Increasing awareness of services for people with multiple sclerosis

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Awareness of multiple sclerosis has been increasing in recent years. However, there are still many issues which the MS Society will be highlighting during MS Week. This year there are three main MS Week themes. These include funding for research, a volunteer recruitment drive, and promotion of the NICE guideline for MS.

In the 30 years since the cellist Jacqueline du Pré made it known that multiple sclerosis (MS) had cut short her career, this complex neurological condition has received more attention than it did in a whole century before. In addition there have been highly visible (and occasionally controversial) promotional campaigns to raise awareness, and characters with MS have featured prominently in films and TV series.

New drugs for people with MS have hit the headlines as they were caught up in the first postcode lotteries of NHS prescription. There then followed a two-year evaluation of their cost-effectiveness by the National Institute for Clinical Excellence and there was further publicity as an innovative risk-sharing scheme was launched that allowed people to obtain beta interferon or glatiramer acetate where appropriate (Department of Health, 2002). The prospect of cannabis-derived treatments and the far-reaching new NICE guideline on managing MS (NICE, 2003) have also raised the profile of the condition.

Why raise awareness?

This year’s MS awareness campaign is running from 18 to 25 April. Mike O’Donovan, chief executive of the MS Society, the UK’s largest MS charity, says the week provides a focus not only for the public but also for the organisation’s thousands of volunteers and supporters. The society’s grassroots are a network of regions and 350 branches, all run by volunteers across the UK. They are the people providing support to people affected with MS in their region 365 days per year. The society believes that coming together for MS Week gives them an extra boost to help reach out to people who need them, people who will help them, and people they need to influence locally. This year there are three MS Week themes:

- Highlighting the need for more research funding nationally;
- Stepping up the recruitment drive to enlist new volunteers at branch level;
- Promoting the NICE guideline.

Over recent years the MS Society has been working closely with health and social care professionals to help deliver consistent standards of high quality care to everyone affected by MS. It has funded or part-funded nearly 80 of the growing number of MS specialist nurses and other professionals now working in the UK. As a direct consequence, the concept of a multidisciplinary approach to MS care is steadily becoming a wider reality. The society works closely with the MS Trust, which trains nurses, and the UK MS Specialist Nurses Association.

Provision of care

Research has shown that specialist nurses have had a significant impact on MS care provision and are at their most effective when they are part of a multidisciplinary professional team influencing the long-term development of a wide range of services (Forbes et al, 2003). Researchers from King’s College London carried out an evaluation of the society’s nurse-funded programme (Forbes et al, 2003) and found ‘dramatic’ improvements had been made and maintained in standards of care provided where a specialist nurse was in post.

There was a significant reduction in the incidence of pressure ulcers and their costly complications. The nurses also helped patients with fatigue management and maintaining psychological stability.

NICE guideline

Mr O’Donovan says many people are still facing a health care lottery, which can start even before diagnosis as they wait for month after uncertain month. The NICE guideline, he says, provides real hope for changing that and represents the most far-reaching step ever taken towards better management of the disease.

‘The society has good reason to welcome it,’ he says. ‘Some years ago we introduced the first standards of MS health care in partnership with the National Hospital for Neurology and Neurosurgery (Multiple Sclerosis Society of Great Britain and Northern Ireland and The Neurorehabilitation and Therapy Services Directorate, 2001). With their emphasis on the need for multidisciplinary care at all stages of MS, they have had a considerable impact. The NICE guideline moves us further on. It also sets a benchmark which will inform the National Service Framework on Long Term Conditions, which will focus on neurological conditions and is due to come into force in 2005.’

The guideline includes 200 recommendations covering general principles of care, diagnosis, disease-modifying therapies, rehabilitation and symptom management. Six of these recommendations have been highlighted as...
Box 1. Areas Particularly Crucial to Improving People’s Access to Services

- **Specialised Services**
  Specialised neurological and neurological rehabilitation services should be available to every person with MS.

- **Rapid Diagnosis**
  Every person who is suspected of having MS should be referred to a specialist neurology service and should be seen again after investigations. This process should be rapid, with people being told how long they will need to wait.

- **Seamless Service**
  Local organisations which pay for local services (Primary Care Trusts in England and Local Health Boards in Wales) should ensure that all organisations in the local health economy agree ways of working and share and publish information about the needs of people with MS in the local area. In particular, they should agree protocols and procedures on how responsibility is shared and how people transfer between different parts of the care pathway.

- **Involving People with MS**
  All services should involve people with MS in all decisions and actions about their care.

- **Follow up**
  Every person with MS should be informed how to make contact with neurological and rehabilitation services when a period of care and treatment ends.

- **Other Health Issues**
  Health service workers in regular contact with people with MS should consider whether the person with MS has a ‘hidden’ problem contributing to their clinical picture, such as fatigue or reduced bladder control.

being particularly crucial to improving people’s access to services (Box 1).

The guideline contains implementation and audit guidance for local health organisations and suggests this should be the responsibility of Primary Care Trusts and Local Health Boards. The MS Society is looking at ways of supporting them in doing this. A ‘toolkit’ for health professionals is being launched during MS Week.

Mr O’Donovan says, ‘We have tasks to suit many talents and skills,’ says Mr O’Donovan. ‘It could be driving, organising events or helping with street collections. On the other hand, it could be campaigning and liaising with health and social services to see high quality standards of care properly delivered to people affected by MS.’

**Funding for research**

Also high on the MS Week agenda is research. The society says more research is needed into repairing the damage caused in MS as well as finding the drugs to treat it. Although there are now drugs that can reduce the severity and frequency of MS attacks, they are only suitable for about one in ten of the 85,000.

Mr O’Donovan says: ‘We must go on looking for more effective drugs to treat symptoms but there is increasing hope that a way can be found to mend the damage and prevent long-term disability developing.’

The society has identified damage repair as a priority in its own research grant funding programme. It recently made a grant of £250,000 to see if adult stem cells can repair the damage to the myelin coating that protects the brain and spinal cord. This leads in turn to damage to the nerve fibres causing a wide range of disabilities.

Another focus for funding was research into fatigue. Nine out of ten people with MS are affected by fatigue and half of them say it is their worst symptom. This can mean that people can be so exhausted they cannot do their job properly or even enjoy playing with their children. A better understanding of fatigue would enable better ways of treating and managing it to be developed.

Mr O’Donovan says: ‘Increased funding is crucial. We have earmarked £1m this year for grants for new research into repair and fatigue and we are already committed to spending more than £11m on around 50 other research projects. Without more money we shall not be able to afford many of the high quality project applications we are receiving that could bring us closer to eliminating this dreadful illness.’

**MS Week**

The national MS Cake Break will also be helping to raise funds during MS Week. This involves people baking or buying a cake and inviting friends to share it in return for a suggested £1 donation to the MS Society. TV show Bad Girls star Claire King, whose father has MS, is leading the drive in a bid to make 2004 the biggest event yet.

And while the society’s 150-strong London Marathon team was securing sponsorship on the first day of MS Week, its branches were setting out to find more people to join them in providing a range of local support services to nationally-agreed society standards.

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**Key words**

Public health, Multiple Sclerosis, Awareness

**References**


**Further information**

The MS Society’s freephone helpline is 0808 800 8000. Its website is www.mssociety.org.uk

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