

NICE's Ocrevus U-turn means people with PPMS can now 'dare to dream'

People with primary progressive MS (PPMS) have spoken of their joy at the first disease modifying drug (DMD) for the condition being made available on the NHS in England.

NICE reversed its earlier decision not to approve Ocrevus (ocrelizumab) in May after the manufacturer, Roche, NHS England and NICE agreed new pricing options.

Yvonne Pettigrew who, like around 14 per cent of all those with MS in England, has PPMS, said: "I can't tell you how exciting it is to have the first drug to treat PPMS approved for use within the NHS.

"Control of my deterioration will give me optimism about a future I hadn't dared dream about."

“I can't tell you how exciting it is to have the first drug to treat PPMS approved for use within the NHS.

Under the ruling, the DMD will be available to those who have had PPMS for 15 years or less, have an EDSS of up to 6.5, and display evidence of MS activity on MRI scans.

Meindert Boysen, director of the Centre for Health Technology Evaluation at NICE, said the earlier draft guidance had acknowledged that ocrelizumab represented an "important development" in an area of large unmet need.

He went on: "Unfortunately we couldn't recommend it at the price offered at that time because it did not represent a cost-effective use of limited NHS resources.

"We are therefore pleased that NHS England and the company have been able to reach an agreement that will see this important new treatment made available to thousands of people with this form of MS."

David Martin, Chief Executive Officer at the MS Trust, which campaigned against the original decision, said the news was "very welcome".

"We commend the willingness of NICE, NHS England and Roche to find a solution which enables people with early, inflammatory PPMS to access a treatment which will allow them to continue working and remain independent for longer," he said, pointing to clinical trials that show Ocrevus could delay the worsening of disability for those in the early stages of progressive disease.

Results suggest the drug, which is given as a six-monthly infusion following two induction doses, has the potential to delay the need for a wheelchair by up to seven years.

"But we know this is just the start," he added.

"More treatments for progressive MS are still desperately needed, and we will continue to fight to ensure everyone with MS can access the treatments they need."

The approval decision currently only applies to England. Roche has said it is working with NHS Wales, NHS Northern Ireland and the Scottish Medicines Consortium to make the drug available across the UK.



New ABN DMD in pregnancy guidelines

Women diagnosed with MS should not delay starting on disease modifying drugs (DMDs) until they have completed their families.

The new UK Consensus on Pregnancy in Multiple Sclerosis: Association of British Neurologists Guidelines, published in *Practical Neurology*, said the wait could lead to a "significant delay" in starting treatment.

Said the authors: "In recent years, there has been an increasing appreciation that neuroaxonal damage starts early in relapsing remitting MS.

"This damage accrues over time and is the likely cause of the progressive disability that occurs later in the condition. Early intervention with DMDs has been shown to reduce/delay long-term disability."

The guidelines, which were developed by a multidisciplinary working group and based on all currently available evidence, recommend professionals discuss pregnancy with all women of child-bearing age before prescribing a DMD.

Welcome

to MS in Practice Issue 5



Welcome to the fifth edition of MS in Practice, the MS Trust's essential update for healthcare professionals working in the multiple sclerosis community.

The historic news that Ocrevus (ocrelizumab) has become the first drug approved for primary progressive multiple sclerosis in England is a huge step forward, especially as this form of MS affects one in ten people with the disease.

We look behind the headlines and take a closer look at the requirements that have been put in place for people to be eligible for Ocrevus (page 1).

We all know that exercise is a good thing. This issue we also explore how it can actually slow the progression of MS and improve fatigue, depression, mobility and quality of life (pages 4 and 5).

David Martin,
CEO, MS Trust

Enquiry service

The service is available to help anyone affected by MS to find the information they need

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

What do you think



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

Specialist nurse and therapist projects are Paru's top priorities



Paru Naik is the MS Trust's new interim Director of Health Professional Programmes. She joined the charity in April.

She brings significant experience from across the NHS including work at The Royal Free, Barts and East Kent Hospitals.

Paru replaces former director Jo Sopala who decided to seek a new challenge

after 12 years at the Trust, which included the creation of the charity's MS Specialist Nurse Programme and devising the Advanced MS Champions pilot project aimed at some of the 40,000 people with advanced MS.

In the past 18 months, the Trust has delivered three champions alongside an additional seven MS specialist nurses.

With the significant caseloads facing so many healthcare professionals, Paru's priority will be to scale up the Specialist Nurse Programme while putting in place a further three Advanced MS Champions.

Help to Make Sense of MS

In the weeks immediately after receiving a diagnosis of MS, it's clear that too much information can be almost as bad as too little. Many people just want the basics in a digestible format and to know where they can go in the future for more details on topics that concern them.

