



multiple sclerosis
specialist nurse association

P O Box 63
Little Marcle
Ledbury
HR8 9AA

01531 670481

admin@ukmssna.org.uk
www.ukmssna.org.uk

Issue 5 June 2006



Fighting the Threat to MS Nurse Jobs

As you might expect, at present the UKMSSNA is concentrating its efforts on supporting people whose jobs are threatened by the cuts being made by NHS Trusts and PCTs. The committee is working closely with colleagues at the MS Trust and MS Society, as well as the RCN and Parkinson’s Disease Nurses, to raise political awareness of the role of the Specialist Nurse and the crucial part they play, not only in providing a service to their patients, but also supporting other health professionals, such as Community Matrons, with specialist knowledge and expertise.

On 3rd February, there was a meeting at the Department of Health to consider the current threats to MS specialist nursing services. A subsequent statement was signed by all the key stakeholders supporting MS nurses and emphasising what would be lost to the MS population if services were cut. It calls upon the government to ensure that PCTs are fully briefed on the rationale for MS specialist posts, and that resources are allocated to MS services to allow the implementation of the NICE Guideline and the NSF.

We are going through a period of change and uncertainty. The UKMSSNA Committee is committed to supporting our members as much as we can through this time. Please contact your regional representative or any committee member if you wish to discuss anything informally and in confidence.

Three specific threats were seen as of particular relevance to MS posts:

- i) the confusion and discrepancies around Agenda for Change;
- ii) the financial crisis in the NHS;
- iii) the Government’s drive to have 3000 community matrons in post by April 2007.

The MS Society, RCN and Parkinson’s Disease Society held a joint symposium in January, attended by representatives of the UKMSSNA, to look at the interface between community matrons and specialist nurses. The report of the Symposium is enclosed with this newsletter.

The funding cuts come at a time when Specialist Nurses are already having to prove their economic worth. MS Nurses will increasingly have to justify their existence and demonstrate that they are “value for money”. There is no doubt that we are able to do this, but we must be able to provide the evidence – and this means more work at least in the short term. The UKMSSNA is in discussions with the two main charities and Dr Foster’s* about research into the services that MS Nurses provide and the difference to patients in areas where there is a secure, effective MS service in comparison with areas where there is poor service, or no service at all – for instance where a CNS post has been frozen when the postholder left. If you are contacted to provide this important evidence, please do your best to help; we appreciate that this is just one more call on your time, when you are already hard-pressed, but it is in all our interests to do this research. We are also investigating the possibility of doing some qualitative research to complement the statistical evidence.

Please look at the UKMSSNA website (www.ukmssna.org.uk) where you will find more information about the various initiatives that the UKMSSNA is involved in as well as formal Statements on some of the issues. Some information will only be in the Members Section – if you can't remember your password please contact our Administrator, Mary Fielding, on 01531 670481 or email admin@ukmssna.org.uk.

If you have any case studies that we could use to highlight the current threat, please email admin@ukmssna.org.uk. The names of individuals will not be quoted.

*Dr Foster, an independent organisation, provides information about the quality and availability of health services. It is a collaboration of healthcare professionals, academics and journalists, and is now the leading independent authority on healthcare performance. It is pioneering new techniques to measure clinical quality and monitor improvement, and its approach has been adopted by many NHS organisations. Dr Foster is legally required to follow a code of conduct that prohibits political bias and requires it to act in the public interest.

Some good news! – the MS Society's Nurse Fund has just funded its 100th MS specialist post. The Nurse Fund is not restricted to nurse posts and has just funded the first MS community psychiatric nurse, another MS clinical psychologist and, for the first time, a joint MS/PD post in collaboration with the PD Society. If you would like further information on the funding available for specialist posts please email servicedevelopment@mssociety.org.uk

Awards News!

Barbara Wingrove won the BJN Award this year and is still on Cloud 9 after the reception at the Savoy. Congratulations to Barbara!



