

Update on Job Losses

The situation is generally unclear, but it appears that, although there are undoubtedly some jobs under threat, the number of these is not as high as originally feared. Some nurse posts that were under threat are now safe. There is, however, an issue about MS specialists being redeployed onto the wards for 1-3 days a week. That practice appears widespread and is obviously of great concern. It is also the case that MS Nurses who leave posts are not always being replaced.

However, there is also positive news that new MS nurse posts are being commissioned. For instance, **Del Thomas** has moved from Gloucester to a new post at Herefordshire PCT. **Karen Vernon** is leaving The Walton Centre to go to Cannock, South Staffs, to set up a new MS service, working alongside Sue Noble. The UKMSSNA has seen more Nurses join in the past six months than it has lost members through job losses (see below).

The UKMSSNA has already written letters to specific PCTs to support 'at risk' individuals. If any member feels that this would be helpful for them, let us know. We will also offer what personal support we can.

We invited male MS Nurses who are members of the UKMSSNA to comment on what differences, if any, there are between the way they approach/provide the service from the way their female colleagues might approach it. What kind of response do they get from their patients - or doesn't it make any difference at all? All contacted said they felt there was no difference – or that they weren't in a position to comment, having only seen it from a male perspective anyway. However, John Porhorely contributed his general experience of being a male nurse.

Nursing from a male perspective – a personal view

John Porhorely, MS Specialist Nurse, Frimley, Surrey

Obviously it is impossible for me to know how female Nurses respond to the needs of their clients, but in nearly 30 years of nursing I have noticed a few things.

- As a student nurse I was pulled off of a night shift on a female ward as it "wasn't really fair on the old ladies".
- The school of nursing very, very rarely referred to me as Student Nurse and addressed all mail to "Mr Pohorely"
- Once trained, I was denied the opportunity to apply for a post on the children's ward "as it would set a precedent"
- the senior nurse stated that all the ills of the NHS could be traced to Male Nurses, particularly foreign ones, and looking at my surname she had assumed I was not British.

We are talking about 1977, but guess what? I voted with my feet. In the interim I have had a male Doctor say that it was not a job for a man and a female Doctor assume I was attracted to men because I was unmarried. I was the last to know as she was so busy telling the rest of the team. Richard and Judy gave airtime to an American who stated that anyone employing a male in a caring capacity was negligent as statistically all child abusers were male. I pointed out that they are likely to be known to the family or a relative so a professional falls outside of that group. This was not long after Beverley Hallet, but that wasn't mentioned.

It didn't make me feel very supported or understood by the profession, but I have never had any problems with patients or relatives. If asked I would say "I am a nurse who just happens to be a bloke, and just in case you are wondering; it is not compulsory to be gay"

The profession has moved on and I have got older along with it. Perhaps I no longer look like a predatory lone sexual deviant about to throw myself on the nearest slumbering Grandmother or kidnap a child. Getting married may have helped but we got weird looks in Australia when we had to explain time and time again that I wasn't the exchange wood/metalwork teacher but a nurse (S'truth Bruce! They've sent us a woolie-woofter).



I am not saying that there have not been reasons for concern. When a rapist was re-admitted to the Enrolment I wrote to the then UKCC to complain. When a male nurse was found to have used IV Hipnoval to rape, I suggested that we place the drug on the controlled drug list to put in place much more stringent controls but I was told that it would be too time consuming. I felt it would have re-assured the public and safe guarded all male staff members from accusations. A week later a post-operative woman accused a consultant of covering up for one of his team who, she alleged, had interfered with her.

