

# MS in Practice

## 2017 conference report

A publication for MS health professionals

Multiple Sclerosis Trust

MS

your essential update



## Should we be thinking hand?

Protecting upper limb function helps people with MS continue to feel human, and it shouldn't be abandoned when lower limb function declines.

The Blizzard Institute launched the #ThinkHand campaign after a survey found 90 per cent of people with MS value arm and hand function over leg function.

Alison Thomson, Research Service Design Coordinator at the institute, told the meeting: "Although disease modifying drugs (DMDs) may not be able to preserve lower limb function in people with MS who already have walking problems, we think some might be able to preserve arm and hand function."

Use of arms and hands meant being able to continue to do the "things that make all of us human", from writing, typing or knitting, to being able to wipe after going to the toilet, she added.

In a bid to raise awareness of the issue, the team have manufactured and distributed more than 3,000 nine-hole peg tests to people with MS around the world.

The tests are currently available from the Clinic Speak website at the price of £9.99.

● Go to [www.clinicspeak.com](http://www.clinicspeak.com) for more information.

## If exercise were a drug...

The best thing we can do for people with MS is help them to make healthy lifestyle choices.

That's according to Dr Martin Duddy, Consultant Neurologist in Newcastle upon Tyne, who said that while new drugs were on the horizon for progressive MS, there was clear evidence that keeping physically active had disease modifying properties.

He advised recommending healthy lifestyle choices wherever possible. "Exercise works, we should be recommending it. We know that smokers progress quicker: the best thing you can do for people with MS is to help them to stop smoking," he said, adding that we were in the midst of a paradigm shift.

**There is clear evidence that keeping physically active has disease modifying properties.**

"We used to think that MS was a game of two halves, the first part driven by inflammation and the second phase being neurodegenerative," he explained.

But new imaging techniques have shown inflammatory activity in progressive disease, and we now know that brain atrophy is present in relapsing remitting MS.

"Atrophy does not start with progressive disease. It becomes clinically relevant, but it's been going on the whole time. If we look hard enough they have been progressing sub-clinically, we just haven't captured it because EDSS is not sensitive enough.

"We do not have drugs that stop neurodegeneration, but we do have drugs that stop inflammation," he said.

Many existing therapies have been tried in secondary progressive MS, including Avonex and Rebif, and primary progressive, like rituximab. But study end points had been based on the understanding of "MS as two diseases".

The OLYMPUS trial of rituximab recorded a negative result, but it showed a two-thirds reduction in disability in under 50s with evidence of brain lesions, for example.

Dr Duddy also mentioned the ASCEND trial of natalizumab in progressive disease. It did not meet its primary end-point of reducing disability, but it did improve arm and hand function.

"We tend to stage people as relapsing remitting or progressive, but we should stage it within a person. We should say your legs are progressing, but your arms are savable," he added.

# Welcome

to MS in Practice  
Conference  
report  
2017



**W**elcome to *MS in Practice*, a new publication for all health and care professionals working in multiple sclerosis in the UK.

In issue one we are talking conference. The event, held in Hinckley in November, was our 21st annual meeting and more than 250 of you gathered to share best practice, update your knowledge and have a little fun along the way. One theme that stood out was the real difference nurses and therapists can make to quality of life by helping people with MS to make healthy lifestyle choices.

For the third year, the meeting was preceded by the Quality in the Delivery of Services (QuDoS) in MS recognition programme ceremony (pages 8 and 9). It was a great opportunity to recognise excellence.



Conference also gave us a chance to thank Pam Macfarlane, who stepped down as MS Trust CEO in December.

She joined in 2004 as the finance director and quickly became a driving force for the charity. Pam has always said it's not about us, it's about people with MS. Since 2009, she has led the team through turbulent times to massive achievements.

Taking the stage at conference, she said it had been a privilege to lead the charity. Well, it's been a privilege to work with her. She has been a truly super boss.

We hope you enjoy reading *MS in Practice*: please let us know what you think.

**Jo Sopala,**

Director of Development, MS Trust

## MS Trust welcomes new staff

The MS Trust has welcomed a new Chief Executive and two new staff members into the fold.



**David Martin**, previously the Director of External Affairs at the leading disability charity Papworth Trust, joined the MS Trust in December.

He said: "I am thrilled to be joining the MS Trust at such a pivotal point. It's 25 years since the charity was founded by Chris and Jill and I think our 25th birthday gives us a great springboard to shout about some of the brilliant things we do, such as the MS Specialist Nurse and Advanced MS Champions programmes.

"These are ambitious projects that we hope will transform the lives of people living with MS across the UK."

