

Study finds MSSNs are still under pressure from increasing workload

A workforce modelling study, carried out on behalf of the MS Trust, found caseloads of up to 2,000 people, overstretched nurses and work left undone.



Prof Alison Leary, author of the report

Complex patient needs, evolving drug therapies and changes to the benefits system are forcing MS nurses to work unpaid overtime and impacting on care.

“At the current recommended caseload range, a considerable amount of work is left undone. This is particularly so of psychosocial care, symptom control and medicines management,” said the paper, which is due to be published in the Multiple Sclerosis Journal.

Anecdotal evidence from the MSSN population, the study found, indicated that demand on services was continuing to grow.

“One of the drivers for this is the increasing treatment options which require extra resource, such as supporting patients with shared-decision making, patient education and monitoring,” it said.

The study first analysed around 70million advanced practice hours, carried out since 2009, to establish patterns in the workload of nurse specialists across long-term conditions.

A workshop then asked 13 MSSNs from across the UK to explain their roles, looking at work environment, physical and psychological domains, social issues, case management, administration and what work was left undone.

Finally, a 24-question survey was distributed via the MS Trust and the UK Multiple Sclerosis Specialist Nurse Association (UKMSSNA). A total of 163 people, or 56 per cent of the UK’s MS nurses, took part.

The work found caseloads of up to 2,000 people and the amount of unpaid overtime carried out by MSSNs equated to 17.2 full-time posts.

“One potential issue is unfilled MSSN posts. In this study, the number of unfilled posts reported by respondents is estimated to be equivalent to 35 FTE,” said the paper, adding that just 17 per cent of respondents said they didn’t regularly carry out unpaid overtime.

Variability in administrative support, which has been shown to increase productivity in other therapy areas, was highlighted, as was the amount of time MSSNs spent supporting patients’ benefit claims and travelling between patients and clinics.

The paper concluded that a caseload of around 315 people was “more realistic” though “not absolute”, as complexities such as comorbidities, symptom control issues or high psychosocial needs needed to be accounted for.

“This figure is based on the average for the group. Five to 10 per cent of the caseload is complex and requires approximately 30 per cent of the available time,” it said, concluding that if more than 10 per cent of patients required two or more hours of MSSN time a week, the 315 figure should be “adjusted downwards proportionally”.

Providing the tools for best practice care

A new toolkit aims to help CCGs in England to commission and deliver best practice neurology services - and avoid thousands of emergency hospital admissions.

The new NHS RightCare Progressive Neurological Conditions Toolkit guides commissioners through the needs of people with MS, motor neurone disease (MND), Parkinson’s and multiple system atrophy, and explains how best to meet them.

“We are urging every single CCG to work with the charities involved to implement this guidance and ensure people with progressive neurological conditions are not neglected.”

Paru Naik, MS Trust

Dawn Chamberlain, Programme Director for Clinical Improvement at NHS England and NHS Improvement, said the project was about reducing variations in care by sharing knowledge across the system.

“Many areas are already providing high quality care in line with best practice,” she said.

continued on page 3

Welcome to MS in Practice Issue 6



Welcome to the sixth edition of MS in Practice.

Will we ever see the day when we and the rest of the neurology sector become a priority in the NHS?

The Neurological Alliance discovered delayed and inequitable access to neuro services among many of the 10,000 people who took part in its 2019 survey (p3). It found that almost one in four didn't even have access to a specialist nurse.

While the new neurology toolkit (p1) and the Raising the Bar project (p4 and 5) should help ensure best practice is shared more widely and reduce variations in care, it seems to me that a national neurology plan is needed – and quickly before the situation in our sector gets any worse.

David Martin,
CEO, MS Trust

MS Trust Enquiry service

The service is available to help anyone affected by MS to find the information they need. Please pass on the information to anyone who might find it useful.

- Ring us on 0800 032 3839 (Monday to Friday 9am-5pm),
- email ask@mstrust.org.uk
- visit www.mstrust.org.uk/infoteam

MS Trust celebrates awards win for patient information

The Information and Engagement team visited the British Medical Association in September for the annual Patient Information Awards.



The MS Trust's Information and Engagement team celebrate their success

The MS Trust entered five different information resources, and we were delighted to receive an award for everything we entered! We were especially pleased to note that it wasn't just the traditional book format that appealed to the judges, they loved our online information too.

The website reviewer commented: "I loved this website, and spent a long time exploring it, learning quite a lot on the way. Visually, it looks great; the structure has been very well-thought out, with multiple links so that users can take different routes to the information they want. The content is very well-written, with just the right tone. The contributions from patients and professionals add a huge amount to the value of the site. This

is a fantastic resource that has had a lot of thought and effort put into it. I strongly commend it."

