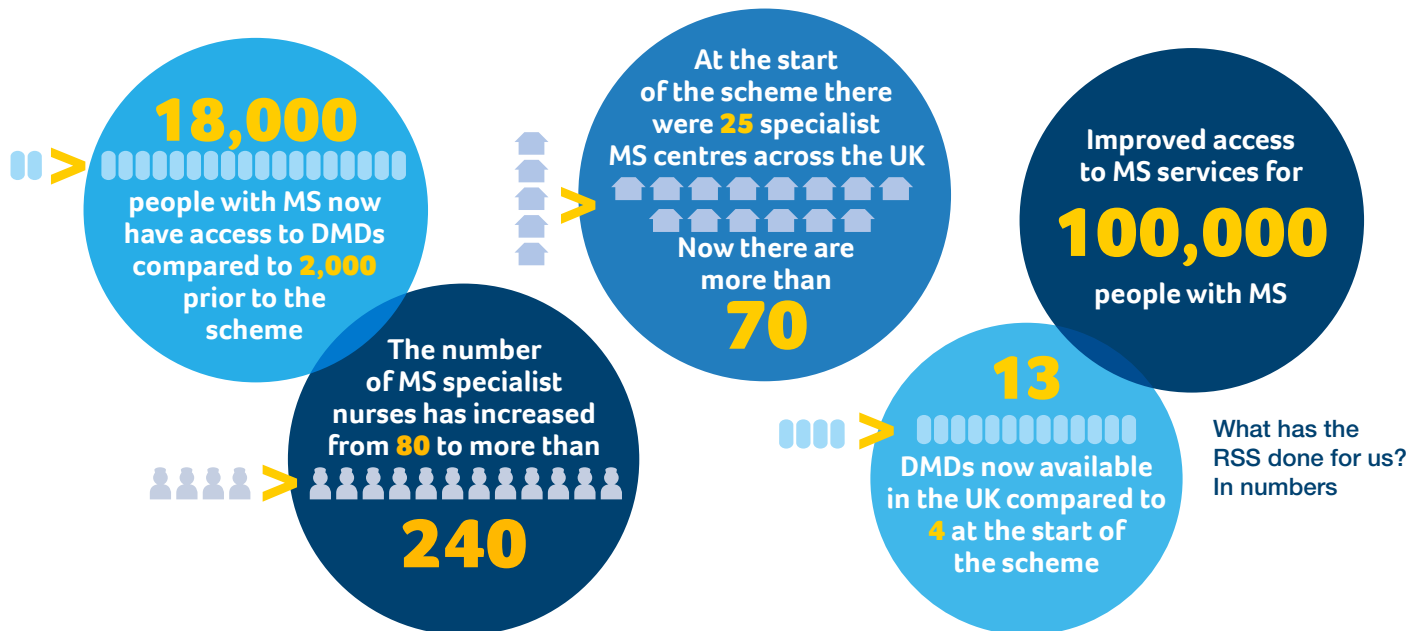


MS in Practice

your essential update



A PUBLICATION FOR MS HEALTH PROFESSIONALS
ISSUE 3 • AUTUMN 2018



Ten years on: Risk Sharing Scheme has transformed MS care and provided hope

The Risk Sharing Scheme (RSS) has done more than prove disease modifying drugs (DMDs) are worth paying for – it has built the very infrastructure of modern MS care.

Final data from the ten-year project, set up in 2002 after NICE decided the first DMDs were not cost-effective, has shown they meet the set target of £36,000 per quality adjusted life year. They also delay disability progression in relapsing remitting MS, the figures show.

Dr Martin Duddy, consultant neurologist, said: “People tend to focus on the financial side of the RSS. But the wall of funding that came from the Department of Health and the drug companies provided our entire infrastructure.”

The ground-breaking partnership between the Department of Health and four pharmaceutical companies – Bayer UK, Biogen Idec, Merck Serono and Teva – was administered by the MS Trust.

The prices of Avonex, Betaferon, Copaxone and Rebif were dropped and all eligible patients given access on the promise of refunds if the drugs weren't cost-effective in the long term.

Under the deal, NHS trusts were funded to set up the clinics needed to deliver and monitor the DMDs, meaning it had a huge impact on the development of services across the UK.

Jo Sopala, Director of Health Professional Programmes at the MS Trust, said: “Back then neurologists had little to offer people with MS. Many were left to deal with complex and unpredictable symptoms alone.

“MS specialist nurses were few and far between, research into the condition was limited and, understandably, hope was in short supply.”

Since then, the number of MS nurses has grown from 80 to more than 240 and there has been a significant increase in the number of specialist physiotherapists, occupational therapists and neurologists.

“More than 70 specialist MS centres have been established across the UK, and, under the RSS, funding was made available for MS specialists to access the best training and education,” said Jo.

“These improvements mean that the scheme has bought tangible benefits to everyone affected by MS, not just those who are on a drug therapy.”

- See page 6 for a summary of the data
- The battle for people with MS is not yet won. See page 7 for the latest on NICE's decision not to approve the first disease modifying drug in progressive disease



Since the last edition of MS in Practice, the world of MS care has lost a very dear friend, Nicki Abel, who died in September.

Nicki was the first MS Specialist Nurse I met when I started working in MS. We arranged to have coffee in the hotel I was booked into and Nicki couldn't stop laughing when she realised that I was staying in the heart of the strip clubs of Birmingham. Somehow it was an appropriate start to an 18-year professional relationship and friendship built on mutual respect, shared values and laughter.

