

## Supporting MS specialist nurses

Each year, the MS Trust hosts a meeting for MS specialist nurses. The meeting is a unique opportunity for UK nurses to come together for clinical updates, to discuss advances in practice and services, to identify opportunities and challenges that lie ahead and to explore ways to respond.

Along with clinical topics, this year's meeting had a focus on demonstrating the value of MS specialist nursing. As NHS reforms begin to bite and the pressure to make savings increases, so the need to show the impact of services becomes more important. Clinical commissioning is fast approaching and it is vital that services can show their value. The MS Trust has launched a report, '*Defining the value of MS specialist nurses*', which lays out the current evidence for MS nursing and recommends further work to strengthen the case. We have also commissioned work on MS specialist nurse caseload. Both these reports are described within this edition of Way Ahead. We will be launching more projects in the next 12 months to help generate more evidence about the difference that MS services make. People with MS greatly value their specialist nurses. The MS Trust will continue to support specialist services and to help secure their future.

## MS nurse given top award

Congratulations go to MS specialist nurse, Debbie Quinn, Isebrook Hospital in Wellingborough, who has been awarded the honoured title of Queen's Nurse from the Queen's Nursing Institute. Debbie will receive the title 'Queen's Nurse' at a ceremony on 23 April in recognition of the high standards of nursing she provides in primary care and the community. The Queen's Nursing Institute works to improve the nursing care of people in the community and in their own homes by identifying and developing nurses who are committed to high standards of care in the community, helping them to make improvements in practice and to act as leaders and role models to others. Well done, Debbie!



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## Fingolimod recommended by NICE

Fingolimod (Gilenya) is a daily oral disease modifying treatment. In March 2011, fingolimod was licensed in the UK for rapidly evolving severe relapsing remitting MS (two or more relapses per year) and for people who have failed to respond to beta interferon.

In March 2012, NICE (National Institute for Health and Clinical Excellence), which issues guidance on whether treatments should be funded by the NHS in England and Wales, recommend that fingolimod can be prescribed for people with highly active relapsing remitting MS who have continued to have relapses despite treatment with a first line beta interferon. This final draft appraisal reverses the decision not to recommend fingolimod made in two previous draft consultation documents.

Also in March, the Scottish Medicines Consortium (SMC), which carries out a similar role to NICE, did not recommend fingolimod for use within Scotland as there was an insufficient robust economic analysis. Novartis have requested further clarification regarding this decision and plan to resubmit further evidence to support its approval.

Around 30,000 people have received fingolimod worldwide. Treatment requires careful monitoring for six hours after the first dose as clinical trials had shown that fingolimod can temporarily slow the heart rate.

In January 2012, the European Medicines Agency's Committee for Medicinal Products for Human Use (CHMP) began a formal review of the benefits and risks of fingolimod. This follows reports of people experiencing heart problems and the death of a 59 year old person in the USA within 24 hours of receiving their first dose. Since the drug has been licensed, six other cases of unexplained death have been reported, three of which were sudden. Other reports include three deaths due to heart attack and one due to disruption of the heart rhythm. It is not known whether these deaths are related to fingolimod treatment. The review should be completed by April 2012.

Whilst the review is ongoing, doctors have been advised to increase cardiac monitoring of people taking fingolimod for the first time. For those with clinically important cardiac effects, monitoring should be continued until the symptoms have subsided. Those being treated with fingolimod should also be

made aware of the risks and advised to report any heart related symptoms to their doctor.

Further information about the review is available on the Medicines and Healthcare products Regulatory Agency (MHRA) website [www.mhra.gov.uk](http://www.mhra.gov.uk)

## FES in the south west

Dropped foot is when weakness in an ankle means the foot drags along the ground or hangs down when walking. FES (functional electrical stimulation) uses small electrical charges applied to nerves in the leg to force the foot into the correct position for walking. Research funded by the MS Trust<sup>1</sup> has shown that this can improve walking speed and fatigue and also reduce the risk of falls.

As FES allows renewed movements in weakened muscles, it is used to complement physiotherapy exercises and to allow people to build up strength and range of movement.

In January 2009, NICE issued guidance which stated that FES could be offered routinely as a treatment for people with foot drop, caused by damage to the brain or spinal cord, including people with MS.

Despite this, funding for FES has varied across the country as decisions are made locally.

In December 2011, the Peninsula Commissioning Priorities Group, which covers the four primary care trusts (PCTs) in Devon, Cornwall and the Isles of Scilly, reviewed the evidence for FES. It announced that FES should be available for people with foot drop caused by damage to the brain or spinal cord whose walking had not improved with other options such as ankle supports. The MS Trust contributed to this regional appraisal.

The decision in the south west follows that of another positive outcome last year in the East Midlands Specialised Commissioning Group, which manages funding decisions for nine PCTs.

1. Barrett CL, Mann GE, Taylor PN, et al. A randomized trial to investigate the effects of functional electrical stimulation and therapeutic exercise on walking performance for people with multiple sclerosis. *Mult Scler* 2009;15(4):493-504.

## Planning takes longer with MS

This study looked at how MS might affect planning, problem solving and performance using a test called the Tower of London test. This test has many varieties but there is usually a board with a few posts stacked with a small number of beads of different colours. These have been arranged by the researcher to show what the target result is.

The person being tested is given an identical board but with the beads arranged in a different order on the posts. They have to rearrange the beads, moving only one at a time from one post to another, to get the target result. Successfully completing the test requires someone to plan all the moves before carrying out what they have planned.

In this study, three groups (people with relapsing remitting MS or secondary progressive MS and healthy controls) were tested on a more difficult version of the test. The researchers measured how long the person took in planning all their moves as well as whether they were successful in completing the test.

They found that people with both types of MS took much longer to plan their moves than the healthy controls. They also showed a greater variation in how long they took to plan as the task was made harder. However, there was no difference between the three groups in how well they completed the task (whether they had all the coloured beads on the correct posts), it just took people with MS longer to think ahead and make their plan.

This has implications for activities in every day life for people with MS. The research results suggest that health professionals and others should give people with MS plenty of time to think something through especially if it involves several planning steps.

StayingSmart is an online resource to help with cognitive difficulties. See pages 10-12.

Denney DR, Hughes AJ, Owens EM, et al.  
Deficits in planning time but not performance in patients with multiple sclerosis.  
Arch Clin Neuropsychol 2012;27(2):148-58.

## Does MS affect personal identity?

A sense of personal identity relies on a number of things which someone thinks are important to them, such as their job, their role within the family, being a good athlete or musician, a smart person or a funny person and many other aspects of themselves.

When someone's life changes substantially, it can affect their sense of who they are. This study looked at how having MS might affect how people saw themselves. 12 people were interviewed and three topics were put forward for discussion: (1) "my body didn't belong to me" (2) "I miss the way I feel about myself" and (3) "let's just try and live with it".

