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Multiple Sclerosis Trust

MS

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Concerns about draft MS Clinical Guideline

In April 2014, NICE (National Institute for Health and Care Excellence) put out its draft Clinical Guideline on The management of multiple sclerosis in primary and secondary care. It covers diagnosis, information and support, treatment of relapses, management of MS-related symptoms and service provision in England and Wales. Developing the draft has taken three years, with a Guideline Development Group at its heart which includes people with MS and MS health professionals.

The MS Trust is deeply concerned about some of the recommendations made, omissions from the Guideline and how usable the document will be. We are also concerned it may give those who commission services the impression they can reduce service levels.

The MS Trust considers that, as it stands, the Guideline will set back the availability and quality of care for people with MS and are encouraging NICE to halt the guideline development process and re-engage with stakeholders to improve its content and usefulness.

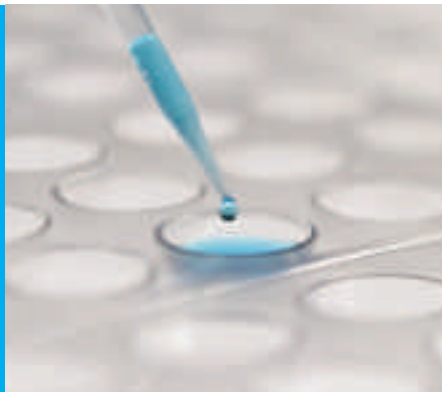
In summary our main concerns are:

- many therapies have been undervalued or omitted because NICE does not rate the standard of evidence available for them, for example, therapies for ataxia and tremor where it is impractical to give a placebo for comparison
- the absence of neuro-rehabilitiation from the Guideline is inappropriate and sends the wrong message to managers and commissioners of services
- two licensed symptomatic treatments, Sativex (nabiximols), and Fampyra (fampridine), were not recommended. We believe these treatments offer different options for people with MS and should be available to those who might benefit
- there is no discussion of how services should be organised and what 'excellence' should look like. No recognition of the importance of specialist health professionals, apart from neurologists; the model of care remains very hospital-based and neglects community-based services
- the Guideline scope omitted symptoms and treatments covered by other NICE guidance, including disease modifying therapies, and bladder and bowel management. As it stands, non-specialists or managers arranging services will need to cross-reference many NICE documents to build a comprehensive picture of how to manage MS. Our concern is they won't have time to do this, resulting in a risk of poorer overall care.

We also have reservations about NICE's process for developing Clinical Guidelines, which offers fewer opportunities for wider stakeholder engagement than its process for appraising new treatments. Too much of the process happens without external scrutiny and validation of decisions by interested and expert stakeholders. As a consequence, this draft guideline fails to meet the needs of the MS community in its scope and its recommendations.

Inside this issue...

Research news: availability of new disease modifying therapies



Dimethyl fumarate (BG-12, Tecfidera)

The Scottish Medicines Consortium (SMC) has approved dimethyl fumarate as a treatment for adults with relapsing remitting MS on the NHS in Scotland. This SMC advice takes account of the benefits of a Patient Access Scheme (PAS) that improves the cost-effectiveness of dimethyl fumarate. This SMC advice is contingent upon the continuing availability of the Patient Access Scheme in NHS Scotland or a list price that is equivalent or lower.

The NICE (National Institute for Health and Care Excellence) appraisal committee met on the 21 May, an announcement on the final guidance for dimethyl fumarate on the NHS in England and Wales is expected in late June/ early July 2014.

Dimethyl fumarate is taken twice a day, as a tablet. In clinical trials, dimethyl fumarate reduced the number of relapses by about one half compared to placebo. This compares with beta interferons and glatiramer acetate which reduce the number of relapses by about one third compared to placebo.

The most common side effects have been:

- flushing and feeling hot
- gastrointestinal upset - diarrhoea, nausea, abdominal pain
- headache.

Alemtuzumab (Lemtrada)

NICE has issued final guidance for the prescribing of alemtuzumab by the NHS in England and Wales. Alemtuzumab is approved as a treatment for adults with active relapsing remitting MS (normally defined as two clinically significant relapses in the previous two years).

NICE recommendations are normally enforceable three months from the date of publication, so neurologists should be able to prescribe alemtuzumab from late August.

This final draft guidance reverses the decision to not recommend alemtuzumab made in the previous draft consultation document issued in December.

Alemtuzumab treatment consists of an intravenous infusion on five consecutive days, followed 12 months later by intravenous infusions on three consecutive days. In clinical trials, people taking alemtuzumab had about half as many relapses as people taking beta interferon 1a (Rebif).

Two serious side effects have occurred:

- overactive or underactive thyroid gland leading to thyroid disorders, affecting approximately 1 in 5 people
- idiopathic thrombocytopenic purpura (ITP), a disorder that prevents blood from clotting, affecting 1 in 100 people.

Monthly blood and urine tests are needed to monitor for these side effects for 48 months after the last infusion.

The Scottish Medicines Consortium is due to publish a decision on the use of alemtuzumab by the NHS in Scotland in July.

Pegylated interferon beta 1a (Plegridy)

The Committee for Medicinal Products for Human Use (CHMP) which advises the European Medicines Agency (EMA) has recommended that pegylated interferon beta 1a should be granted a licence for treating relapsing remitting MS, the final decision on a licence will be issued before the end of August.

Pegylated interferon beta 1a is a new drug, formed by adding polyethylene glycol to interferon beta 1a (Avonex) to increase the half-life of the drug in the body. As a result, pegylated interferon beta 1a is injected less frequently than the other beta interferons – once every two weeks rather than, in the case of Avonex, once every week.

The ADVANCE clinical trial compared pegylated interferon beta 1a taken by injection into the muscle either once every two weeks or once every four weeks. Preliminary results from the first year of treatment found that relapse rates, compared to placebo, were reduced by 36% in the two week dosing group, and 28% in the four week group. Side effects were similar to interferon beta 1a – redness at injection sites and flu-like symptoms.

Laquinimod (Nerventra)

Earlier this year the CHMP turned down the licence for laquinimod in relapsing remitting MS. The manufacturers appealed against this decision. At a meeting at the end of May, the CHMP re-examined the decision and concluded that, based on current clinical trial data, the risk/benefit profile for laquinimod is not favourable and maintained its recommendation that the medicine be refused a licence.

Laquinimod is taken as a tablet, once a day. In clinical trials, people taking laquinimod had about 25% fewer relapses than those taking placebo. It has also been shown to reduce disability progression and brain volume loss.

A clinical trial in relapsing remitting MS (CONCERTO) is currently underway comparing the effect of two doses of laquinimod or placebo on disability progression measured by EDSS. The study is expected to complete in 2018. The manufacturer is also planning clinical trials to investigate the potential for laquinimod in progressive forms of MS.

