

MS in Practice

2018 conference report



YOUR ESSENTIAL UPDATE
FROM THE MS TRUST ANNUAL CONFERENCE
4-6 NOVEMBER, HINCKLEY ISLAND HOTEL



MS healthcare professionals gathered for the 2018 annual conference



Standing up for people with progressive MS

A landmark, multi-centre study into the use of standing frames in progressive MS found they can improve motor function and quality of life.

Professor Jenny Freeman, professor in physiotherapy and rehabilitation at Plymouth University, Dr Wendy Hendrie, Specialist MS Physiotherapist in Norwich, and Dr Lou Jarrett, MS Clinical Nurse Specialist in Exeter (all pictured), presented the results of the Standing up in Multiple Sclerosis (SUMS) study during the MS Trust conference.

“Severely impaired people with progressive MS spend an awful lot of time sitting. We see the physical and psychosocial consequences of this, but many are reversible,” said Prof Freeman.

SUMS set out to discover if standing up at home, with the help of a standing frame, was a cost- and clinically-effective way to avoid some of these complications, such as loss of motor function.

“Most people allocated to the standing group stood regularly, with two thirds continuing to frequently stand over the

MS nurses are overstretched despite increase in numbers

Despite a four per cent rise in the number of MS specialist nurses (MSSNs) working in the UK, the growth has not kept pace with the needs of people living with the condition.

Up to 105 more nurses are needed to ensure everyone with MS can access the specialist support they need.

These were among the findings of a new report from the MS Trust, *MS Specialist Nursing in the UK 2018: Results from the 2018 MS Trust Nurse Mapping Survey*, which updates figures from 2016.

It found the number of whole time equivalent (WTE) MSSNs had grown from 241.2 in 2016 to 250.3 in 2018 – an increase of four per cent. However, in the same period, the recommended sustainable caseload for an MSSN decreased from 358 to 315.

Jo Sopala, Director of Health Professional Programmes at the MS Trust, said: “While we welcome the increase in the number of nurses, the increasing complexity of the role and the additional tasks MS specialist

nurses are expected to take on mean that even more MS nurses are needed.”

Independent research carried out by workforce modelling expert Professor Alison Leary recommended the lower sustainable caseload based on the changing nature of the MSSN role.

Jo explained: “The landscape has changed significantly since our last MS nurse mapping exercise in 2016. We now have more disease modifying drugs (DMDs) being made available, more requirements for complex monitoring and many MS nurses carrying out non-specialist work.”

Up to 77 per cent of people with MS are living in areas where MSSNs have caseloads in excess of 315. Nearly a quarter of people with MS, or 26,000, live in areas where caseloads are at twice the recommended level.

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Welcome

to MS in Practice Conference report 2018



While the world of MS is changing quickly, my personal takeaway from the 2018 MS Trust conference is that caring for people with MS is about much more than disease modifying drugs.

From sex to sleep, and stem cells to standing frames, important issues were highlighted and solutions were shared at the Hinckley conference.

Almost all of the sessions had learning, advice and tips that were taken back and used in centres across the country.

One theme that stood out time and again was the real difference nurses, therapists and health professionals can make to quality of life by helping people with MS to make healthy lifestyle choices.

Trying to squeeze in the highlights of the 22nd annual conference in Hinckley in November into just 12 pages is virtually impossible.

But some of the highlights featured in this latest edition of MS in Practice will give you a flavour of the 2018 conference and give you some insights into how the world of MS has changed over the last year.

With 300 health professionals enjoying many inspiring and informative sessions along with the record-breaking year for posters, there's no doubt that you should already be saving the date of 3 to 5 November 2019 for the next MS Trust conference.

David Martin,
CEO, MS Trust

What do you think



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

Joint working creates progressive neurological condition pathway

A coalition of charities, including the MS Trust, have joined forces with NHS England to produce a new NHS RightCare Pathway for progressive neurological conditions.