The researchers found that having MS often altered the way someone saw themselves. However, this was not usually thought of as a loss but as a change to their identity.

Those who felt the strongest sense of loss were those whose symptoms had the most effect on their ability to fulfill the roles that they thought were important. For example, if someone was very physically fit before they had MS, then their identity was more likely to be affected by physical symptoms because that stopped them being the sort of person that they used to be. This, in turn, was more likely to lead to anxiety or depression.

The researchers suggest that health professionals can support people with MS to maintain their sense of self by assessing which symptoms affect them most and, if possible, helping them to reconnect with the activities and roles that matter most to them, although this may be in a different way from before MS.

Mozo-Dutton L, Simpson J, Boot J.  
MS and me: exploring the impact of multiple sclerosis on perceptions of self.  
Disabil Rehabil 2011 Dec 13. [Epub ahead of print]

## Sense of smell affected

153 people with MS and 165 healthy controls took a multiple choice "scratch and sniff" test. They were given one test strip at a time and asked to identify the smell from a list of four.

About 3% of healthy people and 3% of people with relapsing remitting MS had difficulty identifying the smells. This compared with about 12% of people with primary progressive MS and 69% of people with secondary progressive MS. The difference still existed after taking into account factors such as cognitive difficulties and was not related to how long someone had MS or how severely they were affected.

Silva AM, Santos E, Moreira I, et al.  
Olfactory dysfunction in multiple sclerosis: association with secondary progression.  
Mult Scler 2011 Oct 24. [Epub ahead of print]



# Celebrating ten years of the UKMSSNA



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The UKMSSNA (United Kingdom Multiple Sclerosis Specialist Nurse Association) was launched in 2001 to act as the professional membership organisation for those working in specialist practice with people with MS in the UK. The UKMSSNA has almost 250 members.

The mission of the UKMSSNA is to improve the lives of all those affected by MS through the provision of appropriate healthcare services, education, information, support and sharing of information. It also focuses on the needs and goals of MS specialist nurses throughout the UK. The UKMSSNA is affiliated to the International Organization of Multiple Sclerosis Nurses (IOMSN) which encourages an international collaborative approach to MS nursing and goes towards facilitating good standards of care.

## Key projects and developments of UKMSSNA

**MS clinical management manual: care across the disease trajectory<sup>1</sup>.** Launched in 2003 and adapted from the Canadian MS Nursing Care Plan, this evidence-based, comprehensive, care manual directs and supports MS specialist nurses in the UK. This was updated in both 2006 and 2009 and a further review is planned for 2012.

**Competencies framework for MS specialist care supported by the interactive training guide<sup>2</sup>.** Produced together with the MS Trust and RCN, this tool was designed to provide a competency framework that enables MS specialist nurses to map personal development within their role. [www.mstrust.org.uk/competencies](http://www.mstrust.org.uk/competencies)

**Learning Needs Assessment (LNA) tool<sup>3</sup>.** The design took into consideration other tools, such as the Competencies for MS specialist nurses<sup>2</sup>, and is targeted specifically for MS specialist nurses.

**Slide library and Guidelines, Integrated care pathways and Protocols (GIPs).** Slide library presentations are used as a teaching resource and reflect current best practice, NICE recommendations and the MS nurse role in the management of MS. The GIPs resource was developed with input from MS nurses and other health professionals. These resources enable the UKMSSNA to share best practice and expertise, provide evidence to support the nurses' role, standardise evidence-based care, allow SMART working and

meet standards and guidelines (local and national) such as the NSF for long-term conditions<sup>4</sup> and NICE guidance<sup>5</sup>.

**MS specialist nurses: Adding value and delivering NHS targets: OptiMiSing Standards of Health (DOH 2006)<sup>6</sup>.**

Directed at commissioners, lead nurses and PCT fund holders, this document aims to demonstrate the clinical and cost effective nature of the MS specialists' role and relates this to some of the key Government standards.

**CriMSon audit tool (2008).** Produced to help identify the effectiveness of the MS specialist nurse' role in meeting specific patient needs, but also a valuable tool for demonstrating patients' views of our service. Results are incorporated into our annual report with positive feedback from managers.

**Members' queries and discussion forum.** The emailing facility serves as an invaluable support for MS specialist nurses who may have a challenging clinical issue or need advice on strategic issues such as the setting up of a new service. For example, we recently requested information on neurological assessment training tools that we could adopt within our Trust. Feedback was excellent and again it allows SMART working.

**Ongoing support for new MS specialist nurses.** This includes bursaries, courses in cognitive behavioural therapy (CBT) and more recently, workshops at the MS Trust annual conference for health professionals new to MS who have attended the MS Trust's Development of MS care and management module.

For further information on the role of the UKMSSNA or becoming a member, please contact Mary Fielding (Administrator) at [admin@ukmssna.org.uk](mailto:admin@ukmssna.org.uk) or go to [www.ukmssna.org.uk](http://www.ukmssna.org.uk)

### References

1. UKMSSNA. Clinical management manual - Care across the disease trajectory. London: UKMSSNA; 2003, 2006, 2009.
2. UKMSSNA, MS Trust, RCN. Competencies for MS specialist nurses. Letchworth: MS Trust; 2003.
3. MS Trust, UKMSSNA, King's College London. Learning Needs Assessment Tool for nurses working in multiple sclerosis. London: MS Trust, UKMSSNA, King's College London; 2004.
4. Department of Health. The National Service Framework for long-term conditions. London: DH; 2005.
5. National Institute for Health and Clinical Excellence. Multiple sclerosis - Management of multiple sclerosis in primary and secondary care. NICE Clinical Guideline 8. London: NICE; 2003.
6. UK Multiple Sclerosis Specialist Nurse Association. Adding value and delivering NHS targets. OptiMiSing Standard of Health (DOH2006). Ledbury: UKMSSNA; 2007.

# How many MS specialist nurses do we need – a caseload survey?



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In March 2012, the MS Trust published a report, *Defining the value of MS specialist nurses*<sup>1</sup>. This important study summarises the evidence for specialist nursing, in MS and other specialties, and points to further work which would enable MS specialist nurses to prove their worth and make a case for maintaining and improving services.

Following on from this, a new piece of work funded by the MS Trust looking at the number of patients per MS specialist nurse is now underway. We already know that there is a lot of variation in MS specialist nurse caseload as this has been demonstrated in a recent National Audit Office Report<sup>2</sup>. The audit noted that the number of people with MS per MS specialist nurse ranged from 220 in the East of England to 650 in the North West.

Based on the MS Trust map of services in the UK [www.mstrust.org.uk/map](http://www.mstrust.org.uk/map), there are estimated to be 220 MS specialist nurses across the country. Although this has grown from just three in the 1990s, it is estimated that there is still a significant shortfall. With approximately 100,000 people living with MS in the UK, this means that many of the existing MS specialist nurses have high caseloads and there are reported gaps in services provided.

