



multiple sclerosis
specialist nurse association

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Issue 10 Winter/Spring 2008

Encouraging words from the chair



January was the first UKMSSNA committee meeting for the year, last meeting for some and first for others. We discussed the aims for the year, pressures on our jobs, 'Adding Value' document, qualitative audit protocols and our role as MS nurses on the national pathway that is being developed.

However, to me, the most reassuring aspect of the whole day was quickly reviewing the main aspects of our job roles. There are some differences between those employed by acute trusts or primary care trusts or those working in Scotland and Ireland that have slightly different Health systems. Despite the pressures on proving our worth, quantifying and qualifying everything we do, the most inspiring, encouraging and reassuring aspect that was uncovered is that most of us remained autonomous in our role, deciding on what we did. Most importantly, 90% of our time was spent with MS people either directly or indirectly. This was so enlightening that the people we all came in to the job to care for remain the key focus.

So congratulate and pat yourselves on your back for the tremendous job you all do for people with MS despite the ongoing pressures. Well done to all MS nurses. See you at York.
Kerry



at MS Trust meeting in York

Audit tool: The UKMSSNA will be launching its MS Nurse Audit at York. Those who attended the AGM saw a sneak preview of this easy-to-use toolkit, developed and piloted by a group of 14 MS Nurses, which surveys patients' opinions of their MS Nurse service and then uses a spreadsheet to analyse the results. This will complement other resources provided to members by the UKMSSNA and its partners, the MS Trust and MS Society.

"Adding Value": This booklet is based upon Standards of Health (DH 2006). All primary and acute trusts are audited and measured against 7 domains - safety, clinical effectiveness, clinical governance, patient focus, accessible and responsive

care, care environment and public health. The booklet highlights examples of how MS nurses can achieve targets set in each domain.

We have already distributed over 400 copies of this new publication. Copies will be available in York for you to send to your local commissioners, Directors of Nursing, fund-holders, etc.



Update

Care Manual

A number of hard copies of the UK MS Care Manual have come to light. If you joined the UKMSSNA in 2007 but have still not received a Care Manual, please let Mary Fielding know.

If you would like to receive a CD-ROM of the Care Manual, they are available from the Administrator at a cost of £5.00. Please make cheques payable to the UKMSSNA. Remember that the Care Manual is also available on the UKMSSNA website.

Care Pathways and Protocols

...and other documentation. There are quite a few Guidelines, ICPs and Protocols on the website now – Remember to check this page out – but the Working Group is still looking for any examples you may have for:

- *Bowel*
- *Fatigue*
- *Newly-diagnosed*
- *Palliative Care*
- *Pregnancy*
- *Spasticity*
- *Cognition and*
- *Pain*



If you have examples we can use, please send an electronic copy to Mary at admin@ukmsska.org.uk.

E-mail Distribution List

The e-mail distribution list is a useful way to circulate information and queries to members. Recent examples of these emails include information on Vicki Matthews' workshops, the RCP and MS Trust survey of MS services and a request for help at MS Life in Manchester plus a member's query.

Every time Mary sends out one of these e-mails she gets one or two that bounce back because the name has not been recognised. If your e-mail changes, e.g. because of a change of name on marriage or because your employer changes their domain name, please let her know so that she can update the address book.

If you are not currently receiving emails from the UKMSSNA, please consider joining the Distribution List. They are sent "blind", so your email address is not distributed to all and the risk of increasing spam is lessened.

Members' Queries

Thank you for all your responses to questions asked. But for the rest of you, this is how it works. You read an email with a question from someone and you have an answer - send your reply to Mary (click on "Reply" or start a new e-mail to admin@ukmssna.org.uk) and she will then forward your reply to the person who made the query. In due course, the query and the responses received will be added to the Members' Queries page on the website. Most queries are not time limited, so even if you read the email (or something on the webpage) some weeks or months after it has been posted and you have a response, do please reply so that Mary can add your comment to the webpage. It would be particularly helpful if you see something on the website which is out-of-date or inaccurate to let Mary know.

Membership Renewals

If your subscription isn't renewed within two months of it becoming due, your details are removed from the database, emails and access to the website is removed.

Currently 43 members have signed up to pay by Standing Order. This is a straightforward procedure which makes life a lot easier for all. You can set this up at any time of year to take effect when your subs are next due. You can download a Standing Order form from the website.

Website

Mary will be soon be re-designing the website using new software. The current website will carry on while she's doing this, but you may notice a few anomalies creeping in from time to time. Please bear with us while the website is being re-vamped.