The full list of our awards:

- **Runner Up** (Long Term Conditions): The MS Trust website
- **Highly Commended and shortlisted** (Young Adults): MSTV: a Youtube channel for young people affected by MS
- **Highly Commended** (Decision Making) Disease Modifying Drugs: a guide to treatments for relapsing MS
- **Commended** (Self-Care): Managing your Bladder: a guide for people with MS
- **Commended** (Equality, Diversity and Inclusion): Sex and MS: a guide for Men/Women



Introducing Helen

We are pleased to announce the recruitment of Helen Govey to the post of Health Professional Programme (HPP) Coordinator.

Helen has worked for the MS Trust for just over a year helping us manage our diaries and working primarily on coordinating our very own popular MSiP – a great use of her English degree.

In her new role Helen will have a very different challenge and will be expanding

on her years of administrative experience to learn all about project management. She will be keeping the team together to further improve the recruitment of nurses in the areas of most need for people with MS through our specialist nurse programme (SNP). We wish her well in her new venture.

It's time for policy makers to prioritise neurology, says report

Focus on quality improvement to give people with neurological conditions access to the holistic personalised care they need.

That's according to a report from the Neurological Alliance, which points to delayed and inequitable access to services, and recommends a national neurology plan for England be urgently developed.

Neuro Patience: The National Neurology Patient Experience Survey 2018/19 is based on the views of more than 10,000 people with neurological conditions. It found 38 per cent of people did not have access to a specialist nurse. Forty per cent said their mental health needs were not being met at all.

"The Neurological Alliance is waiting, somewhat impatiently, for people with neurological conditions to be prioritised by the health system, recognised by the benefits regime and given access to appropriate social care," said Chief Executive Sarah Vibert.

The report calls upon the NHS to recognise that neurology as a whole should be a focus for improvement

efforts, highlighting that while the Long-Term Plan singles out some conditions, such as stroke and dementia, others are entirely absent.

Sustainability and Transformation Partnerships or Integrated Care Systems should also include neurology as a priority area for improvement in their plans, it added.

38%
of people with
neurological conditions
did not have access to a
specialist nurse

- To read the full report go to www.neural.org.uk/patient-experience-survey/
- A new NHS RightCare Progressive Neurological Conditions Toolkit (see right) could address the issues raised in the Neurological Alliance report.

Brain bank investment will boost international research

A £3m funding boost will allow the Multiple Sclerosis and Parkinson's Tissue Bank to develop a digital brain bank complete with virtual reality interface.

Original funders of the project, the MS Society and Parkinson's UK, have each invested £1.5m to provide technologies that will produce high-definition pictures of donated brain tissue.

Professor Richard Nicholas, the project's Chief Scientific Advisor, said: "When the tissue bank first opened in 1998 there were practically no treatments for those affected.

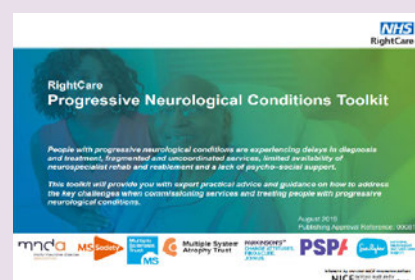
"Things are very different now and it's a privilege to work with an organisation like the MS Society. They recognise

that if we're going to revolutionise the way MS is treated – and find treatments for everyone – scientists need the right tools."

The digital bank means researchers from around the world will be able to access the images, and a 3D interactive application will allow people who are thinking about becoming a donor to explore a "virtual brain".

Prof Nicholas said it marked "an important development in the UK research landscape".

Best tools for the job continued from page 1



"By supporting others to come up to the same standard, we can deliver faster, more joined-up, better care for thousands more people, supporting them to stay well in their own homes."

Common issues the guide sets out include delays in diagnosis or treatment, fragmented and uncoordinated services and a lack of neuro-specialist rehab or psychosocial support.

Providing gold standard neurology care across England, it is estimated, could lead to 2,500 fewer emergency admissions for MS, Parkinson's and MND combined, resulting in an annual saving of £10million.

The project brings together all the tools and information CCGs need to assess and benchmark their current systems and identify areas for improvement.

Paru Naik, Health Professional Programme Director at the MS Trust, which worked with the RightCare pathways team and other patient organisations on the project, said: "We are urging every single CCG to work with the charities involved to implement this guidance and ensure people with progressive neurological conditions are not neglected."

Parkinson's UK, MS Society, MND Association, Sue Ryder, MSA Trust and PSP Association also helped develop the toolkit.

- For more information go to www.england.nhs.uk/rightcare/products/pathways/progressive-neurological-conditions-toolkit/

What do you think



Get in touch
to share your views
msip@mstrust.org.uk

Joining forces to raise the bar on services for everyone living with MS

A nationwide strategy of audit and transformation will allow MS teams to share strengths, tackle weaknesses and provide everyone living with the condition with the best possible outcomes.



Professor Gavin Giovannoni

That was the takeaway from MS Service Provision in the UK 2019: Raising the Bar, a meeting hosted by the Multiple Sclerosis Academy in July, which not only set out a vision for the future but provided concrete steps on how to get there.