Making Sense of MS is a resource tailored to the needs of people recently diagnosed. We introduce the basic facts about MS, and give an overview of what could happen next, along with clear signposting to further sources of information. It consists of a small booklet and a folder with a core selection of information sheets.

- Order Making Sense of MS booklets or core packs, or browse the selection of additional information sheets, at www.mstrust.org.uk/pubs



Move it for MS



We all know how beneficial the right exercise can be for people with MS. The MS Trust has a comprehensive range of information and resources to help people with MS introduce more movement into their lives.

Our Move It For MS DVD with Mr Motivator remains very popular and is now available with a newly designed cover. All the exercises are also available online or can be downloaded from YouTube to watch offline.

We have also worked with neurophysiotherapist Jo Pritchard to present an accessible Pilates session that your clients can join in with from their own homes.

- To see the information on exercise in MS visit www.mstrust.org.uk/exercise
- All our video resources are on our Youtube channel at www.youtube.com/MSTrustGroup

QuDoS is back

After a break last year, the Quality in the Delivery of Services (QuDoS) in MS recognition programme is back for 2019.

The team behind the initiative have launched a new website which will host interviews with past winners and updates on their projects over the coming months.

This year also sees a streamlined nomination process, and new categories such as outstanding MS physiotherapist and outstanding MS occupational therapist.

Nominations close on 15 July. All shortlisted entries will be invited to a recognition event on the eve of the MS Trust annual conference on 2 November.

“The team have launched a new website which will host interviews with past winners.”

QuDoS is organised by pharmaphorum in conjunction with the MS Trust. It has been sponsored by Novartis, Biogen and Sanofi Genzyme.

- For more information or to nominate yourself or a colleague, go to www.qudos-ms.com

International research grant

Applications to the MS International Federation's (MSIF) McDonald Fellowship close on 21 July.

The programme, which enables young researchers from emerging countries to work at an overseas host research institution for two years, consists of an annual living expenses and travel grant of around £30,000.

The host institution will receive a £2,000 annual contribution, which will also cover the candidate's ECTRIMS attendance in year two of the fellowship.

- For more on the joint application process, go to www.msif.org

Success as charity's MS nurse programme reduces wait times

Leicester's MS team has reduced the waiting time for a clinic appointment from seven months to just one to four weeks.

The result is thanks to the MS Trust's Specialist Nurse Programme, which was launched in 2017 to provide MS nurses in areas most in need and has now completed its pilot period.

The initiative saw the charity part-fund MS nurses in Leicester, Bradford and Lanarkshire for 15 months. All three have now been taken on permanently by the NHS.

“We are thrilled to report that there has been a whole range of measurable benefits brought to people with MS in those areas,” said Megan Roberts, Health Professionals Programme Manager at the Trust.

In Bradford, the team were taking up to five days to respond to calls and emails before the new nurse was employed in 2017. Between March 2018 and February 2019, 96 per cent of calls and



Jon Maisey, MS Specialist Nurse in Leicester

emails were returned by the end of the next working day.

The next round of the programme has seen the charity fund new MS nurses in Lothian, South Tees, Hull and North Lincolnshire and Goole, and Coventry, and more are planned for this year.

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New ABN DMD in pregnancy guidelines

As relapse rates naturally reduce during pregnancy, many women with MS choose to stop DMDs, they said.

“However, for those with very active MS, treatment throughout pregnancy should be considered,” said the paper, before outlining safety data for the main MS treatments.

First-line injectables, such as glatiramer acetate and beta interferon, may be continued during pregnancy, and the benefits of breastfeeding on treatment outweigh the risks, for example.

“Patients taking natalizumab will usually have had highly active disease before treatment, and serious consideration should be given to continuing treatment during pregnancy given the significant risk of disease reactivation and/or rebound on stopping treatment,” explained the document, which was co-authored by the MS Trust.

The organisation also helped facilitate the project's working group.

“Pregnancy is not recommended for four months following alemtuzumab and for six months following treatment with cladribine, however after this time there are no contraindications.”

After receiving ocrelizumab, conception should be avoided for 12 months. As it is given on a six-monthly basis, family planning should be considered when initiating and prescribing, recommended the guidelines.

They also state that teriflunomide is contraindicated in pregnancy, and that dimethyl fumarate and fingolimod should be avoided where possible. In the event of a relapse during pregnancy or while breastfeeding, corticosteroids can be prescribed.

Having MS, the authors went on, does not automatically make pregnancy high-risk, and should not in itself limit birthing options.