In his previous role, David was responsible for delivering changes in policy for disabled people by developing successful campaigns.

These included advising the Care and Support Alliance which resulted in the creation of the two per cent social care precept on council tax bills. It raised an additional £372m to better support vulnerable people.

We also welcome **Guy Hannan**, Evaluation Manager, who will initially be focusing on the evaluation of the Advanced MS Champions Programme, and **Kirsty McKenzie**, Policy Officer, who is currently hard at work with all things NICE.

"I am thrilled to be joining the MS Trust at such a pivotal point. It's 25 years since the charity was founded by Chris and Jill and I think our 25th birthday gives us a great springboard to shout about some of the brilliant things we do, such as the MS Specialist Nurse and Advanced MS Champions programmes."

## Resource for young people affected by MS

A new YouTube channel for young people affected by MS, MSTV, will be launched in MS Awareness Week, 23 to 29 April.

It will be a collection of videos on key issues for people aged 11-17 who are affected by MS, either themselves, or via family or friends.

We're looking for young people from across the UK to help us develop these videos, so please highlight the project to any families affected by MS and encourage them to sign up.

● [info@mstrust.org.uk](mailto:info@mstrust.org.uk)



## Shock over NICE's draft injectables decision

The MS community has reacted with shock and dismay to NICE's draft decision to reject five widely-used injectable DMDs.

More than 500 people with MS and 120-plus healthcare professionals took part in an MS Trust survey on the body's decision to recommend Extavia, yet reject Copaxone, Avonex, Betaferon, Plegridy and Rebif.

Of those who took part, 98 per cent of both groups disagreed with the proposed move, and the MS Trust has submitted a "robust and well-evidenced" consultation response.

"We strongly believe all current treatments should remain available to all eligible people with MS. We think that the NICE recommendation was made without reference to clinical practice or experience, and it ignores the significant differences between each of the treatments," said Janice Sykes, Information Management Officer.

NICE has acknowledged all six drugs are equally effective at reducing relapse rate and slowing disability progression and that it has made its decision based on cost.

"We are very disappointed with NICE's recommendations and we do not believe they are in the best interests of people with MS or the NHS," said Janice.

"No consideration has been taken of the potential impacts on people with MS, on specialist MS services, or of the costs these impacts might have."

Sixteen per cent of people with MS and 26 per cent of professionals who responded to the survey raised the issue of the move severely limiting the available options.

For people with MS who experience flu-like symptoms with beta interferon injections, Extavia, which is taken every other day, increases the impact of side effects, said survey respondents.

One MS specialist said: "An injection of interferon every other day is less tolerated than an injection every two weeks... Cost-effectiveness should include the costs of managing side

**"We think that the NICE recommendation was made without reference to clinical practice or experience, and it ignores the significant differences between each of the treatments."**

effects and the (impact) of side effects on employment."

Others highlighted the difficulty those with poor dexterity had with preparing the solution for injection.

The MS Trust thanked everyone who took part in the survey, and noted that anyone already taking Copaxone, Avonex, Betaferon, Plegridy and Rebif would be unaffected by the decision. A final decision is expected in May.

## MS Trust publications

**We have produced an insert with full details of Mavenclad (cladribine) which we will include in all new orders of our DMD book. To order the inserts separately, go to the website.**

A fully updated edition of *Talking With Your Kids* will be published at the end of February.

Stocks of our bladder booklet are running low so we're currently limiting orders to 15 copies. We are updating the book with a view to the new version being ready in November, in time for conference.

Our falls booklet is out of date, so we're pulling the printed version off the shelves. We have updated the online content and will revisit how we incorporate this information into future publications.

## NICE STA: Ocrelizumab for PPMS

The European Commission has granted marketing authorisation for ocrelizumab (Ocrevus) for the treatment of both active relapsing MS and early active primary progressive MS (PPMS). This follows a recommendation from the European Medicines Agency in November that a licence should be granted. NICE is assessing ocrelizumab for primary progressive MS to decide whether it should be prescribed by the NHS in England and Wales. Scotland and Northern Ireland will carry out separate appraisals.

The MS Trust will be explaining to NICE why we think ocrelizumab should be made available on the NHS. To help us make a strong case, we have been collecting the thoughts and experiences of people living with PPMS. We have also spoken to MS specialists about current NHS care for PPMS and ocrelizumab. Once completed, our submission will be available on the website.

## Blog for MS professionals

**We are delighted to announce the launch of our blog feed for health professionals.**

These are blogs written for (and by) Health and Social Care professionals working with people with MS.

Topics include professional development, policy, service development, and much more.