“We expect all participating centres to share their successes and failures so that others can learn from them, and share their materials and experiences with other centres so as to raise the bar for everyone.”

Professor Gavin Giovannoni

Professor Gavin Giovannoni, who spearheaded the project and sits on its steering committee, said: “The objective is to improve outcomes, so that if you have MS, it doesn’t matter where you live or who you see. I’m not just talking about physical medical outcomes, but social and quality of life outcomes as well.

“It’s not about London services being better than those in Birmingham or vice versa, it’s about us accepting that we

all have strengths and weaknesses and working together to address them.”

The main thrust of the meeting was problem solving. This centred around data, patient activation, audit, the social determinants of health, and wellness and lifestyle.

Action stations

Through presentations, discussions and workshops, delegates set out a pragmatic three-year programme of action. MS centres are invited to get involved with the project by becoming pilot sites.

It includes a national quality audit to benchmark current service levels and the immediate adoption of best practice time frames for diagnosis and the induction of disease modifying drugs (DMDs).

A national patient education programme, to help people with MS to manage their condition and navigate services, will also be developed and piloted in year two.

By the third year of the programme, delegates decided, all participating centres would be following the recommendations set out in the Brain Health consensus document. These include managing MS holistically, screening and managing comorbidities and promoting lifestyle interventions.

They would also be working to a ‘no patient left behind’ philosophy, ensuring everyone with MS has access to the services they were eligible for, regardless of their background or location.

Enabling action

To make this happen, a new practical leadership training programme, run by Professor Gabriele De Luca, will be established, and a system to share best practice implemented.

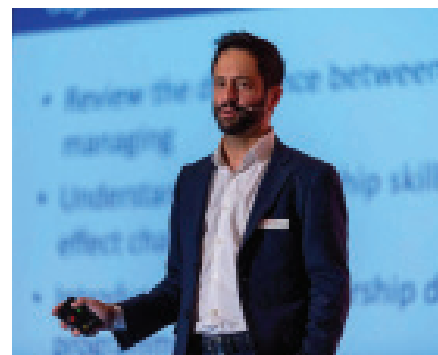
“Most ideas are not new, but how they have been tested and implemented may be.

“We expect all participating centres to share their successes and failures so that others can learn from them, and share their materials and experiences with other centres so as to raise the bar for everyone,” said Prof Giovannoni.

Ultimately, the Raising the Bar project is about the MS community using all the tools they have at their disposal, from data collection to patient activation, to improve outcomes.

“Variance, when it comes to the provision of healthcare services is a euphemism for inequality, representing the ‘haves’ and ‘have-nots’ in society,” said Prof Giovannoni.

“On the other side of the coin, variability creates the engine for change. It is the catalyst for people to do something about the poor services they are providing or receiving.”



Professor Gabriele De Luca

WORKSTREAMS: Practical actions to take this year



 <h3>Data</h3> <ol style="list-style-type: none"> 1. Compile a list of all your MS patients 2. Identify a friendly IT colleague 3. Ask them to link your list to the Patient Administration System (PAS) and to create a dashboard 4. Supplement and link with any bespoke MS information 5. Identify any gaps or errors and update 	 <h3>Patients as partners</h3> <ol style="list-style-type: none"> 1. Volunteer to be a pilot centre! 2. Develop the programme at and with pilot centres 3. Begin to deliver the programme at pilot centres 	 <h3>Audit</h3> <ol style="list-style-type: none"> 1. St.g. to define parameters for audit and disseminate 2. Prepare to use data sources e.g. Blueteq ready for audit (see 'data') 3. Access DMT calculator (RDC), HES data (ST), service component online form (JH) 4. Access MS brain health quality standards 5. Participate in rolling audit (100% agreed) 	 <h3>Social determinants of health</h3> <ol style="list-style-type: none"> 1. Understand how many patients have dropped out of the MS specialist system 2. Develop a screening tool to identify people for inclusion on a high risk register 3. Develop a standard letter for newly diagnosed patients describing the importance of maintaining a healthy lifestyle 4. Design a pragmatic social prescribing study 	 <h3>Wellness and lifestyle</h3> <ol style="list-style-type: none"> 1. Scope your area: what's available already? Can you tap into it? 2. Swap 1 monthly clinic for a wellness and lifestyle clinic for 6 months 3. Monitor the results from that swap... 4. Get to know the needs and motivations of your patients and tailor your info, advice & suggestions 
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Infographic provided by Neurology Academy

Three-years to raise the bar

Year 1

Quality audit rollout

By 31 July 2020, all participating centres will have:

- taken part in a national quality audit
- adopted the International Brain Health Standards-mandated "4+4" policy. This means 75 per cent of patients with uncomplicated MS being diagnosed within four weeks of referral, and 75 per cent of those eligible for DMDs being given a definite start date within another four weeks.