- The document is available at <https://pn.bmj.com/content/19/2/106>

Talking about exercise: How to rise to the challenge and get people moving

We all know that regular exercise can help people live well with MS. But as healthcare professionals, how can we broach the topic sensitively? And how can we help people with limited movement to be more active?



Regular activity is important for all of us, so it's our responsibility as healthcare professionals to bring it up in every consultation with every patient.

That's the view of Wendy Hendrie, Specialist MS Physiotherapist, who said most people were happy to have the "lifestyle conversation" so long as it was handled sensitively.

"We all know how good exercise is for us. If we could make it into a pill we would,"

“In my 30 years of practice, probably the biggest problem I have seen is deconditioning. As people get out of condition, they get weaker and they think it's their MS getting worse.”

Wendy Hendrie

she told *MS in Practice*, adding being active helped with many MS symptoms and boosted quality of life.

Study after study has shown that exercise leads to people feeling better – but it's not a magic cure.

"One of the biggest problems we see in MS isn't always the primary condition but the secondary, insidious complications which can develop as a result of sitting for too long," she said.

"In my 30 years of practice, probably the biggest problem I have seen is deconditioning. As people get out of condition, they get weaker and they think it's their MS getting worse."

Asked how she knew when to bring the topic up, and how she did so sensitively, Wendy said she asked every patient the same question: "how much time do you spend sitting down?"

"Some people will say they do a lot of exercise and you can talk about keeping it up. But it's surprising how many people say: 'I am sitting around for 90 per cent of the day'."

Once you have the answer, you can find out what the barriers are, explain some of the benefits and put in place any needed support.

Said Wendy: "We have ways of measuring patient activation levels, so we know how good someone is at self-motivating. Those who are not might need a bit more encouragement."

Once trust has been established, Wendy finds the issue of weight comes up naturally during these conversations. Being overweight can make mobility and balance even harder and put strain on joints which can lead to unnecessary pain, she said.

"We have to think about sitting and being overweight in the same way we think about smoking. It's about having honest conversations where you are both on the same page, and you are able to get them the support they need," she said.

"No responsible professional should avoid the subject of weight. They should hit it head on. Include the family in the conversation if need be, but never just ignore it."



“ We have ways of measuring patient activation levels, so we know how good someone is at self-motivating. Those who are not might need a bit more encouragement.”

Activity and poor mobility

People with poor mobility may find it next to impossible to get active, but even small changes can make a huge difference.

As people start to lose function in one part of the body, they unconsciously compensate for it, explained Wendy.

“If you’re getting a bit weak in your legs, and struggling to get out of the chair, you start using your arms to push, for example. By doing that, the trunk and body muscles are weakening even quicker.

“Sometimes, just making something a bit more of a challenge can make a huge difference.”

It can be too easy, she went on, for family members and healthcare professionals to reinforce sedentary behaviour in the name of being helpful.

“If you ask the question ‘how much time do you spend sitting around?’ you can see if weakness is caused by deconditioning or the underlying MS.

“I could cite hundreds of examples of people who’ve got off sticks and crutches, just because they have started using their body properly rather than cheating by using the stronger parts,” she added.



Help to get moving

The MS Trust marked this year’s MS Awareness Week with the Move it for MS campaign, calling on people with MS to introduce a little activity into their daily lives.

“Staying active doesn’t need to mean running marathons or going to the gym, it’s about doing it at your own level, at your own pace,” said the team.

As part of the campaign, the charity has produced a range of videos and other resources to help patients get moving. They are all available at www.mstrust.org.uk/exercise

Wendy’s top tips to talking exercise in clinic:

- Start the conversation with: “How much time do you spend sitting down?”
- Ask about activities they have given up since diagnosis – why did they stop? What were the barriers? Could that activity be modified?
- Look at patient activation levels: do they need a bit more support?
- Suggest a pedometer or smart phone step tracker – could they increase their steps by just 200 a week?
- Signpost to trusted sources of information on diet and exercise, like the MS Trust or www.nhs.uk

High levels of caregiver strain among RRMS life partners

Caregiver strain is common in the partners of people with relapsing remitting MS (RRMS) and mild disability.

Results from a study published in *Multiple Sclerosis and Related Disorders* suggest the problem was primarily associated with the patient's cognitive and neuropsychiatric problems.

The study, carried out by a team from the Netherlands, analysed the questionnaire answers of 173 people with RRMS and their life partners.

The people with MS were asked about fatigue, personality, physical, cognitive and neuropsychiatric functioning, and underwent neuropsychological and neurological examinations. Their partners answered questions regarding caregiver strain and the person with MS' neuropsychiatric and cognitive functioning.

Almost a quarter, 24 per cent, of the partners experienced higher than average levels of caregiver strain.