We're keen to add more blogs soon, so please do get in touch if you would like to write for us, or you have a suggestion for a topic, at [info@mstrust.org.uk](mailto:info@mstrust.org.uk)

● For more information about policy issues related to MS have a look at our policy blog for health professionals [www.mstrust.org/health-professionals/health-professionals-blog](http://www.mstrust.org/health-professionals/health-professionals-blog)

# We've come a long way in 21 years of conference: what will the next 21 hold?



Karen Vernon



**MS practise has changed beyond recognition in conference's 21 years – but what do the next 21 hold? Speakers looked into their crystal balls and offered some predictions.**

## Technology

In the 1990s, the internet was still dial-up and mobile phones were stretching the definition of portable to brick-size proportions.

The technological advances we have seen since then have been both unexpected and transformative, said Christine Singleton, Clinical Specialist Physiotherapist in Birmingham.

"Each and every one of us has seen their lives changed by technology. And with all the changing technology we have changing expectations," she said.

Wearable technology has spurred people to take more responsibility for their own health, and assistive technologies like exoskeletons and Mollie Suits are making exercise more accessible.

Christine mentioned gloves, currently in development, that have sensors to monitor spasticity, sensors in people's homes that alert carers if a person with MS falls, and toilets that can analyse stool and urine samples.

"Robots have a huge role to play in rehabilitation. People are inactive for

57 per cent of the time when they are in hospital. Robots can help with that," said Christine.

"Driverless cars may be able to offer mobility and independence to the young, the old and disabled."

Though while we may be on the cusp of a brave new dawn, healthcare professionals are far from being replaced.

"We are all human. Everyone needs a raft of support, from family, friends, healthcare and other professionals. We all respond to love and compassion," said Christine.

## Policy

The way health policy in England is determined has changed beyond all recognition in the last few decades, making predictions for the future extremely difficult.

Sarah Vibert, Chief Executive of the Neurological Alliance, said that 10 years ago, policy decisions were taken by the Department of Health under the Neurological National Framework for Long-Term Conditions.

"We are all human. Everyone needs a raft of support, from family, friends, healthcare and other professionals. We all respond to love and compassion."

“This was reasonably effective, and if you were seeking to influence policy it was clear where to go,” she said. The 2010-12 Lansley reforms, which replaced Strategic Health Authorities and Primary Care Trusts with NHS England and Clinical Commissioning Groups (CCGs) changed all that, she added.

“The question now is how do you influence 200-plus CCGs to put your concerns at the top of their priorities.”

This will not get any clearer as the country prepares for Brexit and copes with political uncertainty, she added.

“We can be certain that for the next four years there will be no new health policy. Brexit will have a huge impact on the workforce and on research funding, which will have a huge influence on the future of the NHS,” Sarah said.

Asking how we can make sure people with MS benefited from new treatments and innovations, she said it was a matter of taking control.

“I think the community will come together to demand change in the NHS, and that has already started to happen. MS Forward View is an example of that,” said Sarah.

### Working practices

Succession planning is key to the survival of MS specialist teams, according to MS Nurse Consultant, Karen Vernon.

“In 2016/17, 45 per cent more UK nurse registrants left the register than joined it. More nurses than ever are leaving before retirement,” said Salford-based Karen.

With so many of the ‘old guard’ moving towards retirement attracting new talent is critical, but not without its challenges.

“Most of us come from neurology or neuro-rehab backgrounds, but nurse training has changed. We need to make new posts for band five, six and sevens so we can train them up and offer them a career.

“We can light inquiring minds very quickly. Some may be challenged by the complexity of the role. The reality is being a specialist nurse is hard work, but the fact is we need to recruit and retain staff.”

Explaining the changes she had seen in the last 21 years, Karen, who was a delegate at the first MS Trust conference, said: “We had a manageable caseload. There was equity of services.

“Today we have 14 disease modifying drugs. We have blood monitoring, increased clinic activity. There are still places in the UK where you have no MS healthcare professionals.”

Despite the advances in therapies and the increasing array of complex responsibilities today’s MS nurses have, one element of the job will remain, added Karen. And that was the focus on advocacy, care and human interaction.

### Treatment

MS treatments have come so far in the last 21 years that it’s not outlandish to think there might be a cure in the next two decades: but it’s not all about drugs.

The MS Trust conference has presided over a groundswell of change that has seen disease modifying therapy options go from zero to 14, explained Dr Trevor Pickersgill, Consultant Neurologist in Cardiff.

“We are starting to look at restorative treatments that might remyelinate the brain, and these are in phase two and three trials,” he said.

“We have drugs, and we want more, but they have to be game changers. They need to be easier to take and they need to be risk free.”

