

## Record-breaking display of expertise

**An array of best practice from across the UK was on display at this year's MS Trust Annual Conference.**

The 2019 poster exhibition featured a record-breaking 48 entries, covering topics from fatigue management and exercise interventions to pregnancy registries and utilising social media.

Caitlin Sorrell, MS Trust trustee, said: "The standard of entries just gets better and better every year, and 2019's posters were absolutely outstanding."

This year's top prize went to Rachel Morrison, MS Nurse in the Western Isles. She won the chance to present her project, an audit of the patient-held, self-managed personal record called **My MS Passport**, on the main stage.

"Use of the MS Passport has given people a personal handheld document to take to all their appointments and admissions to hospital. This has provided empowerment and incorporated regular self-management into their journey with MS," she said.

Three posters were given commendations:

- **Missed appointments – a missed opportunity?** By Tania Burge, Dr Emma Hale and Sarah Cox, Bristol and Avon MS Centre, The Brain Centre, North Bristol NHS Trust.
- **How do people with relapsing remitting MS experience engagement with physical activity during a relapse? A qualitative study.** By Holly Wilkinson, Caroline McGraw, Yiannis Kyratsis and Karen Chung, The National Hospital for Neurology and Neurosurgery, London.
- **Using a HRQoL questionnaire can improve communication and consultations.** By Helen Willis, Broomfield Hospital, Chelmsford, and Sarah Burch and Hilary Bungay, Anglia Ruskin University, Chelmsford.

See the winning poster on page 5

## Outstanding work recognised and shared

**Innovation, excellence, empathy and compassion – the MS healthcare professional (HCP) community has these qualities in spades, as demonstrated by 2019's Quality in the Delivery of Services (QuDoS) in MS programme.**

The QuDoS recognition ceremony, held on the eve of the MS Trust's annual conference, saw outstanding HCPs, teams and projects being rewarded for their contribution to MS care and practice.

David Martin, MS Trust CEO and member of the judging panel, said: "My fellow judges and I were very pleased

to have received such a wide range of entries for this year's programme.

"They clearly show the hard work and innovative thinking of so many teams and individuals working to support people with MS and improve the quality of their patients' lives."

In a bid to share best practice, case studies of the winning entries will be shared on the QuDoS in MS website – [www.qudos-ms.com](http://www.qudos-ms.com) – in the coming months.

The programme, which was organised by pharmaphorum in conjunction with the MS Trust, was sponsored by Novartis, Biogen and Sanofi Genzyme.

● **To see the winners, go to page 11**



*Nicki Ward-Abel's daughter, Sophie, and husband, Adrian, accepted a lifetime achievement award on behalf of Nicki, who died in 2018.*

# Welcome

## to MS in Practice Issue 7



### Welcome to the 7th edition of MS in Practice.

Thank you to every single healthcare professional who came along and helped make the MS Trust conference such a success through your input and engagement. It is so valuable to have this protected learning time away from the frontline.

I always think having time to network and swap notes is amazing and can evoke inspiration and help develop services locally and nationally for people living with MS.

The conference feedback has been overwhelmingly positive. Quotes I have seen included: "Really impressed by my first conference! Speakers, organisation and quality was fantastic. Very smooth running and greatly planned talks. I'll be back!"

"Fantastic conference. Gets better every time I attend. Well done to all the organisers and thanks to the sponsors."

I am now handing over the editorial leadership of MSiP to Paru Naik, our newly appointed permanent Director of Health Professional Programmes who will be in touch with you shortly. Please look out for an email from Paru at the end of March to book early and save your spot back at Jurys Inn for this year's conference, on November 1 to 3.

We are now planning for 2020. It promises to be an equally successful conference with a few changes to the format, some new speakers and topical subjects with time for lots of questions and answers.

**David Martin, CEO, MS Trust**

# Demonstrating value for commissioners and managers



Paru Naik

### Demonstrating value is a key driver in convincing commissioners and managers to recruit additional nurses and therapists in areas of unmet need, Paru Naik, the MS Trust's Healthcare Programmes Director, writes.

As Sustainability and Transformation Partnership (STPs), Accountable Care Systems (ACSSs), Clinical Commissioning Groups (CCGs) and Primary Care Networks (PCNs) develop further, it is imperative any service looking to increase resources and/or demonstrate value gains a competitive edge by acquiring a comprehensive understanding of the new NHS landscape.

HCPs should look to engage and build relationships with the key personnel within and outside their organisation to give themselves the best opportunity to demonstrate their value. People to target include those in information and finance departments, and HR and divisional directors. Understanding how a service is funded, ie payment by results or block funding, is imperative.

A group exercise, supported by the MS Trust's Evaluation Manager Guy Hannan, asked HCPs to consider how they add value and make a difference, and explored ways they could currently go about demonstrating that. The session then outlined how case studies are a crucial way of collecting influential data. They enable HCPs to capture real-life examples of the value they add, both in terms of the impact on patients, as well as the benefits to the wider health system.

