Information

MS Awareness Week
27 April – 3 May 2009

Launch of a kids guide to MS

The MS Trust is looking forward to the launch of a new publication during MS Awareness Week. Aimed at 6-10 year olds, this is a booklet which children can read on their own or with an adult. It provides basic information about MS, covers some of the tricky questions that kids may find difficult to ask and addresses the feelings that children can experience when one of their parents has MS. The publication will also be available to download on the MS Trust website at: www.mstrust.org.uk/publications

Chatrooms during MS Awareness Week

The MS Trust will be running two chatrooms during MS Awareness Week. The first, on the 28 April, will focus on Cognition Issues in MS, and will enable people to discuss problems such as memory, concentration, attention span and how MS can affect mood. The second chatroom is aimed at Partners of people with MS and will run on the 30 April, this session will allow people who share their life with someone with MS to exchange their thoughts and ideas on the issues and problems that this can involve.

For more information visit: www.mstrust.org.uk/chat

Sneak preview of Mr Motivator event

On Friday 24th April, the MS Trust and Mr Motivator will be holding an event in London to let everybody know what people with MS can achieve with the right support. Details will shortly be announced on the MS Trust website so don’t forget to visit www.mstrust.org.uk

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For more information visit: www.mstrust.org.uk/chat

MS Decisions website relaunched

MS Decisions is a web-based source of independent advice for people with MS deciding whether to embark on disease modifying therapy, and if so, which of the available drugs are appropriate. As well as information about the four self-administered DMDs, the revised site also includes a new section on Natalizumab (Gyabin). Visit the MS Decisions website at: www.msdecisions.org.uk

The MS Trust’s revised publication on disease modifying drugs is also expected to launch later this Spring.

Inside this issue...

Lost to follow up

Funding

Also Inside:

Policy and campaigning
Research news
Education
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Government policy 2009 – why clinicians need to take the lead
Nicola Russell, Director of Services, MS Trust, Letchworth, UK

‘Life’s not just being alive, but being well’ Marcus Valerius Martialis AD c40 – c104

Last year was the 60th anniversary of the NHS and it was during 2008 that the initial announcements were made about an NHS constitution. Now it has been formally launched.

The constitution makes pledges to patients and to staff and is a first in the history of the NHS. Its aim is to set out in one place what everyone, staff and patients, can expect from the NHS.

The seven principles of the constitution are:
1. The NHS provides a comprehensive service available to all
2. Access to NHS services is based on clinical need, not an individual’s ability to pay
3. The NHS aspires to high standards of excellence and professionalism
4. NHS services must reflect the needs and preferences of patients, their families and carers
5. The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population
6. The NHS is committed to providing best value for taxpayers’ money and the most effective and fair use of finite resources
7. The NHS is accountable to the public, communities and patients that it serves.

The constitution also lays out six core values:
- respect and dignity;
- commitment to quality of care;
- compassion;
- improving lives;
- working together for patients;
- everyone counts.

What does the constitution mean for a health professional working in the NHS? In essence, as well as bringing together existing rights and principles, it makes some specific pledges to staff:
- to provide all staff with clear roles and responsibilities and to provide developmental support for health professionals working with people with MS. If you are having difficulties contact us and we will see if we can help. Two documents that may provide guidance are: ‘Competencies for MS specialist services’ and an ‘MS commissioning pathway’.
- to provide all staff with personal development and training, I
- to engage staff in decisions that affect them and the services they provide. All staff will be empowered to put forward ways that balance of power toward quality and the role of the clinicians. After far too long, Lord Darzi has reminded us all that it is quality that is important, not just numbers.

I know that as many of you read these words you will be thinking ‘I have heard it all before!’ I would urge you however, to recognise that health professionals have a real opportunity at this time, an opportunity that may not be repeated. For many years managers have held a financially dominated powerbase where quality has been at risk, often coming in a poor second to centrally driven targets.

Lord Darzi’s ‘High Quality Care for All’ sets out a framework that shifts that balance of power toward quality and the role of the clinicians. After far too long, Lord Darzi has reminded us all that is quality that is important, not just numbers.