Keep up to date with research news
Sign up for our weekly research update alert at
www.mstrust.org.uk/research-updates

MS Trust retains The Information Standard

The Information Standard is a certification scheme for health and social care information established by the Department of Health to help patients and the public make informed choices about their lifestyle, their condition and their options for treatment and care.

To achieve The Information Standard organisations need to demonstrate how information fits into the aims of the organisation, how evidence for a particular publication is identified and assessed and how the target audience and expert reviewers are included in the process. To achieve The Standard, organisations have to show that their processes and systems produce information that is:

- accurate
- impartial
- balanced
- evidence-based
- accessible
- well-written.

Health & care information you can trust

The Information Standard Certified Member

The scheme requires that the certified organisation is audited every three years to demonstrate that it still meets the requirements of The Standard. The MS Trust is pleased to announce that following an assessment in March, we have retained our certification as a producer of reliable health and social care information by the Information Standard.

Highlights from the RIMS 2014 Conference

RIMS

In early June, the MS Trust co-hosted the 2014 RIMS (Rehabilitation in MS) Conference alongside University College London Hospitals Foundation Trust. This is the first time RIMS has been held in the UK and the theme of the conference was "**Supporting behaviour change, linking science to clinical practice**." The conference gave the 326 delegates from Europe and beyond the opportunity to learn, share best practice, network, and hear key clinical and opinion leaders in the field of MS. As well as hailing from 26 different countries, the delegates represented a wide variety of professions including MS nurses, physiotherapists, occupational therapists, GPs, psychologists, social workers and speech and language therapists.

Factors influencing behaviour change

The conference opened with Jared Bruce, University of Missouri, USA. He discussed the poor adherence rates to MS treatment, with 40-50% of patients failing to adhere after two years. He looked at some of the cognitive, emotional, lifestyle and medical issues that can contribute to this including anxiety and depression, and then went on to explore avenues for improving adherence to both medical and behavioural rehabilitation interventions.

The patient perspective:
what is behavioural change about and how does it manifest in 'real life'?

In a first for RIMS, two people with MS were invited to give their perspective on the reality of being given a diagnosis of MS, the challenges it brings to everyday life, and how they negotiate the upsets to restore and empower their lives. This session was extremely well received by the audience.

Shana Pezaro, Trustee, the Federation Centre for Independent Living, discussed how different forms of exercise including squats and half-marathons have helped her manage her current health, she described how it had both helped her lose weight and transformed her confidence to the extent that she started dating again. Emma Rogan, Project Coordinator, European MS Platform chose to speak about how taking care of your mental wellbeing was equally important to help you build resilience for the years ahead.

RIMS Honorary Lecture

The final lecture was provided by Professor Alan Thompson, Dean, UCL Faculty of Brain Sciences, University College London, who described the formation of the Progressive MS Alliance to address the needs of people with progressive MS, who constitute over 50% of the MS population.

Management of progressive MS currently focuses on rehabilitation and symptom management as there is no effective treatment to slow or stop progression. However, there is a decided lack of studies focusing on this field, therefore the Progressive MS Alliance hopes to encourage innovative studies that will address both cognitive and motor dysfunction.

Although the ultimate goal is to find treatments that will delay and prevent progression, Professor Thompson strongly believes that good quality rehabilitation and symptom management trials are needed to improve the quality of life for those with progressive MS, and therefore they too need to be a key focus for research over the next decade.

Other plenary sessions

Rona Moss-Morris, King's College, London, discussed a cognitive behavioural therapy (CBT) programme designed to assist people with MS adjust to their diagnosis, and a mindfulness programme developed for people with progressive MS.

Klaus Pfeifer, University of Erlangen-Nurnberg, Germany, described the development of a 'Behavioural Exercise Therapy' programme to promote physical activity in people with neurological conditions.

Paul van Asch, National MS Center, Belgium, presented a review of the many international sports events that have been organised by Move to Sport. This is an organisation that aims to change people's ideas about sport and MS by providing education sessions for health professionals, sport and fitness coaches to enable people with MS to participate in sporting activities in their own environment.

Seminar sessions

Delegates had the opportunity to attend three seminar sessions throughout the conference. There were 14 sessions to choose from, topics included:

- group and individual programmes for fatigue management
- mindfulness to support behaviour change
- effects of cognitive difficulties on everyday life
- maintaining mobility – functional electrical stimulation, fampridine and intrathecal baclofen.

Posters

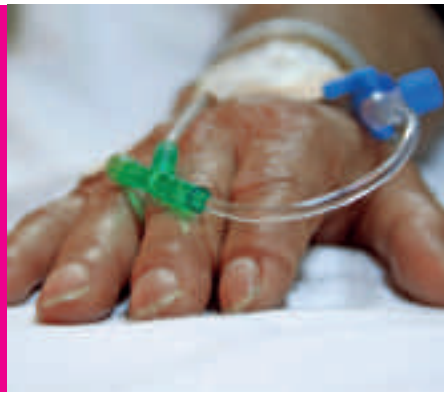
Nearly 100 posters were displayed at conference on a wide variety of topics. Platform presentations included health management, the economic burden of MS, bladder and bowel function and exercise treatment. All other researchers who had posters accepted were given one minute to sum up their research findings in the 'speed poster presentation' slots, which proved to be both lively and informative sessions.

Prizes

The prize for the best oral presentation went to Jon Marsden, UK for his talk on the 'Effect of localized lower limb warming and cooling on neuromuscular impairments and functional ability.'

The prize for the best poster presentation went to Paul Taylor, UK for his poster 'A comparison of external and implanted FES for correction of dropped foot in MS.'

Setting up an alemtuzumab (Lemtrada) service: the Cardiff experience



Gail Clayton, Lead MS Clinical Nurse Specialist, Jacki Smee, MS Clinical Nurse Specialist; University Hospital of Wales, Cardiff

Introduction

Alemtuzumab is an anti-CD52 humanised monoclonal antibody treatment for relapsing remitting multiple sclerosis (MS) that works by depletion, and subsequent repopulation, of circulating T lymphocytes and B lymphocytes[1]. It demonstrated significant efficacy as a treatment for relapsing remitting MS in open label, phase II and the phase III CARE-MS I trial, and demonstrated superiority over interferon beta 1a in the phase III CARE-MS II trial[2]. Administered over the course of two years, the treatment requires infusions over five consecutive days in the first year, followed by three consecutive days a year later.