The key themes that emerged were:

- Managers may not fully understand the services MS HCPs deliver, and how their specialist expertise is drawn upon to do this. HCPs can sometimes explain things with an expectation of an implicit understanding of their work. Interventions should be spelt out
- Understanding the audience is crucial, as this will help determine what types of information will be most compelling (eg commissioners may seek data on cost savings)
- Being more explicit on outcomes, such as the potential cost savings of avoiding emergency hospital admissions, is key

The MS Trust will continue to help MS HCPs better demonstrate their value through workshops for all HCPs, the Specialist Nurse and Advanced MS Champion programmes. Additionally, the MS Trust will be publishing a range of exemplar case studies on its website.

## MS Trust Enquiry service

### What does the Enquiry Service do?

The Enquiry Service is here to help anyone affected by multiple sclerosis find the information they need to better understand MS, to make decisions about life with MS and have meaningful discussions about their care.

### Who can use the Enquiry Service?

Anyone. People who have MS, their family members or friends and also health and social care professionals

### How do people contact the Enquiry Service?

- Freephone 0800 032 3839 (weekdays 9am-5pm),
- email [ask@mstrust.org.uk](mailto:ask@mstrust.org.uk)
- visit [www.mstrust.org.uk/infoteam](http://www.mstrust.org.uk/infoteam)

# We're only at the start of the gut bacteria journey



Dr Peter Connick

**The gut microbiota affects everything, from the immune system and neurological development to the endocrine system and even the blood-brain barrier.**

But we are only at the very beginnings of understanding what this means for medicine as a whole, and MS in particular, said Dr Peter Connick,

Honorary Consultant Neurologist and Senior Research Fellow in Regenerative Neurology at Edinburgh's Anne Rowling Regenerative Neurology Clinic.

"There are many layers of complexity, and they are all so different between us all. You can think of it in terms of how we all have different genomes unless we are identical twins."

Each of us has about three trillion organisms in our GI tract, he explained, adding that everyone hosted a different combination of the more than 5,000 known species of bacteria, fungi and archaea.

Together these organisms weigh around 2kg, making them heavier than the brain, and outnumber human cells by ten to one.

We know the gut microbiota plays a crucial role in the development of the immune system, as well as contributing to neurological development and even interacting with the blood-brain barrier. There is also "exciting data" to suggest this "organ in the gut" can offer clues on MS susceptibility, risk factors and even progression. But, Dr Connick stressed,

such revelations were still a long way off.

"We are really only at the beginning," he said, "There are three things we could look at, and these are composition, productivity and function."

"At the moment we are only looking at composition, or understanding which species are there, because that's where we are in terms of having the technology."

But as the technology progresses – and the evidence base builds – the gut microbiota could play a major role in the future of medicine, he said.

"The really big vision for the 21st century is that we move towards this idea of 'P4' medicine: that's predict, prevent, personalise and participate."

"Rather than saying if we take a hundred people like you, 50 of them will get better if we do X, we will think about individualising our approach to predict how people will respond to individual interventions."

"That's what we are aiming for, and I think we will need these technologies to do that," said Dr Connick.

# Is 'food coma' more common – and more disruptive – than previously thought?

**Food coma, or post-prandial hypersomnolence (PPS), is normal, but it appears to be more prevalent in people with MS.**

Gavin Giovannoni, Professor of Neurology at Barts Health NHS Trust, said it often resulted in patients making drastic alterations to their diet without consulting their MS team.

"It's a real phenomenon and probably relates to the fact that digesting requires blood flow to the gut, and this shuts down other systems," said Prof Giovannoni, who presented the results of a survey conducted via the Barts MS blog.

It found that 85 per cent of 93 respondents regularly experienced some degree of 'food coma' after eating, and that 47 per cent of them had manipulated their diet in an attempt to manage it.

A total of 22.2 per cent said they had reduced the number of meals they ate in a day, 25.9 per cent had tried fasting and

27.2 per cent followed a low-carb diet.

Prof Giovannoni said: "We have patients who are experiencing this and who are altering their diets, whether or not we are advising them, so this is something we need to be aware of."

Highlighting the dangers, Prof Giovannoni presented a case study of a 47-year-old woman with SPMS.

He said: "She is so affected by PPS that she now only eats one meal a day – her evening meal. She does this quite late so she can crash and sleep about an hour later."

"She is a professional and needs to be functional during the day, but she finds if she eats anything substantial, she simply can't work because of her overwhelming desire to sleep."

She had tried caffeine, modafinil and amantadine, which have had limited impact, he explained. As a result, the patient now weighs 47kg and has a BMI of 17.