The work of MS specialist nurses is very complex, involving various roles and a high degree of knowledge and expertise. Different areas of the country require different services and this can make it challenging to calculate an absolute number for an MS specialist nurse caseload. There are many variables to take into account, including how many other professionals, such as physiotherapists and social workers, are available or how the MS specialist nurse manages his/her practice (some need to do more home visits which are more time consuming). Many services have evolved over time perhaps with only one MS nurse and a neurologist.

As there are so many variables to consider, MS specialist nurses are being interviewed for the survey and data collected on the services they offer and any gaps they feel they would like to meet given the needs of the people

they serve. In addition, some MS specialist nurses carry very high caseloads so that patients remain on their list and do not have to go through the added burden of re-referral - this is one of the things that frustrate patients and carers according to the National Audit Office report. Different people will need different levels of input from their MS specialist nurse at different times and it is important to factor this into the calculation. One way of doing this, is to look at the input of the nurse across the MS patient journey.

To try and determine the optimum caseload for the MS specialist nurse, a number of interviews have been undertaken and data collected on different types of services across England, Scotland and Northern Ireland. Data has been collected on how many clinics, home visits and out reach services the nurse provides. The survey has also looked at workload, such as numbers of phone calls made, as almost one third<sup>1</sup> of an MS specialist nurse's time is spent on the phone offering clinical advice, making referrals or helping other health professionals, such as GPs, with expert advice. The information collected is being used to build a model of the work of the MS specialist nurse and his/her caseload. From this, and perceived gaps in service, it will be possible to examine how many extra nurses or other professionals are needed to make up any shortfall. As part of the nurse support programme, the MS Trust will campaign to ensure people with MS have the right access to specialist support.

All of this information will be compared with other studies in people with MS which have identified gaps in services, NICE guidance and the recent MS Trust commissioning pathway. This will allow us to determine the optimum caseload range for the MS specialist nurse working in different environments. In addition, it is hoped it will help managers and commissioners further understand the contribution that the MS specialist nurse makes.

#### References

1. Mynors G, Perman S, Morse M. Defining the value of the MS specialist nurses. Letchworth: MS Trust: 2012.
2. National Audit Office. Services for people with neurological conditions: Department of Health. Norwich: The Stationery Office; 2011.

See the back page to order a copy of the study *Defining the value of the MS specialist nurses* or email: [info@mstrust.org.uk](mailto:info@mstrust.org.uk); tel: 01462 476700. Also available to read online, order or download from our website: [www.mstrust.org.uk/value-of-nurses](http://www.mstrust.org.uk/value-of-nurses)

# Setting the trend: a course in self-management



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The Bradford Specialist MS Team consists of a nurse, physiotherapist (PT), occupational therapist (OT) and consultant neurologist with a specialist interest in MS. The team has a caseload of approximately 650 people with MS in a mainly urban setting. We sit within the acute trust but are able to offer an outpatient and domiciliary service, seeing the patient wherever best meets their needs. We work very much as a multidisciplinary team (MDT) and often case-manage patients to provide coordinated and timely care.

This article describes a 'Living with MS self-management course', initially established by a PT and nurse in 2008. Since then, we have run six courses, inviting approximately 400 people with MS. With the addition of an OT to the team in 2009, and in response to feedback, the course has evolved to better meet the needs of patients. Whilst originally directed at newly diagnosed patients, the course is now rolled out to a wider caseload with a primary focus on self-management.

## Why provide a self-management course?

At the start, the course had a purely educational approach, as we perceived this to be the primary need of newly diagnosed patients. As a team, we made the assumption that all our patients implicitly understood the concept of self-management; however this was not evident in practice. We found that patients were not confident in knowing when and who to contact for advice regarding their MS. We therefore identified the need for self-management and health promotion to be formalised.

The benefits of a group format were that it was an efficient use of our time; it allowed us to educate and involve friends and family members and it also provided the opportunity for peer support. For many, it was the first time they had met someone else with MS and allowed them to share their own experiences of living with the condition. It also allowed informal carer support from the team, but also from other carers.

## What might the course do?

- Encourage active involvement and participation in health management
- Empower patients to make decisions and work in collaboration with the MS team

- Educate and improve knowledge for both patients and families
- Be deliberate and explicit about self-management
- Explain the responsibility of the patient in managing their condition
- Enhance patient's ability to take action appropriately
- Improve patient understanding of the roles of different health professionals
- Encourage and facilitate a healthy lifestyle
- Allow peer support
- Facilitate adjustment to diagnosis and/or a progression

Whilst this group allows us to be direct about self-management and provides a good basis for understanding living with MS, there may be times when further intervention of this type is necessary.

This approach might also be used in our one-to-one sessions, other group sessions and MS clinics. We have found some patients are more accepting of self-management than others and for some it takes time to understand this approach in living with a long-term condition.

## Course format

The course takes place for two hours, one evening per week, over six weeks (Figure 1). It is held at a local, accessible community centre and is funded by the local MS Society branch. The branch volunteers help to host and contribute their experience to the evenings.

If patients decline an invitation or are unable to attend, they are asked again up to three times. One of the reasons we do this is to allow for the varying time needed by some to make their first steps towards accepting their condition, meeting others with MS and talking about their experiences. We invite double the capacity of the venue to ensure a good number of attendees and allow for a drop-out rate.

The course is delivered by the MS team along with others who generously give up their time. Those professionals with an interest in MS who help are provided with feedback and evidence for their continuing professional development portfolios. Complementary therapists and exercise instructors were found via Cancer Network and other regulatory bodies.

**Figure 1: Course plan**

Week	Welcome & drinks 10mins	Part 1: Teaching and discussion 40 mins	Break 20mins	Part 2: Exercise/Activity taster session 40 mins
1		<b>What is self-management?</b> MS Team		<b>Exercise and MS</b> MS Specialist PT
2		<b>Fatigue and MS</b> - MS Specialist OT		<b>Tai Chi</b> - Tai Chi Instructor
3		<b>Diet and MS</b> - Dietician		<b>Pilates</b> - PT
4		<b>Complementary therapies</b> - Massage, Reiki, Alexander Technique, reflexology, acupuncture, relaxation, aromatherapy		
5		<b>Work and MS</b> - MS Specialist OT		<b>Kickboxing</b> - Kickboxing Instructor
6		<b>Group dinner</b> - optional		

Patients are provided with a selection of relevant literature to take away, to help reinforce what they have heard during the sessions. We also provide details of local exercise groups and services to facilitate patient participation beyond the group.

## Impact of the course

The course has set the trend for the patient's journey and their relationship with the MS team by:

- having a flexible and informal approach in a community setting
- being locally relevant
- 'normalising' living with MS
- increasing appropriate self-referrals
- increasing peer support and friendships
- providing a point of reference for the future
- improving understanding of the MDT roles and who to approach for help
- demonstrating the MDT approach and collaborative working
- creating an interest and desire to access the team for support.