Now I am a lone worker and adhere to all the policies, as much for my safe-keeping as anything. I had to fight quite hard to convince my managers that a mobile phone was necessary. When Jill Robinson started as a Support Nurse in the next patch, we agreed to cross-refer if there were any gender issues, but so far it has proved unnecessary. I don't, out of politeness, drop in on people without warning but quite honestly my gender is not something that changes my approach on a visit or clinic appointment. I do training for DMT and need to view injection sites routinely but that has never proved a problem. I encourage the person to invite a friend or relative to the session as "four ears are better than two" and those that know me will say I do go on a bit. I ask about bowel, bladder and sexual function and have not noticed any increase in the reticence of my female patients/clients/customers or PwMS either. I have been approached by two females who have wanted to discuss "marital aids" but have not been swamped with blokes wanting to discuss ED as I imagined. When I came in post the most common reaction from my female colleagues was "Oh goody, a man, you'll be handy for the ED". I had to go away and look it up of course.

I am reminded that only 7% of communication is from the spoken word which leaves a whacking great 93% for tone, pitch and body language. If you get that right I don't feel the gender is a particular issue. As we all know we work with a particularly needy group (and I am not referring to Neurologists). If they feel supported, understood and valued they will respond whatever the gender of the nurse. One things for sure; you can't fake it. I am sure that there are some people that I have not clicked with and that is why it is good to offer some choice, but hopefully I get it right most of the time, even if I do leave the toilet seat UP now and again.

Membership News

Welcome to the following new Members, who have all joined since May:

Margaret Graham
Vicky Lester
Iris Hume
Sally Jones
Deborah McMillan
Joan Regan

Stephanie Heath
Stefanie Maw
Catriona Williamson
Jane Metcalfe
Jill Robinson
Helen Lloyd

Elizabeth Disney
Lynn Cherry
Verity Dods
Dianne Fox
Brenda Hamill
Loreta de la Rosa

Membership now stands at 184, with 27 new members this year, many of them **NEW POSTS!**

New Honorary Members

We are delighted to announce that Professor Judy Wollin, Griffith University, Queensland, Australia, Diane Lowden, the new President of the IOMSN and Josie Ramsay, formerly MS Specialist Nurse at Royal Victoria Hospital, Belfast, have all accepted the Committee's offer of Honorary Membership of the UKMSSNA. They join Kathy Costello, Heidi Maloni and June Halper.

Renewals

It would be appreciated if you could renew your membership of the UKMSSNA as soon as possible after receiving notification. This cuts down the amount of time spent on this surprisingly time-consuming task at the administrative end. Please consider setting up a Standing Order payment to make this easier.

Subscriptions

The Committee have decided that the subscription for Full Members will remain at £30 for the next 12 months, but that Associate Members' subscription will rise from £20 to £30. Associate Members get all the same benefits as Full Members with the exception of voting rights.

Making a Difference

We are looking for nominations for the **Making a Difference Award**. This is for the MS Specialist Nurse who has made a significant contribution to MS care in the past twelve months. Pick up your nomination form at the Bournemouth Conference or download it from the website.

MS Society Nurse Fund

Caron Furnival has been appointed Head of Service Development following the departure of Martin Hunt. The MS Society is now looking to recruit a person to lead the Society's nursing strategy. The Society is also researching the number of hours lost to MS nursing by the reconfiguration of PCTs and the struggle to balance budgets. Results will be available shortly. For further information on either of these items, email cfurnival@mssociety.org.uk

2006 Annual General Meeting – Resolution on new Constitution

This year's AGM will be held on the first evening of the MS Trust Conference in Bournemouth; 7.30pm – 8.30pm at the Bournemouth International Centre. All sorts of incentives to come along – including a raffle!!

The Agenda for the 2006 AGM, Minutes of last year's AGM and the draft of the proposed Constitution can all be found on the UKMSSNA website in the Members' Section. It is too costly in terms of printing, postage and our Administrator's time to post all documents out to you, so please download the details from the website. If you can't remember your password, it's on the back of the 2006/07 membership card.

From Apathy to Action

Presented at the Consortium of MS Centers Conference (CMSC) , Arizona, US. June 2006

Nicki Ward, Lecturer/
Practitioner, UCE, Birmingham



In June this year, a group of us from the UK and Australia facilitated a workshop at the annual International CMSC Conference in Arizona and had just the best time! We felt there were so many initiatives that were going on outside of North America that it was important to broadcast these to all and really demonstrate the quality of care that is being carried out internationally.