In response to the survey, the Barts-MS team carried out an audit of the

phenomenon, during which 350 people with MS, as well as their siblings, partners and friends, were asked to complete a survey one hour after lunch. The Stanford Sleepiness Scale (SSS) was used to objectively assess each participant's level of PPS.

They found that people with MS had a mean SSS of 3.46, compared to 2.52 in people without MS. The mean SSS for people with MS who did not describe having fatigue as a symptom was 2.8.

Almost two thirds, 63 per cent, of people with MS said they had made changes to their diet, such as reducing the portion size and reducing the number of portions eaten in a day.

"Moving forward, we want to confirm these findings with a larger cohort. We want to see if PPS is linked to disability and start to study the impact of individual foods and food groups in much more detail," Prof Giovannoni concluded.



# Tackling pelvic floor-related issues in women with MS



Dr Sohier Elneil

**Whether it's bladder, bowel or sexual dysfunction, pelvic floor-related problems can have a huge impact on quality of life.**

That's according to Dr Sohier Elneil, Consultant Urogynaecologist and Uro-neurologist at University College Hospital and the National Hospital for Neurology and Neurosurgery.

"MS is a major problem and we deal with it on a regular basis," she said, explaining that diseases of the spinal cord impacted negatively on the systems that control pelvic floor function.

"Women with MS are women first, and all these issues are just as problematic for them as they would be for any other woman. Our approach is to treat each patient as a woman who just happens to have MS."

Common issues in this patient group include overactive bladder. Management should focus on "simple things", such as asking the patient to keep a voiding diary, ruling out infection and looking for any underlying causes, such as prolapse.

Women with MS also frequently present with bowel dysfunction, and this can impact on bladder problems.

"Our patients are given a Bristol Stool Chart and that's really helpful because

they can keep a record of what they are producing and when they are producing it. It gives you an awful lot of information," she said.

The most important thing was a physical examination to ascertain if something other than MS, such as haemorrhoids, is causing the problem.

"If you are not used to doing rectal examinations, it can be quite off-putting, but many GPs will be happy to do the assessment for you," said Dr Sohier.

Another common pelvic floor-related symptom is sexual dysfunction, and Dr Sohier said helping patients with such issues was vital. Her team uses dilators, which help with pain during sex by desensitising the vagina, and she also highlighted new evidence for the use of neuromodulation.

"Many of our patients are living very long and happy lives, but they have a lot of issues and we need to work with them to make sure they get the most out of all aspects of their lives," Dr Sohier concluded.

# Helping people with MS get some sleep

**Sleep and MS have a complicated relationship – existing sleep problems can worsen after diagnosis, MS can cause sleep problems and sleep problems can develop independently of, but impact on, MS.**

Obstructive sleep apnoea, restless leg syndrome, REM sleep behaviour disorder, narcolepsy and hypersomnolence have all been reported in MS, and all can impact on symptoms and quality of life.

Dr Neil Stanley, an independent sleep expert, described sleep as a "biological enigma" that was primarily "of the brain and for the brain".

One of the difficulties facing MS health professionals is differentiating between sleepiness, fatigue or another underlying problem.

"The clinician needs to determine the cause of the patient's symptoms, recognising that the words used by the patient to describe the symptoms may be vague," said Dr Stanley, adding that the Epworth Sleepiness Scale was a useful tool to distinguish fatigue from sleepiness.

There is an important link between pain and sleep, so reducing pain improves sleep, but healthcare professionals need to be aware of the impact some pain medicines can have on sleep, he said, and drug side effects also needed to be considered.

Patients who have trouble sleeping can be advised on the principles of sleep hygiene. These include:

- **wake up at approximately the same time every day**
- **increase exposure to light during daytime hours**
- **limit or eliminate caffeine, nicotine and alcohol**
- **only go to bed when sleepy**
- **exercise daily**
- **start winding down around one hour before bedtime**
- **keep the bedroom cool and dark, and only use the bed for sleeping**

Dr Stanley went on to say that cognitive therapy was a useful treatment option for many sleep disorders, directing delegates to the websites [www.sleepful.me](http://www.sleepful.me) and [www.sleepstation.org.uk](http://www.sleepstation.org.uk)

# Vitamin D and bone health in MS

**The role of vitamin D in MS remains controversial but advice on supplementation should be seen in the same context as promoting healthy lifestyle choices.**

Dr Joost Smolders, a neurologist at Rotterdam's Erasmus University, shared his centre's approach to monitoring and managing low vitamin D levels.

"When you start interfering in someone's lifestyle you should have a very good reason for it," he said. While the "gold standard" evidence for vitamin D in MS is far from conclusive, he added, there were "valuable observations" in favour of supplementation that "could not be ignored".

What we do know is that vitamin D plays a vital role in bone health, he said, adding that the threshold of "low" blood vitamin D is widely accepted to be 50nmol/L or less, as measured by 25-hydroxy-vitamin D (25(OH)).