Anonymous patient feedback from questionnaires, which include a numerical rating scale (from 1 to 10), and comments help us to help us to review and adapt the group accordingly. For example, in feedback from our last three sessions people gave ratings between 8 and 10 when asked how useful or enjoyable they found the session.

## Comments from patients included:

"It just opened my eyes. I can now see that I can carry on my life as normal - as normal can be for me."

"I now have a more positive outlook on current matters and possibly more rational thought!"

"It has given me the impetus and motivation to get out of the house, eat healthily and exercise."

"It's helped me not to feel guilty and have more understanding of fatigue and how to deal with it."

"Very informative and allowed me to bring up issues I wouldn't bring up normally."

"It has been useful to know my legal rights at work and where to get support."

## Final thoughts

This course demonstrates a model of good practice, which is in-line with national guidelines and reflected in our patient feedback. It is constantly evolving in response to feedback to ensure we continue to meet patient's needs.

Our team philosophy is to be flexible, approachable, honest and knowledgeable. This, combined with the fact that we really enjoy running the course, contributes to its effectiveness and success.

Looking forward, we will continue to offer this course to all newly diagnosed patients. Whilst a large percentage of our patients have now attended the course, we are reviewing how else we can support them on their journey of living with MS. This year we plan to run an additional session with a different format and timing, but with similar content.

## Information and support

Contact [Emma.Manchester@bthft.nhs.uk](mailto:Emma.Manchester@bthft.nhs.uk) (PT) or [Emma.Matthews@bthft.nhs.uk](mailto:Emma.Matthews@bthft.nhs.uk) (OT) for further information.

See the back page to order a copy of the MS Trust publication *MS and Me: A self-management guide to living with MS*. Also available to read online, order or download from our website:

[www.mstrust.org.uk/msandme](http://www.mstrust.org.uk/msandme)

### References

- National Institute for Clinical Excellence. Multiple Sclerosis: Management of multiple sclerosis in primary and secondary care. NICE Clinical Guideline 8. London: NICE; 2003.
- Department of Health. The National Service Framework for long-term conditions. London: DH; 2005.
- Embrey N Fox L. MS and Me: A self-management guide to living with MS. Letchworth: MS Trust; 2010.

# Secondary progressive MS: the transition



picture: Yamanaka Tamaki

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**This article discusses the experiences of living with the transition from relapsing remitting multiple sclerosis to secondary progressive multiple sclerosis and explores ways the roles cognitive behavioural therapeutic and mindfulness interventions may play in adjustment in managing the transition stage.**

## More information is needed on the transition to SPMS

Despite the transition from relapsing remitting MS (RRMS) to secondary progressive MS (SPMS) being an expected part of the disease trajectory<sup>1</sup>, unfortunately little is known about how or whether the experiences of those with the condition change with increasing disability<sup>2</sup>. Epidemiological studies indicate nearly 10% of people with RRMS reach the SPMS stage after five years, which increases to almost 25% at ten years and 75% at 30 years<sup>3</sup>. Research to date has mainly focussed on the physical aspects of the condition, describing the various symptoms of SPMS, such as fatigue, mobility problems, pain, sleep disturbances, visual problems, weakness, ataxia, spasticity, bulbar dysfunction, sexual dysfunction, and continence difficulties, commonly reported. Studies also indicated that approximately 50% of those with SPMS may also develop some cognitive impairment such as memory and information processing deficits<sup>4</sup>. With regard to the limited but available research on emotional problems, it is argued that rates of depression and anxiety are also considered to be greater in SPMS than in other forms of the condition<sup>5</sup>.

The effectiveness of cognitive behavioural therapy (CBT) to improve the psychosocial outcomes associated with MS has been demonstrated in a number of studies<sup>6</sup>. However, gaps are evident in the literature concerning the change in disease trajectory to SPMS, and a significant lack of literature exists concerning CBT and the transition from RRMS. This is perhaps unsurprising given the paucity of research concerning the experiences of people with SPMS and generally indicates that further research in this area is warranted.

## Importance of information sharing

Edmonds et al<sup>4</sup> argue that people with SPMS are involved in what they feel is a hopeless battle fighting for help with the condition. Despite National Institute for Health and Clinical Excellence (NICE) guidelines on management of MS in primary care affirming the need for information sharing<sup>7</sup>, it appears this position is not being universally adopted. There is a further lack of continuity and coordination of care, linked with a perceived lack of information about services, aids and adaptations, and welfare benefits which results in a strong sense of people with SPMS needing to 'fight for everything'<sup>4</sup>. As MS is an autoimmune disorder, where the body is essentially fighting itself, the value of an additional fight has to be questioned. The unfortunate irony is symptoms are usually more predictable and stable in the SPMS stage<sup>8</sup>. However, for some people, being told they have SPMS can be as much of a shock as the initial diagnosis, with some people with MS living in fear of the word 'progression'. It could be argued the transition to SPMS forces people to rethink their later years and future aspirations. The role of clinicians within the information provision stage also has to be questioned, as some appear reluctant to inform people when they are in the progressive phase of MS<sup>8</sup>. Reasons why this is the case appear not to be evident within the literature, and is a further area worthy of research consideration. It could be speculated that this may be due to clinicians not being able to accept they have somehow failed to halt progression.



picture: Andrew Blight

## Emotional reaction to transition

Despite the problems associated with the lack of information concerning progression, emotional issues are not an inevitable consequence of SPMS<sup>9</sup>. However, the potential disease trajectory can lead to some people to believe they have an untreatable condition. This may partly explain the potential emotional reactions such as fear, anxiety, depression and reduced self-efficacy. This may accentuate a perception of loss, as according to the literature, SPMS results in significant physical and psychosocial losses. In particular, the fear of losing control appears to be significant. This can lead to maladaptive attempts to gain it back, such as giving up important responsibilities, which can result in the construction of an illness 'identity'. For example, people who may be struggling to effectively manage in the workplace may decide that it's an easier option to give up working altogether.

Despite the potential losses, such as occupational role, many people with SPMS eventually find they are able to cope with these fearful and difficult circumstances. Having a realistic mental attitude appears significant in helping to achieve this, as it can protect against the emotional consequences such as fear of the unknown, sadness, and the frustrations that can follow progression. This 'empowerment' appears to involve those with the condition avoiding grieving for things that are not within their control, engaging in positive self-talk, developing a proactive approach, avoiding blaming the condition on anyone else and reclaiming a sense of control by recognising choices still exist<sup>10</sup>.