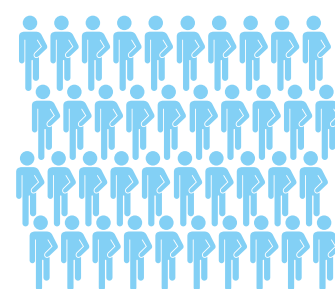
There’s a lot more to treatment than drugs, and Dr Pickersgill said there were other ways to improve the treatment of people with MS.

“Smoking increases MS risk and if you have MS and you smoke you die even younger. If you want to improve the health of your patients across the board, stop them smoking.

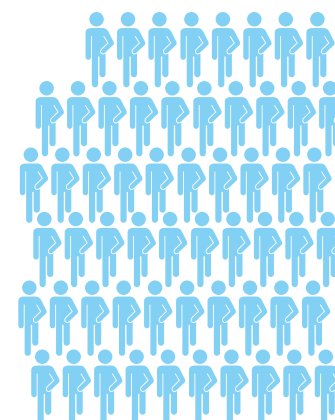
“Physiotherapy is a proven treatment to improve disability in MS and should be available to everyone with MS.”

There are many drug trials ongoing and many are yielding positive results, but there is a lot we could be doing in the meantime, he concluded.

“Physiotherapy is a proven treatment to improve disability in MS and should be available to everyone with MS.”



IN 2016/17  
**45%**  
MORE UK NURSE  
REGISTRANTS LEFT  
THE REGISTER  
THAN JOINED IT



# Using high-risk drugs safely

Disease modifying therapies have transformed the MS treatment landscape, but with greater efficacy has come greater risk.



Professor Neil Scolding

**B**ristol's Professor Neil Scolding gave delegates a whistle-stop tour of what is being done to keep people on DMDs as safe as possible.

"Risk is something that keeps many of us awake at night, but it's important to remember that some of the old drugs are not without risk. Drugs that we think of as being safe, like steroids and interferons, can still do nasty things sometimes."

He added: "We must not forget the reasons we use these drugs is that they work."

## Fingolimod

Fingolimod offers a 50-55% reduction in relapse rate, said Prof Scolding, before looking at the possible side effects. These include infection, liver dysfunction, macular oedema, lung problems and teratogenicity.

Common side effects include influenza, sinusitis, herpes virus and bronchitis. Pneumonia and macular oedema are rare, occurring in between one in 100 to one in 1,000 people.

Rarer still, happening in less than one in 20,000 cases, are progressive multifocal leukoencephalopathy (PML), lymphoma and posterior reversible encephalopathy syndrome (PRES).

Prof Scolding said: "The list of side effects is quite significant, and some are quite frequent. Take a very good drug history to make sure they are not on any contraindicated drugs."

In November, the list of contraindications was extended to include stroke, transient ischaemic attack (TIA) and heart failure.

## Natalizumab

Natalizumab is extremely effective, but around one in 250 people on it develop PML. The brain infection carries a 25 per cent mortality rate and those who survive are often severely disabled.

There is also the secondary complication of immune reconstitution inflammatory syndrome (IRIS), which can occur when PML is spotted and the person with MS is taken off natalizumab.

"Natalizumab works by applying a brake to the immune system, when you take that off, it goes out of control and there is a flood of immune activity that can cause IRIS," explained Prof Scolding.

The risk factors for PML are time on drug, exposure to the John Cunningham (JC) virus, and previous immune suppression.

"We have developed ways of mitigating the risk. We test every six months for JC status and three per cent of people a year become positive. If the patient is at high risk, we talk to them about coming off," he said.

**"It's important to remember that some of the old drugs are not without risk."**

## Alemtuzumab

Alemtuzumab, administered as two courses of infusions 12 months apart, reduces relapse rate by around 70 per cent but is not without its risks. Careful management is required.

Prof Scolding said the side effects could be divided into infusion-related, or immediate, and long-term.

"Infusion-related problems can be quite dramatic," he said, adding systemic side effects during and immediately after infusion included headaches, rashes, fever and nausea. These decrease with each course of the drug.

Neurological effects, while not common, can also occur, he added.

"For a few hours at the time of the infusion people can experience the reappearance of symptoms they have had in the past, such as optic neuritis.

"We use steroids as a pre-treatment for the neurological effects, and antihistamines for the systemic effects."

In the long-term, alemtuzumab can lead to autoimmunity side effects, such as autoimmune thyroid disease (ATD) which occurs in around 35 per cent of cases, though it is responsive to treatment.

Immune thrombocytopenia purpura (ITP) affects one to three per cent of people with MS and in rare cases, fewer than 0.3 per cent, treatment can lead to autoimmune nephropathy. Low platelet counts are easily treated if picked up early, and so monthly blood and urine tests are recommended for four years.

