergency hospital admissions and length of hospital stay
• The severity of disability.

Response from MS charities

The charity MS Trust has some misgivings about the new NICE quality standard.12 Stephen Troussé of the MS Trust says: “Generally we think it’s a positive step forward – it will allow both the health service as a whole and healthcare professionals to clearly see what level of service they’re expected to provide for people living with MS.” But he is concerned that many of the statements are not going to be met, such as the commitment to providing single point of contact and having a comprehensive review at least once a year.

The MS Trust also warn that resources need to be directed at everyone with MS, not just those with RRMS who can be offered DMT. A recent survey conducted by the MS Trust of over 1800 people with MS has shown that people with progressive MS feel that they have less support from specialist services than those with RRMS, with 39 per cent of people with SPMS saying that they saw less of their neurologist or MS specialist nurse once their disease became progressive.13

The three main areas of concern of the MS Trust are:

• The quality standard is too focused towards those who are newly diagnosed and/or RRMS and could drive further inequities, particularly for people with progressive forms of MS who make up around half the total MS population.
• The quality standard fails to recognise the vital importance of MS specialist nurses to people living with MS, in light of recently published evidence about their value.
• The process used to develop the quality standard was flawed, lacking transparency, legitimacy and buy-in from MS specialist neurologists and the wider MS community.

Mr Troussé is concerned that the focus on RRMS in the quality statements could lead to inequities in MS services. “This is something we’re addressing in our new MS Forward View project,” says Mr Troussé. He says that the challenge for MS services is how to use their resources to support the drive for earlier and higher levels of treatment for RRMS while still ensuring that everyone with a diagnosis of MS can receive the appropriate, timely, high-quality care needed to improve experience and outcome.

The MS Society is more cautiously positive about the quality statements: “People affected by MS have told us these standard statements are not always met currently. We hope the publication of this standard helps with our efforts to ensure better quality and more consistent MS care.” The MS Society has a Treat Me Right campaign in which it calls for the right treatment at the right time for everyone with MS. The MS Society points to the way quality of care depends on where you live. Neurological conditions are under-represented within the NHS it says, attracting less funding and resources than cancer, for instance.

The MS Society particularly welcomes the standard setting out the need for a single point of contact to co-ordinate care within a multidisciplinary team of MS professionals.15 This is such an obvious need for an MS patient that it is sobering to think how rarely our patients with MS have a single name and contact number to phone when they have questions. This would, of course, be useful for us as GPs too.

References

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Declaration of interests

None to declare.

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