What makes an MS Specialist Nurse?

117 MS Nurses responded to this online survey at the back end of last year. We are still awaiting the final analysis, but the results will be posted on the UKMSSNA website as soon as we have them.

Thank you to everyone who contributed.

Committee News

The Committee has said its final farewells to Heidi Thompson (NI), Diane Watts (Yorkshire) and Barbara Wingrove (North East), all of whom finish their term of office in March. Our grateful thanks to them for their commitment to the UKMSSNA and to MS nursing in general.

Their places have been taken by Iris Hume (NI), Helen Parry (Yorkshire) and Jane Metcalfe (North East).

Full Committee

North West:	Kerry Mutch (Chair)
West Midlands:	Nikki Embrey
South East:	Maureen Speed
Dorset, Hants, IOW, Surrey:	Jane Ware (Co-Vice-Chair)
Eastern England:	Sarah Olyett
Thames Valley:	Hüseyin Hüseyin (Co-Vice-Chair & Treasurer)
North East:	Jane Metcalfe
Scotland:	Alan Izat
South London:	Caroline D'Arcy
North London:	Janice MacDuff
Northern Ireland:	Iris Hume
South West:	Carol Turner
South Yorkshire:	Helen Parry



Multiple Sclerosis Trust
opening the door to information education and research

Conference 2008 Bursary

The Committee decided at their January meeting to offer a bursary to attend the MS Trust Conference next November. to a nurse with an interest in becoming an MS specialist.

The conference will be in Leeds again, from 2nd – 4th November.

If you would like to nominate someone who falls into this category and who you think would benefit from attendance at the conference, please send details to Mary Fielding, the Administrator, giving your reasons for nominating that person.



Measuring Success Awards.

Multiple Sclerosis Society The MS Society Measuring Success Awards supports services auditing themselves against the NICE MS Guideline. Eighteen sites have registered an interest in the scheme for 2008 where awards of up to £7,000 will be available to reward successful audits. The money can be used to directly improve services for people affected by MS. For more information about the scheme visit the Society's web site, go to the 'For Professionals' page and follow the links to Service Audit. If you would like information on how centres are auditing their service, please contact the Service Development Officer for your area. For contact details phone the Service Development Team on 020 8438 0742.



Royal College
of Nursing

RCN Congress 2008

Would you like to attend this year's RCN Congress in Bournemouth (27th April – 1st May) as representative of the UKMSSNA? If so, the UKMSSNA will pay your travel and accommodation costs (the Congress is free to RCN members). Contact Kerry Mutch on 0151 529 5645 or email kerry.mutch@thewaltoncentre.nhs.uk if you are interested.

UNISON also hold their AGM around this time – the same applies.

New Publications

The MS Society has produced three new guides for carers of people living with MS.

- *Caring for someone with MS: a handbook for family and friends,*
- *MS in your life – a guide for young carers*
- *MS Carers - the man's guide to caring for someone with multiple sclerosis*

There are also new editions of *Diet and nutrition* and *Working with MS*, and a new title *MS and the law*.

You can order copies at www.mssociety.org.uk/publications.

Prague 07: Living with MS: Today and Tomorrow *Kathy Franklin QN*

I was fortunate to attend this free one-day event at the Prague Congress Centre, held on 10 October 2007 by the MSIF and the Czech MS Society (CzMSS), in collaboration with the European Multiple Sclerosis Platform (EMSP).

As an MS Nurse it was a wonderful opportunity to hear (in mostly layman's terms) the developments that are currently underway in other parts of the world. Of particular interest were the sessions on Communication and Daily life, which I recommend for further perusal via the website (www.msif.org).

The event was the first of its kind to be held in the Czech Republic. Leading international MS specialists presented the current and future developments of six key topics, introduced by people with MS. Topics included how MS is diagnosed, how information is provided, options for treatment, therapy, management and daily living. It was attended by 400 people affected by MS, health professionals and MS society staff and volunteers from more than 30 countries and preceded the 23rd Congress of the European Committee for Treatment and Research of Multiple Sclerosis (ECTRIMS) and the 12th Conference of Rehabilitation in Multiple Sclerosis (RIMS) which took place 11-14 October 2007.

In addition to providing a wonderful opportunity to hear about the current and future developments in living with MS, the event celebrated the 15th anniversary of the Czech MS Society and MSIF's 40th anniversary.

I gained greatly from this opportunity; it was a chance to gain insight into aspects of daily living from the perspective of the person with MS. As I was only one of two MS specialist nurses at this event, I felt that it needed to be advertised widely as a worthwhile event when attending ECTRIMS.