Quality is also the key feature in a further DH document entitled ‘Supporting people with Long Term Conditions – Commissioning Personald Care Planning’. This document acknowledges that the NHS needs to be more empowering and less paternalistic and encourages commissioners to be aware of the quality aspects of the services they are funding. In addition this document reminds all employees that embedded in the Operating Framework for the NHS 2009/10 is the statement: ‘Over the next two years to ensure that those living with a long-term condition receive a high quality service and help to manage their condition, everyone with a long-term condition should be offered a personalised care plan’.

Commissioners will therefore have to work with providers to generate care plans for people with long-term conditions, and consider how information from care plans can be aggregated to feed into commissioning decisions, and commission appropriate services.

Patient reported outcome measures (PROMs) are one of the current buzzwords of NHS management. For all health professionals working with people with MS this should be a real boost. We know that people with MS rank good healthcare support very highly. Make sure you know how your patients value your service and that the evidence fits with the wider objectives. This will ensure access to funding.

Many of you will be personally responsible for coordinating or contributing to the personal care plan for an individual with MS. Make sure you know where gaps exist in services available to deliver the personal care plans for your caseload. These gaps should be addressed and discussed with your manager, and with commissioners.

For the last decade clinicians have played second fiddle to managers; now is the time to assert yourself as a clinician, to know your caseload needs and how your service fits with those needs, and to articulate this to the commissioners within your locality.

On the other side of the coin, for health professionals to provide quality care to people with MS they too need to be well informed and supported, and this is where the constitution can be helpful. If you feel you need further development, take your request to your manager aligning the need to the competency requirement for your post.

At the MS Trust we work to provide education and developmental support for health professionals working with people with MS. If you are having difficulties contact us and we will see if we can help. Two documents that may provide guidance are: ‘Competencies for MS specialist services’ and an ‘MS commissioning pathway’.

For further information contact nicola.russell@mstrust.org.uk or vicki.matthews@mstrust.org.uk

References
4. Multiple Sclerosis Trust, Royal College of Nursing. Specialist nursing in MS – the way forward; the key elements for developing MS specialist nurse services in the UK.
5. Multiple Sclerosis Trust, Letchworth, UK

What is a competency framework and who are they for?

The new competencies are for MS specialists across all disciplines and define three levels: competent, specialist and highly specialist. They provide a framework to describe the knowledge, skills, experience, characteristics and attitudes required to deliver effective, safe, quality care to people with MS.

For the healthcare professional they are developmental, empowering and aspirational tools to be used for professional/personal development. For commissioners they inform, together with the commissioning pathway, the complexity of the MS specialist role and patient need. For people with MS, the competencies inform on what to expect from someone working at each level ensuring realistic expectations within that working partnership. For colleagues they guide you on what to expect from someone working at each level, and encourage confidence in performance with clear guidelines on the remit of any given role.

Competencies for MS specialist services
Victoria Matthews, MS Specialist Nurse Advisor, MS Trust, Letchworth, UK

‘Competencies for MS Specialist nurses’ is a document that outlines the role of MS specialist nurses and other professionals undertaking MS specialist posts and defines their competencies within the Knowledge and Skills Framework, and the current structures of the quality based NHS.

Produced in collaboration with the UK MS Specialist Nursing Association and the Royal College of Nursing, it builds on two earlier documents. The key elements for developing MS specialist nurse services in the UK and ‘Competencies for MS Specialist nurses’.
Stem cell study shows promise in RRMS

A team of Chicago-based researchers reported on a stem cell study which involved 21 people with relapsing/remitting MS who had experienced two relapses in the previous year despite treatment with beta interferon.

In preparation for stem cell transplantation all study participants undertook a conditioning course of immune suppressing drugs (cyclophosphamide and either alemtuzumab or rabbit antithymocyte globulin).

The participants were followed for an average of three years. All 21 showed no further worsening of disability as measured by the EDSS scale, and 17 improved by at least one point. 16 people experienced no further relapses following the stem cell treatment.

The researchers recognise that larger randomised trials are needed to confirm these results and pointed to a second, larger multicentre trial with study centres in North and South America.

Oral formulations show promise in phase III studies

Fingolimod

A one-year phase III study of the investigational oral drug FY270 (fingolimod) showed a significant reduction in annualised relapse rate compared with treatment with an injectable interferon beta-1a.