The three types of strain most frequently experienced were other demands on the caregiver's time, the need to make changes in personal plans, and the need to make family changes, said the paper.



The authors concluded: "Our findings highlight the importance of early identification and treatment of cognitive and neuropsychiatric problems in persons with MS.

"As the caregivers' wellbeing is extremely important for their continuing role in assisting the person with MS, it is important to routinely assess caregiver strain in life partners of persons with MS, to create awareness of caregiver strain and to offer caregivers information and access to services and support offered by community organizations."

Reference: van der Hiele K, et al. Caregiver strain among life partners of persons with mild disability due to relapsing-remitting multiple sclerosis. *Mult Scler Relat Disord.* 2019;31:5-11.

CBT may help manage pain

Cognitive behavioural therapy (CBT) may help people experiencing MS pain achieve their goals when used alongside standard care.

A randomised control trial compared the outcomes of two groups of people who were experiencing "at least moderate" MS pain.

"Besides interfering with daily functioning, pain in MS is associated with higher levels of depression and anxiety," said the authors.

“CBT may be helpful for people with MS experiencing pain.”

"While CBT for pain has been found to be an effective treatment in other populations, there has been a dearth of research in people with MS."

Twenty people took part in the study with half receiving 12 sessions of CBT plus standard care. The remaining participants attended an MS-related education course, which also ran over three months, as well as standard care.

Researchers measured changes in pain severity, pain interference and depressive symptom severity from baseline to 15-week follow-up. Participants were also asked to rate their satisfaction with their treatment and their accomplishment of personal behavioural goals.

While both groups rated their treatment satisfaction as "very high" and their behavioural goals as "largely met", only the CBT group demonstrated a significant improvement.

After the treatment period, both groups saw overall pain severity, pain interference and depressive symptoms decrease, though there was no significant difference between the two.

"CBT or education-based programs may be helpful adjunctive treatments for people with MS experiencing pain," the authors concluded.

Reference: Gromisch ES, et al. Cognitive behavioural therapy for the management of multiple sclerosis-related pain: A randomized clinical trial. *Int J MS Care* 2019 Jan 5. [Epub ahead of print].

Large study finds beta interferon drugs increase survival

A study of almost 6,000 people with relapsing remitting MS (RRMS) has concluded that beta interferon drugs can increase survival.

Of the 5,989 participants, all of whom were treatment-naïve at enrolment in Canada or France, 32 per cent were on the treatment for at least six months.

During the 11-year follow-up period, there were 742 deaths. Of these, 649 were matched to between one and 20 controls by country, sex, age, year and disability level at the start of the study.

Analysis showed that taking beta-interferons was associated with a 32 per cent decrease in mortality risk, when compared to not receiving the treatment at all. The effect was particularly evident in those who had taken the drugs for at

least three years and the results were similar in both countries and sexes.

Senior author, Professor Helen Tremlett, from the University of British Columbia's division of neurology, and the Canada Research Chair in neuroepidemiology and multiple sclerosis, said: "Now that we know that life might be extended for people with MS who take these drugs, we do have to consider quality of life.

"Further research to look at this aspect of treatment outcomes is certainly warranted."

Reference: Kingwell E, et al. Multiple sclerosis: effect of beta interferon treatment on survival. *Brain* 2019;142(5):1324-1333.

New Lemtrada side effects lead to EMA prescription restrictions

The European Medicines Agency (EMA) has placed temporary restrictions on the prescription of Lemtrada (alemtuzumab) after reports of new immune-related and cardiovascular side effects.

In addition to the restriction, which will be in place until a full safety review has been carried out, the body has recommended an update of the disease-modifying drug's (DMD) product information.

The move follows reports of immune-mediated conditions, including autoimmune hepatitis and haemophagocytic lymphohistiocytosis, as well as severe neutropenia, in people treated with the medication.

There have also been problems with the heart and blood vessels in the days following infusion. These have included bleeding in the lungs, heart attack, stroke and cervicocephalic arterial dissection, or tears in the lining of the arteries in the head and neck.

Said EMA in a statement: "Healthcare professionals should consider stopping treatment in patients who develop signs of these conditions and patients should immediately seek medical help if they experience symptoms.

"EMA will now evaluate all available data on the safety concerns with the medicine and consider any additional measures necessary to protect patients and whether there should be changes in the authorised use."

In the meantime, clinicians are advised only to start treatment in those with

relapsing remitting MS (RRMS) that is still highly active after a full course of at least two other DMDs, or in those with highly active disease where all other DMDs are contraindicated or unsuitable.

For patients already on treatment, vital signs should be monitored before and during the infusion. If clinically significant changes are observed, the infusion should be stopped and additional monitoring, including ECG, should be considered, said the statement.