Year 2

Patient partner programme rollout

By 31 July 2021, participating centres will have:

- tested a nationally developed patient partner programme designed to help people manage their condition and navigate their local MS services

Year 3:

Holistic management of MS and 'no patient left behind'

By 31 July 2022 all participating centres will:

- be working differently and managing MS holistically
- be collecting data on these new activities as part of an annual national audit
- have embedded a 'no patient left behind' philosophy into all services

First steps: Get auditing

A pilot audit, which will highlight the need for more MS service support at a time when challenges and pressures are mounting, is now open.

All UK sites are encouraged to report:

- A description of their service
- Summary prescribing information
- Cost of DMD monitoring
- HES data on emergency admissions

Once the data has been collected, the work will be submitted for publication. Everyone who takes part will be named as an author.

- To find out how to access and submit your data, which should only take a few minutes, go to www.multiplesclerosisacademy.org/2019/08/05/participate-in-our-audit-of-ms-services/

- For more on Raising the Bar, go to www.multiplesclerosisacademy.org



Share
your examples
of best practice

Get in touch
to share your views
msip@mstrust.org.uk

AFOs and FES are comparable as foot drop interventions

Ankle-foot orthoses (AFOs) and functional electrical stimulation (FES) seem to have comparable effects on walking performance when used as interventions for foot drop, a study has found.

Seven MS outpatient centres across Scotland recruited 85 treatment-naïve people who had been experiencing foot drop for at least three months. Forty-three patients were randomised to receive a custom-made AFO while the remainder went into the FES group.

At baseline, all were assessed using the five-minute self-selected walk test, Timed 25-Foot Walk and oxygen cost of walking, as well as the Multiple Sclerosis Impact Scale-29, Multiple Sclerosis Walking Scale-12, the Modified Fatigue Impact Scale, Euroqol five-dimension five-level questionnaire, Activities-specific Balance and Confidence Scale, and the Psychological Impact of Assistive Devices Score.

Screenings were repeated at three, six and 12 months, and the costs of the interventions in terms of equipment and staff time were analysed.

At 12 months, both groups walked faster ($P = < 0.001$; AFO, 0.73 (0.24); FES, 0.79 (0.24) m/s) but there was no difference between the two. The FES group showed significantly higher Psychological Impact of Assistive Devices Scores in terms of competence ($P = 0.016$; AFO, 0.85(1.05); FES, 1.53(1.05)), adaptability ($P = 0.001$; AFO, 0.38(0.97); FES 1.53 (0.98)) and self-esteem ($P = 0.006$; AFO, 0.45 (0.67); FES 1 (0.68)).

The team also found that FES may offer a value for money alternative to usual care.

The paper concluded: "AFOs and FES have comparable effects on walking performance and patient-reported outcomes."

A dropout rate of 38 per cent, however, has cast some uncertainty on the multi-centred, non-blinded, randomised trial.

Renfrew L, et al. The clinical- and cost-effectiveness of functional electrical stimulation and ankle-foot orthoses for foot drop in Multiple Sclerosis: a multicentre randomized trial. *Clin Rehab* 2019, 33(7):1150-1162.

Early support is essential

Specialist nurses play a pivotal role in supporting people through their first year after diagnosis, a Danish qualitative study has confirmed.



The team, who set out to gain a broad understanding of people's experiences of being diagnosed with MS, interviewed five people about their support and guidance needs in the first year of living with the condition.

The three main themes that emerged from the indicative study were being frightened about the diagnosis, needing help from family and friends and the importance of continuity in nurse contact.

"The patients expressed a need for support and guidance from both families and nurses. They primarily used their families for support, and this was influenced by the family's emotional involvement," said the paper.

"Family members typically did not have the necessary experience to give appropriate guidance. The patients were aware of the impact the disease had on their families, and this sometimes stopped them from seeking support from them."

“The patients expressed a need for support and guidance from both families and nurses.”

The authors concluded that nurses should consider the family's role in each individual patient's care.

Petersen LS, Sorknæs A. Patients' experiences of being diagnosed with multiple sclerosis and their support and guidance needs in the first year of illness. *Edorium J Disabil and Rehabil* 2019; 5; 100046DOSLP2019

Exercise and physiotherapy boost quality of life in MS

Aerobic exercise and physiotherapy improve physical, mental and social functioning in MS and should be used as part of standard practice.