Success Story in Surrey

Almost 6 years ago in Surrey, there was just one MS specialist nurse, now there are six MS specialists, four of which are funded by the MS Society. It's a unique team with two of the specialists being Practitioners (OT and Physio backgrounds), a real skills mix where nurses and practitioners work together providing a seamless county service.

Working with MS Society branches

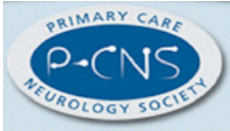
Vanessa Ruddlesden, in Wiltshire, reports that she has an excellent working relationship with two local MSS branches, to their mutual benefit. She says "without their help and support, and lobbying of the PCT and local MPs etc with stacks of supportive letters from members, I doubt that I would have achieved a permanent contract".

"I must say that I think it is beneficial to work together, as the MS Society branches provide me with accommodation for courses that we jointly run; pays my stationery costs etc; contacts me if their members need visits or advice, often before the GPs.

I was presented with a beautiful basket of flowers by one local branch at the MS Information Day that I had organised for them - we had 13 delegates from all professions and about 50 people with MS and their families attended. It was great fun, very successful, and did I blush when the flowers were produced!. Gillingham and Shaftesbury branch were kind enough to award me with a "Certificate of Appreciation" for my "Caring and Concern". I was most touched and sent it to my manager, because it is nice to be appreciated!

Goodbye Lynda

Lynda Finn, Head of Education, left the MS Society at the end of January. Many of you will know Lynda and will know the great contribution she has made to education at the MS Society, for both people affected by MS and health and social care professionals. We wish Lynda well for the future.



Primary Care Neurology - A Practical Approach

Wednesday, 30th April, Cardiff

One of the highlights of the programme is a debate on "Should placebo be used as an active treatment for neurological conditions?" involving one of the most highly respected experts on complementary medicine, Professor Edzard Ernst, speaking against the use of placebo.

Professor Ernst has received training in acupuncture, autogenic training, herbalism, massage therapy and spinal manipulation. In 1993 he established the first Chair of Complementary Medicine in the UK, at the University of Exeter. Talking in favour of placebo is Dr Stephen Allen, pain consultant in Reading for 25 years, where he developed his pain clinic into a large unit embracing a multi-disciplinary approach to pain management, having significant input from both physiotherapy and psychology. This year's programme will deal with a number of practical issues including:

- Straightening out Dizziness - a general practice approach
- Commissioning Neurological Services
- Managing Anxiety and Depression in People with long term Neurological Conditions
- Yellow Flags and Non-Pharmacological Approaches to Management of Chronic Non Malignant Pain
- Management of Facial Pain - learning the essentials
- Recognition and management of an MS Relapse
- Movement disorders - deciphering the organic from the non-organic.

For full details and registration go to www.p-cns.org.uk, where you can also save 10% on the early bird registration fee by booking online. If you have any problems accessing the website then please email info@p-cns.org.uk.

Distance Learning Course for BSc Specialist Practice in Health and Social Care



Multiple Sclerosis Society

2nd May – 4th August 2008



Cost £160 (Bursaries are available from the MS Society for MS specialists)

Birmingham City University and the MS Society are running a Level 6, distance learning, web-based module in specialist practice. The module is aimed at all health and social care professionals looking to explore and develop their role within specialist practice. The training and education provided will develop your competence and confidence to positively deal with many aspects of your specialist role and will help to support you as you work within a dynamic and challenging health and social care agenda. The areas covered by the module are:

- What is specialist practice?
- Presenting to others
- Leadership and management
- Applying evidence-based practice
- Personal and professional development
- Empowering patients
- Initiating change
- Auditing practice and measuring effectiveness
- Influencing others
- The national policy context

Assessment

Two assessments, one web-based and one 2,200 word paper. The award of 12 CATs points at Level 6 will be made on successful completion of the course and assignments.

Apply to the Faculty of Health Admissions Team 0121 331 5500: health@bcu.ac.uk
For further information please contact Nicki Ward by emailing nicki.ward@bcu.ac.uk

Recommended website

www.mcpcil.org.uk is the website of the Marie Curie Palliative Care Institute and has excellent information about the Liverpool Care Pathway for the Dying Patient (LCP).

SAD and Winter Blues – treatment with light *Vicki Matthews*

[This article has been adapted from a Patient Information Leaflet on “SAD, Depression and Winter Blues”

– thanks to Vicki for permission to reproduce it here]

What is SAD?

SAD stands for “seasonal affective disorder” or winter depression, and is often referred to as winter blues in its milder form.