## Interventions to manage transition

It could be argued SPMS does not have the power to change who people are, or how they see themselves, unless they allow it to. Therefore, CBT type interventions, such as cognitive restructuring, can offer potential help in challenging unhelpful thoughts and encouraging people to check the accuracy and validity of their appraisals. By recognising psycho-educative aspects, such as 'thoughts aren't facts', and that 'just because you believe something, it doesn't mean it's true', people with SPMS could potentially be better able to recognise and to accept the actual losses of the condition, rather than catastrophise and worry about future ones that may never happen.

A further improvement in quality of life for those with SPMS can also be achieved by valuing day to day life experiences, living in the moment and by accepting the condition. This would suggest mindfulness offers a therapeutic opportunity. Mindfulness is defined as 'paying attention in a particular way: on purpose, in the present moment, and non-judgmentally'<sup>11</sup>. A recent randomised controlled trial involving people with SPMS highlighted the benefits of mindfulness-based CBT interventions<sup>12</sup>.

People with MS potentially go through stages of denial and isolation, anger, bargaining, depression and finally, acceptance<sup>13</sup>. It could be argued the same process is repeated for people with SPMS and adjustment eventually

occurs naturally. It is our position that CBT and mindfulness based practices could hasten this adjustment process and therefore could relieve emotional distress quicker. This may have relevance as anecdotal evidence would indicate that a decrease in emotional well-being, as a result of the transition in disease trajectory, may well have an impact on healthcare costs.

Consequently, it is recommended there is a paradigm shift towards specific research in SPMS, and that either one-to-one or group based CBT interventions are provided to assist people in adjusting to SPMS. However, given the lack of specialist practitioners within this field, and in order to reach the numbers of people potentially affected, it may be that alternative resources could be employed to reach the maximum number of people, such as self-help DVDs or online courses.

In conclusion, it has been suggested that the transition to SPMS can potentially have a detrimental effect on a person's assumptions about their well-being. It has been suggested CBT and mindfulness-based interventions offer utility in assisting with those emotional consequences that may be present, so that emotional problems are far from inevitable.

### References

1. Kalb R. Secondary Progressive Multiple Sclerosis: clinical challenges & treatment advances. *Int J MS Care*. 2000 (September 2000 Supplement):21-8.
2. Edmonds P, Vivat B, Burman R, et al. Loss and change: experiences of people severely affected by multiple sclerosis. *Palliat Med* 2007;21(2):101-7.
3. Tremlett H. Secondary Progressive Multiple Sclerosis. *MS in Focus* 2009;13:13-4.
4. Edmonds P, Vivat B, Burman R, et al. 'Fighting for everything': service experiences of people severely affected by multiple sclerosis. *Mult Scler* 2007;13(5):660-7.
5. Montel S, Bungener C. Coping and quality of life in one hundred and thirty five subjects with multiple sclerosis. *Mult Scler* 2007;13(3):393-401.
6. Dennison L, Moss-Morris R. Cognitive behavioral therapy: what benefits can it offer people with multiple sclerosis? *Expert Rev Neurother* 2010;10(9):1383-90.
7. National Institute for Clinical Excellence. Multiple Sclerosis - Management of multiple sclerosis in primary and secondary care. NICE Clinical Guideline 8. London: NICE; 2003.
8. Smith A. Secondary progressive MS: meeting the challenge of person centred care. *Way Ahead* 2009;13(1):8-9.
9. Kirkpatrick Pinson DM, Ottens AJ, Fisher TA. Women coping successfully with multiple sclerosis and the precursors of change. *Qual Health Res* 2009;19(2):181-93.
10. Malcomson KS, Lowe-Strong AS, Dunwoody L. What can we learn from the personal insights of individuals living and coping with multiple sclerosis? *Disabil Rehabil* 2008;30(9):662-74.
11. Kabat-Zinn J. *Wherever you go, there you are: Mindfulness meditation in everyday life*. New York: Hyperion Books; 1994.
12. Grossman P, Kappos L, Gensicke H, et al. MS quality of life, depression, and fatigue improve after mindfulness training. *Neurology* 2010;75(13):1141-9.
13. Beiske AG, Svensson E, Sandanger I, et al. Depression and anxiety amongst multiple sclerosis patients. *Eur J Neurol* 2008;15(3):239-45.

## MS Trust project on transition

The MS Trust will be holding a chatroom in May 2012 on the transition from relapsing remitting MS to secondary progressive MS. More information can be found on page 16.

In the near future, we also aim to provide a publication on this topic for people with MS and would welcome your ideas and thoughts; please email [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

# Using the StayingSmart online resource in clinical practice



Pauline Shaw and Joan Regan, MS Specialist Nurses, Guy's and St Thomas Hospital NHS Trust, Dulwich Community Hospital, London

Cognitive impairment prevalence rates have been reported in 40-70% of people with MS<sup>1</sup>. Those affected are less likely to be in employment and engage in social activities<sup>2</sup>.

Memory, attention, planning, information processing, word finding and visuospatial problems are areas of cognitive function that are commonly reported to be compromised.

**A reliable memory** is a fundamental requirement of day to day functioning. The three components of memory consist of:

- encoding - getting the information in
- consolidation – transferring the information into the long-term store
- retrieval – getting the information out.

People with MS often appear to have difficulty with encoding and retrieval of information causing potential problems with remembering appointments, paying bills on time, recalling what someone has just told them, forgetting what they have just read and difficulties recalling recent events.

**Attention problems** are often reported by people with MS as difficulties with concentration and keeping on track with a task, staying abreast with a conversation and being able to follow the storyline of a book or film.

**The executive functions** of the brain such as planning and organising, when affected can cause the person with MS to have difficulties in making future plans, solving problems, organising and prioritising day to day activities and functions.

Some people with cognitive impairment require more time to **digest new information**. It may take them longer to process the information and formulate a response, causing them to feel embarrassed and frustrated.

**Language difficulties** can present with changes in verbal fluency, slower speech, word finding problems and difficulty forming words possibly resulting in low self-esteem.

**Visuospatial problems** occur when people experience difficulty assembling items, reading maps, orientation and recognising objects correctly.

Any of these cognitive symptoms can result in the person with MS feeling frightened and anxious, along with impacting on relationships and employment. This in turn may lead to periods of depression and subsequently exacerbate any cognitive symptoms.

## Screening and support for cognitive problems

### Guy's Neurological Disability Score (GNDS)

Cognitive dysfunction may go undetected and recognising it early in the disease process is important in assisting patients to understand the symptoms and deploy useful management strategies. Screening for cognitive dysfunction is a domain of the Guy's Neurological Disability Score (GNDS)<sup>3</sup>, an assessment tool used by an MS nursing team in South London. The cognitive domain encourages the nurse to detect cognitive problems by asking if the patient or family have noticed any problems with concentration and memory over the past month and whether they require help to manage this. The problem is then assigned a grade based on criteria shown in Figure 1.