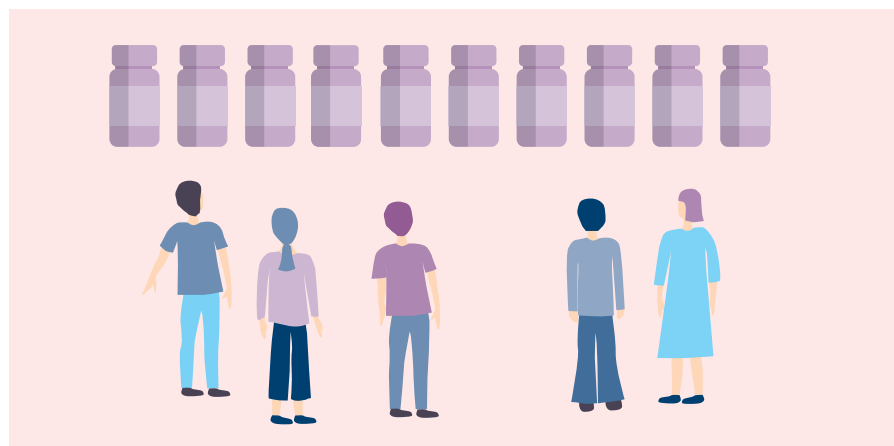
That was the conclusion of a systematic review and meta-analysis, which looked at studies on MS and exercise, physiotherapy and yoga carried out between 1990 and 2017.

Eighteen studies met the inclusion criteria. Analysis found that aerobic exercise was effective at improving satisfaction with physical functioning, $d=0.35$ (95% CI=0.08 to 0.62), mental functioning, $d=0.42$ (95% CI=0.11 to 0.72), and social functioning, $d=0.42$ (95% CI=0.15 to 0.69) in people with MS.

Physiotherapy was also found to be effective for physical functioning, $d=0.50$ (95% CI 0.19 to 0.80), mental functioning, $d=0.44$ (95% CI 0.14 to 0.75) and social functioning, $d=0.60$ (95% CI 0.21 to 0.90).

Yoga, however, was not found to have a significant effect on any of the quality of life domains analysed.

Alphonsus KB, et al. The effect of exercise, yoga and physiotherapy on the quality of life of people with multiple sclerosis: Systematic review and meta-analysis. *Complement Ther Med* 2019, 43:188-195.



NICE says no to Sativex – again

Patient and professional groups have reacted with frustration to NICE's draft decision to reject Sativex as a treatment for MS spasticity.

The medicine was first turned down in 2014, but a review prompted by the change in the legal status of cannabis-derived medications in November had offered fresh hope.

Draft guidance published in August recognises that Sativex can be an effective treatment for people who have not responded to other therapies but goes on to reject the drug on cost-effectiveness grounds.

Paru Naik, Health Professional Programme Director, MS Trust, said: "The MS Trust is hugely disappointed that, once again, Sativex has been turned down because it is too expensive for the NHS."

Dani Gordon, Vice-Chair of the Medical Cannabis Clinicians Society also described the document as "disappointing".

"It fails to recognise that this is a quality of life medication, hugely beneficial for helping improve people's level of functioning – people who are dealing with chronic serious medical conditions which have no cure," she said.

The MS Trust has reviewed the draft guideline and had responded to NICE as part of the consultation process. The final document is expected to be published in November.

PUBLICATION NEWS

Updated guide now available

Our popular guide to spasticity triggers has been extensively reviewed and expanded to provide people with MS with more information about muscle spasms and spasticity. The new book explains what causes spasticity and spasms in MS, provides self-management tips and presents the full range of treatment options.

This resource also includes tools to help discover what might be triggering a person's spasms, and a diary to record fluctuations across the week. We hope it will be a valuable resource for people with MS to use in conjunction with carers and therapists to cope with this common and distressing symptom.

With thanks to our reviewers, in particular Liz Keenan, Val Stevenson and Katrina Buchanan from The National Hospital for Neurology and Neurosurgery, London.



● The book can be ordered from www.mstrust.org.uk/pubs

Ozanimod proves more effective than Avonex in phase III trials

Two phase III trials have found oral ozanimod can reduce relapse, MRI-detected disease activity and brain atrophy when compared to Avonex.

Both studies met their primary endpoints of reducing relapse rates, as well as the secondary MRI endpoints, said the US National MS Society in a press release.

In the SUNBEAM study, 1,346 participants were randomly assigned to one of three treatment groups.

One set of patients took 0.5mg of oral ozanimod daily and an inactive placebo was injected into muscle once a week, while the second group took 1mg of oral ozanimod a day and a weekly inactive injection. The

third group injected Avonex and took an oral placebo daily. The treatment period was 12 months.

No cardiac-related side effects were observed during dose escalation and no serious infections occurred in the ozanimod group. Increases in liver enzymes were reported across all groups and resulted in two people discontinuing ozanimod.

The RADIANCE study saw 1,313 people randomised to the same treatment patterns as SUNBEAM for 24 months.

Four participants experienced a transient reduced heart rate and no serious infections were recorded.

"In a pooled analysis of both phase III studies, ozanimod was not shown to slow disability progression significantly more than Avonex," added the press release.

The studies also found that all trialled doses reduced loss of brain tissue significantly more than Avonex.