Nicki was an incredible woman, an inspirational teacher, a trail blazer and a passionate advocate for people with MS. Nicki's vast experience and knowledge put her at the forefront of MS nursing and professional development. Her impact on people with MS cannot be overstated. I'll bet we all remember the first time we heard Nicki talk about sex and I'll bet it changed the way we all thought and talked about it with people with MS. Whilst this is an area in which she was an acknowledged expert it was by no means her only specialist subject and the breadth of her expertise should be remembered.

We will all remember Nicki with a smile alongside her exceptional work in MS. She taught us all that life is to be lived and enjoyed. Nicki never shied away from dealing with difficult issues and was always first on the dance floor. The perfect balance.

Her legacy will live on through the work of all of us.

Jo Sopala,

Director of Health Professional Programmes, MS Trust

Happy birthday, MS Trust

Leading figures in the MS world have thanked the MS Trust for 25 years of support as the charity marks its silver anniversary.

Founded by Chris Jones and Jill Holt in 1993, what was then the MS Research Trust has helped to change the landscape for people living with the condition.

Speaking of her own diagnosis in the 1980s, Chris said: "My GP didn't know, my neurologist thought I shouldn't know, the books in the library were out of date and the internet didn't exist.

"We were told: 'You've got MS. Go home and learn to live with it'."

Since then, as well as providing resources for people with MS and their families, the charity has played a major role in supporting specialist healthcare professionals. It helped set up the MS Nurse Forum in 1996 and Therapists in MS (TiMS) in 2003.

Karen Vernon, co-chair of the UK MS Specialist Nurse Association (UKMSSNA) said many nurses, herself included, would not be where they are today if it wasn't for the charity.

"It has been invaluable in terms of developing my professional network through education, involvement in projects and by providing unbiased patient perspective," she said.

"The charity is constantly adapting to the challenging world of doing more for

less, but the quality never changes. It is not afraid to challenge the status quo, to raise inequity in standards of care and to try to provide solutions."

TiMS co-chair, Wendy Hendrie, said the charity had provided 25 years of support, information, innovation, inspiration and enthusiasm.

"The thing that makes the MS Trust stand out is the people who work in the organisation: their ethos is to work alongside professionals in partnership, supporting and sharing best practice and never being afraid of trying new ideas," she added.

Here's to the next 25 years.



Data compares ideal and realistic caseloads

New insights into the current workload and conditions of MS specialist nurses will be presented at the MS Trust annual conference.

The charity's two-part nurse mapping and caseload modelling project has updated the sustainable caseload figure published in 2014. It has also examined how this number measures up to the reality nurses face every day.

Guy Hannan, Evaluation Manager at the MS Trust, said: "We know there are still too few MS nurses in the UK to care for

the population of people living with the condition."

The project has established the number of nurses currently in post and mapped the provision of support across the country.

"This will enable us to identify areas lacking in sufficient numbers of MS nurses and then to work with MS centres and funders to ensure adequate coverage for the future," added Guy.

- See page 11 for an update on the MS Trust Specialist Nurse Programme

RCP says botox shouldn't be used in isolation

Botulinum toxin (BoNT) is effective for spasticity when prescribed by a multi-disciplinary team (MDT) as part of a larger programme of management.



That's according to the Royal College of Physicians (RCP) in its updated Spasticity in Adults: Management Using Botulinum Toxin national guidelines.

The document emphasises both the importance and the difficulty of treating the symptom, which affects around 60 per cent of people with severe MS.

"Spasticity can be painful, distressing and a potentially costly cause of disability," said the document, adding the management was challenging because of the diversity of presentation and aims of treatment.

"It will normally include a combination of physical and pharmacological management, often using a variety of different approaches according to the individual patient's needs."

Not all spasticity requires treatment, however, and the RCP recommended intervention only when it is likely to have a "meaningful benefit".

"The selection of appropriate patients and the definition of clear, achievable, realistic and measurable goals are crucial to the successful use of botulinum toxin in spasticity management," the authors said.

Common treatment goals include pain relief, preventing contractures and deformity, or making it easier for the person to either care for or use the affected limb.

The RCP document, which updates 2009 guidelines, also says BoNT should not be used in isolation.

"Physical management is fundamental to treatment, aimed at alleviating aggravating factors, symptom relief, improving function and preventing deterioration. BoNT is an adjunct to meeting the wider rehabilitation aims of the patient, carer and treating team," said the guidelines.

"It should not be used in isolation, but in parallel with appropriate physical therapy and other anti-spasticity strategies and, importantly, postural management programmes."

It goes on to say that managing spasticity required input from the whole MDT, including doctors, nurses and therapists.

- To read the full document, go to www.rcplondon.ac.uk/guidelines-policy/spasticity-adults-management-using-botulinum-toxin

What next for QuDoS?

The Quality in Delivery of Services (QuDoS) in MS care awards evening will not be held this year.

Organisers say they hope the event, which has taken place on the eve of the MS Trust Annual Meeting for the last two years, will be back.

"We hope to run the programme in 2019 and would still love to hear from individuals or teams working on initiatives to improve the lives of patients," said a Louise Bellamy, Senior Project Manager at pharmaphorum, which organises the programme.

"Please get in touch with the QuDoS team if you'd like to share your work or tell us about a colleague that deserves recognition."

- Louise can be contacted on louise.bellamy@pharmaphorum.com or 01932 359203

'Promising' phase three statins in SPMS trial underway

The largest ever trial into the use of the statin simvastatin in secondary progressive MS (SPMS) is getting underway.