Liver function tests should be carried out before and during treatment. If there are any signs of liver damage, elevations in liver enzymes or hepatic dysfunction, such as unexplained nausea, vomiting, abdominal pain, fatigue, anorexia, jaundice or dark urine, Lemtrada should only be re-administered "following careful consideration".

"Patients who develop signs of pathological immune activation should be evaluated immediately, and a diagnosis of haemophagocytic lymphohistiocytosis considered," said EMA, adding that immune activation symptoms can occur up to four years after the start of treatment.

- **For more information go to www.mstrust.org.uk/lemtrada-restriction**

US gives green light to siponimod for SPMS

The US Food and Drug Administration (FDA) has approved Mayzent (siponimod) for use in active secondary progressive MS (SPMS).

The oral treatment, which has also been approved for use in clinically isolated syndrome (CIS) and relapsing remitting MS (RRMS), is suggested for use in people with SPMS who still experience relapses.

In a clinical trial of 1,651 people, Mayzent was shown to be able to slow disability progression and reduce the number of relapses in active SPMS when compared to placebo.

The drug is currently being reviewed by the European Medicines Agency for marketing authorisation. NICE has confirmed it will start an appraisal for NHS use in July 2019.

If approved in SPMS, it will become the country's first available treatment for this form of the disease.

MS pain drugs reclassified

Pregabalin and gabapentin, often prescribed for neuropathic pain in MS, are now class C controlled substances across the UK.

The reclassification means they can no longer be supplied on a repeat prescription basis and pharmacists need to dispense the drug within 28 days of the prescription being written.



Unless a system for the electronic prescribing of controlled substances is in place, all prescriptions for pregabalin and gabapentin will need to be hand-signed.

The move, which was announced in October, followed a warning from the Advisory Council on the Misuse of Drugs that there had been a rising number of fatalities linked to the misuse of these drugs. Prescriptions for pregabalin had increased by 350 per cent and gabapentin by 150 per cent in just five years.

This was linked to reports the medications were being increasingly misused for the feelings of euphoria, relaxation and general calming they can produce, particularly when used with other drugs.

The new rules came into force on 1 April.

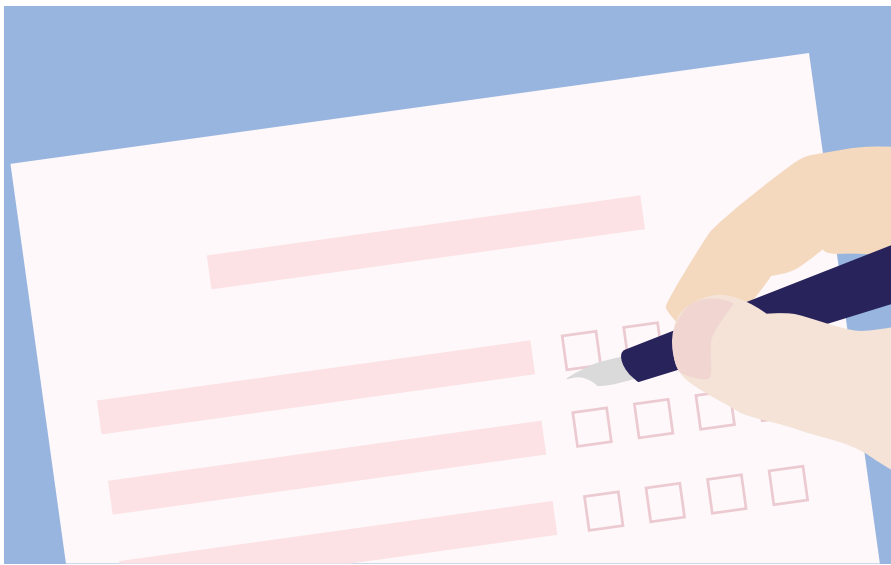
What do you think



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

Routine QoL checklist can improve communication and consultations

Routinely assessing health-related quality of life (HRQoL) in clinic allows people with MS to focus on the impact of their condition and helps professionals provide holistic care.



Dr Helen Willis, MS Specialist Nurse at Broomfield Hospital, Chelmsford, studied the use of the Multiple-Sclerosis Impact Scale-29 version two (MSIS-29v2) in clinic for her PhD thesis project.

Her intention was to find out if assessing HRQoL routinely in practice was feasible and valuable, and the results were positive.

“Rather than using the MSIS-29v2 to measure changes in the physical and psychological impact of HRQoL, the value rests in its ability to empower patients to consider the impact of their MS in a structured manner,” she concluded.