After an initial period of fear once our abstract had been approved, we were passionate to show what the Brits are all about!! We planned a really busy 90 minutes, mainly around the theme of how education can empower patients. We secured sponsorship from TEVA for flights and accommodation which was both very supportive and generous of them.

The workshop was opened by Andrew Russell, CNS in York, who provided a lively overview of the evolution of MS Nursing in the UK; then Tim O Malley, Clinical Nurse Consultant in Brisbane, provided the same, but from an Australian perspective. Rhona MacLean, Lecturer Practitioner in Leeds, discussed MS-specific educational opportunities available in the UK for both healthcare professionals and people affected by MS, highlighting specific projects that had been developed by MS nurses. Tim discussed the benefits and limitations of the 'expert patient'; Pauline Shaw, CNS at St Giles Hospital, London presented her work on promoting choice amongst pregnant women who have MS and Kerry Mutch, CNS at The Walton Centre, discussed how information is given to patients and how this encourages a sense of control. I looked at whether fatigue management groups made a difference to an individual's perspective of their fatigue and Bernie Porter, MS Nurse Consultant in London, completed the workshop by explaining how patients were supported whilst making their choice of their DMTs and examined the website-MS decisions.

We were thrilled at how well our work was received; many North Americans not being aware of the huge impact MS nurses have had in MS care in the UK and were really rather envious of the autonomy we have to design and carry out such innovative work. I feel we can safely say that we were a great success!!!

MS Clinical Management Manual

The revised and updated Care Manual was launched at the CHARMS meeting in September. It has several new chapters, including *Changing Agendas in Community Care*, *Palliative Care*, *Considerations for the Nurse working in the MS Arena* and *Evidence-based practice and Self-audit* as well as extensive revisions and additions to existing chapters. It is now published in two volumes. A free copy will be supplied to all UKMSSNA members on renewal of their membership subscription. If you have renewed in the last few months, or are a new member, the Care Manual will be sent to you automatically - when we have worked out how best to distribute them! We do hope to have some on the UKMSSNA stand at the MS Trust Conference in Bournemouth so that you can at least have a look at them and drool. Our grateful thanks to Serono for funding the production of the Manual and to the Working Party for their hard work in reviewing and updating it.

Model Protocols

The new Care Manual contains model protocols and care pathways, but we have also taken up Sam Colhoun's suggestion of developing model protocols and putting them on the website for members to download. Sam is now chairing a Special Interest Group to do this along with Nikki Embrey and Claire Lowndes.

If you use any documentation which would be useful to the Group, or are interested in helping with this piece of work, please contact Sam on email: samantha.colhoun@uhb.nhs.uk and/or Mary (admin@ukmssna.org.uk).



New Presentations on the Slide Library!!

The UKMSSNA slide library was

launched in Oxford in March 2005. This valuable teaching resource is intended to aid UKMSSNA members in their educational role and was developed from presentations donated by health care professionals around the country. A working group collated and edited these presentations to provide a comprehensive library of slides.

Since its launch, the slide library has received a very large number of "hits" and informal feedback has been very positive, although an evaluation form distributed via email had a low return rate so we have not been able to audit usage properly. Nonetheless, further funding from TEVA in 2006 has allowed us to update the existing library and add new material. The new presentations will be available on the website very soon and include:

- Families living with MS
- Pregnancy and MS
- Health Issues for women with MS
- Coming to terms with MS
- Exercise Activity and Health
- The needs of people with MS

We are grateful to TEVA Pharmaceuticals for generously sponsoring the project and to Onyx Health for all their input. We hope that you find the library useful and welcome comments or suggestions, good or bad.

*Kate Watkiss and Denise Cooper
for the Slide Library Working Group*

New publications

The Young Person's Guide to MS by Kerry Mutch

This book is produced by the MS Trust and is aimed at 11-15 year olds who have a parent with MS. The book has basically been written by them and for them. Young people were asked what

questions they needed to know and gave the responses on how they are

affected by MS. The book is basically divided into two, the first half being questions about MS, treatments and symptoms, the second half addressing emotions, how to deal with them, hints and tips for coping. There are lots of quotes and comments from young people already living with MS in their family, with the aim of reducing the loneliness and isolation that teens can feel.