The phase three study, MS-STAT2, will include 1,180 people across 30 sites in England, Scotland, Wales, Northern Ireland and the Republic of Ireland.

Study leader Professor Jeremy Chataway, consultant neurologist at University College London Hospital, said: "Simvastatin is a very promising treatment prospect for SPMS.

"People with this form of the condition have been waiting decades for a drug

that works, which is why there's such excitement around being able to start the trial."

Phase two trials have indicated the drug could reduce brain atrophy and delay disability progression.

"While it's still early days, we believe simvastatin could change lives," added Prof Chataway.

- Anyone with patients interested in taking part in the study is asked to refer them to the UCL website www.ms-stat2.info

What do you think

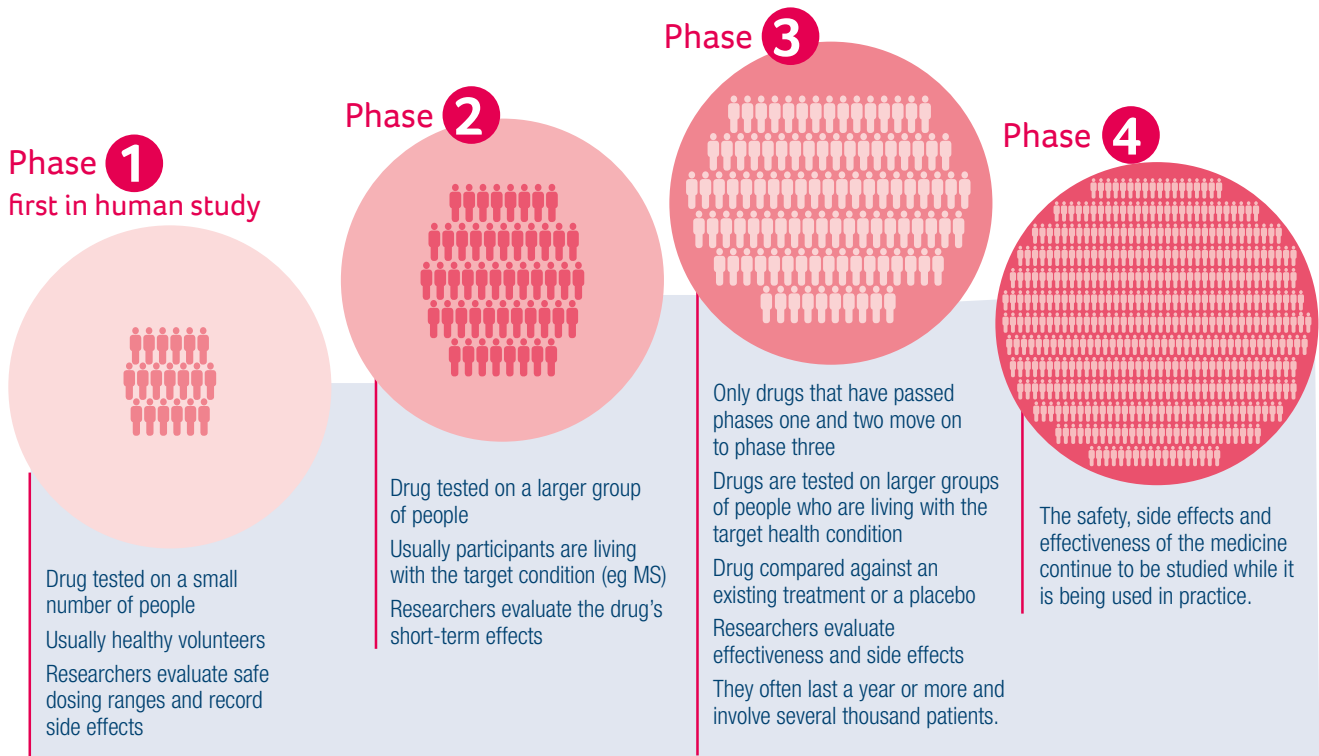


Get in touch to share your views
msip@mstrust.org

Talking about... Clinical trials: Research in clinic

Talking about clinical trials is all in a day's work for healthcare professionals working in MS. And while explaining the process and results of clinical trials may seem daunting and time-consuming, nurses and therapists already have all the skills they need to do it quickly and efficiently.

DEVELOPING DRUGS: CLINICAL TRIAL STAGES



Source: <https://www.nhs.uk/conditions/clinical-trials/> Inspo: http://nationalevents.cityofhope.org/KnowledgeCenter/City-of-Hope_Clinical_Trials.pdf

Translating headlines into clinic conversations

“It is part of our professional responsibility in the NHS to be involved in research at some level. We need evidence for most of what we do. It's only through understanding what works and what doesn't that we can ensure we are offering the best interventions.”

Prof Jenny Freeman

When someone finds an internet forum extolling the virtues of a new diet, or an article describing the latest breakthrough, their first port of call is usually their MS care team.

Jenny Freeman, Professor of Physiotherapy and Rehabilitation at the University of Plymouth, said it was important to take enquiries seriously.

“They are asking because they trust your opinion,” she said, adding it showed they were taking an active role in managing their condition.

“If it's a newspaper clipping, briefly read and quickly critically analyse it. Then walk them through it and highlight any bits you

might be sceptical of. The best way to do that is to be honest and open.”

Nurses and therapists will also need to judge the person's level of health literacy.