Figure 1. Guy's Neurological Disability Score (GNDS)

Grade	Observation
0	Unaffected
1	Not noticeable to others
2	Noticeable but not require help
3	Requires help, orientated
4	Not fully orientated
5	Completely disorientated

## StayingSmart online resource

Patients who are graded as 1, 2 or 3 by GNDS cognitive domain are encouraged to explore self-help strategies such as the StayingSmart web-based resource. Patients will often disclose for example how they struggle with their memory, but then realise with the right prompts they can recall recent events. StayingSmart, as an example, offers useful strategies for managing memory problems which can be customised to individual needs. Problems with word finding is another often reported symptom; the StayingSmart website also gives useful hints and tips on addressing word finding problems, along with gadgets and gizmos that can be helpful.

## Multiple Sclerosis Neurological Questionnaire (MSNQ)

Further comprehensive assessment and investigation may be necessary for patients scoring 3 and above in the GNDS cognitive domain. The Multiple Sclerosis Neurological Questionnaire (MSNQ)<sup>4</sup> has been developed as an alternative brief screening tool for use in clinical practice. It is a self-administered test and comprises 15 questions that reflect neuropsychological competence. Examples of questions include “do you need to have instructions repeated?” and “do you laugh or cry with little cause?”. The MSNQ then directs the health professional towards onward referral for more structured neuro-psychometric testing.

## Moving on successfully – information on memory and thinking

Screening often highlights the needs of people with MS and their families for further information on cognition. This finding led to the concept of organising an information event to facilitate self-management strategies for people with cognitive problems. Previous group educational events for people with MS, together with feedback at routine appointments, confirmed this need. A service user also sought the views and opinions of people with MS which was fed back to the nursing team at a planning meeting and resulted in the development of a half-day information event named as ‘Moving on successfully – information on memory and thinking’. The objective of the event was for people with MS and their relatives to be able to identify specific symptoms associated with cognitive involvement and learn strategies and techniques to manage them using a range of resources and strategies.

The GNDS assessment tool was used to select people for the event. Those who scored between Grade 1-3 were invited to the event along with a friend or relative, if they wished. In total, 14 people with MS (15% of those invited) attended the day of the event along with two relatives.

A local school provided a suitable venue for the event offering a disabled access and good public transport accessibility. Five health professionals took part in the day: three MS specialist nurses, an occupational therapist and a speech and language therapist.

To begin with, the event was launched with an overview of

cognition. To enable and encourage the day to be patient led, the participants were divided into three groups, to encourage people to identify and discuss individual symptoms, experiences and the solutions they had found helpful. The symptoms covered included difficulties with word finding, attention and concentration, speed of thinking, memory and problem solving. Each group was facilitated by an MS specialist nurse, occupational therapist or speech and language therapist. The individual group findings were fed back to the whole group by presenting one symptom example and two ideas of how to manage the problem. For example:

### Symptom:

“I often forget what I want to say and loose the thread.”

### Management suggestions:

“Ask my husband to give me a prompt.”

“Be patient and wait.”

Available interactive resources to help manage cognitive dysfunction were demonstrated including StayingSmart. An overview of StayingSmart was given and a specific section of the website was explored in more depth. The example used was a person forgetting where they leave their keys and exploring the useful tips and advice on how to manage and overcome this.

The event concluded with a personal account and experiences of a service user.

## The value of an information event and StayingSmart for people with cognitive problems

The majority of participants (13 in total) completed evaluation forms for the event and highlighted the benefits of the event:

“Coming as a partner has helped me to be more understanding and tolerant when he is having a bad day.”

“I liked the idea of the website – very helpful.”

“It’s good to know it’s not just you who has the problem.”

“The best part of the day is being with fellow MS people and being able to exchange experiences and concerns.”

The StayingSmart website [www.stayingsmart.org.uk](http://www.stayingsmart.org.uk) was found to be a useful and flexible tool for people with MS to navigate, in order to help manage problems with cognition both in their own environment and in a group education meeting, and allows an interactive approach to learning.

### References

1. Langdon D. Cognition in multiple sclerosis. *Curr Opin Neurol* 2011;24(3):244-9.
2. Krupp LB, Christodoulou C, Melville P, et al. Donepezil improved memory in multiple sclerosis in a randomized clinical trial. *Neurology* 2004;63(9):1579-85.
3. Sharrack B, Hughes RA. The Guy’s Neurological Disability Scale (GNDS): a new disability measure for multiple sclerosis. *Mult Scler* 1999;5(4):223-33.
4. Benedict RH, Munschauer F, Linn R, et al. Screening for multiple sclerosis cognitive impairment using a self-administered 15-item questionnaire. *Mult Scler* 2003;9(1):95-101.

# StayingSmart – how do you use it?

Lynn Fox, Information Officer, MS Trust

Pauline Shaw and Joan Regan have given an excellent account of managing MS cognitive problems in clinical practice and the role the online resource StayingSmart can play. To find out how other health professionals are using this resource we recently carried out a short survey.

71 health and social care professionals completed a questionnaire either online or at the MS Trust annual conference. Over 70% of survey respondents were recommending StayingSmart to people with MS and their relatives once a month or more, and reported that 41% of people with MS rated StayingSmart as "very useful". 80% of respondents were using StayingSmart to update their own knowledge of cognitive problems in MS and recommending it to colleagues.

What the health professionals liked best about StayingSmart were the practical tips for daily living:

**"The tips are useful and enable patients to self-manage their cognitive problems."**

**"It gives an opportunity to provide people with MS, who themselves identify cognitive challenges, with a support tool they can use to 'pick and mix' for their individual circumstances."**

There were great ideas about how we might be able to improve the resource such as using more video content, provide ideas about how to run workshops on cognition for people living with MS, and hosting a Facebook page for people to share their problems and coping mechanisms.

But the message that came back from the responses we received was that some health professionals still aren't aware of StayingSmart.

**"If we don't use it, it won't work! Promote it more often!"** – So this, unashamedly, is what we're doing.

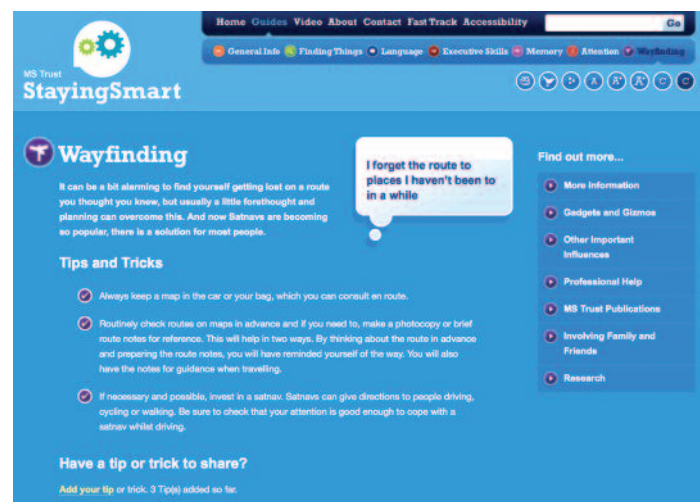
**The aims of StayingSmart are to:**

- support learning about cognition in MS
- build confidence in managing cognition in MS
- facilitate sharing of knowledge about and experience of cognition in MS.