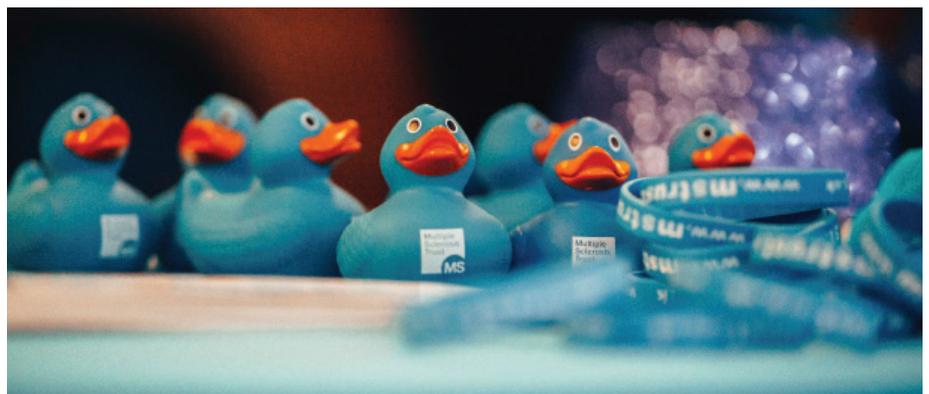
It offers local NHS commissioners practical solutions and resources to help combat inequality and make sure everybody living with neurological conditions gets the support they deserve.

For MS, this means improving the efficiency of disease modifying drug management, employing data and technology to free up MS specialist time, ensuring people with progressive MS are

not becoming disconnected from MS services, and tackling the high caseloads of MS nurses.

According to the NHS and Care Quality Commission 2017 Adult Inpatient Survey, patients with neurological conditions reported poorer experiences of care, as well as lower confidence and trust in the services to treat their neurological condition.

The MS Trust's coalition charity partners are MS Society, Parkinson's UK, Sue Ryder, MND Association, MSA Trust and PSP Association. The Pathway will be launched early in the new year.



Helping people to get active for MS Awareness Week 2019

Regular, moderate exercise is an important part of maintaining good health and wellbeing for people with MS.

Evidence shows it can help with many MS symptoms as well as improve general quality of life.

During this year's MS Awareness Week, which runs from 22-28 April, the MS Trust will highlight the many benefits of staying active with MS and encourage everyone to pop on their pumps and introduce a little activity – big or small – into their daily routine.

A selection of fun and accessible exercise videos for people with MS, developed in

partnership with a neuro-physiotherapist, will also be launched.

The videos, suitable for all levels of ability and designed to be easily used at home, will be available on our website, at www.mstrust.org.uk and our YouTube channel, www.youtube.com/mstrust

We will also host a special #WorkoutWednesday event on 24th April and we'd love MS teams across the country to get involved.

● Further details will be released soon on our website or get in touch on comms@mstrust.org.uk for more information.

Stem cell transplantation for MS is ‘no walk in the park’

Stem cell transplantation is a promising treatment for some people with MS – but it’s still early days and the procedure is in no way benign.

That was the warning from Dr Eli Silber, Consultant Neurologist at King’s College Hospital in London, who gave conference an update on the evidence for autologous hematopoietic stem cell transplantation (AHSCT).

Dr Silber said: “AHSCT warrants ongoing investigation as a treatment option. This is effective in people who have disease that is deteriorating but it’s not going to work for everyone.”

Reviewing the evidence, he pointed to a 2017 study. It found around 70 to 80 per cent of people with relapsing-remitting (RRMS) treated with AHSCT demonstrated complete suppression of disease activity for between four and five years.

Optimal candidates appeared to be young, have an EDSS of less than six, a high frequency of relapses, MRI markers of inflammation and shorter disease duration.

As of January 2018, 54 people have been treated at King’s and Imperial hospitals, he said. Of those, 86 per cent were free from disability progression at 24 months.

Three people with RRMS (10 per cent) and five with progressive MS (20.1 per cent) have experienced disability progression.

There were four ICU admissions and 12 re-admissions. Since January 2017, three patients have died, though two were not thought to be treatment-related.