It can take a up to five years for these problems to arise, so long-term monitoring is required.

"The most common infectious complications are herpes and listeria. These are not the only complications, we all need to keep an open mind and look for potential opportunistic infection," said Prof Scolding.

There are 20 times more incidences of herpes infection in alemtuzumab patients compared to those on beta interferons. Bristol added acyclovir to its prophylaxis protocol in 2009, and this has proved to be very effective, said Prof Scolding.

Listeria infection can be extremely serious in immune suppressed people with MS and centres should attempt to mitigate the risk.

"Listeria has a long incubation period, and can sit around for three months before causing a problem. In healthy people it can cause a mild infection, but can cause severe infectious disease, sepsis and meningitis in people with MS.

"There have been four or five cases published. Out of 13,000 people treated that is a risk of 0.26% which is small but significant. The problem is, the bacteria is already in the gut at the time of treatment."

In terms of prevention, the safest advice is co-trimoxazole, at 960mg, three times a week for one month after each treatment cycle, he concluded.

● **For full details of the risks and benefits of all 14 disease modifying drugs, see MS Decisions**  
[www.ms-trust.org.uk/decisions](http://www.ms-trust.org.uk/decisions)

# How to manage risk in advanced MS

We live in a world of uncertainty, and that's difficult: especially if you have a raft of complex healthcare needs.

**M**anaging risk in people with advanced MS isn't easy, but the keys to success are compromise, documentation and review, said Dr Barbara Chandler, Consultant in Rehab Medicine in Inverness.

"Safety is a key issue: we all find ourselves in situations where we have concerns, and it's not comfortable but we have our training, our professionalism and our experience. There are so many risk assessment tools out there, but the key things are to identify the risk, and to think about likelihood and impact," she said.

People with advanced MS will have acquired several disabling symptoms. They will have bladder and bowel involvement, often dysphagia, fatigue and communication difficulties. Some will be percutaneous endoscopic gastrostomy (PEG) fed.

This places them at a variety of risks, from pressure sores and urinary tract infections, to choking and suicide, and makes the coordination of their care complex, said Dr Chandler.

First, identify the context of the risk, considering the environment, the probability of the risk becoming a reality, and what impact that would have, she said.

**"Once you have a plan, it's key to review it, you may even need to go back to the beginning again. If it works, that doesn't mean it will keep working."**

Next evaluate and discuss potential strategies with the person with MS, their family and carers, remembering they may all have different perspectives on acceptable levels of risk.

"A lot of the time it will be about compromise," said Dr Chandler, emphasising the importance of documenting everything.

"Once you have a plan, it's key to review it, you may even need to go back to the beginning again. If it works, that doesn't mean it will keep working."

Dr Chandler gave advice on dealing with types of risk, such as medication risk and assessing fitness to drive. She said there were many drug risk calculator tools which could be utilised, and encouraged delegates to pick the brains of their more experienced colleagues.

That was particularly important if you fear someone is at risk of suicide, she added.

"Look at protective factors and come up with a management plan. Most areas will have a crisis team, and you might want to contact their GP," she said.

"Make sure they have a plan and someone to contact. Write it down and share it: do not hold a situation like that on your own."

Assessing risk is something we do, often without thinking, but approaching the process formally allows professionals to put strategies into place.

*Dr Barbara Chandler on the right*

## People with MS overestimate benefits and underestimate risk



*Professor Dawn Langdon*

**P**eople with MS tend to overestimate the benefits of treatment while underestimating the risks, meaning they have a higher tolerance of risk than clinicians think they should.

Professor of Neuropsychology Dawn Langdon presented the findings of a systematic review, looking at risk perception among people with MS, and a new protocol developed by her team to address the findings.

"There is a very complex landscape of risks and benefits for the drugs we are prescribing," she said, adding that factors such as disease severity and duration had a significant impact on the level of risk people with MS were willing to accept with their treatment.

Benefits and Risks of Medication for MS (BRIMMS) is a new protocol developed by the team based on the findings of the systematic review. It presents information in the way people with MS prefer, and has been compared to traditional ways of communicating risk in a single-blind, four-condition, four-period crossover trial.

"However beautiful we think the graphs are, they are not designed to impress us but to communicate information. The statistics need to be meaningful to people with MS and they need to relate to their situation," said Prof Langdon.

BRIMMS-based consultations can present the information both written and aurally, and both were shown to significantly increase patient understanding, when compared to the usual methods.

In conclusion, she said the current provision of information was not optimal, and that evidence-based formats, like BRIMMS, can improve understanding and treatment certainty.