Speaking to MS in Practice, Helen said that structuring the consultation around the form gave people an opportunity to contemplate the full range of MS symptoms.

Helen and her colleagues, who asked the 311 study participants to fill in the questionnaires while in the waiting room before their appointment, also benefited from the change, she said.

“Because patients score each area on one to four, we could focus on the things that are most affecting them.

“The team could then use the answers to guide any requirements for therapeutic interventions or referrals to other members of the MDT,” she said, adding this helped offer “holistic patient-centred care through shared decision making”.

“Physical and psychological impact scores of the MSIS-29v2 before and after the interventions were compared. At times, these interventions really did contribute to improved HRQoL in some patients.”

Helen, who also found overall job satisfaction improved over the course of the study, recognised that routinely using the forms would entail some logistical changes.

“At the beginning, it does take a little bit longer, but I would really encourage people to persevere. Yes, you’re changing the way you practice, but it is for the better,” she said.

The study

Helen split her study into two phases.

During the first, patients completed the MSIS-29v2 before each routine consultation between November 2014 and November 2015. Data from 311 people, all of whom had attended between one and five appointments, were used in the final analysis.

In phase two, Helen chose 15 participants who had attended at least two MSIS-29 sessions and interviewed them about their experience of the questionnaires. She also spoke to three healthcare professionals who were involved in the research.

The conclusions

The study concluded that introducing HRQoL assessments using the MSIS-29v2 was:

feasible

– patients were able to complete the form quickly and easily before their appointment

valuable to patients

– the structure of the MSIS-29v2 allowed patients to focus their thoughts so they could provide their healthcare professional with relevant information

valuable to healthcare professionals

– the assessment helped professionals to identify important issues, suggest interventions and monitor progress over time

useful

– it improved patient-clinician communication and helped patients become more aware of the impact of their condition

Do you know how much your service spends on DMD monitoring?

Every MS centre knows the high burden of monitoring people on disease modifying drugs (DMDs), but few know how that equates to actual costs.



Rachel Dorsey-Campbell, Senior Lead Pharmacist in Neurosciences at Imperial NHS Trust
Photo by Brendan Clayton Photography/Neurology Academy

A new online calculator allows teams to estimate how much time and money goes into tasks such as booking and chasing blood results at the touch of a few buttons.

Rachel Dorsey-Campbell, Senior Lead Pharmacist in Neurosciences at Imperial NHS Trust, has helped The Neurology Academy, which provides specialised healthcare professional education, to develop the tool.

“We have all these different patients on all these different treatments. Over time, all the monitoring that goes along with that has just been absorbed by services and I think people are now at breaking point,” said Rachel, adding things were not about to get any better.

“We’ve now got Ocrevus for primary progressive disease and a new treatment for secondary progressive is likely later this year, so the number of patients we have on treatment is only going to get bigger.”

The tool consists of an online questionnaire that populates an Excel spreadsheet. Once data on patient

“They will be able to work out what’s happening within their service: how much time it’s taking and whether they should restructure or reallocate duties to make their service more efficient.”

Rachel Dorsey-Campbell

numbers and staffing levels is plugged in, it estimates the number of whole-time equivalent hours that service is spending on monitoring and converts that into pounds and pence.

Rachel said: “A service can use this information in staffing business cases. They can go to their management team and say: ‘we spend this amount of time and spend this amount of money managing these patients’.

“They will be able to work out what’s happening within their service: how much time it’s taking and whether they should restructure or reallocate duties to make their service more efficient.”

Monitoring infrastructures have evolved on a site-by-site basis, meaning each has a different way of doing things, Rachel added.

Online DMT modelling tool

To use the online DMT modelling tool you will need:

- the number of patients on each DMD at your centre
- the NHS Agenda for Change banding of the staff who manage monitoring
- the approximate amount of time given over to DMD monitoring

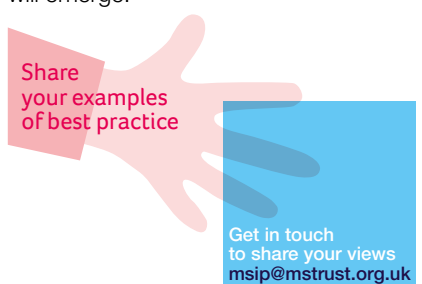
To enter your data, go to www.multiplesclerosisacademy.org/resources/commissioning

For more information or if you would like support to use the tool, email AmandaWorpole@neurologyacademy.org

At Imperial, for example, a large proportion of the monitoring is carried out by the pharmacy team. In other places, DMD monitoring eats into specialist nurse time and contributes to variations in care.

“Teams could use the tool to make a case for non-clinical staff to undertake some of these monitoring duties, which would free up nursing time.”