“AHSCT is not a walk in the park. Patients spend days and weeks in hospital and then we are following them up. We have to make sure we are honest about that,” said Dr Silber.

More evidence and longer follow up is needed, he said. Two new trials, BEAT-MS in the USA and STAR-MS in the UK, are expected to shine more light on the topic.



Could statins be useful in SPMS?

More than 100 people have already been randomised on the largest-ever trial of statins in progressive MS.

Dr David Paling, Consultant Neurologist in Sheffield, said the phase two study MS-STAT had suggested the drugs could slow the rate of brain atrophy and disability progression in progressive disease. MS-STAT 2 hopes to replicate this in a phase three trial of 1,200 people with secondary progressive MS.

He said: “In the last 25 to 30 years, there’s been a revolution in how we understand MS, particularly relapsing remitting. But we still have no disease modifying drugs for people in the progressive stage.”

The phase two MS-STAT study saw 140 people randomised to either placebo or simvastatin, and 64 of the control and 66 of the intervention group were included in the final analysis.

The mean rate of brain atrophy in the statins group was 0.3 per cent a year, compared to 0.6 per cent in the placebo group.

At baseline, the placebo group had a mean EDSS score of 5.57 and the intervention group were 5.76. At 24-months follow up, the placebo group had progressed to a mean score of 6.35 whereas those treated with simvastatin were at 5.93.

MS-STAT 2, in which participants in the active group will be given 80mg of oral simvastatin a day, will use EDSS reduction as its primary outcome measure. It is expected to report in November 2023.

● For more information, go to www.ms-stat2.info



Delegates proved they knew their macrophages from their lymphocytes during an interactive workshop. Dr Matt Craner, Consultant Neurologist in Oxford, led a 90-minute immunology in MS session, which saw healthcare professionals get crafty in the pursuit of knowledge. Using pipe cleaners, ping pong balls and marker pens, they demonstrated the process of immune-mediated demyelination.

Talking is the first step to treating sexual dysfunction in MS

Sexual dysfunction affects around half of people with MS and its impact cannot be underestimated. Luckily, there are things nurses and therapists can do, and simply having the conversation can help people feel less alone, conference was told.



Sexual dysfunction in men is common but treatable

Sexual dysfunction, in men at least, can usually be treated if you can give them the opportunity to talk about it.

Professor Brian Birch, Honorary Associate Professor of Urology and Consultant Urologist in Southampton, said: “Men may be more comfortable talking to women than to men about sexual issues.”

For those experiencing low libido, he recommended checking testosterone levels and using replacement therapy if necessary. Psychosexual counselling is often useful for premature ejaculation, he added.

“Men may be more comfortable talking to women than to men about sexual issues.”

Professor Brian Birch, pictured left

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MS nurses are overstretched despite increase in numbers

“MS nurses do a fantastic job, going above and beyond what is required of them. But as they become more and more stretched, increasingly nurses are finding they don’t have the time to focus on some aspects of care, things like psychological care and symptom management,” said Jo.

- Read the full report online at www.mstrust.org.uk/nursemapping
- Alison Leary’s full report into MS nurse caseloads will be available later this year

At the MS Trust, we believe that nobody should have to manage MS alone which is why we are funding MS specialist nurses in the areas of greatest need through the Specialist Nurse Programme.

We have already funded new MS nurses in a number of areas. These include Leicester, Bradford and Lanarkshire, as well as South Tees, Hull and Goole/North Lincs. A new post will also be funded in Coventry.

Go to our website to find out more about the scheme www.mstrust.org.uk/health-professionals/ms-trust-projects/specialist-nurse-programme

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Standing up for people with progressive MS

36-week trial. It resulted in significant improvements in motor function as determined by the Amended Motor Club Assessment Scale. Greater benefits were associated with longer standing times,” said Prof Freeman.

“Importantly these improvements were shown to be cost-effective and within the NICE threshold for willingness to pay for NHS interventions.”

Overall, the programme was shown to be both clinically and cost-effective.