“We do this all the time: it's no different. Of course, if you already know them, you will have a good feel as to what level of detail they want,” Jenny added.

Sometimes, it may be too much to deal with in clinic and may require some desk research or a chat with a colleague.

“If it's not in your area of expertise, or you haven't heard about it, just tell them that and that you will check it out. It's worth doing: you never know what you will discover.”

“Projects now have to supply a lay summary of results, but they are not distributed at the same level as the research publication.

Dr Klaus Schmierer

Call for plain English results

Research is becoming more accessible – but there’s still a long way to go, said Dr Klaus Schmierer, reader in clinical neurology at Queen Mary University London.

A system of distributing “plain English” translations of research papers was “urgently needed”, he added.

“They are not usually written for a lay audience. Unless you are in the field, it can be difficult to understand all the nitty gritty detail.”

A growing emphasis on patient-public involvement (PPI) is starting to change things, but the pace is slow.

“Projects now have to supply a lay summary of results, but they are not distributed at the same level as the research publication,” he said adding these summaries were only usually available on www.clinicaltrials.gov

Klaus hopes this gap will close as PPI gains momentum. For example, his team has recruited a patient as a funding co-applicant for an upcoming trial.

“That will really help with translating any outcomes, because she will ensure we explain it in a way that people can understand,” he said.

Raising awareness

Evidence-based medicine means having the confidence to know we are providing the best care, medications and interventions. But it can be difficult to recruit enough people to take part in trials.

“A significant barrier is that people simply aren’t aware there are studies they could be taking part in,” said Professor Jenny Freeman.

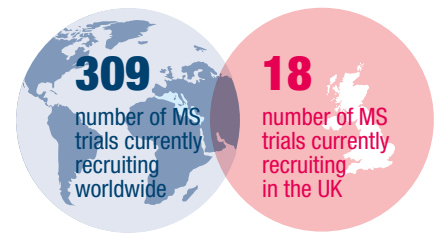
If health professionals don’t know either, the conversation is something of a non-starter.

National MS charities, including the MS Trust, are a good source of information, as are the National Institute for Health Research (www.nihr.ac.uk) and the Clinical Trials Gateway (www.ukctg.nihr.ac.uk).

Local is usually better, though, so keeping in touch with colleagues will help. Once you know about the project, speaking to a patient about it is easy, said Jenny.

“All you need to say is ‘there’s a study in this area that might be quite appropriate for you’. Tell them what it is investigating and ask if they want information about it sent to them. Most say yes.

“Then just let the person running the study know. It’s easy: it’s just a matter of remembering to do it.”



References: www.clinicaltrials.gov and www.ukctg.nihr.ac.uk

Lifting the lid on trials

Real-life experience is opening a window on the often mysterious world of clinical trials.

Helena Jidborg Alexander, who has MS and works for the MS Trust, has been writing about being part of a study for the charity’s website.

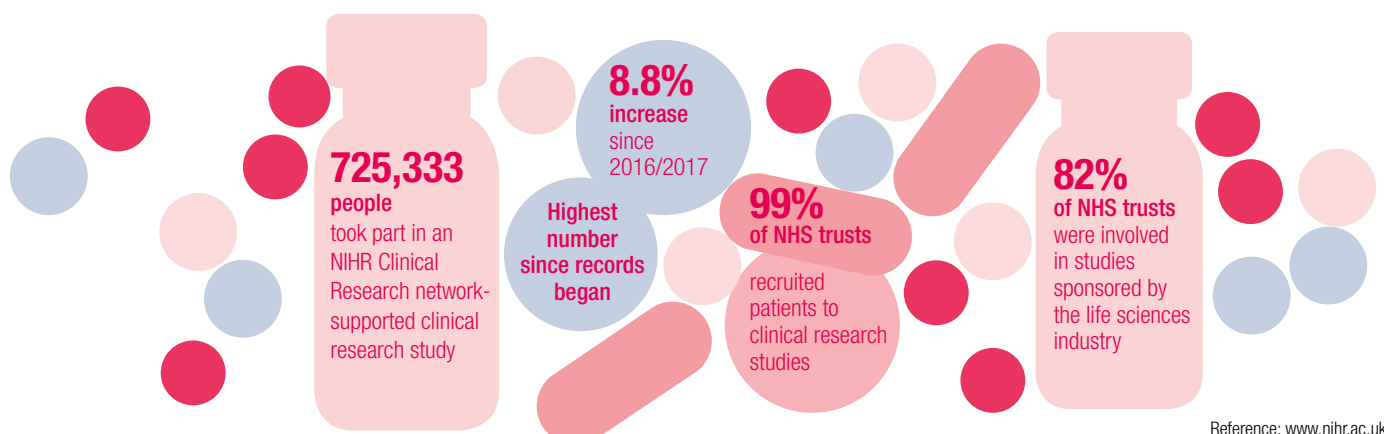
Starting with how she made the decision to get involved, a series of blogs and vlogs are taking readers on the journey from enrolment to follow-up.

- Go to www.ms-trust.org.uk/hellies-clinical-trial-adventures



Helena Jidborg Alexander

ACROSS ENGLAND IN 2017/ 2018:



Reference: www.nihr.ac.uk

Exercise and activity preserve self-esteem

Exercise and physical activity can help people with MS feel more independent and supported as well as cope with the changing demands of the condition.

A team from Brunel University carried out 16 in-depth interviews with people with MS to find out about their attitudes towards exercise and physical activity.