As more people use the tool, it is hoped that a national picture on the most effective monitoring methods will emerge.





TiMS groups focus on partnership working to improve care for all

In this latest TiMS update, we wanted to give you a summary of what we have been doing over the last few months.

TiMS has been involved in meetings with NHS England to look at commissioning specialist neurological services. The meetings have looked at questions including what constitutes a good service, what specialist services should look like, what patients need from a specialist service, and when patients need such services. We will let you know the outcomes when we can.

We have also been working on a competencies, knowledge and skills framework. These are general and profession-specific competencies for OTs and dieticians working with people with progressive neurological conditions. They are available on the Motor Neurone Disease Association website, www.mndassociation.org and physiotherapy competencies will follow.

The separate TiMS Skills and Knowledge Framework, which was featured in issue three of MS in Practice, has been requested more than 200 times so far. It is currently being evaluated.

We are also involved in filming short videos on basic posture management, and writing a Managing Ataxia booklet. Both will be available soon on the MS Trust website, www.mstrust.org.uk

The TiMS Research Group is currently gathering data from people with MS who have used the Self-assessment Annual Review Form. We will keep you updated with the results.

To get involved in any of these projects or to let us know about ways you have found of working more effectively, please get in touch on therapistsinms@mstrust.org.uk We want to ensure all therapists working with people with MS can benefit from your experience.

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



Wendy Hendrie



Pam Bostock

Website additions will help nurses share ideas and provide best practice

It's been a busy few months in the MS world. This year's MS Awareness Week was held from 22 to 28 April. It helped raise awareness of the condition and raise money for the MS charities that support research and help patients and their families live with their condition.

This year, the MS Trust looked at the benefits of exercise with their Move It for MS campaign. The MS Society focused on surveys for people with MS and their carer to obtain up-to-date information on what they need from services and care.

The UKMSSNA's board have completed a number of important projects since the last edition of MS in Practice.

Our new blog is live on our website, www.ukmssna.org.uk It is a great way to share information and inform colleagues of upcoming events.

The Care Manual has been updated and is also now live on the website. We would like to thank everyone who got involved in this huge piece of work – the updated manual is a credit to you all.

We hope it will help MS nurses old and new to find all the information they need to navigate their way through the MS world.

The UKMSSNA would also like to encourage all colleagues who haven't already done so to consider taking the International MS Nurses Examination.

We know the idea of an exam can be scary, but it's a great way to ensure you have the most up-to-date knowledge and it also counts towards your Continued Professional Development (CPD). There is more information available on our website.

Finally, we would like to thank you all for your continuing hard work in supporting the MS community.

Nicola Daykin, UKMSSNA

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



Nicola Daykin

From research to clinic – embedding study results into everyday practice

The team behind a landmark study into the use of standing frames in progressive MS want to make sure their findings make a difference.

As reported in the last edition of MS in Practice, the multi-centre Standing up in Multiple Sclerosis (SUMS) study concluded that using the frames could improve motor function and quality of life in people with significant MS-related physical disabilities.

Now the team behind the trial, which has been published in *Lancet Neurology*, want to ensure the findings are embedded into everyday practice.

Jenny Freeman, Professor in Physiotherapy and Rehabilitation at Plymouth University, and chief investigator of the trial, said: “People with MS who have more severe levels of disability often find it difficult to remain physically active and many health professionals are at a loss as to how to help.”

The standing frame programme is a relatively simple and inexpensive way to achieve this, she said.

“With initial help from physiotherapists to set up the programme, and some ongoing help from their spouse or carer, people with MS can undertake supported standing on a regular basis within their own homes.

“I really encourage physiotherapists to support people to achieve this, by talking to them about the programme and by sharing this evidence with their colleagues and commissioners,” said Prof Freeman.

A number of resources designed to help MS professionals offer the intervention have been added to the study’s website. These include videos on how to set up and use the standing frame, as well as a guide on how to order the equipment.

- **To find out more about SUMS, including help to implement a standing frame programme in your centre and to hear from the trial participants themselves, go to www.plymouth.ac.uk/research/sums**



Stand up for people with advanced MS

SUMS set out to discover if the frames were a cost- and clinically-effective way to avoid some of the complications associated with sitting, such as loss of motor function.

The study of 140 people compared the impact of usual care to usual care plus using a standing frame for at least 30 minutes, three times a week for 16 weeks.

The team found an improvement in both motor function and quality of life in the intervention group as compared to the usual care group.

When the intervention group was split into programme “compliers”, defined

as people who stood for a total of at least 64 minutes each week, and “non-compliers” there was also a correlation between using the frame more and higher levels of motor function improvement.