All animals react to the seasons with changes in behaviour and moods. Humans are no different and are likely to eat and sleep a little more during winter months with a dislike of the dark mornings and short days. For some this can be very severe with symptoms that disrupt life and cause significant problems. SAD tends to begin from the end of September through till April, and is at its worst in the darkest winter months.

Who suffers with SAD?

It is estimated that 2% of the population in Northern Europe suffer badly and 10% are coping with milder symptoms. The milder symptoms are called sub-syndromal SAD or winter blues. The distribution across the world is similar to that of MS. There is less incidence of SAD the nearer you get to the equator and it is also less common in countries where there is a good covering of snow in the wintertime. It is more common in women and can occur in children and adolescents.

Why do people get SAD?

The cause is not fully understood (like MS) but it is believed that those parts of the brain controlling daily rhythms and moods are stimulated by the amount of light entering our eyes. The body clock is kept in regulation by light and part of SAD is connected with the body clock. In the night, a substance called melatonin is produced by the pineal gland. This makes us sleepy.

The bright light of daybreak signals the gland to stop production of melatonin and allows for waking and activity. There is now evidence to link bright light to increased production of serotonin (5HT). This is a neurotransmitter.

WHAT are the problems?

The most likely problems that people with SAD experience are

- Oversleeping but never feeling refreshed and energised
- Difficulty in getting out of bed in the morning
- Needing to sleep in the afternoon
- Feeling lethargic, unable to cope, with everything seeming an enormous effort.
- Over eating and craving carbohydrates and fats.
- Mood changes, feeling depressed or miserable, guilty or anxious.
- Behavioural changes with avoidance of company, feeling irritable or indifferent towards others and loss of libido
- Physical symptoms such as joint pains, vague aches, upset stomachs, increased constipation, and lowered resistance to infection.

What can be done?

Light therapy is an effective way to manage SAD or winter blues. There are two basic types of light therapy - bright light and dawn simulation.

Bright Light using a light box is measured in ‘lux’ and between 2500 and 10,000 lux is required for between 15-45 minutes a day. The light box is placed so that the light reaches the eyes at a sensible distance. Patients can continue normal activity such as reading and watching TV, and do not need to stare directly at the light box. Alternatively, a light visor enables them to move around the house whilst receiving light therapy.

Dawn simulation copies the natural sunrise by increasing the light at normal wake-up time. This is very useful as an addition to light boxes for severe SAD, or as a stand alone for mild cases. It is

particularly useful for those who find it hard to get going in the morning.

How often/long does light therapy, have to be used?

It varies from person to person. SAD sufferers use them daily in winter, slowly reducing as the spring emerges. Use of the light box can be adjusted as the days get longer. The power of the light box will determine the length of the time it is switched on. They are best used in the morning, and sometimes a second session can be added in the afternoon. It should be avoided in the late evening as this may make sleep difficult. If getting up is very problematic then bright light first thing or a dawn simulator will be helpful. The devices are safe for children (but not babies, no data is available), pregnant women and whilst wearing glasses or contact lenses.

The Mental Capacity Act and how it will affect health care staff and professionals

The Mental Capacity Act, fully introduced 1st October 2007, is about safeguarding the interests of people who may lack mental capacity to make decisions for themselves, now or in the future. The Act creates a clear legal framework on how to act and make decisions on behalf of people who lack mental capacity to make specific decisions for themselves. The Code of Practice for the Act gives practical guidance on how the Act works on a day to day basis.

Principles of the Act:

A person must be assumed to have capacity unless it is established that they lack capacity. A person is not to be treated as unable to make a decision unless all practicable steps to help them have been taken without success. A decision made, under this Act, for or on behalf of a person who lacks capacity must be done, or made, in their best interests. Before the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

What health care staff and professionals need to know about the Mental Capacity Act:

Everyone has the right to make decisions for themselves and must be helped and supported as much as reasonably possible to do so. Health professionals should communicate information in a way that makes it relevant and understandable for patients. Mental Capacity is decision-specific so if a person cannot make one decision, for example where to live, this does not mean they lack mental capacity to make other decisions. Their wishes, feelings, values and beliefs should be taken into consideration, as well as the views of people close to them.

Anyone is protected from liability including health professionals if they have followed the Act's guidelines and acted in the person's best interests. The Act introduces a new Independent Mental Capacity Advocate (IMCA) service. The role of an IMCA is to support and represent people who lack mental capacity through potentially life changing decisions such as an accommodation move, or serious medical treatment if they have no one appropriate who can be consulted. As part of their statutory duty health care staff, especially doctors, need to know when to instruct an IMCA. To deter people from abusing, ill treating or neglecting vulnerable people, the Act introduces a new criminal offence of ill treatment or wilful neglect of a person who lacks mental capacity.