Comi G, et al. Safety and efficacy of ozanimod versus interferon beta-1a in relapsing multiple sclerosis (SUNBEAM): a multicentre, randomised, minimum 12-month, phase 3 trial. *Lancet Neurol* 2019 Sep 3 [epub ahead of print]

Cohen JA, et al. Safety and efficacy of ozanimod versus interferon beta-1a in relapsing multiple sclerosis (RADIANCE): a multicentre, randomised, 24-month, phase 3 trial. *Lancet Neurol* 2019 Sep 3 [epub ahead of print]

Respect their intelligence and break it down: Talking MS with young people

Explaining MS isn't the easiest thing to do at the best of times, but many healthcare professionals will be faced with the task of talking about the complex condition with children.

Whether you're talking to the offspring of people currently living with MS or one of the increasing number of paediatric patients receiving a diagnosis, it can be difficult to know where to start.

The secret, according to Katie Hanson, neurology and MS CNS at Great Ormond Street Hospital (GOSH), is remembering they are not stupid.

"Many of them will be doing GCSE or A level biology, so they tend to have a good idea of what you are saying. We find it helps to break things down into simple analogies.

“Many of them will be doing GCSE or A level biology, so they tend to have a good idea of what you are saying. We find it helps to break things down into simple analogies.”

Katie Hanson

"We talk about a phone charger, with the wires inside representing the nerves and the casing representing the myelin. As the casing comes away and the wires get frayed at the ends, the charger doesn't work properly anymore."

Honesty is the best policy, she went on, explaining that crucial information shouldn't be sugar coated for younger ears.

"We have to tell them that MS affects the nervous system, and that means that we don't know how it will affect them in the long run," said Katie, whose patients are mostly teenagers.

All the current evidence points to the impact of early treatment on future progression, so getting children with MS onto DMDs as soon as possible is crucial to the GOSH team.

Paediatric-onset MS therapies are largely the same as those used in the adult population, Katie said, adding that ocrelizumab and cladribine had both come online in recent months.

Katie's top tips for talking about MS with children and young people:

- Be honest
- Break the science down into simple analogies
- Make use of all available resources – check out the MS Trust's Young People and MS page at www.mstrust.org.uk/young-people-ms

Said Katie: "We explain that there is no cure, but whatever treatment they choose will significantly reduce their relapses. It's their decision to make, and we will help them, but it is based very much on what suits their lives."

There are lots of resources that MS healthcare professionals can use when explaining MS to young people. Katie added that her patients, the youngest of whom is 11, appreciated paper-based information that they could take away and read at their leisure.



Campaign's one message – get in touch with your specialist and seek support

As much as services try to avoid it, people with MS can sometimes 'fall off the radar' – but the team in Ayrshire and Arran have a plan to bring them all back into the fold.



How does 1MSg work?

- A press release was circulated
- Emails were sent to all GP practices, district nurses and other healthcare professionals across Ayrshire and Arran
- Posters and flyers were sent to local pharmacists, optometrists, care homes and peer support groups
- The campaign was shared on the NHS Ayrshire and Arran intranet
- A single point of contact for all queries and referrals was established
- All resources, such as posters and flyers, were provided by the 1MSg campaign team

The Douglas Grant Rehabilitation Centre launched the 1MSg campaign, urging people in the area to 'Take Control, Know Your Choices', in May.

Mhairi Coutts, MS Specialist Nurse at the centre, said that, nationally, one in ten people with MS did not see a specialist at least once a year as per NICE guidelines¹.

"We can only build relationships with our patients if we see them regularly. This regular contact also means that if a patient finds their condition is getting worse or they just have a simple question, they are more likely to pick up the phone to us," she said.

“As well as reaching people with MS who may be lost to follow up, 1MSg also serves to raise the profile of the service among NHS colleagues who may have MS patients not known to the specialist team.”

Mhairi Coutts, MS Specialist Nurse

The 1MSg campaign, which was launched nationally in 2016 and is sponsored by Biogen, is about making sure everyone with MS in the area knows the service is there for them, whether they have disengaged with the team or were never referred in the first place.

"Primarily it is a local disease awareness campaign which aims to encourage people living with MS to engage in regular and quality contact with us," said Mhairi.

"While we do offer an annual review by a member of the MDT, sometimes people choose not to attend appointments if they are keeping well. We accept that people can fall off the radar from time to time, but they need to know they can self-refer back to our service at any time."

As well as reaching people with MS who may be lost to follow up, 1MSg also serves to raise the profile of the service among NHS colleagues who may have MS patients not known to the specialist team.

"They can contact us for expert advice or they can refer to our service using the referral template provided as part of the campaign," Mhairi added.



Early results

"Since our launch, GP surgeries have contacted us to say they were happy to display our poster in their waiting areas. One surgery has even opted to notify all of their MS patients individually about the 1MSg campaign.

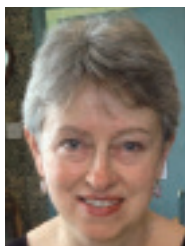
"Although it's still early days, I think this is very encouraging and demonstrates we are already doing what we were hoping to achieve – getting the message out to patients, carers and our health and social care colleagues."