“These results suggest it should be a recommended management option for people with progressive MS who find it difficult to stand and walk,” she said.

- Go to the SUMS website for more information: www.plymouth.ac.uk/research/sums

Denise Middleton and Lesley Catterall, both based at Milton Keynes, spoke about sexual dysfunction among women with MS.



There are many treatments, including creams, injections and vacuum pumps for erectile dysfunction.

Pharmacological interventions, such as Viagra, are also effective, but it's important to note that they work best after being taken for four to eight weeks.

Some MS drugs may also have an impact: dopamine induces ejaculation and serotonin delays it, so look at medications that reduce or increase levels of these hormones, he explained.

Talking about sexual dysfunction in women

MS Specialist Nurse Lesley Catterall and Denise Middleton, MS Clinical Specialist, outlined the importance of talking sex in clinic.

Lesley said: "Women with MS want us to initiate the discussion. Some healthcare professionals believe sexuality and sexual dysfunction are not part of our role, so the problem is often overlooked."

Sexual dysfunction may be connected to bladder or bowel difficulties or can be caused by the MS itself. Anti-depressant, anti-spasmodic and anti-hypertensive drugs may all have an impact, and women's health issues, such as the menopause, also need to be considered.

Denise said: "There are few medical treatments for women but there is an increasing number of strategies to help. Good sex usually takes place in a good relationship so speak to women about how to enhance that part of their life."

“Women with MS want us to initiate the discussion. Some healthcare professionals believe sexuality and sexual dysfunction are not part of our role, so the problem is often overlooked.”

MS Specialist Nurse Lesley Catterall

TOP TIPS FOR WOMEN

UTIs?

Avoid glycerine-based sex products – opt for water- or oil-based lubricants and vaginal moisturisers

Fatigue?

Consider the best time of day to have sex and think about positions that conserve energy, such as spooning

Spasticity?

Experiment with different positions or try a rolled-up towel under the small of the back. Increasing spasticity medications before sex can help but requires planning

Catheter?

Suprapubic catheters are more conducive to a healthy sex life than indwelling catheters.

Feel uncomfortable starting the sex talk in clinic? Here are Lesley and Denise's suggested opening lines:

"Some women/men with MS find..."

"I have a booklet you might find useful and I am happy to discuss anything you want to..."

"In my experience..."

"I realise this is a very personal subject, but..."



There are several resources on the MS Trust website. These include links to our booklets, a blog by Lesley and Denise, and *MS, Sex, Sexuality and Intimacy: A Guide for Healthcare Professionals*.

www.mstrust.org.uk/sex

Managing neuropathic pain in MS is about so much more than drugs

There's no simple or fast answer to managing pain in MS. Listening to people and offering simple, realistic explanations of the nature of pain and how best to manage it are good first steps. That's according to Susan Barnes, Consultant Nurse in pain management in Salford.



Susan Barnes presented on pain management during a session chaired by MS Specialist Nurse, Jane Metcalfe.

A session at conference looked at the mechanics and possible treatments of neuropathic pain in MS.

"It is common in MS to experience persistent pain, which is pain that has been present for three months or more. It's beyond the time span expected during healing," said Susan.

This degrades health and function and can make people very worried and anxious.

"When people have ongoing pain and all their investigations come back negative, they start to think they are going mad and that no one believes their pain is real. Reiterate that you do believe the pain is real," she said.

"We have to explain that the persistent pain sensation does not mean something harmful is occurring in their body. There are changes in the way their pain nerves talk about pain. These nerves are misbehaving and constantly creating pain signals which have no useful warning message."

Many factors, including stress and anxiety, can have a negative impact on someone's perception of pain, so

reassuring them that the pain isn't causing any harm can help.

While drugs to help manage neuropathic pain do exist, it's important to be aware of their limitations, said Susan.

"We have to be clear and set realistic expectations by explaining that pain medications may only reduce persistent or neuropathic pain by 30 to 40 per cent," she said.

