

MS Professional

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www.ukmssna.org.uk

UKMSSNA Discussion Forum goes Live!!

The UKMSSNA's own online Forum is now open and awaiting your comments and queries. Go to the Members' page on our website and click on "Discussion Forum" on the left hand menu (<http://www.ukmssna.org.uk/members/forum/>). To make a contribution you'll have to register; if you just want to read messages click on "Guest". You now have the choice of posting your queries on the Forum or sending them via the Mailing List (ukmssna@ukmssna.hinterland.nu). The Forum is only available to members of the UKMSSNA.

The advantage of the Forum is that answers to queries can be seen by everyone, not just the person who posed the question, and it's also a good place to discuss and debate issues in the "safe" environment of a members-only site.

Webpage for New MS Nurses

Thanks to Nicki Ward for suggesting that we have a webpage for MS Specialist and Support Nurses with less than two years experience. At the moment it has the West Midland MS Nurse Group presentations "Setting Up a Multiple Sclerosis Specialist Nursing Service" and "Moving your Multiple Sclerosis Specialist Service Forward". Thanks to them for permission to use this. I'll add more items shortly. The link is http://www.ukmssna.org.uk/members/new_nurses.html or from the Members' page and the link on the left-hand menu.



The MS Trust and the Risk-sharing Scheme

A response to the MS Society statement from the MS Trust.

Having worked hard with Peter Cardy and Glyn MacDonald of the MS Society to initiate the DH Risk-sharing Scheme (RSS), it is disappointing to see the current stance of the MS Society as shown by their statement in the last issue of the UKMSSNA newsletter. When it was initiated, people with MS were having a miserable time in the UK and the RSS has undoubtedly been responsible for the greatest improvement of MS services ever.

However, the important thing is that the facts are correct, hence this response to the MS Society statement:

The RSS involved a numbers of parties; Department of Health (DH), the Health Departments from Scotland, Wales and Scotland, Association of British Neurologists (ABN), Royal College of Nursing (RCN), UKMSSNA, MS Society, MS Trust, Teva Pharmaceuticals, Bayer Healthcare, Merck Serono and Biogen Idec. Only the MS Society has withdrawn its support.

The RSS was only set up to look at the four drugs and whether they are cost effective.

The Health Service Circular 2002/004 which set out the rules for the RSS remains the legal framework for allowing the DMTs to be prescribed on the NHS. The MS Trust has a letter from the DH which states:

- patients already in receipt of treatment would be able to continue receiving it until they and their doctor decided it was appropriate to stop;
- local NHS bodies would no longer be required to fund treatment for new patients meeting the 2001 ABN criteria, though they would of course still be able to do so at their own discretion.

From the Department's perspective, continued patient access to these treatments is therefore closely linked to continuation of the scheme.

Without the RSS there would undoubtedly be a funding problem especially in the current climate.

The cost of the research element of the RSS is about £1m per annum which covers the collection of the data. This cost is borne by the five funders (DH and four companies) it is not NHS money.

There is no evidence that the RSS has stopped prescribing of other MS drugs such as Tysabri. Any delays for Tysabri were down to local issues such as an infusion suite etc., not a problem with the RSS.

To get any paper published takes time especially if you want it in a reputable journal. The independent writing committee performed the task in reasonable speed.

The Scientific Advisory Group is trying to develop a better cost efficacy model which will be valuable both within the RSS and also for the future as cost efficacy is an ongoing issue for all drugs for MS.

At the outset of the RSS there were approximately 70 MS specialist nurse posts. Now there are approximately 220 and many organisations have funded posts; the DH, the companies through the MS Fast Track Scheme, coordinated by the MS Society, and the companies direct. These MS specialist posts have brought improved services to everyone with MS not just those on drug therapy.

The RSS has provided educational support for all the MS specialist nurses.

If you have any questions please contact me on nicola.russell@mstrust.org.uk

*Nicola Russell
Director of Services
MS Trust*

Sativex licensed for use alleviating spasms

The Medicines and Healthcare products Regulatory Agency (MHRA) have licensed Sativex to treat spasms.

There is plenty of information about Sativex; check out the usual MS Trust, MS Society and MSRC websites. [Link: <http://www.gwpharm.com/uploads/sativexconsrelease16.6.10.pdf>]

Teva: correction

Tom Bendall and Glyn Wright work for Teva Pharmaceuticals Ltd rather than Teva UK (separate companies).

Refusal to leave delivery where requested or delivery left with inappropriate person:

Tom does *not* need to know if there are special arrangements for the patient; that is best kept between the centre and the homecare company, unless there is a problem with the service, in which case let Tom know what the problem is and he will be happy to help.

Health and Social Care Act 2008 Code of Practice - consultation

The closing date for this DoH consultation is 15th July; extended from the 23rd June due to the election. It is of relevance to community staff, and invites comments and views on the draft 'Health and Social Care Act 2008 Code of Practice for healthcare, including primary care, and adult social care on the prevention and control of infections'.