The advent of new therapeutic agents such as alemtuzumab can pose a challenge to professionals as they struggle to balance treatment benefits and minimise adverse events[3]. The potential for secondary autoimmunity, particularly thyroid disease - idiopathic thrombocytopenic purpura (ITP) and Goodpasture's syndrome - following treatment with alemtuzumab necessitates the need for a robust post treatment monitoring programme for 48 months after the last dose. Since 2002, the MS team in Cardiff has treated 90 patients with alemtuzumab. Now approved by the National Institute for Health and Care Excellence (NICE) as an NHS treatment in England and Wales we are keen to share our experiences of setting up and managing an alemtuzumab service.

This article aims to:

- provide information on setting up the service
- explore patient selection and pre-treatment counselling
- discuss infusion-related, and long-term, side effects
- outline monitoring requirements
- identify potential challenges.

Setting up the service

It is widely recognised that MS nurses are well placed and motivated to develop new services and manage whole episodes of patient care[4]. Indeed at the time of planning the service, taking the lead on developing disease specific services within agreed protocols formed part the Chief Nursing Officer's key roles for nurses.

It is acknowledged that the key to the safe and effective administration of intravenous (IV) agents for MS is the establishment of specialist neurological infusion units[3]. However, at the time there was no such facility available in Cardiff. This led to the *ad hoc* delivery of treatment by the MS nurses working long hours on the neurology ward. It soon became evident that a protocol for managing alemtuzumab treatment was needed.

Developing the protocol

In order to develop a protocol to safely deliver the service, the MS nurses undertook specific training. This included chemotherapy training, liaising with the research nurse at Adenbrooke's Hospital, Cambridge, and education on the interpretation of blood results for associated adverse reactions. Training in the use of infusion equipment was completed, and competence in its use was assessed as the MS nurses had not worked on the ward for many years. Following this a nursing care plan and information for ward-based doctors was developed.

The team worked closely with other departments, including pharmacy, to develop the protocol. Capacity to follow-up patients post-treatment was limited, but the appointment of a research fellow with an interest in the treatment saw the development of a monthly clinic. This evolved to become nurse-led.

Figure 1. (right)
Alemtuzumab protocol

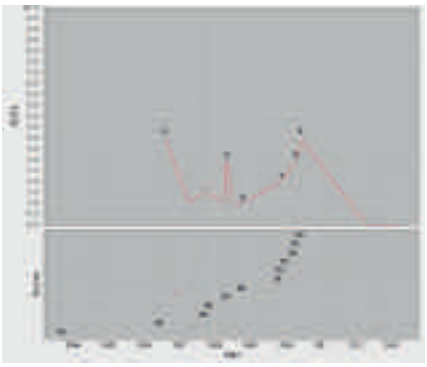
Patient selection

The MS team in Cardiff adopt a multidisciplinary approach to patient selection for all disease modifying treatments (DMTs) and have developed an assessment form which highlights the key selection criteria including:

- disease onset
- clinical relapses
- magnetic resonance imaging (MRI)
- cognition
- family plans
- benefits and risks
- exclusions.

Patients are often identified through the rapid access relapse clinic and by the accurate documentation of clinical relapses on a dedicated database (see Figures 2 and 3).

Figures 2 and 3. Clinical relapse documentation



Pre-treatment screening and counselling

Prior to the initiation of treatment with alemtuzumab, patients are provided with written information regarding potential infusion-related, and longer term, side-effects. Female patients are requested to have an up to date cervical smear and family plans and contraception are discussed. The importance of full commitment to the long-term monitoring requirements are highlighted – the manufacturer recommends that monthly blood and urine tests are carried out for 48 months following the last infusion. Baseline pre-treatment bloods are checked including full blood count, liver function tests, thyroid function tests, and urea and electrolytes test. Immunisations or vaccinations should be given at least six weeks prior to the course of treatment. Varicella zoster virus, human papillomavirus and hepatitis immunisation should be offered if required as patients are more susceptible to infection with these agents following treatment with alemtuzumab.

Administering the infusion

Once selected, patients are admitted to the Neurology Day Unit. The team adopts a "buddy" system whereby patients coming for their initial treatment will be matched with one attending for a second course. Patients are counselled about the potential infusion associated reactions (IARs) prior to signing a consent form. They are also advised that they may experience a transient worsening of neurological deficits during the infusion.

In clinical trials more than 90% of patients treated with alemtuzumab reported an infusion related adverse event[1, 2].

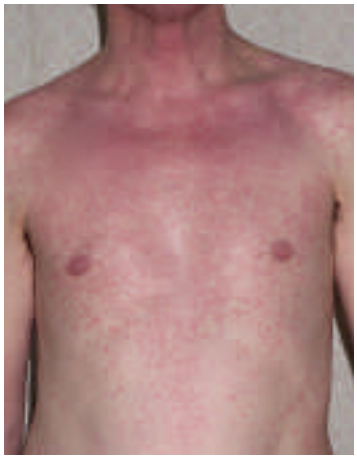


Figure 4. (right) Infusion related rash

Very common	Common
Headache	Insomnia
Flushing	Dizziness
Nausea	Tachycardia, hypotension
Urticaria, rash, pruritis	Dyspnoea, chest discomfort
Pyrexia	Dyspepsia
Fatigue	Generalised rash
	Pain

In order to minimise IARs the following medication is prescribed:

- 1g IV methylprednisolone infused over one hour immediately preceding the first three doses
- 1g paracetamol
- 4mg chlorpheniramine
- 2.5 mg nebulised salbutamol
- 10 mg metoclopramide
- 30-60mg codeine phosphate
- prophylactic treatment with 200mg acyclovir twice a day is commenced on day one of the infusion continuing for one month thereafter to prevent herpes infection.

During the four hour infusion period vital signs are recorded half hourly, and for two hours post infusion. In Cardiff patients remain in hospital overnight.

Post infusion information

Following the treatment, patients are provided with a self-management folder which includes appointments, monitoring commitments, information, correspondence and blood result forms for their completion. They are advised to bring this to all appointments and to record any concerns regarding side-effects.

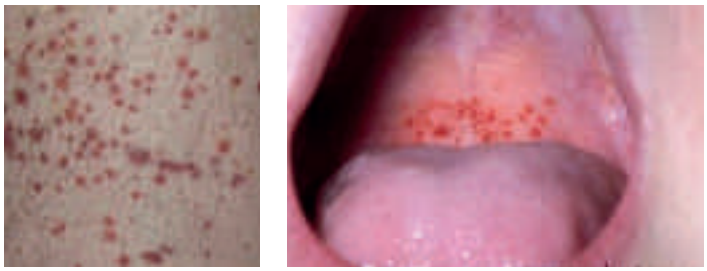
Long-term monitoring

Education and advice on the signs and symptoms of long-term autoimmune conditions are provided to patients. They are encouraged to report any signs of:

- idiopathic thrombocytopenic purpura (ITP)
  - easy bruising
  - petichiae (pinpoint, round spots that appear on the skin as a result of bleeding under the skin)
  - heavier than usual menstrual bleeding
- thyroid disorders
  - excessive sweating
  - unexplained weight loss or gain
  - eye swelling
  - rapid heartbeat
  - increased fatigue
  - irritability
  - constipation
- Goodpasture's syndrome
  - blood in urine
  - swelling in legs or feet.