● For more information on testing BRIMMS in your centre, contact Prof Langdon on [D.Langdon@rhul.ac.uk](mailto:D.Langdon@rhul.ac.uk)



# Third annual QuDoS programme recognises excellence in MS



Healthcare professionals dedicated to making the lives of people with MS better have been celebrated.

The third annual Quality in the Delivery of Services (QuDoS) in MS recognition programme was held at the Hinckley Island Hotel ahead of conference.

A partnership between the charity and pharmaphorum, the scheme celebrates best practice and innovation across the sector.

Neurologist Dr Trevor Pickersgill, who compered the evening, said the quality of entries had been “exceedingly high”, and had showcased the hard work and innovative thinking of the UK’s MS professionals.

“It’s not about us, it’s about the patients: if you listen to them, they will give you all the answers you need.”

MS nurse Rachel Morrison, NHS Western Isles MS Service



**Outstanding Specialist Nurse**  
**Sarah White**, St George’s Hospital, London

Sarah, who has developed annual patient information days, was described as the “lynchpin” of St George’s MS services.

Her team said she had been instrumental in improving access to phlebotomy for DMD monitoring, and manages a significant patient caseload as well as her managerial role.

She described the award as a “great honour” adding that there were “very many MS nurses out there doing equally as good a job as me”.

“Nurses are doing great things in the face of challenging circumstances. I could not do my job without the team I work with.”



**Outstanding Pharmacist**  
**Aoife Shields**, Principle Pharmacist, MS, University College London Hospitals NHS Trust

Aoife has developed rigorous screening protocols and monitoring guidelines for all DMDs, requiring significant changes in MS and pharmacy services.

A ‘no bloods, no drugs’ policy, a pathway for unwell people with MS that sees them reviewed four times a week and new homecare services can all be credited to Aoife’s work.

She said: “It’s wonderful for pharmacy to be recognised for our contribution to supporting people with MS. Pharmacy can really add value to the safety and governance of providing new drugs.”

She added that the award was testament to her whole team.



**Outstanding Allied Health Professional**  
**Tania Burge**, MS Specialist Physiotherapist, North Bristol NHS Trust

A true team player, Tania has recruited, developed and trained a team of ten instructors with a special interest in MS at a local leisure centre.

This has allowed her team to offer quality of life-improving services, including swimming, running and climbing, to people with MS.

“It’s just amazing to have won this award. There’s so much that goes on during the year and it’s great to have this event.

“It’s a lot of work, but it’s really worth it,” she said, “we make a difference to people’s lives. There is so much we can do to improve quality of life.”

“Thank you to the MS Trust and QuDoS committee for recognising the work we are doing.”

Dr Adnan Al-Araji, Royal Stoke MS Centre

**Outstanding Physician**  
**Dr Adnan Al-Araji**, Consultant Neurologist, Director and Lead, Royal Stoke MS Centre

Excellent leadership skills have enabled Dr Al-Araji, a “genuine team player” to develop and improve MS services in Stoke.

A passion for clinical work and strong relationships with nurses, imaging and medical departments have led to a team that work together seamlessly to support people with MS.

“Thank you to the MS Trust and QuDoS committee for recognising the work we are doing,” he said, adding his “fantastic team” lived by the adage “excellence is not accidental”.

Dr Al-Araji was unable to attend the event and his award was collected on his behalf by MS Specialist Nurse at the Royal Stoke, Nikki Embrey.



“We are working to educate everyone to practitioner level to eliminate any fragmentation of care.”

Michelle Davies, Dorset MS Service



### Team of the Year Dorset Multiple Sclerosis Service

Every one of the Dorset team either is, or is on their way to being, an advanced practitioner in MS, and they care for people from diagnosis to end of life.

The team, which has a caseload of more than 1,200, consists of nurses, physiotherapists, occupational therapists, a DMD coordinator, an administrator and two MS neurologists.

Michelle Davies, Team Lead and Specialist MS Practitioner, said: “Because we care for everyone, we don’t have that imbalance of services. We are working to educate everyone to practitioner level to eliminate any fragmentation of care.”



### Judges’ Special Award NHS Western Isles MS Service

Technology has been utilised to allow people with MS in this large, remote, rural area to get access to the care they need, when they need it, despite being so far from physical services.

Numerous initiatives, such as Jabber Virtual Clinics, a texting service that sends reminders of upcoming blood tests, and Attend Anywhere virtual drop in clinics, have been instated.

MS Nurse Rachel Morrison said: “I am so delighted, for me and for the whole team. But it’s not about us, it’s about the patients: if you listen to them, they will give you all the answers you need.”