"It is important to explain that some pain medications are not going to work straight away. They may take between four and six weeks to be effective."

Medications

Medications used at Susan's clinic for the management of neuropathic pain include the anti-depressants amitriptyline, nortriptyline and duloxetine.

These come with the potential side effects of drowsiness, dry mouth, constipation, low blood pressure, fast heart rate, urinary retention and weight gain.

Anti-convulsants gabapentin, pregabalin and carbamazepine are used for the management of trigeminal neuralgia. They carry the possible side effects

of headache, dizziness, drowsiness, tiredness, depression or gastrointestinal symptoms.

"No one pain medication works better than another. It's a process of elimination to determine which is the most effective for each individual. Factors such as tolerability, adherence and patient preference should be considered.

"Once we have used these, there is nothing else. It's a difficult message but we have to be honest with people."

Opioids, such as morphine, are not very effective for persistent or neuropathic pain, and when taken long-term can cause more health problems than benefits, she said.

If morphine is used, the *Faculty of Pain Medicine: Opioids Awareness* guidelines advise a ceiling dose of 120mg per 24 hours.

"A dose greater than this will not provide any additional pain relief, but you will cause more health problems. Opioids can make the brain more sensitive to pain signals, so people can sometimes feel their pain improves if they take less opioid," said Susan.

“No one pain medication works better than another. It’s a process of elimination to determine which is the most effective for each individual. Factors such as tolerability, adherence and patient preference should be considered.

Susan Barnes



What is neuropathic pain?

Neuropathic pain is a malfunctioning of the body’s pain signalling system. It is caused by damage to the nerves that carry information between the brain and spinal cord, and the rest of the body.

Susan said: “The brain is triggering an alarm to tell us there is a problem, and that alarm keeps alarming. But there’s no damage causing it.

“The perception is that it’s getting worse, but what’s happening is the pain nerves are firing faster and stronger.”

Common forms of neuropathic pain in MS:

Lhermitte’s sign is a shooting pain which travels from the neck and down the spine. It can travel into the arms, legs, fingers and toes, and can feel like a ‘buzzing’.

Dysaesthesia can affect any part of the body, but most commonly impacts the leg or foot. It is sometimes a stabbing pain that gets worse at night, or can be a burning or itching sensation.

The MS hug affects the intercostal muscles and feels like a tightness around the chest. It is sometimes described as an intense crushing feeling and can be triggered by heat, stress or fatigue.

Trigeminal neuralgia is a facial pain that feels like a brief electric shock or stabbing sensation. It can be confused with dental pain. There is often no trigger, but it can be prompted by talking, washing the face or even brushing the teeth.

“The brain is triggering an alarm to tell us there is a problem, and that alarm keeps alarming. But there’s no damage causing it.

Susan Barnes

What do you think

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

It's everyone's job to promote the role of a healthy lifestyle in managing MS

People living with MS often ask what they can do to help themselves and to regain some control over their lives. The answer is maintaining a healthy lifestyle – but we all know that's easier said than done. A panel of experts discussed what we could do to help.



Above: MS experts discuss the benefits of a healthy lifestyle during the MS Trust conference

Patient-centered solutions to promote brain health

While early treatment is the starting point when it comes to protecting the brain, supporting people to live a healthy life is just as important.

Professionals need to give people with MS the tools they need to self-manage, said Professor Gavin Giovannoni, Professor of Neurology at Barts Hospital and the London School of Medicine and Dentistry. He explained that the next phase of the Brain Health initiative was to embrace the principles of patient activation.

"It's important to give people early help, before they are disabled. The earlier we make an impact the more of the brain and the spinal cord there is to save," he said.

In recent years, treatment goals had moved from reducing relapses to achieving 'NEDA', or no evidence of disease activity. The next logical step, said Prof Giovannoni, was to concentrate on reducing brain volume loss, as this would protect people with MS from worsening disease progression as they get older.