Congratulations too, to Vicki Gutteridge, who won the "Making a Difference" Award and received a beautiful Irish Crystal vase from Nicki Ward on behalf of the UKMSSNA.

MS Nursing Exam



The MS Nursing International Certification Examination (to give it its full title) will be held this year on **Thursday November 2nd in Bournemouth.**

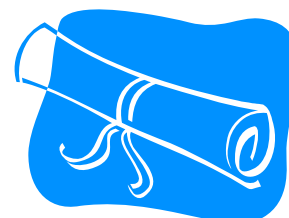
Carol Turner, MS Nurse in North Devon, sat the exam last year and says:

"In an ever uncertain NHS we need our specialism recognised and the MS examination helps us to do that. It also looks great on your CV, shows motivation and gives you a personal sense of worth. I passed it, so there is hope for everyone!"

The cost to you is just £35 as the IOMSN offer scholarships to cover the full cost of the exam which is \$250 US.

The closing date for applications is **Friday 18th August** – which may sound a long way off, but if holidays intervene, it will come up very quickly.

Contact Mary Fielding for a Handbook and application form. If you have any queries contact Nicki Ward: nicki.ward@uce.ac.uk, tel: 0121 331 6177





UKMSSNA Website @

www.ukmssna.org.uk

We now have our own website where we can keep you up to date with happenings within the UKMSSNA, and out in the wider world. Do check frequently to see what's new. Members have access to the "Members' Only" section where you will find a Register of Members who have given permission for their details to appear (if you aren't on there and have no objections, please let Mary know), the Slide Library, Committee information including a list of committee members and their contact details and Minutes of meetings. If you are a member and don't know the password, contact Mary on 01531 670481. We would welcome comments about the website (the feedback so far has been very positive) and also any information, requests for help, articles which we can put on the web. In the longterm we hope to set up a "Bulletin Board" (but I'm still learning the technology MF).

Regional News

SE London have developed a Protocol for relapse management for oral methyl prednisolone and will be auditing the findings. They also want to develop a set of guidelines for referral.

Wales: The Welsh Assembly is funding a project for two years to help GPs and Practice Nurses during which time the MS Nurses must run 8 clinics in GP practices concentrating on symptom management.

Several regions have reported that DMT funding is being blocked in various Trusts across the UK, including Northern Ireland and Wales. However the Welsh Assembly is funding Mitoxantrone and Campath.

NE England: All GP surgeries have signed up to the GMS contract to provide enhanced services and are developing a patient database. Specialist Nurses have now been told that they must do one day a week working on wards to reduce the need for agency nurses. This has highlighted the need for training for ward nurses.

Some regions are working with local MS Society branches to produce Service Directories.

Revising the Byelaws

The Committee has reviewed The Byelaws and Standard Rules of Procedure (SRP) and will be putting a completely revised Constitution, combining the Byelaws and SRP, to the membership shortly. This one document rationalises the anomalies found in the previous two documents and is in line with UK voluntary sector and charitable practice. You can read the draft Constitution on the website on the Members' Section. If you have any queries or comments about this, please contact Mary Fielding on 01531 670481.

New Committee Members needed!

There are still vacancies on the Committee, as some regions of the country are not represented (see previous newsletter or website). In particular, by the time of the AGM in November, some committee members will have come to the end of their tenure and will be standing down. Full Committee meetings are held in January, May and September with "mini" meetings held at conferences during the year. Being a committee member is an opportunity to get involved in special projects such as the Slide Library and Care Manual and to represent your region's views and contribute to debate at national level.

Contact Co-Chairs Sylvie Hurst on 01634 82500 or Nicki Ward 0121 331 6177 for more information

Membership Renewal

It would be very much appreciated if you could renew your subscription to the UKMSSNA *promptly*, when you receive your renewal notice.