This link will take you to the document :

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_114737.pdf

This link will take you to the electronic response form:

<http://www.info.doh.gov.uk/questionnaire/cppci02.nsf>

Lynne Brown
MS Society
UK Programme Lead: Nursing

Do not cut specialist roles, warns SHA chief

Sent by Nicki Ward

30 June, 2010 | By Steve Ford

Specialist members of the NHS workforce must not be sacrificed in order to find efficiency savings, a government advisor and strategic health authority chief executive has warned.

NHS East Midlands chief executive and Department of Health commissioning advisor Barbara Hakin told a conference session that productivity could actually suffer if trusts took the approach of using specialists to fill generalist gaps.

For example, an investigation in May by HSJs sister title Nursing Times found many trusts across the country had begun requiring clinical nurse specialists to undertake general ward duties.

But Dame Barbara said: "It is absolutely critical that we keep... individual elements of the workforce doing the things they, and they alone, can do," she told delegates.

"If we don't keep those specialisms – whether those specialist skills sit with a doctor, a nurse, a paramedic or a social worker – I think there's little chance of us having the capacity to deliver what we have to do in the future," she said.

Dame Barbara described the next few years of tightened finances as a "monumental challenge" for the NHS. She said using the workforce more efficiently was the "number one

fundamental way” of increasing overall NHS efficiency, but warned that staff must be supported.

“We’ve got a real responsibility over the next few years to support them through these difficult times, so they have the right skills and the right development.... to do even better than we’re doing now.”

Meanwhile an academic who helped Barack Obama with his presidential election campaign is working with the NHS on an initiative to mobilise frontline staff on improving productivity.

Marshall Ganz, a lecturer in public policy at Harvard University who was credited with devising the grassroots organising model for the Obama election campaign in 2008, is helping the NHS Institute for Innovation and Improvement develop a productivity drive, which is due to get underway next month.

Helen Bevan, the institute’s chief of service transformation, said: “In terms of what we’re trying to achieve in our quality and productivity challenge, the results are going to depend on the extent to which we.... can make an emotional as well as a rational connection to our clinical workforce.”[Link: <http://www.hsj.co.uk/5016531.article>]

Also from Nicki:

The High Impact Actions for Nursing and Midwifery were developed following a ‘call for action’ which asked frontline staff to submit examples of high quality and cost effective care that, if adopted widely across the NHS, would make a transformational difference.

Nurses and midwives responded by submitting more than 600 examples in less than three weeks.

The Essential Collection aims to highlight just some of the stories behind those submissions by providing details not only of what was done, but also ‘how they did it’. These examples are intended to provide illustrations of good practice which you may not already have seen. Most importantly they are examples of how real people have made a real difference.

The Essential Collection is not designed to be tell you ‘how to’ make the changes; but it does signpost you to some of the many excellent resources already available that relate to the areas identified within the High Impact Actions.

[Link: http://www.institute.nhs.uk/building_capability/general/aims/]



Multiple Sclerosis Society

Online event: Work and MS - Staying in work

Date: Monday 5 July 2010 to Sunday 18 July

Location:

www.mssociety.org.uk/awarenesstalks

From Monday 5 July 2010, you can watch the video (and/or read the transcript) of an interview with Jo Sweetland, BSc (Hons), research occupational therapist at the Institute of Neurology, UCL, linked to the National Hospital for Neurology and Neurosurgery and Marlo Donato Parmelee on Staying in Work and MS.

This event will coincide with the launch in July of the Worklife website [www.yourworkhealth.com] aimed at helping people living with a long term fluctuating health condition to stay in work.

From Monday 12 July 2010, anyone can log on to our online Q&A board for one week until Sunday 18 July to ask your questions to Jo and Marlo.

If anyone would like to send us their questions before the Q&A week starts you can do so by contacting the Information Team on 020 8438 0799 or via email at infoteam@mssociety.org.uk and we will post them on their behalf.

The lack of certainty in MS, coupled with the variety of different jobs that people do, can raise quite complex issues for people in the workplace.

CBT Masterclass

I understand that the CBT Masterclass last weekend went well. To view Huseyin's photos go to:

<http://picasaweb.google.co.uk/Hus.Huseyin/CBTJULY2010#>

If you attended the course, do let us know what your thought about it. If the feedback is good, we'll see about holding a further course later in the year.



Government's Spending Challenge

The Spending Challenge is an open invitation to contribute to the government's Spending Review, helping to rethink public services to deliver more for less. It has been open initially to public sector workers (until 8th July), but is now open to the wider public.

The Prime Minister and Deputy Prime Minister have committed that the government will look at every single idea that comes in. All the suggestions will be considered by a team of officials at the heart of government. The final Spending Review, which will set out detailed spending plans for all government departments, will be published on October 20th.

It has been suggested that the UKMSSNA should get a collective response of some ideas from members that we consider and submit on your behalf to the Treasury.

For more information go to the Spending Challenge website <http://spendingchallenge.hm-treasury.gov.uk/> Of course you can make your own submission, but we hope that you will submit your ideas to the UKMSSNA who can put together a collective response. If several people have the same, or similar ideas, then it might give the submission more clout.

I'm not sure if this also applies to Northern Ireland, Wales and Scotland, so my apologies in advance to Scottish, Welsh and N. Irish members if it doesn't.

Mary Fielding
Administrator