### Access to Patient Information in Care Frimley Park Hospital MS Service, Surrey

The team developed Treatment Agreements to help people with MS take responsibility for their care and feel more involved in decision making.

The drug-specific one-page document outlines the benefits, risk and responsibilities of treatment and is for people embarking on a DMD for MS. It is fully explained by an MS nurse.

Dr Matt Craner, Consultant Neurologist at Frimley Park, said: “We are a really strong team and that is what enables us to look at different ways of working, and different ways we can improve the lives of people with MS and their families.”



### Innovation in Care MS Buddy Scheme, Wessex MS Therapy Centre

Innovation with a human touch: the MS Buddy Scheme is designed to tackle loneliness and isolation among people with MS.

Volunteer Coordinator Carol Coates established a bank of MS buddies to visit people in their own homes, working tirelessly to find suitable volunteers as well as get all the necessary policies and procedures in place.

Rosie Eliot, Director of the Wessex MS Therapy Centre, thanked the MS Trust and QuDoS panel. “We are very proud of all the hard work the staff at the therapy centre put in on a daily basis to help people with MS live a quality life.” She added that the team were “delighted to have won an award”.



### Real-world Evidence in Care Therapeutic Opportunities Team (TOPS Team), North Bristol NHS Trust

The TOPS team is a collaboration between clinical and research MS specialists. It includes scientists, orthotists and local gym instructors who combine their experience and expertise to promote long-term symptom self-management.

The team measures qualitative and quantitative outcomes and provides local commissioners with cost and value evidence, sustaining services for years to come.

Tania Burge, Physiotherapist and TOPS member, said: “To have won as a team is amazing. People come to us thinking there’s nothing we can do, but we work with everyone, not just those who are eligible for DMDs. Everyone’s goal is different, and we work together to get them there.”



### Judges’ Special Award Neurological Examination Nurse Training Course, Salford Royal NHS Foundation Trust

More than 200 nurses working with people with MS have attended the two-day course, which has been running since 2012 and was developed by Salford’s team of neurological consultants and MS nurses.

It trains nurses to assess patients’ sensory and motor responses, improves their ability to identify warning signals and leads to better care and treatment.

Karen Vernon, MS Nurse Consultant, said: “I am extremely proud that we have won this award on behalf of all the team at Salford who have helped develop the programme to what it is today. It’s a pleasure to be able to help nurses develop and we have to thank all the patients who give their time willingly.”

# Preserving dignity and autonomy in end of life care

Never close the door on someone with advanced MS: they need your time and expertise to preserve their autonomy and dignity.



“More than half, 55.8%, of people with MS die in hospital. Do they really need to be in hospital? Can they be better managed?”

Consultant Neurologist Dr Eli Silber said: “People with MS want to decide for themselves with dignity, care and support. They need symptom management.

“These are not old people. Sometimes they are young with young families and you need to support the families. The most important currency we have is our time.”

Helping people with MS to make better lifestyle choices is key to avoiding comorbidities that can impact on MS.

He said: “They often get small vessel disease, which can lead to stroke, which contributes to disability. How much is the MS and how much is stroke?”

“People with MS smoke and drink, they get depressed, because it’s bloody awful, but it’s impacting on the MS. Monitor for osteoporosis, so we can keep them out of hospital.”

Preserving the function that remains in those with advanced disease for as long as possible is extremely important to maintaining dignity and a sense of self.



“To cure sometimes, to relieve often, to comfort always”

“Many people would prefer to have function in their hands, so they can wipe their own bottom, even if they can’t walk,” said Dr Silber, adding it was safer for MS teams to manage MS symptoms, such as neuropathic pain.

“Lots of GPs or palliative care HCPs over rely on opiates, but these can lead to constipation, and our patients already have bowel dysfunction. Neuropathic pain needs neuropathic pain drugs.”

Help people under your care avoid having to go into hospital, and if they

do need to be admitted, make sure you know they are there and put discharge plans in place.

Dr Silber advised delegates to work closely with palliative care, which tends to offer services that cover home, community and hospital.

“The staff are not scared of death or of dealing with families, or having uncomfortable conversations. Working with palliative care requires being integrated with social services,” he said.

In terms of end of life care, teams should look at advanced care planning, including refusal of treatment and lasting power of attorney, wherever appropriate.

“More than half, 55.8%, of people with MS die in hospital. Do they really need to be in hospital? Can they be better managed?”

“We need to respect people’s autonomy. If you can manage this, you are respecting their autonomy and their dignity, and you can give them what they need.”

He concluded that it was the health professional’s role: “To cure sometimes, to relieve often, to comfort always”.