"In large studies, people with MS tend to fall and it's not surprising that people with MS have a two to four times increased risk of fractures when compared to the general population," he said.

Low vitamin D levels, however, could be a compounding factor.

Dr Smolders explained: "People with MS tend to have quite low vitamin D levels, especially those with PPMS where half of people have levels below that considered optimal for bone health."

This could be because higher levels of disability are linked to lower levels of exposure to sunlight, he said.

He went on to say that studies have shown low vitamin D levels can predict MS outcomes, including the number of active-T2 lesions on MRI, and relapse risk. Lower levels of vitamin D also correlate with higher levels of disability progression. There is, however, no evidence to suggest that high-dose is any more effective than mid-dose supplementation in mitigating these risks.

"I am very focused on thinking about this within the framework of the Brain Health programme that was launched a couple of years ago," said Dr Smolders.

"It encourages us to think about proper healthcare and include lifestyle factors that patients can engage in to contribute to their own health."

Smoking cessation, limiting alcohol intake and keeping active have all been associated with favourable outcomes in studies, yet no clinical trials have confirmed the efficacy of interventions.

"I think it is fair to say that vitamin D can be regarded as an extension of these measures. The prevention of the lowest vitamin D levels has, at the very least, benefits for bone health but can also be beneficial for the disease course of MS," said Dr Smolders.

At his clinic, vitamin D levels are determined and advice on supplementation given to anyone with a 25(OH) of 50nmol/L or less, he said.

"We advise supplementation levels ranging from 800 to 4,000 IU/d. 800 IU/d is adequate for preventing vitamin D levels of 50nmol/L or less. Vitamin D levels of more than 100 nmol/L may be better and can be achieved with 4,000 IU/d," concluded Dr Smolders.

## Rachel's passport to care takes top poster prize

Rachel Morrison, Western Isles Hospital

Audience: Rachel Morrison with Nurse, NHS Western Isles based on the NHS Western Isles 'My MS Passport' pathway

### My MS Passport

#### Background and Aim

- People living with multiple sclerosis (MS) often find it difficult to keep an up to date record and history of their MS
- Secondary complications resulting from lack of accurate communication can be minimised if an accurate record of care and previous history is documented in a clear and organised format.
- This quality improvement project ran over the past 4 months evaluating the personal clinical and cost effectiveness of a hand held, self-managed personal record for people living with MS.
- It sought to explore the experiences of using a MS Passport perspective of both the person with MS and people that are involved with their care.

#### Results

- Twenty three participants (with MS 12 female and 8 male, aged 24 – 71 years) and three professionals recorded their experiences.
- Analysis resulted in the emergence of four themes described here and supported by anonymised participant quotes:

#### Methods

- Participants were selected to share their experiences of using a MS Passport throughout the 16 weeks of the study.
- They were asked to provide feedback, if possible during or after each time they attended appointments to record reflections on how it felt when using their MS Passport, changes they were experiencing, and any other comments they wished to make.
- Participants were not given a detailed guide of what to record so as not to direct responses.
- Recordings were logged



#### "Noticing a difference"

The variety of changes people reported in their experience at appointments as well as wide ranging symptoms such as confidence, mood, self management and empowerment are captured in the Feedback below.

"A great aid to help keep me organised it is really helpful to have everything together in the one place"

"It is amazing to feel prepared and I am beginning to realise that this is my condition"

"I feel much more confident going to my appointments. Especially if I am asked to give a history."

#### "Feeling like the old me"

A sense of normality gained from utilising the MS Passport, and the physical, psychological and social benefits experienced.

- demonstrated by the following participant quote:

"I don't look at the MS Passport as a weakness it is just like the keep it journal my sister says."

#### "Getting Organised"

People reflected the value placed on having guidance and support in establishing a comprehensive hand held document; including the importance of initial support and discussing issues such as initial population of information care plans etc thus enable them to build a comprehensive log and any address any other issues associated with starting to use their MS Passport

"As I have everything to hand it enables me to map my progress. It takes a lot of the pressure away that I previously had me when attending the GP everything is clear in my care plan and my release pathway is there for me to share with any professional and."

"Best thing that could ever have happened for me as I have short term memory problems"

#### "Will I be able to do this?"

This highlights the issues faced by people living with a progressive and fluctuating condition in implementing the MS Passport. Many participants talked about how the unpredictability of their condition affected their ongoing ability to recall and document events, and that this could change on a day-by-day basis.

"To begin with I felt that this was just another paper exercise and was very sceptical I felt it would be hard work the whole time. Initially over the first few weeks it was and now that it has been provided I have a very comprehensive MS Passport with all the relevant information that I need... It really has given me a sense of control and confidence back to my life. It and has taken away a lot of the fear of the future and helping me to focus on the here and now."