“Exercise and physical activity were a way of coping with the condition. However, participants described the strategies used not only for coping with MS but also in maintaining their identity, which symbolised much more than having a diagnosis with MS.

“Participants desired to be known for their individuality; physical activity was therefore used as a way to shape and preserve their sense of self,” said the authors.

They found the importance attributed to exercise and physical activity moved “beyond the physical and the psychological to also include social connectivity”.

Interviewees spoke about the social interaction they experienced through exercise classes, which offered a space in which to engage in “friendly banter and peer support”. They also talked about connecting with others through their capacity to undertake leisure activities.

Participants expressed a deep sense of loss attached to their condition. Despite this, the interviews found exercise and physical activity were often used as a way of coping with MS.

Some said it did this by giving them structure. Others explained that the support they received from friends, family or MS specialists to stay active was a coping strategy in itself.

Reference: Stennett A, De Souza L, Norris M. The meaning of exercise and physical activity in community dwelling people with multiple sclerosis. *Disability And Rehabilitation* 2018 Aug 20:1-7.[Epub ahead of print]

Sexual dysfunction linked to depression

A study found that people with MS experiencing sexual dysfunction had significantly worse average disease-related disability and depressive symptom scores.

A total of 162 people completed an MS Intimacy and Sexuality Questionnaire-19 during their neurology appointments at the Mellen Center for Multiple Sclerosis at Cleveland Clinic. Almost two thirds, 64.2 per cent, were experiencing sexual dysfunction.

The data were merged with information on mood, disability and quality of life collected as part of standard practice.

Those experiencing sexual dysfunction had a higher prevalence of pain, fatigue and depression. They were more likely to have been referred for a behavioural medicine consultation in the previous year and to have been prescribed an antidepressant.

“Those experiencing sexual dysfunction had a higher prevalence of pain, fatigue and depression.”

“Assessment and treatment of depression may serve as a starting point for intervention in patients with MS who experience sexual dysfunction. Identifying individuals who are at risk for sexual dysfunction concerns may help with clinician and patient burden in terms of routine assessment of this symptom,” said the authors.

● **For advice on speaking to your patients about sexual dysfunction from specialist nurses Nicki Abel, Lesley Catterall and Denise Middleton, check out the MS Trust Health Professionals blog at <https://www.mstrust.org.uk/health-professionals-blog>**

Reference: Domingo S, Kinzy T, Thompson N, et al. Factors Associated with Sexual Dysfunction in Individuals with Multiple Sclerosis: Implications for Assessment and Treatment. *International Journal Of MS Care* 2018;20(4): 191-197.

Ten year RSS data show four-year delay to EDSS 6

Disease modifying drugs (DMDs) can delay disability progression, the 10-year Risk Sharing Scheme data have shown.

Final results from the long-term study, set up after the first DMDs for relapsing remitting MS (RRMS) became available in 2002, were published in the *Journal of Neurology, Neurosurgery and Psychiatry* last month.

The study recruited around 5,000 people on interferons and glatiramer acetate between 2002 and 2005. They were followed-up for a decade and compared to datasets that modeled the natural disease course without treatment.

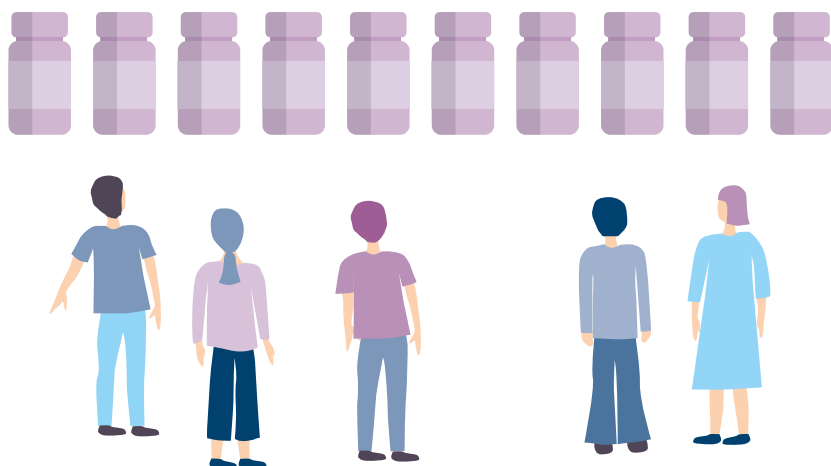
Around 17 per cent of participants left the study when they switched to a more active drug, and a further 18 per cent stopped treatment altogether.

Among the remaining cohort, the average time to EDSS six was 12.5 years for those in the treatment group, compared to 8.4 years in the models. That equates to a four-year delay in the need to use a stick when walking.

Treatment was more effective in people with a lower EDSS at the start and those with shorter time between disease onset and starting therapy. Women did better than men, as did those who took no treatment breaks.

However, the benefits of treatment appeared to decrease over time. Study authors noted that this effect was worthy of future investigation.

Reference: Palace J, Duddy M, Lawton M, et al. Assessing the long-term effectiveness of interferon-beta and glatiramer acetate in multiple sclerosis: final 10-year results from the UK multiple sclerosis risk-sharing scheme. *J Neurol Neurosurg Psychiatry*. 2018 Sep 21:jnnp-2018. [Epub ahead of print]



Frustration and disappointment as NICE rejects Ocrevus in PPMS

Charities, healthcare professionals and people with MS have been left reeling by news that the first licensed treatment for progressive disease will not be available on the NHS in England or Wales.