Living With Fatigue by Michelle Ennis

Fatigue is one of the major problems for people with MS. This book examines some of the factors that can contribute to an individual's fatigue, and gives practical suggestions and ideas for coping with problems. Quotes from people with MS help to explain the experience of fatigue and how others find ways to live with the symptom.

MS Topics

Publications which provide people with MS with a high-quality overview of information and issues. Recent additions to the range:

- Bladder problems

- Bowel problems
- Cognition

Factsheets

Factsheets deal with regularly changing aspects of MS. Recently updated factsheets:

- Mitoxantrone (July 2006)
- Stem cells (August 2006)
- Tysabri (September 2006)

All of the above are available from the MS Trust. As a potential distributor of these publications, please ensure that your patients note the Trust's contact details so that they can contact it for other information, if necessary.

MS Essentials

Since the last newsletter the MS Society has published four new titles in their MS Essentials series

- Muscle spasms and stiffness
- Finding and funding residential care
- Exercise and physiotherapy
- Guide to healthcare services

Also new is *Listen to the voices of people with MS*, which features interviews with people on the eleven Quality Requirements of the NSF together with suggestions for action on each one.

All publications can be ordered from www.mssociety.org.uk or by ringing the Information Team on 020 8438 0799

MS Trust Development Module in Clinical MS: Specialist Level

If you know of any new or potential new MS specialist nurse posts, please let Paula Manson know: 01462 476704 or email: paula.manson@mstrust.org.uk

Education, Training & Events

MS Specialist Nurses Course 2007

This will be held in York at the Royal York Hotel from March 6th - 7th 2007. There will be plenty of time for discussion and interaction so please put the dates in your diaries! If there is anything which you would like included in the 2007 course please contact catherine.thornley@mstrust.org.uk as soon as possible.

MS Trust Education Dates for 2007

Study Day	Feb 8 th 2007	Stoke
MS Specialist Nurses Course	March 6 th -7 th 2007	York
Development Module	April 16 th -20 th 2007	Hitchin
Therapists in MS Study Day	May 16 th 2007	Venue tbc
Master class for MS CSNs	June 12 th 2007	Subject & venue tbc
Study day in MS and MND	September 12 th 2007	Norwich
Development Module	October 1 st -5 th 2007	Hitchin
Annual Conference	November 2007	Dates and venue tbc
Master class	December 4 th 2007	Subject & venue tbc

MS Society Awareness talks for people with MS

Please advise your patients of the following talks arranged by the MS Society. If they would like to find out more or book a place, ring 020 8438 0705.

19 th Oct, 7pm	Acupuncture & Pain in MS	Derby
23 rd Nov, 6.30pm	Disease Modifying Drugs	Kings Fund, London
18 th Jan 2007	Barbara Chandler on Pain and MS	Teleconference talk & questions for up to 80 people.

The next Newsletter will be published in January 2007. In the meantime –



Happy Christmas to all our Members!

The development of a mobile aromatherapy service in partnership with The Multiple Sclerosis Specialist Nurse Service in Durham Dales PCT

Aromatherapy is the controlled use of essential oils to promote health and well-being, which has become a more common and accepted form of treatment (Price 1993). Conventional treatment strategies, such as medication, may not be successful in managing many symptoms in multiple sclerosis and this may cause patients to consider complementary therapies as an alternative. Massage is thought to be of benefit for pain for a variety of reasons (Howarth 2002). It is thought to stimulate afferent nerve fibres that reduce the transmission of nerve impulses. Pain, however, is a complex multi-dimensional phenomenon that impacts on an individual's bio-psychosocial and spiritual wellbeing. It may also be that massage too has some benefits on pain and other problems. Studies by Sato et al (1997) and Kurosawa et al (1982) found that massage caused a reduction in stress levels by stimulating the production of stress relieving hormones. An animal study by Lund et al (1999) also found that massage could reduce blood pressure and increase pain thresholds.