The study had three treatment arms whereby 1,292 study participants were randomized to receive either oral fingolimod 0.5 mg once daily, oral fingolimod 1.25 mg once daily, or the active comparator interferon beta-1a given once weekly by intra-muscular injection.

At one year, participants given fingolimod 0.5 mg saw a 52% reduction in annualised relapse rate compared with those on interferon beta-1a. The fingolimod 1.25 mg dose group saw a 38% reduction in annualised relapse rate compared with the interferon beta-1a group.

The drug manufacturer says regulatory submissions remain on track to be completed in the US and EU at the end of 2009.

Cladribine

Results of a two year phase III study comparing cladribine against placebo indicated that cladribine significantly reduces relapse rates in people with relapsing/remitting MS. Based on these positive results, the manufacturers, Merck Serono, hope to submit the drug for licensing later this year.

A primary finding of this study was that, although participants felt sexual health should be included, it was not routinely part of practice. The study highlighted several barriers to health professionals’ communication about sexual issues, including:

1. Lack of clarity about professional roles: whether aspects of sexuality should be included, it was not routinely part of practice. The study highlighted several barriers to health professionals’ communication about sexual issues, including:

2. Concern to respect service users’ privacy, and anxiety about sexuality should be part of their role or whether others in the team addressed it.

3. Concerns to the service user of, their sexuality being unheard or ignored (the unsought enquiry), or being given the opportunity to talk about their concerns, and addresses the issue of unsought enquirers, asexual attitudes and lack of awareness.

The Recognition Model

The Recognition Model has five stages and is aimed at health and social care teams working with people with disabilities, including people with MS. The purpose of the model is to highlight how the team can protect, support and restore the sexual health of service users whilst allowing each practitioner to work within their own personal and professional boundaries.

At its core is the recognition of the person with MS as a whole, with sexual needs like all others. It draws on existing skills within the team and depends on every team member (regardless of role) positively responding to direct or indirect questions, as well as affirming the relevance and priority service users may attach to sexual expression.

This model supports a team approach. It acknowledges that not every individual in the team may be willing or able to work at all stages. It allows open discussion to plan around the strengths and skills of team members to ensure sexual health is protected and supported consistently for all service users.

References

New study links lack of vitamin D with increased risk of MS

A study published in the online journal PLoS Genetics has provided further evidence of a link between a lack of vitamin D and increased susceptibility to MS.

Researchers at the University of Oxford and the University of British Columbia have demonstrated how vitamin D interacts with a gene variant known as DRB1*1501 – one of the main genes implicated in genetic susceptibility to MS. Presence of the gene is believed to increase the risk of developing MS three-fold.

The study authors claim these results support the use of vitamin D supplementation during pregnancy and in young children.

Relevant research findings

A primary finding of this study was that, although participants felt sexual health should be included, it was not routinely part of practice. The study highlighted several barriers to health professionals’ communication about sexual issues, including:

1. Lack of clarity about professional roles: whether aspects of sexuality should be part of their role or whether others in the team addressed it.

2. Concern to respect service users’ privacy, and anxiety about sexuality being unheard or ignored (the unsought enquiry).

3. Examples of service users wanting information but their enquiries being unheard or ignored (the unsought enquiry).

4. A minority of practitioners holding asexuallising attitudes and holding to the belief that older people or those with severe incapacity would not have sexual desires.

5. Lack of awareness about the potential importance of sexual concerns to the service user.

6. Practitioners feeling vulnerable and unsupported in addressing sexual concerns by the team, their health Trust, or the professional body they belonged to.

Based on these findings a new sexual health model is proposed to enable teams to overcome obstacles associated with sexual expression amongst people with disabilities. The model clarifies professional roles, indicates how people with MS might be sensitively encouraged to talk about their concerns, and addresses the issue of unsought enquirers, asexual attitudes and lack of awareness.

Lorna Couldrick, Senior Lecturer, School of Health Professions, University of Brighton, UK
Stage 1. Recognition of the service user as a sexual being

The cornerstone of the model is recognising people with MS as fully human, with sexual needs like all others. This includes single people and those living alone, as well as people living with or away from partners. While a person may choose to express their sexuality through celibacy, it can never be assumed that an individual, however incapacitated, is asexual.