- **MS services who would like to run their own 1MSg campaign can go to www.1msg.co.uk for more information.**

¹ GEMSS Patient Survey Meta-Analysis. MS Trust. November 2015. Available at: <http://support.mstrust.org.uk/file/Evidence-for-MS-Specialist-Services.pdf>. Last accessed: May 2019

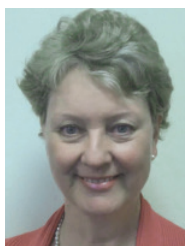


TiMS' new project hopes to build consensus on useful outcomes



Wendy Hendrie

At the Therapists in MS (TiMS) Working Group meeting in September we spent time updating the TiMS part of the MS Trust website. We think it looks much cleaner and, as a result, it should be easier to find your way around now. It has lots of useful information for therapists about all areas of managing the care of people with MS. Please recommend it to colleagues and also encourage them to join TiMS if they haven't already done so.



Pam Bostock

Looking over the site gave us an idea for a new TiMS project: developing a battery of useful therapy outcome measures for people with MS. The outcome measure section of the website already has links to some measures, but we thought it would be useful to try and get a consensus list so that we can try to standardise the measures used. We would like to hear from you if you think this would be a useful resource in your own practice. We will

also be sending out a form later this year to ask you what measure you use on a regular basis. In the meantime, we are pressing ahead with projects such as the Self-Assessment Review form and a Service Audit Tool.

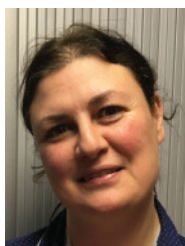
If you are coming to the MS Trust conference in November, please come along to the TiMS meeting at 8.15am on Tuesday November 5 (you don't have to be a member). We'd also love to meet you at the TiMS stand which will be manned by members of the Working Group.

Wendy Hendrie and Pam Bostock
Co-chairs, TiMS

- **For more on joining TiMS and accessing our resources, email therapistsinms@mstrust.org.uk or visit www.mstrust.org.uk/TiMS**



Updates and consultations: It's been a busy summer for the committee



Nicola Daykin

The summer has gone by so quickly, but the work at the UKMSSNA has continued over these months. The committee has looked at a number of MS treatment reviews and work has continued on the slide library and care manual. The committee welcomes any member's queries about MS practice and will endeavour to answer them all.

The IOMSN exam will be held in November. It is too late to register, but if you are considering taking it next year, please check the UKMSSNA website for information.

There have been a number of courses over the summer including the Neuro Examination Course and Neurology Academy's MS Master Classes.

We would like to thank the organisers and providers of these events for helping to keep MS nurses informed and assisting with changes in practice and improvements in service development. This is especially useful after the Neurological Alliance published a report on inadequacy in service provision and patients experiences of neurological care

(see page 3). For information on upcoming courses, check out the UKMSSNA website.

Another great event, which will take place in November, is the MS Trust Annual Conference. It is a great meeting that provides ongoing support, education and knowledge to MS nurses and allied healthcare professionals who work in MS.

It's sad to note that a year has gone by since we lost a beloved member of the MS community, Nicki Ward-Abel. The committee would like to acknowledge and honour her achievements. She has left a great legacy and continues to be sadly missed by her friends and colleagues of the MS world.

Nicola Daykin,
UKMSSNA committee member

- **If you aren't a member and wish to join, please contact us via www.ukmssna.org.uk**

MS Trust's SNP makes it official: Specialist nurses are worth every penny

Increased patient satisfaction, lower emergency hospital admissions and greater equity of services – MS nurses are proving they can provide it all.

These are among the results presented by the pilot sites for the MS Trust's Specialist Nurse Programme (SNP), which majority funded MS nurses and helped the centres develop and audit quality improvement projects.

The teams, in Bradford, Lanarkshire and Leicester, have used the programme to demonstrate the value of their extra MS nurse and all three posts have now been taken on by their NHS trusts.

In Bradford, the service is reaching ever more people to re-engage those lost to follow up and is more accessible through increased capacity and social media outreach.

Leicester's MS nurse team's work with other specialists in Trust and the community was described as "a step-change" that resulted in the more holistic treatment of people with complex needs.






And in Lanarkshire, the team used patient survey data to show the service had saved £45,929 in reduced hospital admissions since the start of the SNP programme.

All three sites also improved patient satisfaction by significant margins.






How does the SNP work?