Above from left: Prof Jenny Freeman, Nicola Macleod and Prof Gavin Giovannoni

The Brain Health team is planning to develop an app, called MS Advisor, which would allow people with MS to 'rate' their service on a number of metrics. It will also ask about smoking, diet and alcohol, sleep and comorbidities to get people thinking about how lifestyle impacts on their MS.

For more on Brain Health, go to www.msbrainhealth.org

“ We can use a 30-second discussion, and that can be enough to trigger a stop attempt.

MS Specialist Nurse Nicola Macleod

“ Every one of us can provide some of the support that people need. We need to help people to be their own agents of change.

Professor Jenny Freeman



Above left to right: Nicola Macleod, expert patient Liz Thompson and Prof Jenny Freeman

Just a few minutes can change or save a life

Helping someone to stop smoking or cut down on alcohol may sound like a long conversation, but quick interventions can make a big impact.

Nicola Macleod, an MS Specialist Nurse in Edinburgh, said using short, evidence-based interventions gave health professionals the opportunity to raise the issue and refer on to specialist services if needed.

“Lots of people want to help themselves and that’s part of our role. You do not need to be an expert in the field to be able to give lifestyle advice,” she said.

In terms of alcohol, Nicola recommended explaining NICE guidelines class “hazardous drinking” as more than 14 units a week. That’s equivalent to about six pints of beer or six 175ml glasses of wine. It can help also to highlight the benefits of cutting down – more energy and weight loss, for example, she added.

“There is very good evidence that we should be encouraging people with MS to stop smoking. We can use a 30-second discussion, and that can be enough to trigger a stop attempt.”

Evidence suggests the best way is to ask if the person smokes and to explain the best advice was to quit with support and treatment. If they engage, they can then be referred onto local cessation services.

“You are not pretending you are the expert, you are signposting,” Nicola told the conference.

“ Lots of people want to help themselves and that’s part of our role.

MS Specialist Nurse Nicola Macleod

Get patients moving to give them back control

Evidence suggests exercise is neuro-protective, neuro-regenerative, helps with MS symptoms such as spasticity and fatigue, and contributes to overall wellbeing, physical and mental health.

In short, it is a simple and effective way to help people manage their condition, said Professor Jenny Freeman, Professor in Physiotherapy and Rehabilitation at the University of Plymouth.

“Every one of us can provide some of the support that people need. We need to help people to be their own agents of change,” she said, adding that asking about exercise and physical activity should be part of every consultation.

There are many barriers, including mobility issues, fatigue and low self-confidence, and Prof Freeman acknowledged that it was hard to even get started, let alone stick to it.

“Be confident that exercise is safe for people with MS. Talk to them about what might be putting them off, and what you can do to help,” she said.

Her two main pieces of advice were to start small and to help people find a form of physical activity that they enjoyed.

“There’s a whole variety of ways to move. The idea is to build confidence and help people to make it part and parcel of their life. Include behavioural management strategies to help them stick with it.

“Exercise is one thing that can help give people more control over their life,” Prof Freeman concluded.

Share your examples of best practice

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



Wendy Hendrie



Pam Bostock

Breathing space at conference

The MS Trust conference in November 2018 saw a record attendance of more than 70 therapists. We hope you all found the programme useful for your practice and were able to spend some time networking with other therapists who have an interest in MS. One of the highlights of the conference was the Helen Ley Memorial Lecture given by Rachael Moses, a Consultant Respiratory Physiotherapist based in Preston (see opposite page). It focused on ways of assessing and managing people with MS who have respiratory problems, an area that is often neglected because of a lack of knowledge or dedicated respiratory teams.

Rachael explained that spirometry decline correlates with higher EDSS scores and people with MS who are chair- or bed-bound are at increased risk of developing acute or chronic respiratory failure. Early recognition of people likely to develop respiratory complications is important so that management strategies such as NIPPY or lung volume recruitment bags can be implemented before serious or even life-threatening complications arise. Respiratory tract infections are also the most common cause of hospital admissions in people with respiratory muscle weakness due to neuromuscular disease.