Our Administrator is employed for only ten hours a week and so chasing up people who do not renew within the month their subscription is due takes valuable time which could be better used and is costly to the UKMSSNA. If you have any suggestions which would improve the system, do please let Mary know.

46 new members have joined the UKMSSNA in the last twelve months; 11 of whom have joined in 2006. The total membership is 174; 15 are Associate Members.

Model Pathways, Policies, Procedures and Protocols

The Care Manual is in the process of being updated and will be re-launched later this year. The review panel would like to include examples of model care pathways, policies, protocols, etc. We had some good examples from the email request which went out earlier this year and Sam Colhoun, Claire Lowndes and Nikki Embrey offered to form a working group to pull this together. Please send copies (preferably electronic copies by email) of the paperwork you use in your own work to Mary Fielding to pass on to the working group.

MS Society Measuring Success Toolkits

Of the six pilot sites selected to evaluate the scheme two have completed audits, focus groups and action planning and two are waiting to set a date for action planning. All 430 recipients of the toolkit have been asked to evaluate its effectiveness and usability and this, plus the evaluation from the full pilot sites, will be used to revamp

the toolkit later this year. The new toolkit will also link key elements of the NSF. The scheme is designed to help with implementation of the NICE guidelines - not just focusing on quantitative and descriptive data but involving user-focused and qualitative data to ensure action plans that are not based solely on what is managerially or politically expedient but on what matters most to users of the service. For more information email servicedevelopment@mssociety.org.uk.

How are you/your team getting on with the NICE Guideline and the NSF on Long Term Conditions? Demonstrating that you are meeting the recommendations is yet another good way of strengthening your position as an MS Specialist Nurse. What's happening in your area of the country? Let us know!

The MS Society is sponsoring an award with the Queen's Nursing Institute in 2007. The award aims to influence innovation and best practice in MS community nursing and will have two elements: a grant of £7,500 to develop a year long project of direct benefit to people affected by MS, and professional support and development for the practitioners involved in the project. A call for project proposals will be going out in the summer. If you have an idea of how community services could be improved for people with MS and would like to put your ideas into action, contact the Service Development Team at the MS Society; email servicedevelopment@mssociety.org.uk

Thanks

The UKMSSNA wishes to acknowledge with thanks the unconditional support given by Serono for their help with the Care Manual and new display boards, to Teva for the Slide Library and to Biogen Idec, Schering Health Care, Teva and Serono for assistance with committee meetings.

Publications

The Young Person's Guide to MS: Kerry Mutch has been working with The MS Trust to produce a book primarily aimed at 10 -15 year olds with a parent with MS. The book was inspired by a series of 'MS in the family' workshops run by Kerry. Based on what young people themselves have said, the book will answer some of the questions young people have about MS, enable them to explore their feelings about how MS affects them and help them to realise that they are not alone in the feelings they may be experiencing. Available in August 2006, to reserve a copy, send your name and postal address to: info@mstrust.org.uk

MS Together – a DVD for people diagnosed with MS: This DVD is for people who have been diagnosed with MS and those close to them. It is free of charge from the MS Trust.

MS Topics is a series of publications from the MS Trust, for people with MS, that provides a high-quality overview of information and issues. MS Topics now available include:

- Diet
- Linoleic acid
- Talking about MS
- Conception, pregnancy and becoming a parent
- Cannabis –cannabis-based medicine
- Pain
- Fatigue
- Bladder symptoms

Coming soon:

- Cognition: memory and concentration

A guide to MS for GPs and primary care teams: The first comprehensive guide to MS for GPs, it covers MS symptoms, current and emerging therapies, questions patients ask their GPs, the NICE guideline, continuing care, end of life, complementary and alternative medicines, equipment, respite and carer support. It also contains practical templates for use by practices taking up the enhanced service for MS.

Further clinical support tools for primary care will be available later in the year. Hard copies are charged at £10 and the guide (and order form) can be downloaded free from www.mssociety.org.uk/gps.