The National Institute for Health and Care Excellence (NICE) has decided ocrelizumab (Ocrevus) in primary progressive MS (PPMS) does not represent value for money.

“The overwhelming emotion is disappointment,” said consultant neurologist Dr Martin Duddy.

He spoke of the “optimism and excitement” over a “new era in MS care” when trial results, showing the drug reduced brain atrophy and slowed disability progression in primary disease, were announced.

“The real problem is the people who have been coming to clinic for two to three years with PPMS. I have been saying to them ‘next year I might have something for you’,” said Dr Duddy.

“Now there’s a drug there and I can’t give it to them. That’s incredibly frustrating and it’s hard for people and their families to understand.”

In a final appraisal document, NICE acknowledged that slowing disability progression allowed people to continue to work and to preserve their independence.

The paper, which compared the cost of treatment to that of standard supportive care, also recognised the large unmet need in progressive disease.

“However, cost-effectiveness estimates from the (drug) company’s base-case model were far higher than those NICE normally considers an acceptable use of NHS resources,” it said.

Manufacturer Roche explained the authority could not consider a discounted price in PPMS because it was different from the cost already agreed for use in relapsing remitting MS.

The company’s UK general manager, Richard Erwin, said: “We ask that NICE is given the flexibility to consider an indication-specific price for ocrelizumab in PPMS.

“The challenge with ocrelizumab for PPMS could also have huge implications for future access to innovative medicines for people in the UK.”

“Now there’s a drug there and I can’t give it to them. That’s incredibly frustrating and it’s hard for people and their families to understand.”

Roche is committed to working with NICE and NHS England to find a solution, he added.

In Scotland, Ocrevus has already been rejected for use in RRMS. The Scottish Medicines Consortium is planning to appraise the drug in PPMS next year.

Charity ‘won’t give up’

Blocking access to the first treatment to be licensed for PPMS will heighten inequities in care, the MS Trust believes.

The charity has vowed to keep fighting for people with progressive forms of the disease, following NICE’s decision to approve Ocrevus in RRMS but not PPMS.

Director of Health Professional Programmes, Jo Sopala, said: “People with PPMS risk becoming the forgotten people with MS and it is critical that NICE overturn the decision for ocrelizumab as soon as possible.”

A survey conducted by the MS Trust in 2016 found people with PPMS spent much less time with their healthcare team than those with RRMS.

“People with PPMS risk becoming the forgotten people with MS and it is critical that NICE overturn the decision for ocrelizumab as soon as possible.”

“People have been desperately waiting years. Now there is a licensed treatment, they should not be deprived of the hope a DMD offers,” added Jo.

She went on to thank the nearly 500 people affected by MS and healthcare professionals who contributed to the charity’s response to a public consultation on NICE’s draft decision.

“Now there is a licensed treatment, they should not be deprived of the hope a DMD offers.”

What do you think



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

View from the frontline: Creating MS nurse clinic template letters

Stepping into the role of an MS specialist nurse from a ward background was a daunting experience for Southampton’s Mavis Ayer. She talks us through how creating clinic template letters helped.



Mavis Ayer

Developing the skills needed in clinic consultations is a steep learning curve, especially when there is no formal training in how to run clinics, writes Mavis.

MS is a complex disease and being able to provide a meaningful and patient-centred consultation, within the allocated time, is challenging to say the least.

The templates I have developed helped me in my journey as an MS nurse, and they have evolved over the last three years to accommodate the ever-changing landscape of MS care.

“They are flexible, meaning they can be modified to reflect the services available, ensuring the focus is always on patient care.”

Mavis Ayer

They have become an essential tool in communicating with patients, as well as the other healthcare professionals who also care for them.

GPs are often the primary care professional looking after people with MS, and the clinic template letter gives them all the information they need to do that. Not only does this promote preventative healthcare and improve quality of life, it also leads to potential savings for the NHS.

The template also helps me to promote self-management in consultations, by giving me a space to write a care plan.

I underline tasks for GPs and other healthcare professionals, and work with patients to agree tasks for them to do before our next meeting — my patients call this their “homework”.

Focusing on self-management is essential in any long-term condition, as it empowers people to take ownership of their health. This, in turn, helps them to better manage their disease.

I hope the template letters I’ve created will help new MS nurses and other

healthcare professionals run their clinics.

They are flexible, meaning they can be modified to reflect the services available, ensuring the focus is always on patient care.

- To download and edit Mavis’ clinic template letters, go to www.mstrust.org.uk/health-professionals/resources/ms-practice

Creating clinic letter templates?

Follow Mavis’ Top Tips:



Content and length

be as succinct as possible

Grammar and English

always proofread your letter

Avoid jargon

ensure the letter is pitched at your patient’s level of understanding

Care plans are essential

make sure you include one either at the end or the beginning of the letter

REMEMBER

clinic letters are legal patient documents. Check the content is factual and true to the consultation. You can use ‘as stated’ or ‘patient verbalised’ to directly quote the patient. Any opinions gathered from other clinicians must also be written down.

REMEMBER

the consultation is the patient’s time and the templates are for guidance. Always go through the patient’s list of concerns first.

Fatigue management is as individual as patients are

There's no such thing as one-size-fits-all management for one of the most common symptoms of MS.



Sarah Chatfield

This was among the findings of a literature review, carried out by occupational therapist Sarah Chatfield, that compared group to individual fatigue management.

"I had anticipated finding that group therapy would be more effective than therapy provided on a one-to-one basis," said Plymouth-based Sarah.