Particularly with respect to ITP, pictures are shown, and the images are reinforced during clinic appointments.

Figure 5. Signs of ITP



Other potential side-effects include opportunistic infections, cancers, human papillomavirus and herpes simplex types 1 and 2.

It is also important to note that irradiated blood products should be administered following alemtuzumab to prevent graft versus host disease.

In order to minimise risks and ensure early detection of the potential side effects, a management plan including monthly full blood count and urinalysis is carried out, along with six monthly urea and electrolyte tests, and thyroid function tests. The MS nurse plays an important role in motivating patients to continue this monitoring.

Managing the challenges

Whilst we have successfully treated 90 patients with alemtuzumab we have also become aware of some of the challenges that may face centres that intend to deliver a similar service. Despite ongoing education, some patients fail to attend their appointments or to adhere to blood monitoring requirements. This is a challenge for MS nurses and poses a clinical risk.

Providing a responsive service, with cover during the evening or at the weekend, is difficult and the education of ward nurses and on call doctors is vital. Access to neuroradiology and timely MRI scans can prove difficult at times. Accompanying this is the need for comprehensive administrative support to ensure that the patient journey runs smoothly and to coordinate the work of the MS team and the day unit.

Whilst setting up and delivering the service has posed some challenges, it is evident that alemtuzumab is a highly effective treatment that can have a positive outcome on the lives of people with MS.

The authors would like to acknowledge the work of the whole MS team in setting up the clinic at the University Hospital of Wales, Cardiff.

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Primary progressive MS: new version now available

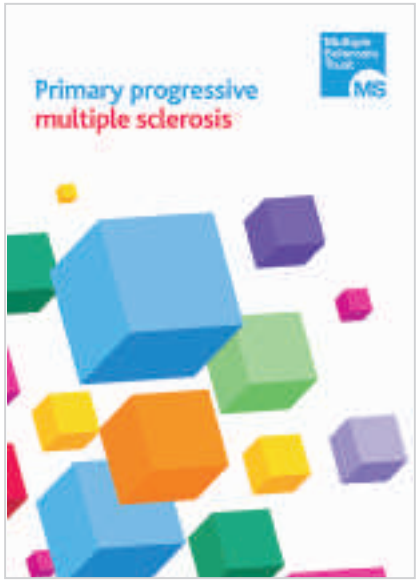
The MS Trust is pleased to announce that our book for people with primary progressive MS is now available. The book has been revised to incorporate up-to-date information on the diagnostic criteria and an expanded section on trials currently underway in primary progressive MS.

The book also includes sections on:
- how PPMS differs from the other forms of MS
- symptoms
- progression
- management – both drug and rehabilitation strategies
- living with PPMS
- other sources of information and support.

There is also a key information section for those who simply want a brief overview of the condition.

A diagnosis of primary progressive MS is given to 10-15% of people diagnosed with MS, so there are at least 10,000 people living with primary progressive MS in the UK alone, but comprehensive information specifically on this type of MS is still scarce. This book hopes to address that.

Primary progressive MS can be particularly challenging as progression and advancing disability are more evident from the outset of the condition than with other forms of MS. This book explores both the physical and emotional aspects of a diagnosis of primary progressive MS.



We hope the information will enable people with primary progressive MS to interact effectively with their health professionals in terms of understanding, exploring possible management strategies and by presenting the condition in a realistic manner.

To order copies of Primary progressive MS email: **info@mstrust.org.uk**; tel: **01462 476700**. Also available to read online, order or download from our website: **www.mstrust.org.uk/publications**

Introducing FACETS into practice: an evidence-based group fatigue management programme

Vicky Slingsby and Alison Nock; MS Specialist Occupational Therapists, Poole Hospital NHS Foundation Trust

Introduction

Up to 92 per cent of individuals with multiple sclerosis (MS) experience severe fatigue, many daily. Approximately two-thirds of people with MS consider fatigue to be one of their three most troubling symptoms[1]. Fatigue has been defined as 'a subjective lack of physical and/or mental energy that is perceived by the caregiver to interfere with usual or desired activity'[2]. FACETS (Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle) is a manualised, group-based intervention for the management of MS fatigue that incorporates energy effectiveness and cognitive behavioural approaches[3].

Sometimes there are attitudinal barriers that stop people from successfully applying lifestyle changes to their daily lives. Cognitive behavioural approaches allow such barriers to be addressed in a structured way. FACETS is designed to be delivered by health professionals routinely involved in the management of MS, supported by a clinical psychologist, and is thus compatible with a wide range of existing health service structures (such as the NHS). The programme has been designed for people with MS who are ambulatory, either with or without mobility aids.

The FACETS research programme (Chief Investigator - Prof Peter Thomas, Bournemouth University) was funded by project grants from the MS Trust, the MS Society and the BUPA Foundation. The aim of the research programme was to develop and evaluate a fatigue management intervention for people with MS that blends occupational therapy and cognitive behavioural approaches. Development of the FACETS intervention was led by Dr Sarah Thomas along with a multidisciplinary team from Bournemouth University and the Dorset MS Service[4]. After piloting the intervention, the research team undertook a national multicentre randomised controlled trial to see whether FACETS is beneficial for people with MS[5]. FACETS was found to be effective in reducing fatigue severity and improving self-efficacy [6].

The FACETS programme

The primary aim of the FACETS programme is to provide participants with knowledge, tools and strategies to self-manage their fatigue. The objectives of the group are:

1. To normalise the experience of fatigue.
2. Learn ways to use available energy more effectively.
3. Learn ways to develop 'helpful thinking styles' about fatigue.

The programme is run as a closed group. Each of the six sessions builds upon the previous one. The ideal group size is eight to ten participants. Participants have reported that a community venue such as a hotel makes a welcome change from a hospital setting and leads to a more relaxed and social atmosphere. Overall we have found morning sessions to be the most popular as many people with MS report that their energy levels are best in the mornings.