With this recognition, a positive approach to sexual health is possible. It requires skills of validation, normalisation and affirmation, acknowledging the importance the service user may attach to sexual expression. It also includes broader concerns such as appearance, social opportunity, and privacy. All disability professionals, regardless of role, should respond positively to questions raised by the service user. The following is an example of how positive recognition might be achieved:

“This is an important question (validation). It is a concern several of my patients have raised in the past (normalisation). However I don’t think I am the best person on the team to talk to (acknowledging limitations). The nurse in our team has much greater expertise than I do. Can I ask the nurse to contact you?”

This approach affirms the individual’s sexual identity without taking the practitioner outside of their professional boundary. Acceptance of the enquiry through the processes of validation, normalisation and affirmation, opens the door for further communication about the issue with other health professionals who may be better placed to explore the different levels of the enquiry. Recognition of the individual’s sexual identity and acceptance of their enquiry is the crucial first step towards supporting and assisting the restoration of the individual’s sexual health.

Stage 2. Provision of sensitive, permission giving strategies

This requires skills to invite disclosure whilst respecting an individual’s right to privacy. Because sexuality is a private affair, it is not always possible to know who has concerns. Therefore, all individuals should be given the opportunity to discuss establishing and maintaining wanted sexual relationships. Clear and direct permission is necessary but need not mean the use of intrusive questions. Techniques include indirect questions or statements. For example, as part of an initial screening assessment the following might be used:

“If you do have any questions you wish to explore about your personal relationships or sexual expression, do let your key worker know. We have quite a lot of resources within the team and if we can’t help we probably know someone who can.”

Key worker, nursing and occupational therapy assessments all provide timely opportunities to raise the subject. Where the practitioner feels confident to move to the next stage of exploration the following could be said:

“I find some people also want to talk with me about their relationships or have questions about sex. I am happy to discuss these if you do have any concerns.”

Where there are communication difficulties, it may be necessary for the speech and language therapist to raise the subject. Dialogue is not the only option, permission can also be provided through printed service leaflets or posters in clinical areas. Where a team member, for any reason, is unable to provide permission, arrangements need to be made within the team to ensure every service user is given the opportunity to disclose sexual concerns if they wish to.

Stage 3. Exploration of the concern

This requires obtaining sufficient information to understand the impact of the disability on intimate relationships and sexual health. Sexuality has many facets, without exploration it is not possible to take appropriate action. The issues to be explored may be much broader than those related purely to the human sexual response cycle. It may be about social opportunity, self-identity, or moving a relationship towards intimacy; for example, how hoist use or a stoma can be managed during a sexual encounter. It could also be about role changes between sexual partners, or grief when one has to move into a separate bed. It may concern the management of fatigue, spasticity or pain. This stage of exploration could be managed by specific team members if not every one in the team feels able to do this.

Stage 4. Address issues that fit within the teams’ expertise and boundaries

This requires analysing sexual problems, devising specific, targeted goals that are within the team’s professional competencies. Physiotherapists might address biomechanical issues that cause discomfort during intercourse. The occupational therapist might help a couple to prioritise sexual activity as part of fatigue management, or provide information on simple electronic equipment such as a vibrator. The speech and language therapist might assist the aphasic patient to communicate sexual concerns with their partner. The psychologist may address emotional adjustment, including issues relating to body image and self-perception. A goal might be to provide condition specific sexual information such as the MS Trust publication, ‘Sexuality and MS: A Guide for Women’. Goal setting should include access to any assistance available to the general population such as social opportunity, privacy, erotica and the use of sex workers.

Stage 5. Referring on when necessary

There will always be issues that fall outside the team’s competence, and referral on, or provision of information about other services is necessary. This requires knowledge of resources available in the locality. Often quite simple issues may trigger referral, for example, referral back to the GP for a medical review or to the family planning clinic for contraceptive advice.

Where there are relationship issues and members of a couple are open to such interventions, it may be appropriate to refer people to organisations such as Relate, a UK-based provider of relationship counselling and sex therapy.