Aromatherapy massage has the potential to contribute to effective symptom management strategies in MS, and although much of the current evidence is anecdotal it has been offered in addition to, not instead of, other conventional treatments. Currently it is not unusual to find medical doctors in France using aromatherapy.

In 2004, following a government directive that palliative day care should include around 15% of non-cancer patients, the Butterwick Hospice staff approached the MS Specialist Nurse working within Durham Dales PCT in an effort to address this locally. The nurse managing complementary therapies within the Hospice had identified a need to make aromatherapy more easily available to people with MS and their families, in order to make a measurable difference to the patients and their carers. Due to the rural nature of the area and the distances needed to travel to access the service, the creation of a mobile service has successfully addressed the needs of those patients unable to travel. It was decided to try a flexible approach to patient referral in an effort to maximize access to the aromatherapist. The patient was offered 1 treatment a week for 6 weeks, free of charge, following referral from a variety of sources. These patients were then offered replacement oil blends, similar to those used in the six weeks of treatment, mixed by the aromatherapist and sent by post at no charge. Patients were offered home visits or a day care place at one of 3 Butterwick sites, the latter to include neuro-physiotherapy assessment/treatment if required. The lack of locally accessible resources solely for the use of people with MS resulted in a high take-up of these services and was reflected in the MYMOP (measure your medical outcome model) outcome compiled by Butterwick staff. The service was funded by a grant from St James' Place Foundation for one a year pilot scheme and, if found to be beneficial to people with MS, would ensure further funding. The success of this pilot has encouraged continuity funding for the next two years (following the results of MYMOP and an evaluation questionnaire – *for a copy of MYMOP contact barbara.wingrove@chs.northy.nhs.uk*).

The benefits reported ranged from better sleep patterns to recommencement of hitherto abandoned sexual activity, and intimacy. I have referred carers as well as patients as the service is offered to both.

In an effort to ascertain therapist effectiveness the questionnaire also requested information about the value of aromatherapists' treatment and teaching technique. All aspects of the survey were positive and have ensured the continuation of the service for patients with MS. I feel this partnership between the MS specialist nurse and the Butterwick Hospice staff is a model of best practice. It is to be evaluated by a research team from the University of

Southampton to verify that it meets the recommendations of the NICE guideline for palliative care and improves the lives of families living with a life limiting condition that is not cancer.

Current outcomes have been:

- Measurable improvements in the patients feeling of wellbeing.
- Measurable improvements in the relationships between patients and carers.
- Opportunities to build and strengthen relationships working in partnership with other community care providers.
- Response to identified need through a service model that is equitable.
- An opportunity to lead the way in service development in the field of palliative care for MS patients.

I hope this article emphasises the need for collaborative working in the palliative care arena and proves to be a successful model of best practice and encouragement to other partnerships in the future.

Barbara Wingrove

now MS Specialist Nurse, Sunderland Royal Hospital, formerly at Durham Dales PCT

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UKMSSNA newsletter Sept06 - News from the MS Society

Queens Nursing Institute Award

The last UKMSSNA newsletter mentioned that the MS Society is sponsoring a Queens Nursing Institute award to influence innovation and best practice in MS community nursing. A call has now gone out for proposals. For further information, go to www.qni.org.uk

UKMSSNA Committee Meetings

Members are welcome to attend meetings as observers to find out what happens in committee. If you have an interest in becoming a Committee member, but are not sure what it entails, why not come along as an observer. The next meeting in January will be in London. Contact Mary for details.

Weddings!



Now this is a serious publication, but sometimes life can be too serious – so here's some welcome light relief; although judging from Carmel's photo, at least one groom found the thought of marriage to an MS Specialist a bit overwhelming!!

Congratulations to Nicki Ward (now Ward-Abel)

and Carmel Higgins (now Wilkinson).