Overview of the programme content

Session	Title	Summary of content	Homework
1	What is MS-related fatigue?	General introduction; expectations; icebreaker (quiz); types of fatigue; contributing factors; conceptual map/model of fatigue in MS	Activity/ fatigue diary
2	Opening an 'energy account'	Rest - functions; barriers; techniques; diaphragmatic breathing exercise; sleep hygiene	Rest/activity/ sleep planner
3	Budgeting energy and smartening up goals	Types of activity; balancing activity and rest; moderating activity using the toolbox; lifestyle factors; goal setting	Goal setting exercise
4	The stress response; the cognitive behavioural model	The stress response (fight/flight); ways of coping with stress; introducing the cognitive behavioural model	Fatigue thought diary
5	Putting unhelpful thoughts on trial	Unhelpful thought patterns; challenging unhelpful thoughts; levels of belief	Thought challenge sheet
6	Recapping and taking the programme forward	Revisiting expectations; introducing the 'force field'; group activity to revisit themes of the programme; rationale of 'Keeping on Track' planner	'Keeping on Track' planner

Integrating FACETS into our practice

Now that the trial has been completed, we are running three groups per year as part of our service and plan to continue with this schedule. We are running the FACETS programme at a local independent hotel and this venue provides easy access with appropriate facilities for participants. To date we have run two groups and each has had commitment from eight to ten people with MS for the full six weeks. As FACETS is already evidence-based, we are simply sending out an evaluation questionnaire for feedback at the end of the programme and holding a follow-up review session about a month after session six has taken place.

Feedback from participants has been highly encouraging and positive:

"Thank you – it was good to hear real issues face to face and have time/permission to talk about the whole complex business of MS in a safe and caring environment. The group helped me feel relaxed and confident to speak about anything. I have steered away from 'groups' and found online forums rather depressing - this was a really positive experience!" FACETS group member, 2013

"The course is not only relevant and interesting but also very energising and positive. I always leave feeling uplifted and better equipped to cope." FACETS group member, 2013

It has been an extremely positive experience for us to work jointly with Bournemouth University and the MS Society and through this collaborative working we feel we have developed new perspectives, insights and skills.

MS Society FACETS training

The UK MS Society is now supporting the national roll out of FACETS training for health professionals and we are co-facilitating these one-day courses. The training programme was first launched in 2012 at MS Life. Since then, a total of 99 people have been trained at various venues across the UK, including Manchester, London, Belfast and Glasgow.

The one-day training course aims to equip attendees with the skills and knowledge to deliver the FACETS programme in their own practice. On completion of the training day, attendees receive the facilitator's handbook, PowerPoint presentations and participant handouts. The training is open to health and social care professionals routinely involved in the management of MS, with an understanding of MS fatigue, experience of facilitating group work, and a general awareness of cognitive behavioural principles.

The table below presents a breakdown by profession of those who have attended the training days to date:

FACETS attendees

Physiotherapists	20
Occupational therapists	48
Nurses	20
Other (incl. counsellors, psychologists, MS therapy assistants)	11
TOTAL	99

The training course has been well received:

"The course was fantastic - best training I have had in a very long time."

"So well presented and supported - plan to train the other 3 members of my team to start groups in the New Year."

"Very informative and enjoyable."

"The course was brilliant - this will be the programme we will run."

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For more information about training opportunities to deliver the FACETS programme,
email: education@mssociety.org.uk

Life on hold: the experience of living with neuromyelitis optica

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Introduction

Until recently, neuromyelitis optica (NMO) was viewed as a severe form of multiple sclerosis (MS) and was treated similarly. However, Lennon et al[1] identified a specific antibody against the antigen aquaporin-4 (found in 70% of people with NMO) which has led to an increased understanding and the knowledge that NMO is a separate disease to MS.

The onset of NMO is usually through a devastating relapse of optic neuritis or transverse myelitis causing significant disability. Optic neuritis (unilateral or bilateral) is associated with blindness, loss of colour vision, central scotoma and pain on eye movement[2]. Longitudinal extensive transverse myelitis (more than three vertebrae) is associated with bilateral motor weakness, sensory loss including numbness, banding, intense paraesthesia, paroxysmal tonic spasms, neuropathic pain, itching, and bladder and bowel dysfunction. Brain stem involvement may occur, and may cause prolonged hiccoughs, nausea, vomiting, vertigo or respiratory failure[3].

Residual disability in NMO is acquired through relapses, resulting in severe visual loss and/or paralysis of limbs. This highlights the importance of both timely and effective treatment. There are four aims of treatment[4-6] for NMO:

- acute treatment of relapses
- prevention of relapses
- symptom management
- rehabilitation.

First-line therapy for acute relapses is high dose methylprednisolone[3, 5], plasma exchange[6] may be considered if there is a poor response to steroid treatment. Steroids and immunosuppressants are used for the prevention of relapses[2, 5, 6].

Method

Participants were recruited from the northern NMO centre. 28 patients were invited to the study through an information sheet. They were selected to ensure a varied sample of age, gender and disability. 19 patients agreed to participate, although four withdrew before participating in the interview. Reasons given for withdrawal were family difficulties (n=2), work schedule (n=1) and ill health (n=1).

All 15 participants who agreed to be interviewed had residual disability from previous relapses of optic neuritis and myelitis. Nine participants tested positive for aquaporin-4 antibodies. Visual loss ranged from partially impaired vision in one eye to complete loss of vision in both eyes, and four participants were registered blind. Motor loss ranged from poor balance and weakness in one leg requiring sticks/crutches to tetraplegia (one participant), and four participants were wheelchair users. Sensory loss included complete numbness, neuropathic pain, tight banding around the trunk and paroxysmal spasms. Seven participants had stopped working due to their symptoms, six were in part-time work, two participants had never worked and three were studying part-time. Nine participants were married and had longstanding relationships (minimum 20 years). Two participants lived alone and four lived with their parents.

Data collection

Participants were interviewed using a semi-structured interview schedule that aimed to elicit participants' feelings, their experience of diagnosis, experiences of health care, changing nature of, and their attitude to, NMO over time, daily impact of symptoms (both physically and psychologically), and adjustment and coping methods.

Results

From the data, five major interconnected themes were identified which contribute to an individual's experience of living with NMO:

- diagnosis and treatment
- symptoms
- adjustment
- identity
- support.

Diagnosis and treatment of NMO

This theme included initial symptoms, getting a diagnosis, treatment of relapses and recovery, and the fear of future relapses due to the potential disability that could accrue. The initial symptoms of myelitis or optic neuritis occurred quickly, yet resulted in the participant requiring rehabilitation for many months. The process of getting a diagnosis for such a rare condition as NMO was arduous and learning to live with a disability had a major impact on participants.

Initial symptoms included double vision, pain upon eye movement, loss of vision in one eye, sudden vision loss, intense neuropathic pain, tight banding sensations, paraesthesia, and loss of sensation in arms and/or legs, lack of coordination, paralysis of limbs and retention of urine. The majority of participants (n=11) highlighted how rapidly initial symptoms presented, reaching a peak within 48 hours with no previous illness or warning signs.

"So I was driving through town. . . I noticed right there in front of the Mosque where they were praying, I had to pull over and phone someone to come and get me, I'd gone blind, that's how that happened."