How can patients plan ahead?

The Act extends the way people can plan ahead if they have the mental capacity to do so by:

- Making a Lasting Power of Attorney (LPA) where they choose someone that they trust to make decisions should they ever lose the mental capacity to do so for themselves. There are 2 types of LPA, one for property and affairs and one for personal welfare
- Writing down or telling others about their wishes and preferences about future treatment and care, and explaining their feelings and values that led to these

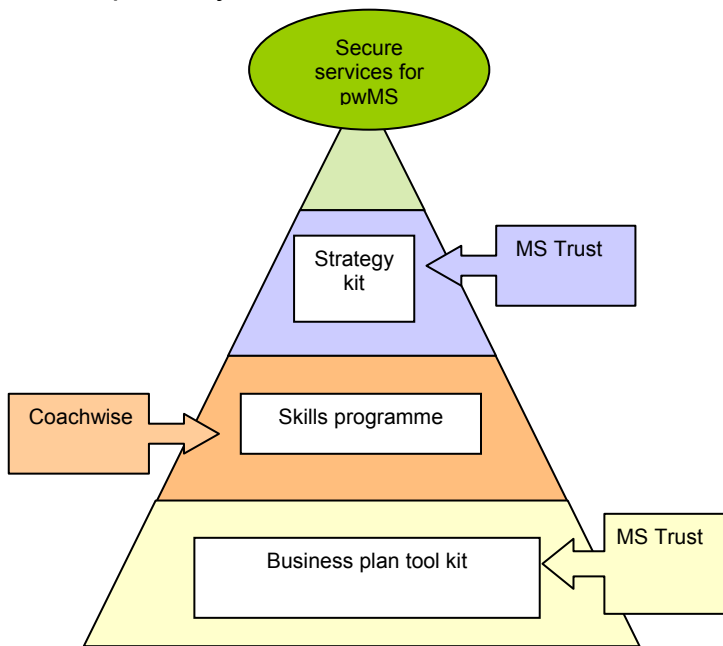
preferences. These must be taken into account when determining what is in their best interests.

For further information, individuals can call 0845 330 2900 or email customerservices@publicguardian.gsi.gov.uk or visit www.publicguardian.gov.uk

MS Trust Skills Workshops

These workshops are designed to help meet the challenges faced by specialist nurses in an increasingly competitive market.

An overview of the business planning tool kit, tips and templates on how work strategically and best use your business plan are part of the day. Local Information on who to contact about commissioning and care pathway work for MS services is also



provided to support informing and influencing key stakeholders.

Dates for the Skills Workshops are:

18th March	North East and North West
19th March	Yorkshire and Humberside
20th March	East Midlands
1st May	Central South
12th May	Northern Ireland
13th May	Scotland
9th June	North West
18th June	London South
19th June	London North
23rd June	Thames corridor
27th June	South West

Contact the MS Trust to book your place.

International MS Nursing Exam. – Re-certification of Multiple Sclerosis Certified Nurses

The Multiple Sclerosis Certified Nurse (MSCN) certification is recognised for five years. MS Nurses who took their examinations in 2003 are required to re-certify this year. Nurses who took the exam in 2002 but did not re-certify last year, will have to re-sit the exam if they wish to regain their certification.

To renew your certification status, you have the option of re-certifying by submitting Learning Activities (LA) accumulated over the five-years or retaking the Examination in November. You should receive an MSCN Recertification Application Form. automatically, but if you don't please contact Mary Fielding.

Lapsed Certification If you do not re-certify when the five-year term has ended, your MSCN certification will lapse and you will have to re-sit the exam to regain your certification.

Applications for re-certification must be submitted to the UKMSSNA by August 8th, in order for us to process them and get them to the US for their deadline of August 29th. Late applications cannot be accepted.

Any MS Nurse with at least two year's experience who wishes to sit the exam for the first time in November should contact Mary Fielding for an application form. A bursary from the IOMSN is available to members and the committee have agreed that the annual membership subscription will now include the cost of the exam.

However, as the cost is highly subsidised by the IOMSN, should a person register for the exam and not take it, they will be billed for the total cost of \$250 unless there are extenuating circumstances.

Further information about re-certification and the exam is available on the IOMSN website www.msnicb.org. or the PTCNY website www.ptcny.com or contact Nicki Ward at Birmingham City University.