This is why one of the goals for the TiMS Working Group in 2019 is to develop a respiratory pathway for people with MS to help therapists manage respiration more effectively. If you would like to be involved in developing this project or have already

written a respiratory pathway we would love to hear from you: therapistsinms@mstrust.org.uk

Finally, we wish you all a very happy and healthy 2019.

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

Cognition Study Day, 27th March 2019

TiMS and the MS Trust are organising a study day on 'understanding cognition in MS clinical practice'. This is taking place on Wednesday 27th March 2019 at Jurys Inn Hinckley Island Hotel. The cost is £75 +VAT and includes lunch and refreshments.

It will be an interactive study day where workshops are facilitated to encourage discussion, sharing of skills and experience to deepen knowledge and understanding to improve clinical practice. The day will be suitable for AHPs and nurses with a basic knowledge of cognition.

To book your place or for more information go to www.mstrust.org.uk/cognitionstudyday



Nicola Daykin

A reflection on the last year

As we start a new year, it seems fitting to reflect on 2018. It was a sad year, which saw the death of Nicki Abel. This was huge loss to the MS world and she is greatly missed by colleagues and friends alike. Nicki had a depth of information on MS and was always willing to go that extra mile to improve the lives of her patients and to ensure MS nurses had the training they needed. She was always willing to share her expertise and knowledge and her lectures were always fun and light-hearted. Nicki will be remembered for enthusiasm, her laugh and her joy of living.

UKMSSNA: latest news

Board members are working to update the UKMSSNA care manual and slide library, making them easier to use and more relevant to today's MS landscape.

We welcome the 20 new members who joined the UKMSSNA last year, and to congratulate those who passed the MS International exam in November.

The board would like to thank Sam Colhoun, who is stepping down as co-chair of the group. We would like to wish her all the best for the future

and thank her for her hard work, dedication and commitment to the UKMSSNA over the years.

We would also like to thank the MS Trust for a brilliant conference in November. As always, the charity hosted a variety of presentations that allowed all MS health professionals to gain new skills and knowledge.

With a continually-changing MS world, with new medications, technologies and therapies coming thick and fast, the Trust did an amazing job of pulling all the information together as well as making the conference enjoyable.

MS: latest news

It is worth noting that Gilenya has been approved for use in childhood MS, and the Scottish Medicines Consortium has approved Ocrevus for relapsing remitting MS.

And finally, we would like to wish everyone a happy and healthy new year.

Nicola Daykin, UKMSSNA

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

Managing respiratory function is simple, cost-effective and life changing

Respiratory difficulties are a common and debilitating problem in advanced MS, but simple, cost-effective interventions can help reduce infection and improve quality of life.

Rachael Moses, a Consultant Respiratory Physiotherapist, offered delegates advice on getting people referred into specialist services and outlined techniques nurses and therapists could employ to help.

Delivering the Helen Ley Memorial Lecture, Preston-based Rachael said: “One thing that really frustrates my MS colleagues across the country is that the respiratory team will not see their patients. My advice is to ask about other respiratory comorbidities.” She added that services would be more likely to accept referrals for people who had asthma, COPD or sleep apnoea.

Left unmanaged, the issue will lead to further complications, such as chest infections.

Rachael said: “It’s not just about the ability to breathe normally, it’s about cough. The first thing we need to be able to do to get a decent cough is to take a deep breath in, and how many people with MS can do that?”

She recommended using a hand-held spirometer to measure peak cough flow (PCF) and teaching lung volume recruitment techniques, such as breath stacking, to those with a PCF of less than 270.

People who were unable to breath stack by themselves could benefit from a lung volume recruitment bag. And for people with a PCF of less than 155, a cough assist machine could help avoid infections – and costly hospital admissions.

“It’s not just about the ability to breathe normally, it’s about cough. The first thing we need to be able to do to get a decent cough is to take a deep breath in, and how many people with MS can do that?”

“There are lots of interventions that are not rocket science and that are cost effective. A breath stacking bag is £25, and a cough assist machine is between £3,000 and £5,000.

“Provide the evidence and you can make changes,” said Rachael.