#### Conclusions

- Use of the MS Passport has given people a personal hand held document to take to all their appointments and admissions to hospital. This has evidenced empowerment and incorporated regular self-management into their journey with MS.
- Associated with the use of the MS passport it was reported that it had encouraged a wide-range of physical, psychological and social benefits.
- It is important to consider Provision of initial and ongoing guidance and support and regular reviews with programmes of this nature.
- NHS Western Isles are looking to utilise this documentation for all long term conditions and are developing an app version in conjunction with M Power.



continued from page 1:

The winning poster by Rachel Morrison, MS Nurse in the Western Isles: an audit of the patient-held, self-managed personal record called **My MS Passport**

● All posters are available to download from the MS Trust website. Go to [www.mstrust.org.uk/conference-posters-2019](http://www.mstrust.org.uk/conference-posters-2019)

# MS teams can save lives in the vulnerable months after pregnancy



**Maternity services only typically work with women for up to two weeks after a baby is born, meaning MS teams play a key role in identifying worsening mental health, domestic abuse or medical complications.**

Trudy Williams, Maternal Medicine Specialist Midwife at St George's Foundation Trust spoke about the importance of vigilance in the post-partum period, and shared common red flags to look out for.

"The reality is," Trudy told delegates, "you will probably have more contact with a woman with MS once they have had the baby than many other health professionals.

"The most important thing is to ask questions as part of a holistic assessment."

Parents with MS are more likely to suffer with depression, she added, pointing to figures from the MBRRACE-UK Mothers and Babies reports. These have shown suicide to be a leading cause of maternal death, particularly in the first six weeks to one year of the baby's life.

"Suicide accounts for one in seven maternal deaths," said Trudy, adding that underlying mental health problems were often unmasked during pregnancy.

Some of the red flags healthcare professionals could look out for in pregnant and postnatal women include do not attend (DNAs) and a significant change in mental state.

She also discussed de-prescribing, saying that pregnant women on medication often had concerns around the safety of their unborn child.

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**“If you feel something is not quite right, pick up the phone and ask someone about it. Sharing information between teams is key to reducing maternal mortality and morbidity.”**

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"The 2018 MBRRACE highlighted maternal mortality related to pregnant women changing or stopping medications because of these concerns, and the importance of preconception counselling," she said.

Trudy also emphasised the value of MS teams and maternity services working together in order to support women with MS, both pre- and postnatally.

"If you feel something is not quite right, pick up the phone and ask someone about it. Sharing information between teams is key to reducing maternal mortality and morbidity," she said.

Collaboration between St George's MS team and Maternal Medicines Midwives, for example, has identified a pregnant woman at risk of suicide, and a mother suffering with ongoing physical and psychological morbidity a year after giving birth.

In the absence of other complications, Trudy went on, women with MS can usually give birth according to their own choices without the need for particular intervention or surveillance.

The Preventing Maternal Mortality project offers information and advice on spotting and reacting to red flags.

- **Go to [www.rcpsg.ac.uk/college/this-is-what-we-stand-for/policy/maternal-health](http://www.rcpsg.ac.uk/college/this-is-what-we-stand-for/policy/maternal-health) for more information and to watch a video on preventing maternal mortality.**



# Joining forces to care for MS mums to be



Sarah White

**Creating a combined maternal medicine and MS service pathway is a simple way to ensure pregnant women with MS receive person-centred, quality care.**

Sarah White, Lead MS Clinical Nurse Specialist at St George's in London, has worked with Maternal Medicine Specialist Midwife, Trudy Williams, to establish joint clinics.

During this consultation, at between 28 and 34 weeks, all parties work together to develop a comprehensive plan for the labour and postnatal period.

This may include a post-natal DMD plan, a birthing plan, relapse management, and advice on breast feeding, symptom and fatigue

management after the baby is born. They also discuss physical needs and any relevant referrals, such as to occupational therapy.

"It gives us a really good, firm plan on how to support the woman through her pregnancy, birth and after the baby is born. It's a much more collaborative way of working and is much easier for the patient. It's an opportunity to really individualise care," said Sarah.

Setting up the service, which sees between 12 and 15 patients a year, had been relatively straightforward, she went on.

The most challenging element had been finding a room for the joint consultation, a problem which was overcome by 'tagging on' a slot to a regular clinic when required.

# Balancing risk and benefit in pregnancy



Dr Peter Brex

**Healthcare professionals should consider pregnancy when prescribing DMDs or symptom management medication to women of childbearing age.**

Dr Peter Brex, Consultant Neurologist at King's College Hospital Foundation Trust and co-author of the newly published UK consensus on Pregnancy in Multiple Sclerosis: Association of British Neurologists Guidelines (see MSiP issue 6), said that the risks and benefits depended on the patient.

"It should be explained to the woman with MS that there is often limited evidence for safety of medication during pregnancy, as few clinical studies are performed in pregnant women, but this doesn't necessarily mean the treatments are harmful.