"The findings, however, have shown to be inconclusive in ascertaining which delivery modality has the biggest effect on reducing the impact and severity of fatigue."

A search of the literature found 198 relevant studies, yet after accounting for duplication and applying the exclusion criteria, just 14 were reviewed.

Studies were excluded if they were more than 10 years old, included pharmaceutical intervention or were not specific to either MS or fatigue management.

"The general findings suggest individual therapy may be more effective compared to group-based interventions due to the closer working relationship between patient and therapist, and the opportunity to individualise programmes," said Sarah, who conducted the study as part of her MSc programme.

However, there are also advantages of group-based therapy in terms of learning from each other. Peer support was found to be one of the most beneficial outcomes of group interventions – but only for some people, she added.

While current practice in the NHS focuses on energy conservation strategies, this review suggests cognitive behavioural

Sarah's key points for practice

- It is not the way therapy is delivered, but the content of the programme that influences positive outcomes in fatigue management
- Adding CBT techniques to energy conservation strategies is likely to provide better outcomes
- One size does not fit all! Fatigue management interventions must be considered on an individual basis, based on a person's current needs
- Access to expertise in a range of interventions will enable therapists to provide the most appropriate delivery of therapy for each person

therapy (CBT) techniques might be more effective. The practicalities in terms of resources, though, may make this difficult, the paper recognises.

"It is fair to hypothesise that people who respond well to social situations are more likely to benefit from group therapy than those who are more introverted," said Sarah's literature review.

The later group may find their needs overshadowed in a group, and so may engage better with a one-to-one interaction, it concluded.

Reference: Chatfield, S. Fatigue management for people with Multiple Sclerosis: is group therapy more effective than individual therapy? Unpublished.

Share your examples of best practice

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

Books to help with the day-to-day

Talking about sexual, bladder or bowel dysfunction in clinic isn't easy – but difficulties are common and can cause considerable distress.

Help is on hand in the shape of the MS Trust's Living Well range of publications, designed to offer people with MS practical advice on day-to-day living.

"We have been busy updating *Sex and MS: A Guide for Men* and *Sex and MS: A Guide for Women* to ensure that they are fully inclusive of sexual preference and offer sensitive and trustworthy information," said Linden Muirhead, Director of Information and Engagement at the trust.

"Next up will be *Managing Your Bladder* and *Managing Your Bowels*, which should be published in time for conference in November."

At the event, the MS Trust will also have updated publications on primary progressive MS and secondary progressive MS. Also available will be a revised Disease Modifying Drugs book, updated to include Mavenclad and Ocrevus, but with Zinbryta removed.

- Order publications online from www.mstrust.org/shop





Wendy Hendrie



Pam Bostock

How to help therapists know what they don't know

Many therapists reading this article will have been working with MS for many years and, as a result, will be confident in the management of people with this condition.

Others will have just started out on the specialist journey or may be seeing people with MS as part of a mixed caseload.

At any career stage, it is often difficult to identify what it is that they don't know. With this in mind, Therapist in MS (TiMS) has been involved in two competency projects.

The first, the general neuro-competencies for allied health professional, developed in collaboration with Parkinson's UK and the Motor Neurone Disease Association, is nearing completion. We will let you know when it's ready.

Many of you may have already seen the second, which is a supporting skills and

knowledge document. We will be asking you to send us your comments on this shortly.

The two documents will complement each other and provide us all with a way of ensuring we all have the skills and knowledge necessary to manage people with MS effectively.

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



Gail Clayton

Busy times show no sign of slowing for the UKMSSNA

At a two-day committee and strategy meeting in June, all working parties came together to develop a plan for the next 12 months.

Our commitment to representing the voice of MS nurses was reasserted. Supported by our policy advisor, we will continue contribution to NICE Technology Appraisals and attend scoping workshops and round-table events.

During the meeting, we appointed our new co-chair, Sarah White, who will take over from Sam Colhoun from November. Everyone at the UKMSSNA would like to thank Sam for her enthusiasm and leadership over the last two years as co-chair and seven years as a committee member.

The committee would also like to congratulate Del Thomas, who received an invitation to the Queen's Garden Party in June in recognition of her services to people with MS. Del has also been nominated as the UKMSSNA representative for the IOMSN.

In keeping with our revised constitution, Emily Whisker was appointed treasurer at the meeting, and several new committee members were assigned to provide improved

regional representation. To find out who your local representative is, see the UKMSSNA website, or come and see us at our MS Trust conference stand.

We have lots going on at this year's meeting, which runs from 4 to 6 November. On the Sunday, the IOMSN certification exam will take place at 9.30am and if you're new to MS don't forget to attend the new nurses/therapists workshop at 11am.

The AGM, during which we will appoint a new vice-chair, will take place at 5.15pm on the Monday (5th November). We look forward to seeing you there.

Gail Clayton, UKMSSNA

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

Boosting access to specialist nurses: looking back over one year of the SNP

In the last year, the MS Trust's Specialist Nurse Programme (SNP) has worked with services across the country to strengthen teams and increase access to specialist nurses.



The charity estimates that as many as 68,000 people with MS in the UK have inadequate access to an MS nurse. That's what the SNP has set out to change.

And in the next 12 months, the charity has pledged to roll the programme out to a further 10 centres.

"We believe that everyone with MS in the UK should have access to an MS nurse, regardless of where they live, or the type of MS they have," said Jo Sopala, Director of Healthcare Professional Programmes.