To help people work out which type of thinking is tricky, StayingSmart starts with everyday problems.

There are different levels of information for each aspect of cognition considered, a brief explanation of the different cognitive issues in MS and Tips and Tricks where people are invited to share their experiences of how they manage the symptom.



This is supported by video footage of people describing their experiences of cognitive difficulties in the workplace and at home.

For health professionals, each section also includes an extensive evidence base. The MS Trust also provides StayingSmart cards that health professionals can distribute to people with MS. These are available to order from the back page.

A Kindle has been awarded to Nadine Morley, MS specialist nurse, Horsham Hospital, West Sussex for her answers to the survey prize questions:

## What do you like best about StayingSmart?

- It is interactive and allows easy access for most people.

## What could StayingSmart do better or have added to increase its usefulness?

- An App for smart phone or to be able to access without the web.
- Assist patients who are less computer literate.

There were some great ideas and we will use these as we develop StayingSmart further. Thank you to all who took part in the survey and if you have more thoughts on how we can further improve StayingSmart, or any of our other resources, do let us know.



# Education news



## MS Trust professional development programme - what we do and how you can participate

It is a core aim of the MS Trust to provide educational events for health professionals who work to support people with MS. Since September 2005, the Education Team have organised a broad programme of events across the UK, bringing professional development opportunities to nearly 5,000 health professionals who have an interest in MS. We seek to bring the best clinical expertise together with practitioners interested in supporting people with MS, to improve care and services.

### For MS specialists

**Development of MS care and management for specialists** – an accredited week long residential course aimed at the new-in-post MS specialist. Since 2005, 235 specialists, mostly nurses but also physiotherapists and occupational therapists, have completed the development module.

**Specialist study days and masterclasses** – one day advanced level events on topics including depression, the Mental Capacity Act, spasticity, fatigue and postural management, as well as updates on recent developments in drug therapy from MS neurologists. Upcoming events are planned on Sexuality and MS and Advanced MS. Over 200 MS specialists have attended these events.

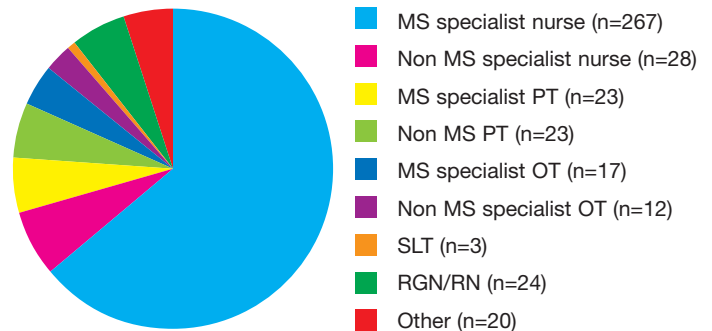
**MS Specialist Nurse meeting** - a two-day annual event for MS nurses, with a varied programme covering clinical and service development.

**The MS Trust annual conference** for health and social care professionals – nearly 2,000 delegates have attended our conference since its launch. In 2011, 99% rated the conference as excellent and 88% of attendees said they would proactively change their clinical practice as a result of what they had learned.

### For generalists

**Study days** - nearly 1,500 health professionals have participated in our study days held across the UK. These events provide a comprehensive overview of MS treatments and therapies. Study days are arranged to meet local demand and have also been organised in collaboration with professional groups, such as Therapists in MS (TIMS) and Association of Chartered Physiotherapists Interested in Neurology (ACPIN).

Figure 1: Who attended MS Trust educational events in 2011?



## Interested in attending or developing a study day?

The Education Team can provide up to date information about upcoming events or you can check the website for events scheduled in your area.

If you would like the MS Trust to organise a Study Day in your area or for your organisation, just contact the Education Team [education@mstrust.org.uk](mailto:education@mstrust.org.uk) who will be glad to discuss it with you. We have all the expertise to plan an event and engage expert speakers.

## New Education Team member

We are delighted that Tanya Spencer, our new Education Officer, has joined Delia and Brenda in the team. Tanya brings a wealth of experience in event management and this much needed increased capacity in the Education Team will allow us to offer an increasing variety of events and course formats.

## MS Trust annual conference, 4-6 November 2012

We promise this year's MS Trust annual conference for health and social care professionals will provide a mix of plenary and seminar sessions covering the latest research and clinical practice. The venue will again be Chesford Grange in Kenilworth and you can be assured of plenty of time to network with professional colleagues from across the UK and from further afield! See the MS Trust website for more information and booking [www.mstrust.org.uk/education](http://www.mstrust.org.uk/education)



## The information needs and preferences of people newly diagnosed with MS

The MS Trust has commissioned a piece of research to explore the information needs of people who are newly diagnosed with MS and their families and carers. The research has two aims:

**Principal aim** – to explore the information needs and preferences of people who have been newly diagnosed with MS, their family and carers.

**Secondary aim** – in the light of the information needs and preferences of people newly diagnosed with MS that have been identified above, to evaluate current MS Trust resources to meet those needs.

The research project will run from January to June 2012 and has two key phases. First, a range of qualitative methods will be used to gain an understanding of the experiences and views of people with MS. Topics for discussion include how people access information about their condition, what their preferences are and how the information is supported by others. Health professionals play an important role in many of these areas. In addition, the research will explore what people with MS use information for, for example whether they use it to make decisions about treatment or to gain reassurance.

The research methods comprise telephone interviews, in-depth face to face interviews and focus groups. Most of the participants will be people with MS, diagnosed within the last five years. One focus group and a number of interviews will also be undertaken with family members and carers. The findings from the interviews and groups will be used to inform the secondary research aim.

The second phase of the research analyses the MS Trust's Information Service and resources using a range of methods including patient journey mapping, observation of the MS Trust's Information Service and analysis of how it is used.

The research will include discussions with health professionals, particularly MS specialist nurses, to elicit their views on information. The aim is to determine whether health professionals have different views on the information needs of people with MS or can identify gaps in information provision. The findings from the qualitative work will be mapped against the current MS Trust service

and its usage, which will assist the MS Trust in planning the next phase of its work for people who are newly diagnosed with MS.

If you would like further information about the project please contact Jane Havercroft on 01462 476700 or [jane.havercroft@mstrust.org.uk](mailto:jane.havercroft@mstrust.org.uk)

## A chance to broadcast to the nation!

We are excited to announce that the MS Trust has been selected for a Radio 4 Appeal, to be broadcast on 20 May 2012.