The SNP offers a package of support that includes:

- 80 per cent of the initial funding for the first 15 months of a permanent MS specialist nurse post
- accredited training through the MS Trust's MS specialist foundation course
- mentorship for the post-holder from the SNP manager
- support for the whole MS team to improve and develop the service
- support to collect service data using tools based on the MS Trust's highly regarded Generating Evidence in MS Services (GEMSS) programme

	Before the Specialist Nurse Programme	Following the Specialist Nurse Programme
	44% of people referred to the MS nurse service were offered a holistic assessment with an MS nurse within 20 working days of being referred.	↑ 88% of people referred to the MS nurse service were offered a holistic assessment with an MS nurse within 20 working days of being referred (Sept 17–Sept 18)
	58% of people with MS on the MS nurse service caseload had seen an MS nurse in the last 12 months.	↑ 71% of people with MS on the MS nurse service caseload had seen an MS nurse in the last 12 months (Jan 18 – Sept 18)
	Waiting time for an MS nurse appointment = 7 months	↑ Waiting time for an MS nurse appointment = 1 – 4 weeks (Sept 18)
	33 people with MS involved in education session 0 health professionals involved in education sessions	↑ 117 people with MS involved in education session ↑ 85 health professionals involved in education sessions
	734 MS nurse-led clinic consultations delivered in the 12 months before new MS nurses came into role. (1 st Sept 2016 – 30 th Aug 2017)	↑ 1688 MS nurse-led clinic consultations delivered in the 12 months when the new MS nurses came into role. (1 st Sept 2017 – 10 th Aug 2018)

Leicester's results

	Before the Specialist Nurse Programme	Following the Specialist Nurse Programme
	Average time from referral to the MS nurse service to 1 st appointment = 6 weeks or 30 working days	↑ 92% of people referred to the MS nurse service were offered a holistic assessment with an MS nurse within 15 working days of being referred (March 18 – Feb 19)
	39% of people with MS on the MS nurse service caseload had seen an MS nurse in the last 12 months	↑ Approximately 57% of people with MS on the MS nurse service caseload had seen an MS nurse in the last 12 months (March 18 – Feb 19)
	Waiting time for an MS nurse appointment = 3 months	↑ Waiting time for an MS nurse appointment = 5–10 working days for routine reviews and within 5 working days if urgent
	Zero people with MS involved in education session Zero health professionals involved in education sessions	• Zero people with MS involved in education session – session planned for June 19 ↑ 15 health professionals involved in education session (community-based OT's and nurses)
	655 MS nurse-led clinic consultations delivered in the 12 months before new MS nurses came into role. (March 17 – Feb 18)	↑ 1045 MS nurse-led clinic consultations delivered in the 12 months following the new MS nurse coming into post (March 18 – Feb 19)

Bradford's results

	Before the Specialist Nurse Programme	Following the Specialist Nurse Programme
Activity	55% of respondents had seen an MS nurse in the last 12 months.	↑ 79% of respondents had seen an MS nurse in the last 12 months
	32% had been offered an annual review with an MS specialist nurse in the last 12 months	↑ 51% had been offered an annual review with an MS specialist nurse in the last 12 months
	An average of 1.4 consultations with MS specialist nurse in the last 12 months	↑ An average of 2.0 consultations with MS specialist nurse in the last 12 months
Experience	58% felt the service gave trust them and confidence in expertise	↑ 75% felt the service gave trust and confidence in expertise
	49% felt involved in decisions about their care	↑ 64% felt involved in decisions about their care
	78% found advice on accessing other HPs helpful	↑ 92% found advice on accessing other HPs helpful
Impact	35% MS nurse service contact resulted in at least one positive wellbeing impact	↑ 45% MS nurse service contact resulted in at least one positive wellbeing impact
	13% admitted to hospital about their MS in the past year	↓ 11% admitted to hospital about their MS in the past year
	9 nights average time spent in hospital per admission	↓ 6.5 nights average time spent in hospital per admission

Lanarkshire's results

- To find out if your team is eligible for the SNP programme, contact the MS Trust on 01462 476700.

Fun festive ideas!

Did you know that there are lots of fun and easy ways to get involved with Team MS Trust this Christmas? Below are just a few of the many ideas on our website.



To view even more visit www.mstrust.org.uk/christmas-giving

Join Gail at London Marathon 2020

MS Clinical Nurse Specialist, Gail Shore has decided to take on the London Marathon in 2020 to raise money for the MS Trust. Despite being apprehensive (she has never run more than 10K before), she explains why she is taking on this iconic event to support our work.

"I wanted to take part because I like a challenge and I wanted to give something back to the MS Trust. They have been so

supportive to me and my patients. I have attended the MS Trust conference each year since I started in post, which has been invaluable to my role; very informative, educational and great for networking and getting new ideas.

"My motivation is to not let anyone down! That includes my patients, family, friends and definitely myself. Doing it for the MS Trust gives me even more of an incentive."

Everyone at the MS Trust wishes Gail the very best of luck with her training! If you or someone you know has a place in the 2020 London Marathon, perhaps through the ballot or a running club, we would love you to join our team. We pride ourselves on supporting our running teams all the way to the finish line (and beyond).

- Visit www.mstrust.org.uk/ballot to find out more.

SAVE THE DATE

MS Trust conference 2019
3 – 5 November,
Hinckley Island Hotel

For more information go to
www.mstrust.org.uk/conference
or email
conference@mstrust.org.uk



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