The NICE guidelines for the management of multiple sclerosis in primary and secondary care state:

“Every person (or couple) with persisting sexual dysfunction should be offered the opportunity to see a specialist (with particular expertise in sexual problems associated with neurological disease) and offered, as appropriate, advice on lubricants and the use of sexual aids, and other advice to ameliorate their sexual dysfunction”.

Advocacy may be necessary where resources are unavailable or inaccessible. It may include offering disability expertise to generic services.

Conclusion

Sexual health is integral to positive concepts of self and quality of life. One couple, living with MS, described what sexuality meant for them by saying:

“It is not just erectile dysfunction. It is life giving and life affirming. In our relationship, it has been about having children but much more besides. For us it has meant affirmation, reconciliation, celebration and healing”.

Sexual expression carries a lot of meaning for people whether they are living with a disability or not. Sexual health should therefore be included within holistic health and social care for people living with MS. The Recognition Model of sexual health is a more practical approach to achieving what is set out in the national guidelines. It highlights how existing skills can be used to protect, support or restore the sexual health of people living with MS. The model clarifies the responsibilities of individual practitioners as well as the combined professional practice of the team. It is hoped that the model will be used to move teams of health professionals forward in this complex area of practice.

References

4. Golding J, Golding E. Personal observations on sexuality of people with MS. European MS Platform (conference proceedings, Oslo: European Multiple Sclerosis Platform; 2001

www.mstrust.org.uk
Call: 01462 476 700
Lost to follow up: What are the implications?

Dr Yogendrah Jagatsinh, Specialist Registrar Rehabilitation Medicine, Walkergate Park Centre for Neurorehabilitation, Newcastle-upon-Tyne, UK

The NICE MS guidelines state that specialist neurological and neurological rehabilitation services should be available to every person with MS, when they need them. These needs may arise because of new symptoms, disease progression, loss of function, or when an individual’s circumstances change. Yet for a significant proportion of the MS population, such services are geographically inaccessible. Here, Dr Jagatsinh discusses the problems posed by geographically isolated areas across the UK, and how the problem can be overcome through the development of local outreach services such as one that was established in North Northumberland in 2007.

Introduction

MS is a very variable and individual condition. A person may see changes in the way they are affected by their MS as a result of a relapse, progression of the condition, the presentation of new symptoms or secondary complications. If there is no regular review in place, such problems often go untreated and unmanaged.

This was the case for a significant number of people with MS living in Northumberland, who were situated approximately 70 miles away from their nearest specialist MS centres based in either Edinburgh or Newcastle. It emerged that the distance between Northumberland and the nearest specialist MS centre proved a significant barrier for people with MS who were consequently ‘lost to follow up’. Worryingly, people with MS living in this area had often had no contact with neurological services since initial diagnosis and a period of preliminary interventions.

Benefits of an outreach service

To address this problem, an outreach service was developed in Berwick-upon-Tweed, Northumberland. The service offers access to an MS specialist nurse and a neuro-physiotherapist as well as a range of complementary therapies such as reiki, Indian head massage, hot stone massage and reflexology. People with MS, and their families and carers, were invited to attend the service which is available twice a month after normal working hours, from 5pm until 8pm. In addition to the professional advice, support, and complementary therapies that are available, the outreach service also provides a social opportunity for individuals to chat informally amongst themselves. Occasionally, guest speakers give talks on topics relating to the management of MS.

Since the service was introduced in 2007, it has welcomed 39 service users from both sides of the border. 29 patients had problems requiring treatment and/or referral. As a result of informal consultations/discussions at the outreach centre, a number of referrals have been made. Amongst the problems people presented with were: bladder dysfunction, trigeminal neuralgia, musculoskeletal pain and stiffness, mobility and posture, social and sexual health issues.

Tellingly, many of the patients attending the outreach service had no regular follow-up and had simply ‘got on with things’, not realising that help might exist for symptoms. Feedback from both people with MS and carers using the service suggests that they value the opportunity to discuss problems and issues that would otherwise have gone unacknowledged and potentially untreated.