"The risk of treatment needs to be balanced against the risk of stopping them, whether this is worsening relapse frequency or a recurrence of a symptom, such as depression."

Despite new guidelines on the management of pregnancy in MS, there is limited evidence for many therapeutic interventions, Dr Brex explained, adding that it was important to talk to any woman of childbearing age about the potential impact of treatment on pregnancy.

"If a woman becomes pregnant on a treatment which might cause harm you should liaise with their obstetrician and they may require closer monitoring, eg. with more frequent ultrasound scans," he added.

Dr Brex concluded by highlighting the importance of working with registry teams to record drug-exposed pregnancies and build the evidence base. He also said that he and a team of colleagues hoped to launch an independent pregnancy register in 2020.

## SIGNPOSTS FOR HCPS

UK Teratology Information Service: [www.uktis.org](http://www.uktis.org)

The International Teriflunomide Pregnancy Exposure Registry/LEMTRADA (Alemtuzumab) Pregnancy Exposure Registry/Tecfidera Pregnancy Registry (tecistry): Manchester Centre for Clinical Neurosciences, 0161 206 0534, [neuroresearch.nurse@srft.nhs.uk](mailto:neuroresearch.nurse@srft.nhs.uk)

## SIGNPOSTS FOR PATIENTS

Best Use of Medicines in Pregnancy' (BUMPS) for patients

[www.medicinesinpregnancy.org](http://www.medicinesinpregnancy.org)

Mums Like Us: [www.mumslikeus.org](http://www.mumslikeus.org)

# Time to assess the value of end-of-life care in MS



**Some people with MS will die from the disease and its complications – and they deserve access to quality palliative care.**

Dr Jonathan Koffman, Reader in Palliative Care at King's College London's Cicely Saunders Institute, called for research into the impact and cost effectiveness of palliative care in neurological conditions during the Helen Ley Memorial Lecture.

"We've known for decades that people who live and die from advanced MS experience a litany of different distressing symptoms.

"MS and its associated complications will kill some people and I think they deserve care which is grounded in good evidence and that makes a difference," he said.

The literature holds many examples of the value of end-of-life care in cancer, but this work has not been replicated in non-malignant conditions, said Dr Koffman.

He added that there was often a reluctance among healthcare professionals to engage in advanced care planning.

"We don't talk about death in society. But 57m people die across the world every year. It's the biggest public health issue we never speak about."

The right step to helping people to achieve a 'good death' is asking the right questions. These include enquiring as to the patient's understanding of their condition at that point in time; their

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**“We don't talk about death in society. But 57m people die across the world every year. It's the biggest public health issue we never speak about.”**

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fears and worries for the future; their goals when time gets short; and what outcomes would be acceptable and unacceptable.

Said Dr Koffman: "These questions need to be repeated because it's a process of unravelling the patient's truth as new events occur in relation to their illness."

Currently there is an "enormous mismatch" between patient wishes and the reality, he said. While most people would prefer to die at home, for example, the majority experience an expensive death in hospital.

"We know that palliative care works with cancer patients, but we don't know its value in neurological conditions. We need better evidence because we have a moral responsibility to do better for people with MS and their families."



# Starting advanced care planning conversations early

**Advanced care planning conversations aren't easy, but they are essential to understanding patients' wishes as their disease progresses.**

That's according to Dr Ruth Isherwood, Consultant in Palliative Medicine, and Catherine Kelly, Palliative Care Nurse Specialist, both based at Strathcarron Hospice in Denny, who spoke about talking to people about percutaneous endoscopic gastrostomy (PEG) insertion.

Dr Isherwood said: "We wanted to focus on the importance of early discussions about all aspects of advance care planning, and seeing PEG as just one part of understanding the views of patients.

"It is also really important to encourage everyone to discuss the wishes for the future while they are well enough to do so and before there is any cognitive impairment due to the MS."

Advanced care planning gives the family, carers and healthcare team an idea of the patient's wishes and helps avoid issues around capacity later on.

"It's about being prepared and knowing that the person in front of you understands what's going on," said Catherine.

They said the PEG conversation should start at the first signs of dysphagia, such as recurring chest infections, weight loss, not coping with saliva, hunger and dehydration.

Dr Isherwood said: "Conversations about PEG should not be had in isolation. They should be had in the broadest sense of what is right for the person in front of you.

"We need to be able to talk about it as a procedure that requires a hospital stay. For most people, it will be straightforward, but for them to be able to make an informed decision you need to talk about possible complications."

**“Conversations about PEG should not be had in isolation. They should be had in the broadest sense of what is right for the person in front of you.”**

Not everyone will want or need to go ahead with the procedure straightaway, and there are measures they can take to optimise swallowing in the meantime.