". . .started off I had a bath one Tuesday night and noticed my right leg from my foot to the ankle when I put it in the hot water the water felt cold . . . by Thursday it had gone right up to the top of my leg. I couldn't stand up and I had lost use in my left leg altogether."

13 participants reported difficulty attaining a diagnosis of NMO, and four sought a second opinion either privately or abroad. These participants reported misdiagnosis, most commonly MS (n=12). Other alternative diagnoses included transverse myelitis, cerebral vacuities and meningitis. Two participants who were diagnosed with NMO during the last two years considered themselves to "be lucky", as they were seen by neurologists who were knowledgeable of NMO which improved the speed and accuracy of the diagnosis.

Participants reported fear of the future, fear of the unknown, fear of death and the realisation that further relapses could happen, meaning they would have to change their life plans. Despite this, the majority of participants reported relief at finally having a name for their condition.

"After a series of tests they came up with a diagnosis, phoned me and said you've got Devic's syndrome, you can look it up online. So I looked it up and I found that I was likely to go blind, stop breathing and drop dead, I thought this is not the best way to tell somebody. But then it was a great relief to have a name for whatever condition I had."

Participants differed in what they wanted from their health professionals, though all appreciated honesty alongside listening to their needs. A major frustration for all participants was not feeling listened to by their health professionals.

Once diagnosed with NMO, patients were likely to have further relapses. Immunosuppressants and long-term steroid treatments used to prevent relapses in NMO had unwanted side effects such as weight gain, indigestion, osteoporosis, acne and stretch marks. Medications such as antacids, calcium and vitamin D supplements were given to reduce the risks of side effects. All participants were affected by side effects; younger females in particular were concerned about their image and the views of their peers.

"This weight thing really upsets me, I see all these slim girls and they're able to wear what they want, look really nice and I have to wear a jacket. So the weight thing is still a big issue. I looked like a hamster, I was really ballooned out. I've got the steroids so they make you hungry and they make you just want to eat loads but I have to have them because otherwise I'd probably be poorly again."

Impact of symptoms on daily life

The most prevalent symptoms reported were visual disturbances due to optic neuritis (n=13), including blurred vision, lack of colour vision and two had no perception of light.

". . . it's not like I expected to be blind, but actually being unsighted isn't as scary as sighted people think it is, that's my own personal view. . . as long as I can maintain independence, hearing kicks in and other things come into play. Because you can still be independent sightless and sightlessness isn't black. I hope that I shall be gardening for years."

Spinal lesions caused bilateral motor weakness, sensory loss including numbness, banding sensations, intense paraesthesia, neuropathic pain and bladder or bowel dysfunction.

12 participants had neuropathic pain that was constant and/or paroxysmal, using descriptions such as burning, intense paraesthesia, tight banding, cramps, spasms, electric shock, icy or scalding sensations or numbness. Areas of worst pain were in the legs (predominantly bilateral), central back and arms. Pain significantly affected participants' daily life by impacting upon their daily activities, mood, walking ability, enjoyment of life and relationships.

"The pain would come on for no reason at all. Start from your toe to ankle to mid-thigh. It would only last 40 seconds until it goes off, but it's terrible pain that pulls my foot up it was that bad. It may occur several times an hour or day; it's so unpredictable."

Bladder issues such as urgency, frequency, hesitancy of micturition and incontinence were a major concern for nine participants. Bladder problems caused embarrassment, humiliation, decreased self-confidence and reduction in social activities, thus affecting the participant's independence.

". . . I have to plan everything, if I was to go out shopping, we have to make sure that I've done my catheter before we go out, make sure there are toilets about; I have to take spare clothes in the car in case I have an accident."

Adjustment

Participants had to feel they were in a "stable phase" without relapses before they could adapt their lifestyle, make adjustments and start coping with their situation. This period varied for each individual but was helped by increased lengths of time without relapses. The need to "just get on with life" was highlighted by 14 participants.

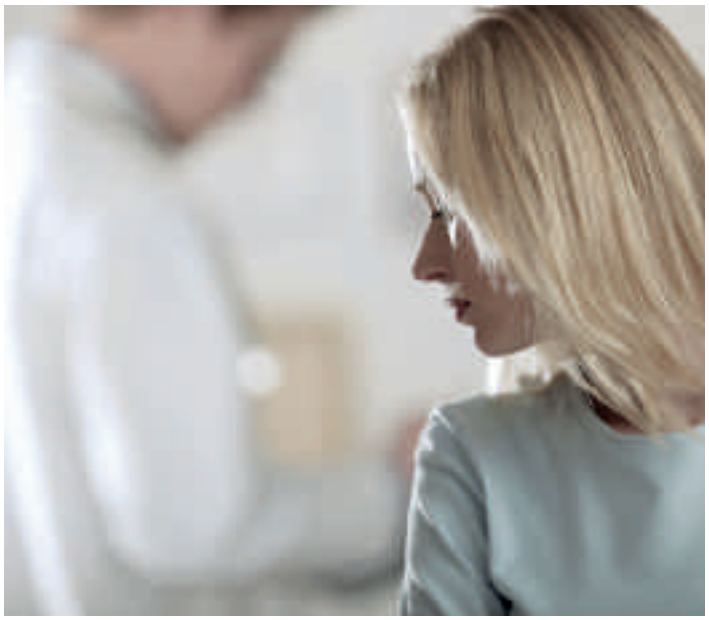
The uncertainty of the condition meant they could not predict what was going to happen tomorrow or in the future, and so they preferred not to think about it and live for today. 11 participants retained hope that their situation would improve and get better. Participants reported they felt their "life was on hold" and they wanted to match the "normality" and life goals and concerns of their peers and family members such as independence, attending university, employment and relationships.

"I just feel I've missed out on all my 20's, like you're almost left behind. What I mean is in the scheme of life I'm 33 soon so you don't want to be living with parents. I'd have liked to have had a family, I'd have liked to have had my own place, be capable, I've lost a lot of confidence through having NMO and the treatment with the weight gain and things."

The main frustration for all participants was a reliance on others and a lack of independence due to their physical limitations. Frustrations were often due to a change in role including limitation of physical activities, inability to complete activities perceived as their duty, driving restrictions and resulting financial pressures. Others' ignorance of NMO, difficulties socialising and negative reactions of others towards them added to their frustrations.

Identity

Participants, especially females, were concerned about their image compared to their peers and press publicity about ideal figures, and were self-conscious about weight gain and changing shape as a consequence of steroid treatment. They compared themselves to a time before NMO when they were slim and could wear fashionable clothes. These changes in their figures and clothing caused embarrassment, which in turn had an impact on their social skills, resulting in a fear of socialising and eventually self-imposed isolation. Participants were appreciative of those who saw beyond their symptoms, such as visual loss or wheelchair use and valued friendships from people who knew them before their NMO diagnosis.