**BBC  
RADIO**

92–95 FM



This is a great opportunity for us to reach out to people who may never have heard of the MS Trust, to let them know what we do and to ask for their support. The money raised will fund some of the work that comes out of our research project, helping us to provide people diagnosed with MS with the information they really need.

Our last Radio 4 Appeal in 2008 brought in over £12,000, vital funding which helped us to provide information for hundreds of people with MS and their families. With 50 people being diagnosed with MS every week in the UK and with a 36% increase in enquiries to our Information Service since 2008, we desperately need to bring in more donations to meet this increasing demand.

Please spread the word and encourage people to listen to our appeal. If you can display a flyer on your notice board, we'd love to hear from you. Contact [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) or Tel: 01462 476707.

You can hear our appeal on Radio 4 on Sunday 20 May at 07:55 and 21:26 and on Thursday 24 May at 15:27. You can also listen online after the broadcast at [www.bbc.co.uk/radio4/appeal](http://www.bbc.co.uk/radio4/appeal)

# Publications: what's new?

Spasticity triggers  
What to do if you have a worsening of  
your muscle stiffness and/or spasm



## Spasticity triggers

Spasticity and spasm are common symptoms of MS. Factors, such as infections, skin irritations or bladder and bowel problems, can all significantly worsen spasticity or trigger spasms. Identifying and managing these triggers can help to effectively manage spasticity.

To identify any trigger factors that may be affecting someone's spasticity the MS Trust has published *Spasticity triggers* by physiotherapists Jane Lough and Paula Cowan. The book guides people through common triggers and allows them to put together a list to discuss with their health team. A spasticity and spasms diary also helps to identify patterns of symptoms and potential triggers. The authors will write more on this subject in a forthcoming issue of *Way Ahead*.

See [www.mstrust.org.uk/triggers](http://www.mstrust.org.uk/triggers) to read online, order or download from our website

## Posture

A new online publication on posture by the MS Trust explains why good posture is important and offers practical steps to help people with MS improve how they stand, sit and lie. Written by physiotherapist Helen Conyers, the pages look at good and bad posture, the role of core muscles and some ideas for thinking about posture. The book *Are You Sitting Comfortably*, which looks at posture for people who spend most of the day sitting, is still available.

See [www.mstrust.org.uk/pubs](http://www.mstrust.org.uk/pubs)

## Disease modifying therapies - what you need to know

The new online edition of this book is available on the MS Trust website and printed copies will be published in May 2012. This edition has been updated to include new information on beta interferon drugs, glatiramer acetate, natalizumab and fingolimod.

To order copies of these books and other MS Trust publications email: [info@mstrust.org.uk](mailto:info@mstrust.org.uk), tel: 01462 476700. Also available to read online, order or download from our website.

See [www.mstrust.org.uk/pubs](http://www.mstrust.org.uk/pubs)

## Defining the value of the MS specialist nurses

The significant variation and deficit in MS specialist nurse support for people in the UK is described on page 5. NHS reforms and rising financial pressure mean that MS services need to make themselves visible to a new group of clinical commissioners and provide objective evidence of the difference they make.

As part of the MS Trust's Nurse Support Programme, *Defining the value of MS specialist nurses* was published in March to advance our understanding about the opportunities and challenges in showing the real impact of MS specialist nursing services. The report summarises a study commissioned by the MS Trust from Mynors Suppiah, in which they reviewed existing research on MS nurses and specialist nurses in other specialties and undertook two in-depth case studies of the MS nurse teams based in Greater Manchester and in East Kent. The study also involved a mapping exercise, based on the responses to a national nurse survey in 2011, to show regional variations in the availability of MS nurse time. The resulting map is an invaluable tool for both local and national campaigning.

The report makes a series of important recommendations for future work, including the need to:

- describe the different service models currently operating amongst MS nurse services and how these fit with the long term conditions agenda
- define clearly what is meant by 'caseload' and make explicit the assumptions underpinning the idea of an acceptable caseload, according to service model
- share good practice across the MS nursing community in terms of efficient and effective working practices
- develop a set of evidence-based quality standards for MS nursing services
- up skill MS nurses in evaluating their services through data collection, clinical audit and patient experience
- present data on the value of MS specialist nurses to make a robust case to the future commissioners.

We know how important MS nursing services are to people with MS, and the MS Trust will continue to take forward work in this area in 2012.

See the back page to order a copy of the study *Defining the value of the MS specialist nurses* or download from our website [www.mstrust.org.uk/value-of-nurses](http://www.mstrust.org.uk/value-of-nurses)

## Publications

For a complete listing of all our publications and factsheets visit our website at [www.mstrust.org.uk](http://www.mstrust.org.uk)

### Publications for health and social care professionals

- MS information for health and social care professionals  
**NEW EDITION**
- Competencies for MS specialist nurses
- Defining the value of the MS specialist nurses **NEW**
- Spasticity care pathway

### Publications for people with MS – (a sample)

- Spasticity triggers **NEW**
- At work with MS: managing work and life **NEW EDITION**
- MS and me: A self-management guide to living with MS
- Are you sitting comfortably?
- Living with fatigue **REVISED**
- MS Trust publication list 2012 **NEW**
- StayingSmart card

### Factsheets – (a sample)

- Functional electrical stimulation (FES)
- Fampridine (Fampyra)
- Fingolimod (Gilenya)
- Spasticity and spasms
- CCSVI **NEW**

All items are free unless otherwise stated, 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

*giftaid it* 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 28p of tax on every £1 that I gave up to 5 April 2008 and 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.

## What do you think?

### Advanced MS

Whilst MS is considered a serious long-term condition that can, in rare severe cases, lead to death, MS is not thought of as a terminal illness, and most people with MS will live just as long as anybody else.

The MS Trust aims to develop resources to support people with MS, their carers and health professionals about end of life issues, such as choices, palliative care, planning ahead, and advance decisions.

We would welcome your ideas on this difficult subject; please email [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

In the next issue of Way Ahead, Colin Campbell, consultant in palliative care, St. Catherine's Hospice, Scarborough, will be addressing this topic.

### Transitions chatroom

The MS Trust will hold a chatroom on 16 May 2012 on the transition from relapsing remitting to secondary progressive MS. The session runs from 10am until 7pm and will enable people with MS to ask questions of health professionals and share their experiences.

See [www.mstrust.org.uk/chat](http://www.mstrust.org.uk/chat)

Please let us know if you would like flyers or posters for this event.

## MS Awareness Week 2012

The week of 30 April to 4 May 2012 is MS Awareness Week 2012. There is, like last year, the opportunity for everyone to 'Be Bold in Blue'. If you want to hold an information stand, contact [info@mstrust.org.uk](mailto:info@mstrust.org.uk) for posters and materials for your MS awareness activities.



See [www.mstrust.org.uk/msawareness](http://www.mstrust.org.uk/msawareness) for more information.

**Multiple Sclerosis Trust**

**MS**

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