Record-breaking year for poster entries

MS healthcare professionals contributed a record-breaking 47 posters to this year’s MS Trust Annual Conference. The posters were of a high standard and showcased a wide range of information and best practice from teams and centres from around the country.

POSTER WINNERS

Winner 2018

“I’m in a very good frame of mind” – the experience of standing frame use in people with progressive multiple sclerosis.

By Hendrie W, Dennett R, Jarrett L, *et al.*



Highly Commended

Development of a maternal medicine and multiple sclerosis service.

By White S, Coward J, Davies H.

Commended

Multiple sclerosis nurse clinical template letters. By Ayer, M.

Piloting the MS self-reported assessment tool for people with multiple sclerosis. By Davies M, Thain J, McDowall K, *et al* (on behalf of TiMS).

Investigating referral patterns to physiotherapy and occupational

therapy: A clinical audit. By Laverty J, Harford M, Magecha M, *et al.*

Unplanned admission to hospital of person with progressive multiple sclerosis – a care pathway for ward staff. By Olding M.

Enhancing rehabilitation services in advanced MS: the role of a sports-trained multiple sclerosis assistant practitioner (MSAP). By Powell O, Burge T, Davies-Smith A, *et al.*

● To view the posters from conference, go to www.mstrust.org.uk/conference



Try something new in 2019

Shake off the winter blues and make your New Year's resolutions a reality! Here are some ideas to inspire you...



Mission 100

Every week 100 people are told they have MS. Your mission, should you choose to accept it, is to raise £100 in 100 days and ensure the 100 people diagnosed with MS every week get the information and support they need and deserve. Mission accepted – how do I raise the money? Anyway you like! **Download your Mission Pack now** www.mstrust.org.uk/mission100

London to Brighton bike ride

Join our team on the 15th September for the 10th anniversary of this popular cycle ride. Leave the buzz of the city behind you, to ride 54 miles to Brighton's beautiful seafront. Register for £55 per person and challenge friends or family to join you! **Visit** www.mstrust.org.uk/londontobrighton

Miles for MS

Set your own distance challenge this May to support people living with MS. Whether it is 10 miles or 100 miles, you pick how far you want to go and do it your way. Walk, swim, cycle, run, row... it's up to you! **Find out more** www.mstrust.org.uk/miles

Skydiving

Make 2019 the year you tick this off your bucket list. Freefall from 10,000 feet before parachuting back to the ground, at one of 20 airfields across the country on a date which suits you. **Find out more about this thrilling fundraiser at** www.mstrust.org.uk/skydive

The Asics London 10k

This could be your year to take on a run! Start with this 10k on the 21st July and we'll support you all the way to the finish line. Run past wonderful landmarks in the capital in a festival atmosphere and wear your MS Trust t-shirt with pride. **www.mstrust.org.uk/asics10k**

Be Bold in Blue

None of these for you? Well don't forget that you can Be Bold in Blue anytime of the year! Hold a blue cake sale or perhaps organise a blue themed quiz in your local area (we have a quiz pack available to download). **Visit the website to find out more** www.mstrust.org.uk/blue

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

Thank you

Thank you to all of you who got involved in 2018 to raise money for the MS Trust. Over £17,500 was raised by MS health professionals doing it your way; climbing, walking, baking, jumping, celebrating and more!

It was great to meet so many of you at our annual conference and hear what you have been up to. Through your generosity, buying raffle tickets, Christmas cards and decorations, you raised a fantastic £2,001.18 over the three days!

We could not continue our work assisting you and the people affected by MS who you speak to every day, without this fantastic support and we cannot thank you enough.

We look forward to lots of you getting involved in 2019!



A regular gift of £5 a month helps us fund our enquiry service, so we can continue to offer friendly, informed and evidence-based advice on all aspects of MS.

- To set up a direct debit, please complete and return (via freepost) the form at: www.mstrust.org.uk/donate/regular-giving

SAVE THE DATE

MS Trust Conference 2019

3–5 November



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