Support

Families were generally supportive, although participants reported sadness regarding their dependence upon family members. Participants worried about how they would cope with aging, how they would cope if they lost their partner, and the wellbeing of their spouse or parents due to the duties of caregiving.

For nine participants, pets provided benefits including meaning for life, a routine, companionship, safety, security and increased independence. Dogs and cats were classed as a "best friend" who provided unconditional support and affection regardless of the participants' disability. Participants frequently reported social comparisons, which were usually divided into one of two themes: either "people are better off than me" or "there is always someone worse off than me".

Discussion

This study highlighted the fear and worry that future relapses may cause loss of sight or paralysis. This concern is different to those living with other relapsing conditions such as MS[7, 8], as although there are similar concerns regarding unpredictability of relapses, they do not have to contend with the prospect of such sudden onset of disability.

The majority of participants were initially diagnosed with MS; however, it has now been shown that NMO is a different disease to MS both in terms of its management and the pathway of the condition[2, 3, 5]. This misdiagnosis caused difficulties in achieving a successful treatment plan for many participants.

As NMO is such a rare condition, many health professionals have poor knowledge, and little understanding or appreciation, of the speed with which relapses need to be diagnosed and treated. Patients with NMO tend to be under the care of MS neurologists where the emphasis of relapse treatments is to speed up recovery[9] rather than preventing disability[5].

In MS, progression of the condition is usually the cause of disability, compared to NMO where relapses are the cause of disability, therefore the emphasis of treatment is very different[2-4]. There is, therefore, a need to provide information, education and increased awareness of the differences between NMO and MS for health professionals[10-12]. Participants adhered to a prolonged steroid regime due to the fear of future relapses and potential disability of other symptoms.

The observable side effects of steroids, particularly weight gain and significant stretch marks, had a large impact on a person's image and confidence, causing reduced socialisation and subsequent lack of peer support that ultimately negatively affected their daily life. This required dietary and exercise input from a multidisciplinary team to minimise the impact.

Participants adjusted to their new lifestyle as time increased from the initial event. If relapses occurred frequently, participants had difficulty accepting their situation and were unable to plan for the future resulting in them "putting their life on hold". In an extended period of time without relapses, participants developed coping strategies to effectively manage both the psychological and physical difficulties of NMO in daily life. The process of adjustment followed a similar pattern in all participants, but the time taken to adjust differed between individuals and appeared to be dependent upon the frequency of relapses.

Conclusion

Although NMO shares similarities with MS, it is differentiated by the speed and severity of relapses, causing significant disability at the onset of the condition. These results suggest that NMO has a major impact on a person's identity through the physical and emotional changes it causes, that adjustment is a lengthy and individual process and that people with NMO utilise support from various sources of which healthcare services are essential.

Acknowledgements

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New book on secondary progressive MS available soon

Secondary progressive is a misunderstood aspect of MS. For the person with MS, the change in diagnosis can feel like having to face uncertainties and emotional upheavals all over again. Some may have seen changes in their condition that the MS team is initially unwilling to define as secondary progressive. Others may have put from their mind the fact that for most people relapsing remitting MS will eventually develop into secondary progressive, or felt that they would not themselves have to face this transition.

The lack of disease modifying drugs is sometimes seen as meaning there is no treatment for progressive forms of MS. Whether this is due to lack of awareness or to poor communication, many people feel a sense of abandonment.

To counter these misconceptions, this summer the MS Trust will publish a new book about secondary progressive MS. This will look at:

- the processes that are happening as the pattern of someone's MS changes and why it takes time for the MS team to be able to confirm the new diagnosis
- the range of approaches to treating secondary progressive MS with symptomatic treatments and rehabilitation
- the emotional side of the transition to secondary progressive MS and ways to manage this
- the growing level of research into progressive forms of MS.

The book is illustrated by comments from people with MS and health professionals who work with them to show that people don't have to face secondary progressive MS unsupported.

MS specialist nursing in the UK: results of a survey

Introduction

Between the 10 March and 10 April 2014, the MS Trust carried out a self-report survey of all specialist nurses working in MS recorded on their database. The survey was conducted to:

- confirm the number of MS specialist nurses in the UK
- clarify any differences between the number of posts (headcount) and whole time equivalent (WTE) workforce
- indicate whether there is a shortfall in MS specialist nurse posts
- describe the balance of funding for MS specialist nurses between the NHS and other sources
- identify the current challenges facing UK MS specialist nursing
- identify regional variations in the provision of MS specialist nursing across the UK.

Method

The survey was launched at the MS specialist nurses' meeting, where delegates could respond to the survey using a hand held voting device. Eligible nurses, defined as those with a 100% MS caseload or neurology specialist nurses with a caseload that includes MS, who did not attend the meeting were contacted by email and asked to complete the survey online. In total the survey was sent to 283 specialist nurses working in MS (245 MS specialist nurses, 38 neurology specialist nurses). The survey was also sent to 41 nurses who work with people with MS in roles including MS support nurses and infusion nurses, however their responses were excluded from the analysis, as were those of the neurology specialist nurses. Four nurses were excluded from the survey due to personal circumstances, for example maternity leave or long-term sickness. The response rate of those asked to complete the survey was 97%.

The preliminary analysis of the survey responses addresses the first four of the points above. A more detailed analysis will be carried out later in 2014 to identify the challenges facing, and regional variations in, MS specialist nursing in the UK.

Key findings

Number of MS specialist nurses in the UK

There are 245 MS specialist nurses with 100% MS caseload in the UK, they were asked whether they worked full-time or part-time.

All MS specialist nurses in Wales work full-time, for the remainder of the UK around one-third are in part-time roles. The whole time equivalent (WTE) equates to a work force of 216.

Shortfall in MS specialist nurses

To calculate the number of MS specialist nurses needed in the UK, and consequently any shortfall, requires consensus on:

- the prevalence of MS in the UK – the generally accepted figure has been around 100,000[1] people, but a recent epidemiological study has estimated the figure at 127,000[2]
- an acceptable caseload of patients per whole time equivalent nurse.

As there is no singly agreed figure for the prevalence of MS, we calculated a range using both the higher and lower figures above as a boundary. Regarding an acceptable caseload, unpublished work by the MS Trust suggested an optimal caseload of 300 patients per WTE[3]. It should be noted this is not a definitive figure, caseloads should be lower than this if for example the area covered is rural or remote and therefore longer travelling times are needed for outreach clinics or home visits, or if the service has a high proportion of patients requiring complex case

	Total	Responders	Non responders	Not contacted	Response rate of asked	Response rate of all
MS specialist nurses	245	237	6	2	98%	97%
Neurology specialist nurses	38	35	1	2	97%	92%
ALL	**283**	**272**	**7**	**4**	**97%**	**96%**

management. Conversely a higher caseload may be more manageable if the service doesn't handle injection training for disease modifying therapies, or in an acute hospital based service where there is also a community MS service that see those with more complex needs.