MS Essentials: Five new leaflets have been published since the last UKMSSNA newsletter:

- Fatigue
- Women's issues (pregnancy, menstruation, contraception and menopause)
- Support for people severely affected by MS
- Pain and sensory symptoms
- Complementary and alternative medicine

Working with MS, for employers and people with MS, has been revised to take into account changes to the DDA and *What is MS* has now been translated into Hindi, Punjabi and Urdu.

These publications are free and you can download or order them on www.mssociety.org.uk or you can order copies from MS Society Publications, PO Box 142, Bedford MK42 0FA.

MS and palliative care: a guide for health and social care professionals: Based on a study of palliative care and MS developed at Kings College Hospital, this new guide includes information on the challenges of advanced MS, optimising quality of life during advanced phases of MS, advance planning, living wills and end of life care.

Introducing MS: A 25 minute film made by the Stockport branch of the MS Society, featuring interviews with a neurologist, an MS nurse and people affected by the condition. An ideal companion to Getting to Grips courses, it is a valuable resource for individuals and families or friends of people new to MS. The MS Society has produced a limited number in both VHS and DVD format, available through the Information Centre and Helpline. One copy is on offer to every UKMSSNA member to keep; email education@mssociety.org.uk.

MS Trust Conference and Training

MS Trust Annual Conference 2006:

Date: Thurs 2nd - Sat 4th November 2006

Venue: Bournemouth International Centre
All MS specialist nurses will receive an Information pack in June.

MS Trust Masterclass in Depression and MS

A masterclass in Depression and MS which will be held in September 2006 is currently being developed. For further information Contact Paula Manson: 01462 476704 or email: paula.manson@mstrust.org.uk

MS Trust Advanced Study Day

Date: 10th July 2006

Venue: Liverpool Marriott Hotel City Centre

Cost: £65 + VAT

An interactive learning day to develop the knowledge of health and social care professionals with a good working background in MS. Topics include: 'Aggressive MS', workshops on physical and psychological pain and coping strategies, 'MS in the family' and 'Current trials in MS.' Contact: Cathy Garner: 01462 476704 or email: cathy.garner@mstrust.org.uk

News from the MS Society

User involvement in service development

The user involvement programme ensures that service users are at the heart of improving MS services by offering high-quality training, support and resources in a systematic way across England and Wales. It is government policy to involve and consult patients and the public in the planning and development of service provision. By becoming part of a More4Me group, service users can share their knowledge and their experiences of MS to bring about change. We hope MS nurses will share information about the new national programme with anyone who might be interested in getting involved. For an information pack, email servicedevelopment

@mssociety.org.uk or to find out more email placy@mssociety.org.uk.

Transforming local support

The Society has embarked on a project to improve local support for people affected by MS (PaMS), recognising that the present set up of local branches does not meet everyone's needs. Plans aim to ensure that a variety of activities and support is available to all PaMS, wherever they live. This will include access to information events and courses about MS, support groups for particular people such as carers or younger people with MS, and access to advocacy services.

The Society wishes to work in partnership with MS nurses and other professionals to develop new services. Pilots are nearing completion and news about the national programme will be available later in the year. For more information, contact Nancy Burge on nburge@mssociety.org.uk

Carers Programme Survey 2006: Professionals Supporting Carers

The MS Society carries out an annual survey to explore an issue of particular relevance to carers. In 2006 the focus was on the help needed by professionals to support the carers with whom they come into contact. MS Nurse Specialists are in a key position to respond to concerns expressed by carers, to identify their needs and to signpost them on to local forms of support. The results will enable the Society to develop resources for MS Nurses and other professionals to help them in this role.

Contact Joanna Ridley for more information at jridley@mssociety.org.uk

The UKMSSNA welcomes contributions to this newsletter on any aspect of MS nursing care. We reserve the right to edit articles. The deadline for the next newsletter is **Friday 8th September** for publication in the first week of October. Email admin@ukmssna.org.uk with your contribution.