Tucking the chin forwards, modifying the texture of food and eating smaller amounts at a time can help, the pair said, adding that it was important to avoid rushing, tipping the head backwards and using straws or syringes.

## RUTH AND CATHERINE'S TOP TIPS TO CONDUCTING AN ADVANCED CARE PLANNING CONVERSATION

### Starting the conversation:

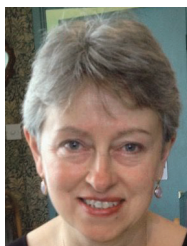
- be prepared
- think about time, place and the people who should be involved
- it can be helpful to reflect on a particular trigger
- seek permission to take the discussion forwards
- explore how much the patient and their family already know
- ask what they think will happen

### During the conversation:

- allow time
- silence can be helpful
- provide information in sections
- check how much of the information is being understood
- share hopes and concerns
- acknowledge emotion

### Closing the conversation:

- summarise the discussion
- ask if you have reached a shared understanding
- agree the next steps
- document the discussion and decisions, then share these with the relevant professionals
- offer ongoing support



Wendy Hendrie



Pam Bostock



Michelle Davies

## A fond farewell to Wendy

**We were delighted to see so many therapists at the TiMS meeting held during the MS Trust annual meeting. As I stepped down as co-chair at the conference and Pam will be stepping down next summer, we took the opportunity to look back over the six years of our tenure.**

One of our first actions was to divide the Working Group into four sub-groups: service development, education, research and communication/promotion. This enabled us to work on a number of projects concurrently. The group has run study days and made educational podcasts and videos. We have consulted on MS research projects and conducted our own research. We have developed a self-assessment annual review form, which is currently being piloted, and are working to develop a respiratory pathway. We have represented TiMS at national meetings including NHS England

and NICE. We have worked with PDUK and MNDA to develop a Competency Framework for people with progressive neurological conditions and sent out more than 250 copies of our own Skills and Knowledge Framework for OTs and PTs. We are also working on an audit of services. Not a bad list of achievements!

I would like to thank my TiMS colleagues in the Working Group for being so determined, passionate and hard-working and a huge thank you to Pam for her friendship and support over the years. I will miss you all. Wherever you work in the country, please keep fighting for specialist posts and for on-going access to therapists for people with MS.

**Wendy Hendrie** (retiring co-chair)  
**Michelle Davies** and **Pam Bostock**  
Co-chairs of TiMS

● Contact us at  
[therapistsinms@mstrust.org.uk](mailto:therapistsinms@mstrust.org.uk)



## Committee changes and website updates



Nicola Daykin

**We hope everyone had a merry Christmas, and a happy new year to you all.**

The UKMSSNA has been continuing to work hard to keep all the information on the website up-to-date, answer members' queries and keep all our members informed of changes in the MS world. The site now has a members' query forum, where people can post any issues they are having or highlight good practice.

There have been a number of changes in the association in terms of people leaving and new people coming into place. We would like to thank everyone who is stepping down from the committee, especially former co-chair Karen Vernon, for their time and dedication over the years.

We would also like to give a warm welcome to all our new members, including a special thanks to Emily Whisker for stepping up to be the committee's co-chair.

This year's UKMSSNA Making a Difference Award has been presented to

Yvonne Copeland. A very big well done to her for all the hard work she puts into MS nursing.

We would like to thank the MS Trust which, as always, put on a wonderful conference with lots of information and advice to inform our practice, not to mention a great quiz and disco which were perfect for networking as usual. As usual, there were a variety of fantastic speakers who were able to teach, update and simplify MS research, as well as share new innovative ideas.

Thank you also to Shift.ms for their new video about the importance of the MS nurse role. It also highlights the stresses of the job and recognises that we are, at the end of the day, just people trying to do a job.

Keep up the good work,

**Nicola Daykin**,  
UKMSSNA committee member

● If you aren't a member and wish to join, please contact us via [www.ukmssna.org.uk](http://www.ukmssna.org.uk)

# Celebrating hard work and best practice

The 2019 Quality in the Delivery of Services (QuDoS) in MS recognition event saw the community come together to shine a light on best practice.

Categories on the night included Innovation in Practice and Team of the Year, while a special Lifetime Achievement Award, presented to the family of the late Nicki Ward-Abel, received a standing ovation.