A health economics evaluation found the standing frame was just £268 more expensive than usual care at an estimated cost of £15,000 per quality adjusted life year (QALY).

This, Prof Freeman highlighted, was “way below” the threshold for NHS implementation, which usually sits at between £20,000 and £30,000 a QALY.

New MS Trust resources

MS and the family



The content team has reviewed and updated our crucial publication ‘Talking with your kids about MS’.

This fresh and frank booklet gives ideas about how to communicate what an MS diagnosis means to children, and reassurance that family life will go on much as normal. MS affects everyone in the family, and so we believe that support like this is vital.

Get involved

We’d love to hear from any healthcare professionals who would like to get involved with reviewing and improving our material, both printed and online.

If that sounds appealing, or if you have any ideas for information resources you would like to see, let us know by emailing Claire, our Content and Engagement Manager, at claire.winchester@mstrust.org.uk

Get involved with Team MS Trust!

Thank you to everyone who has got involved in fundraising and awareness for the MS Trust over the past few months.



We have seen MS health professionals get involved in so many ways, from running the London Marathon to holding a raffle, or taking part in Miles for MS to having a cake sale!

We would like to say a particular thank you to everyone who got involved in MS Awareness Week. Whether you put up an information stand, posted on social media, or Moved it for MS, like this fab Neuro-Pilates class in Retford (pictured), it was brilliant to see so many of you be a part of this important week.

For more inspiration of how you can support the MS Trust, check out these ideas...

London to Brighton Bike Ride

Join us on 15 September and be a part of the fantastic London to Brighton cycle ride. Pedal 54 miles from Clapham Common to Brighton's magnificent seafront, and reward yourself with fish and chips, a beer or an ice cream (or all three!) by the sea.

www.mstrust.org.uk/londontobrighton

My Garden Party

It's party time! With summer on its way why not bring a little sunshine to your day with your very own My Garden Party. Be it indoors or out, at work with colleagues or in your garden with family and friends, make it fun with tea and cake or games and fizz.

www.mstrust.org.uk/mygarden

Ben Nevis

Join our team trekking to the summit of the UK's highest mountain this September and enjoy some of Scotland's most breath-taking scenery with magnificent views across the Grampian Mountains. Step out of your comfort zone for an experience you'll be sure never to forget!

www.mstrust.org.uk/bennevis

Look out for Kenny!

Long-term MS Trust supporter Kenny Smith is currently taking on his biggest challenge to date, by cycling around the UK in 50 days. We are asking the whole MS community to get behind him and give him a cheer as he goes through towns and cities across the UK. Find out if he is cycling through a town near you by visiting

www.50dayscyclerride.uk

Run for MS

Why not join Team MS Trust and #Run4MS? Choose your distance, find a run and call MS Trust to join our Running Club. We're here to help you with your fundraising and training. Let us know your chosen challenge and we'll get you proudly sporting a blue MS Trust top and tying those laces before you know it!

www.mstrust.org.uk/run

- For more information call 01462 476707 email fundraising@mstrust.org.uk or visit www.mstrust.org.uk/events

Clare goes extra mile

MS nurse Clare Langham was part of the MS Trust team in the Santa Run in December and will be lacing up her running trainers again in October, for the Royal Parks Half Marathon.

Not content with this though, Clare, together with fellow MS nurse Bethan Tredwell, is trekking the Three Peaks for the MS Trust!

"Beth and I are currently the only MS specialist nurses covering east Kent with a case load of 2,000 patients. We are both passionate and motivated towards the care our patients receive, and most of the training we are provided with to ensure we can deliver the best care is funded by the amazing team at the MS Trust. However, not only do they support every MS healthcare professional they also provide information and support to everyone affected by MS. Their motto quite simply is no one should face MS alone."

On 13 July, Clare and Bethan's mission is to take on the National Three Peaks Challenge, which involves climbing the three highest peaks in England, Scotland and Wales in just 24 hours!

"We wanted to do a 'little' challenge to help raise some much needed funds, to give something back to this amazing charity and ensure we can continue to deliver the vital service we do."

- To support Clare and Beth on their journey go to uk.virginmoneygiving.com/Team/BethandClareandthe3peaks

MS specialist nurses are providing care and support to people affected by MS across the UK – saving the NHS more than £70,000 a year. We can only continue to do this with your help.

- For more information please visit: www.mstrust.org.uk/donate

SAVE THE DATE

MS Trust conference 2019

3 – 5 November,
Hinckley Island Hotel

Book online at:

www.mstrust.org.uk/event/ms-trust-conference

Contact

conference@mstrust.org.uk
for bursary details.



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