“It's so much more than a job, it's a vocation. I like to think of us as an extra person in someone's corner, fighting against multiple sclerosis.”

The first SNP to be recruited was Jon Maisey in Leicester.

"It's so much more than a job, it's a vocation," said Jon. "I like to think of us as an extra person in someone's corner, fighting against multiple sclerosis."

Allison Smith, MS nurse in Leicester, said the programme had made a tremendous difference. "It's had a huge impact both in terms of the number of people we are able to see and the quality of our service," she added.

The Lanarkshire team, which welcomed Claire Millar, Claire Purdie and Julie Wilkie in September last year, had been lacking enough MS nurses for some time.

When an experienced MS specialist nurse left, the MS Trust worked with the team to fill the vacancy.

The project also helped to recruit an additional MS nurse as well as a neurology specialist nurse to work across the MS and Parkinson's caseloads.

Karen Maclure, who manages the service, said: "The SNP has helped the service to develop and flourish, and, most importantly, reach people with MS."

Other sites to benefit include Bradford, where Sally Fox has been working since November.

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

What next for SNP?

The Specialist Nurse Programme (SNP) aims to get MS nurses into areas where there is greatest need — and work is still going on to achieve that goal.

In recent months, the MS Trust has worked with the MS teams at North Lincolnshire and Goole and Hull Royal Infirmary to establish a joint nursing service. A new MS nurse has been funded and an existing vacancy filled.

Teams at James Cook University Hospital in Middlesborough, and the Anne Rowling Clinic in Edinburgh have both added a third nurse to their ranks through the SNP.

"We are looking forward to working with all the MS teams who are part of the SNP and are continuing to work with several other sites to establish more posts," said Megan Roberts, Health Professionals Programme Manager.

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 charity'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 charity's highly regarded Generating Evidence in MS Services (GEMSS) programme

Festive fundraising

With Christmas just around the corner, have you ever thought about using your festive activities to make a difference for people living with MS?



From a Christmas cake sale to a holiday fun run, check out our festive fundraising ideas to get you started:

Purchase our Christmas cards and spread awareness of MS with every one you send. Check out the brochure inside this issue of MS in Practice www.mstrust.org.uk/christmas

Take part in a family fun run Join our team in the London Santa Run or find your own festive run around the country www.mstrust.org.uk/santa

Organise a Christmas collection in your clinic Get in touch and we can provide you with everything you need.

Festive Jumper Day

Join friends and colleagues on **Friday 7th December** and wear your Christmas jumper with pride. And remember antlers, Christmas slippers or any other festive wear will do!

Fun for the little ones

Do you have children that go to playgroup, nursery or school? Download your free Reindeer Rally fundraising guide, pass it onto the group leader or head teacher and encourage them to make a difference.

www.mstrust.org.uk/reindeer

Take on a Christmas Challenge

Hold a mince pie or brussel sprout eating competition, wear a different Christmas item for the 12 days of Christmas, hold a Christmas wrapping contest or take part in 'festive fines'. The possibilities are endless.

www.mstrust.org.uk/festivefundraising

Organise a Christmas Cake Off

Or what about a lunchtime cake sale? For more info and to download your Christmas Cake Off fundraising guide, go to www.mstrust.org.uk/cake-off

Whatever you choose to do we will support you all the way and the money raised will help us to make sure no one has to manage MS alone.

- Call 01462 476707
email fundraising@mstrust.org.uk
or go to www.mstrust.org.uk/festivefundraising
for more information

Support Ellie's marathon effort

MS nurse Ellie Garlick has taken on the Great Eastern Run for the MS Trust.

At the time of going to print, the Hinchingsbrooke Hospital NHS Trust nurse was getting ready to take on the 13-mile, half-marathon route on October 14.

"When I got my job as an MS nurse I only had a very basic understanding of MS. The MS Trust funds a fantastic, accredited week-long degree module for every newly appointed MS professional. Attending this gave me the education I needed to actually be the specialist nurse my badge says I am.

"This means I am hopefully of some use to the people I care for and I can be effective in supporting them to live as well as possible with their MS."

Education is expensive though – each place on the course costs £1,765.

"That's why I'm trying to do my bit to raise money, so they can continue to make sure the knowledge and skills of professionals working with people with people with MS live up to their job title," said Ellie.

- To sponsor her, go to uk.virginmoneygiving.com/giving/EllieGarlick

Lifeline appeal

If you missed our first ever BBC Lifeline appeal on the BBC which was presented by Radio 1 DJ Scott Mills you can still view it on the MS Trust's YouTube channel www.youtube.com/mstrust

We are so thankful to have had this opportunity to showcase the work we do and highlight the need for more MS nurses.

SAVE THE DATE

MS Trust Conference 2019

3-5 November



Follow us on Twitter
[@MSTrust](https://twitter.com/MSTrust)
[@MSTrustforHPs](https://twitter.com/MSTrustforHPs)

Contact us:
01462 476700
info@mstrust.org.uk
msip@mstrust.org.uk



Multiple Sclerosis Trust

Spirella Building
Bridge Road
Letchworth Garden City
Hertfordshire, SG6 4ET

Registered charity number:
1088353



MS in Practice published by

Editorial: Amanda Barrell
Design: Emily Wilkinson
www.lemonade-studio.co.uk
Printed by Pureprint
on behalf of the MS Trust

You can unsubscribe or change your email and postal preferences at any time online at support.mstrust.org.uk or by phoning 01462 476700.