## Winners



Amy Smissen, Carolyn Angell and Claire Fenlon, Chilton MS Centre Nutrition Team with Richard Jarvis of Novartis

### Team of the year

**Winner:** Nutrition Team, Chilterns MS Centre

**Commendation:** Wye Valley NHS Trust, Community MS Team, Wye Valley NHS Trust

**Commendation:** West Herts Neuro Service MS Team, Hertfordshire Community Trust



Karen Vernon with Gail Shore, Dan Kucharczyk and Alison Clarke, RWT MS Nurse Team

### Innovation in Practice

**Winner:** Pathway redesign projects, RWT MS Nurse Team,

Royal Wolverhampton Trust

**Commendation:** Wye Valley's Home Phlebotomy Service,

Wye Valley NHS Trust

**Commendation:** Bristol Community Health, Bristol Community Health



Carrie Day and Mavis Ayer, UHS MS Team

### Innovation in Digital Services

**Winner:** My Medical Record, UHS MS Team, UHS My Medical Record Team and NIHR CLAHRC Wessex

**Commendation:** NHS Ayrshire & Arran DMT Service, NHS Ayrshire & Arran



Karen Vernon

### Outstanding MS Nurse

**Winner:** Karen Vernon, Salford Royal Foundation Trust

**Commendation:** Katie Hanson, Great Ormond Street Children's Hospital

**Commendation:** Iris Hume, South Eastern Trust

### Outstanding MS Physician

**Winner:** Dr Barbara Chandler, Raigmore Hospital

**Commendation:** Dr Jonathan O'Riordan, Tayside and NE Fife Regional MS Unit

**Commendation:** David Paling, Sheffield Royal Hallamshire Hospital



Joela Matthews with Rachel Dorsey-Campbell

### Outstanding MS Pharmacist

**Winner:** Joela Matthews, Barts Health NHS Trust

### Outstanding MS Occupational Therapist

**Winner:** Susan Hourihan, National Hospital for Neurology and Neurosurgery, London

**Commendation:** Gillian Burden, Wye Valley NHS Trust



Wendy Hendrie with Jody Barber

### Outstanding MS Physiotherapist

**Winner:** Jody Barber, Central London Community Healthcare

**Commendation:** Sarah Brenton, Dorset Healthcare University NHS Foundation Trust



The SELKAM regional MS Nurse Advisory Group

### Judges' Special awards

Lindsay Lord, Salford Royal NHS Foundation Trust  
SELKAM regional MS Nurse Advisory Group



# Could you practice what you preach in 2020?

**We all know the benefits of exercise in maintaining good health and wellbeing, not just for yourself but for your patients too. So if you do nothing else this year, how about picking one of these great ideas...**

## One step at a time

Imagine seeing the sunrise across Snowdonia as you reach the summit of Mt Snowdon, or perhaps walking along the spectacular Jurassic Coast. If you are looking for even more adventure how about trekking the Great Wall of China or climbing Mount Kilimanjaro? There are lots of walking adventures to choose from.

## Pedal power

Could you get on your bike for MS? From a one day event like the London to Brighton cycle ride, or sitting in the saddle for several days to cycle from London to Amsterdam, there are challenges for both experienced and novice cyclists!

## Lace up your trainers

From 5k fun runs to marathons, we've got running options for all! We have places in the Asics London 10K, or there is the Big Fun Run which is open to mums with prams and little tots. The family dog can even take part in the Dog Jog. There are running events across the country, so pick the one for you.

## Miles for MS

Can't see something that suits you? Miles for MS is our virtual challenge that takes place throughout May and YOU decide your challenge. Simply select the distance that you would like to complete over the month and how you would like to complete it. Swim, cycle, walk, roller skate... or a combination of them all!

## Do it your way!

There are so many ways you can get involved to raise awareness and support the MS Trust in your clinics. Fundraising as part of a team can be a great way of building team spirit. We've got loads of suggestions, whether you organise a charity night, run an information stall/collection or host a dress down day, we are here to support you.

For more information on any of these or other ideas please: call **01462 476707** email **fundraising@mstrust.org.uk** or visit **www.mstrust.org.uk/fundraise**

**A regular gift to the MS Trust enables us to plan ahead, to support people living with MS in the UK.**

All our services are offered free of charge to people affected by MS, their family and friends.

Did you know that a regular gift of just £5 per month could help provide information publications to a person affected by MS? It could also help to ensure that a person worried about their MS symptoms receives friendly, informed support from a member of our Enquiry Service.

We want to be there for everyone affected by MS, today, tomorrow and every day after, but we can't do it without your help. You really can make a difference. To find out how, visit: **www.mstrust.org.uk/regular-giving**



# Thank you

**What a wonderful end to the year it was to meet lots of you at our annual conference. Over the three days, your generosity in buying raffle tickets, Christmas cards, decorations, star badges, and more, meant you raised a fantastic £2,726.53.**

That's not all though! Through all of the other brilliant fundraising across the year, the total raised by health professionals for the MS Trust in 2019 was over £50,000. This is an incredible amount and we can't THANK YOU enough.

Did you know you can also support the work of the MS Trust by simply displaying a poster or two in your clinic or putting out a collection box? We can send you your very own selection of posters that your patients might be interested in. Order yours today at: **www.mstrust.org.uk/hp-promo**

We look forward to supporting lots of you with your fundraising in 2020 and making this the best year yet!

## SAVE THE DATE

**MS Trust conference 2020  
1-3 November**

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



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