Encouragingly, funding for the outreach service has been secured for a further three years from the MS Research and Relief Fund and the local branch of MS Scotland. The venue is provided by Northumbria Foundation NHS Trust, and a local organisation supported the purchase of physiotherapy equipment. Voluntary sector partnership has been crucial to this innovative service development which is now recognised amongst the local MS population as a locally based, high quality, multidisciplinary clinic.

Furthermore, the principles outlined in the recent Lord Darzi review support the creation of such services. The NHS Next Stage Review states:

‘People want a greater degree of control and influence over their health and healthcare. If anything, this is even more important for those who for a variety of reasons find it harder to seek out services or make themselves heard. Personalising services means making services fit for everyone’s needs. When they need it, all patients want care that is personal to them.’

A distance of 70 miles may indeed make it difficult for people with MS to seek out services for themselves and to access a personalised care plan. If people with MS are unaware of available services they may not seek help and may continue to struggle with problems that can be treated. If, as the Darzi report suggests, everyone with a long term condition is to have a personalised care plan, follow-up needs to be accessible and available locally. Where outreach services cannot provide the necessary specialist care or treatment, they can at least ‘sign-post’ these patients to an appropriate specialist.

North Northumberland is not unique in its geographical detachment from specialist MS centres. Indeed, two similarly geographically isolated areas where this model could be applied with great effect are West Northumberland and the western Scottish Borders. Plans are currently underway to develop a similar service in Hexham, West Northumberland, which is expected to open in Spring 2009.

Service users of the outreach clinic set up in Berwick-upon-Tweed have highlighted the importance of regular contact with healthcare professionals. Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate. The informal, patient-led approach provided by an outreach service gives people with MS the opportunity to link back into a review system according to their individual needs.

This particular case highlights the need for co-ordinated service planning to ensure that suitable services are available to people with MS within a reasonable travelling distance. Where this is not possible the establishment of satellite services or peripatetic teams ought to be considered.

References

**Fundraising**

MS Awareness Week: 27 April – 3 May 2009

**The £50 Fundraising Challenge**

What can you do to raise £50 for the MS Trust?

As part of this year’s awareness raising activities, we are asking all our supporters to help by raising £50 for the MS Trust. If enough of you get involved, it will really add up and make a big difference.

The more people out there making fundraising efforts on behalf of the MS Trust, the more awareness we will raise and the more money we will generate to spend on services for people with MS.

- A single £50 donation could keep 12 health professionals up to date with the latest in MS management for a year, via ‘Way Ahead’.
- If 1 in 10 of our supporters raised £50 we could support twice as many research projects.
- If 1 in 3 of our supporters raised £50 it could cover the cost of running our information service and website for a year.

**Fundraising ideas...**

Please get your thinking caps on and decide what you’re going to do to raise your £50 - get your colleagues involved too! Here are some ideas to get you started...

- Collection box on reception
- Coffee morning
- Sponsored silence, weight loss, head shave, leg wax etc.
- Sell MS Trust lapel pins
- Bag packing at local supermarket
- Swear box
- Donate the contents of your small change jar – start saving now!
- Car boot sale
- Sale of homemade cakes, biscuits, handmade cards etc.
- Charity car wash
- Dinner party – ask us for a ‘My Supper for MS’ pack
- Sell unwanted items on eBay

For a fundraising pack contact our fundraising team at fundraising@mstrust.org.uk

More information at www.mstrust.org.uk/fifty

**Running events in 2009...**

**Great Manchester Run**, 17 May 2009 - do you have your own place? If so, please get in touch as we’d love to have you on our team.

**British 10K London Run**, 12 July 2009 - £15 registration fee plus £99 in sponsorship (or £500 for a team of six).

**Great North Run** (half marathon), 20 September 2009 - £42 registration fee plus £250 in sponsorship.

Call us to register or visit www.mstrust.org.uk/run

**Are you brave enough to ‘Jump in June’?!**

MS therapists Christine Singleton and Geraldine Mann raised over £5,000 for the MS Trust through sponsored parachute jumps in 2005. We also saw four MS Nurses: Jane Wars, Rhona MacLean, Annette Leach and Sylvia Hurst, raise £3,500 by skydiving in 2003 and MS Nurse Kerry Mutch raised over £600 in 2004.