The GEMSS programme (Generating Evidence in MS Services), will allow us to model optimal caseloads for different types of services, but for the purpose of this analysis the figure of 300 was used. The shortfall based on the higher and lower prevalence figures, was found to be between 126 and 214 whole time equivalents.

The level of shortfall varies between the four nations, with England having the greatest shortfall.

MS specialist nurse funding

Nurses were asked about how their posts were funded. Overall, 87% reported that they were solely funded by the NHS.

In England, 12 reported being solely funded by a pharmaceutical company with an additional four reporting mixed funding from a pharmaceutical company and either the NHS or another source. Two reported being wholly or partly funded by a charity. Though funding in England is predominantly through the NHS, the detailed picture is complex and fluid. Depending on employer, service model and, to some extent, caseload, posts are funded either through national 'specialised commissioning' by NHS England or through local Clinical Commissioning Groups (CCGs). There is a widespread lack of clarity about commissioning responsibilities and a well-documented need to create efficiencies across the NHS which generate real savings[4]. Further analysis is required to fully describe the detailed NHS funding arrangements for MS specialist nurses and other elements of MS services.

In Scotland, one MS specialist nurse reported being solely funded by a pharmaceutical company and an additional three being wholly or partly funded by a charity.

In Wales, no MS specialist nurse reported being wholly or partly funded by a pharmaceutical company or a charity.

In Northern Ireland, one MS specialist nurse reported being wholly funded by a pharmaceutical company and none reported being funded by a charity.

Conclusions

MS specialist nursing in the UK has grown steadily over the past twenty years and is a well-established and vital element of a high quality MS service. The response rate to the survey indicates a strong level of engagement by the community of MS specialist nurses to ensure there is accurate data about their roles, sources of funding for their posts and the challenges they face in their local situation as well as from changes in the wider healthcare context.

In order to provide service managers and commissioners from both national specialised commissioning and local CCGs with relevant information, the MS Trust will be undertaking further analysis of the survey data.

Everyone with a diagnosis of MS should have easy and timely access to an MS specialist nurse who can provide them with the specialist knowledge and support they require to remain active, engaged and as well as possible. This survey helps strengthen the case for continued focus on the availability of MS nurses across the NHS.

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For the full findings of this survey go to:
www.mstrust.org.uk/downloads/mssn-survey-report-2014.pdf

MS Trust Study Days

MS Study Day in partnership with Yorkshire ACPIN

Venue: Queens Hotel, Leeds
Date: Wednesday 17 September 2014
Price: £55 + VAT for ACPIN members, £65 + VAT for non-members

Topics include:

- diagnosis of MS and latest drug management
- spasticity management in MS
- neuropsychology of MS
- fatigue management in MS
- therapeutic management of ataxia.

One day symposium on sexual dysfunction in people with MS and other neurological disorders

Venue: National Hospital for Neurology and Neurosurgery, London
Date: Monday 29 September 2014
Price: £55 + VAT

We are delighted to be working in partnership with the National Hospital for Neurology and Neurosurgery to run a one day symposium on sexual dysfunction.

Topics include:

- neurology of sexual function and dysfunction following neurological disease
- an andrologist's perspective of sexual dysfunction in neurological disorders
- a gynaecologist's perspective of sexual dysfunction in neurological disorders
- practical management of sexual dysfunction in neurological patients
- involving the partner
- altered body image and sexual health – a patient's perspective.

Publications

For a complete listing of all our publications and factsheets visit our website at **www.mstrust.org.uk**

Publications for health and social care professionals

- ☐ MS information for health and social care professionals 4th EDITION
- ☐ Spasticity care pathway

Publications for people with MS – (a sample)

- ☐ Managing your bladder: a guide for people with MS
- ☐ Managing your bowels: a guide for people with MS
- ☐ Disease modifying drug therapy
- ☐ Primary progressive MS REVISED

Postcards

- ☐ At work with MS
- ☐ Posture
- ☐ StayingActive
- ☐ Practical guide: to bladder and bowel in MS

Factsheets – (a sample)

- ☐ Alemtuzumab
- ☐ BG-12
- ☐ Laquinimod
- ☐ Cognition
- ☐ Depression
- ☐ Diet
- ☐ Pregnancy and parenthood

All items are free, but if you would like to make a donation towards our costs, we would be very grateful.

☐ I enclose a cheque made payable to the MS Trust

I want the MS Trust to treat this donation and all donations I have made for the four years prior to this year and all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations. Date:___/____/____ Signed_____

I confirm that I will pay an amount of Income Tax and/or Capital Gains Tax in each tax year (6th April to 5th April) that is at least equal to the amount of tax that all the charities or CASCs that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I give on or after 6 April 2008. Please notify us if you change your name or address.

Name

Job title

Address

Postcode

Telephone number

☐ I am happy to be contacted by email:

email address

Return to: MS Trust, Spirella Building, Letchworth Garden City, Herts, SG6 4ET

The MS Trust will use your details:

- to keep you informed about our work, including our fundraising
- to pass to our wholly owned subsidiary companies MS Trust (Education) Ltd and MS Trust (Trading) Ltd which exist only to carry out our educational objectives and to raise funds for the MS Trust.

We will not sell or pass your details to anyone else (unless we are required to by law). If you object to either use of your details, please let us know.

Supporting the MS Trust

Above: Liam with some of the other cyclists

Liam Rice, MS Nurse Specialist from the Royal Hallamshire Hospital in Sheffield, took part in a sponsored cycle ride from London to Paris last year and raised over £2,200 for the MS Trust. Here he tells us about the challenge and why he got involved.

"I'd always fancied doing something like the London to Paris cycle ride and it was a big challenge for me as I only took up cycling a few years ago. I wanted to show my kids that anything is possible if you make the effort. Also, I wanted to make people more aware of MS and try to make it less frightening for people when they are newly diagnosed.

"I wanted to help the MS Trust as they have been fantastic and really supportive. People don't always remember that nurses on the front line need access to up to date information and research to give to the people we support. Having the MS Trust as a resource makes my job a lot easier.

"I found the fundraising easier than I'd thought as I got into it little and often. I asked everyone I know for sponsorship, I also held a fundraising event with my band in Sheffield. I followed the MS Trust's advice and it worked, I got a lot of support.

"The ride itself was an absolute buzz from beginning to the climactic finale. Training was key – that and a good sense of humour! I have had a brilliant, heart-warming experience and have been able to help people with MS."

We are now booking for a London to Paris cycle ride from 20-24 May 2015. For more information about that or any of our other fundraising events, please call **01462 476707** or **visit www.mstrust.org.uk/getinvolved**

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