We want to see more health professionals taking to the skies in 2009!

Call for an information pack or book online at: www.mstrust.org.uk/jump

**Photography competition**

Following the success of our Art of Movement competition in 2007, we will be launching a new photography competition in MS Awareness Week. The competition will be open to anyone affected by MS and full details will be announced on 27 April on the MS Trust website.

We will be distributing posters to clinics and centres to advertise the competition to as many people as possible. If you are able to display a poster, please contact Michelle Constable on 01462 476707.

**Join Jo on Just Walk!**

Jo Sopala, our Fundraising and Marketing Director, will be taking part in Just Walk – a sponsored walk across the South Downs - on Saturday 9 May 2009. We hope you will join her!

The walk starts from Goodwood Racecourse near Chichester, in an area of outstanding scenery. For more information visit: www.mstrust.org.uk/justwalk

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**MS Trust Annual Conference – Save the date!**

The MS Trust Annual Conference 2009 will be held at Chesford Grange, Kenilworth, Warwickshire. The conference will run from 8 - 10 November.

We are delighted to announce that the following speakers have already agreed to participate:

- **Professor Alan Thompson**, Garfield Weston Professor of Neurology and Neuroprehabilitation, Institute of Neurology, UCL
- **Primary Progressive MS and its management** will be the focus of Professor Thompson’s presentation.

- **Baroness Susan Greenfield**, Professor of Pharmacology, Lincoln College, Oxford University and Director of the Royal Institution
- **Understanding the cognitive challenges in MS** and *Baroness Greenfield’s research concentrates on understanding brain functions and disorders as well as the physical basis of consciousness.*

- **Associate Professor Judy Wollin**, Griffith University, Queensland, Australia
- **This session will offer an insight into the research and practical issues surrounding quality of life that affect people with MS and their families.**

- **Dr Dawn Langdon**, Reader in Neuropsychology, Royal Holloway, University of London
- **The practical management of cognitive deficits for people with MS and the launch of SatiyngSmart, a web-based resource about cognition.**

- **Professor Mark Freedman**, Chair of Medicine, Ottawa Hospital, Canada
- **MS – where are we now and what does the future hold?** Professor Freedman who specialises in investigating immune mechanisms of MS, will look at the future for MS care and innovation.

- **Dr Diane Playford**, Senior Lecturer in Neuroprehabilitation, Institute of Neurology, UCL
- **How to keep people with MS in work** will be the focus of this session.

**Study Days**

Study days are open to all health and social care professionals with an interest in MS. These courses will provide a broad overview of MS with a more in-depth understanding of certain aspects of the disease and related symptom management.

The next general study day will take place on Thursday 2nd April at Barceló Cardiff Angel Hotel in Cardiff. The programme for this study day includes the following sessions:

- **An overview of MS**
- **Dr Mark Cosburn, Cardiff Research Fellow, Cardiff**
- **Fatigue management for people with MS**
- **Paula Cornelius, Clinical Specialist OT in MS, Cardiff**
- **Understanding the cognitive challenges in MS**
- **Anita Rose, Consultant Clinical Neuropsychologist, Liverpool**
- **Understanding and managing spasticity**
- **Dr Alan Halligan, Consultant Clinical Physiotherapist in MS, Cardiff**
- **The role of the MS nurse within the MDT**
- **Jacki Sme, Clinical Nurse Specialist, Cardiff**
- **Contingence issues in MS**
- **Anne Guishard, MS Contingence Nurse, Cardiff**

**Education events in 2009**

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<td>5-9 October</td>
<td>Hitchin Priory, Herts</td>
<td>Development Module in clinical MS: Specialist Level – targeted at new-in-post MS Specialists</td>
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<tr>
<td>8-10 November</td>
<td>Chesterford Grange, Kenilworth</td>
<td>General Study Day</td>
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<tr>
<td>December</td>
<td>General Study Day</td>
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Further details with regard to our education events will follow in the next issue of Way Ahead.

Visit the health professional pages on our website, where you can find the latest update about our education courses: www.mstrust.org.uk/professionals

To register your interest or if you require any further information regarding the above events please contact the Education Team at the MS Trust on 01462 476704 or by email, education@mstrust.org.uk.