# Distress is a human reaction, not mental ill health

Distress is a normal human reaction to circumstances outside of our control, and shouldn't be confused with mental ill health.



**“Most people we work with are not mentally ill, they are experiencing distress. Having MS is distressing and when we are distressed we don't present the best version of us.”**

**D**r Jo Johnson, a Consultant Neuropsychologist in West Sussex, said a diagnosis of MS bombarded sufferers with a range of thoughts and emotions they then had to find a way to process.

“As people we are flawed. While most of us are fit enough not to experience relapse or fatigue, all of us know what it's like to have feelings we don't especially want or like,” she said.

“Most people we work with are not mentally ill, they are experiencing distress. Having MS is distressing and when we are distressed we don't present the best version of us.”

Because MS is a neurological condition, with the potential to change feelings, thinking and behaviour, the interplay between cognition and mental health also needed to be considered, she added.

“Ask yourself is this really mental illness that requires medication and treatment or is this a normal mind suffering? Is it

to do with cognition? Is it a reasonable, human reaction?”

If you decide it is not a mental illness, Dr Johnson recommended utilising Acceptance and Commitment Therapy (ACT), a version of “third-wave cognitive behaviour therapy”.

“As human beings, what we do with emotional discomfort is get rid of it. We all have different ways of doing that: violence, anxiety, some people just turn it out. We either avoid it or we run away

“You can't get rid of your negative thoughts and feelings, and challenging them embeds them further. ACT is about noticing them and asking if they are helpful.

“When you get MS a lot of your goals get taken away, but your values do not change. Help people decide what their values are, and choose goals based on them.”

Helping people to keep their minds healthy and remembering all our brains essentially work in the same way were Dr Johnson's top tips.

“With mental health people tend to talk about mental ill health, but what keeps the mind healthy? We need to recommend sleep hygiene, gratitude, self-compassion, avoiding alcohol and drugs, relaxation and moderate exercise,” she said, adding this was just as important for healthcare professionals as it was for people with MS.

## Tools offer symptom management insights

MS is an extremely complex condition with an extremely long list of symptoms, making it hard for healthcare professionals to cover their full range during a consultation.

**M**ichelle Davies, MS Service Lead and Specialist Practitioner, spoke about the TiMS self-reported assessment, which has been designed to help.

It lists a full range of issues the person with MS may face, and asks them to indicate if they would like to discuss any in particular.

“It enables the person with MS to know what might be discussed. If people do not know what can go wrong, how do they know to ask?”, she said. “It enables us to see the whole picture, and helps us to use our time efficiently.”

Michelle said the tool could be used by any member of the team, and had been in development since 2014, when NICE recommended everyone with MS should have an annual review carried out by a person with expertise in MS.

“It was important to us to think about who the assessment was for and find out what they wanted to get from it,” she said.

She added that practitioners could sometimes be biased towards talking about subjects they were knowledgeable in, and the tool can help them break out of that cycle.

● **To find out piloting the tool in your clinic, contact Delia on [delia.britter@mstrust.org.uk](mailto:delia.britter@mstrust.org.uk)**

**“It enables the person with MS to know what might be discussed. If people do not know what can go wrong, how do they know to ask?”**

# Get involved!

We can only continue our work thanks to the fantastic people who help us raise money.

Perhaps you'd like to get involved in fundraising yourself, or maybe you could encourage others by displaying posters or leaflets in your workplace. If there is anything you can do to support the MS Trust, big or small, we would be so grateful. Please get in touch!

- Contact our fundraising team on 01462 476707 or [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) or visit [mstrust.org.uk/get-involved](http://mstrust.org.uk/get-involved)



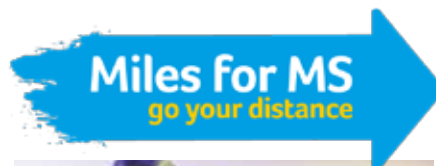
## Be Bold in Blue this MS Awareness Week

This MS Awareness Week (23-29 April 2018) you can help to make sure no one has to manage MS alone by Being Bold in Blue.

Perhaps you could organise a blue-themed MS information stall at work, encourage people to dress up in blue for a donation or get sponsored to wear blue nail polish for the week (popular with the men)!

The more people who know about Be Bold in Blue, the more money we can raise so please do spread the word. MS Awareness Week is our chance to raise the profile of MS and to show how we can help people affected by it.

- Get your free fundraising guide today at [mstrust.org.uk/beboldinblue](http://mstrust.org.uk/beboldinblue)



## Introducing Miles for MS: go your distance this May

Miles for MS is our new fundraiser for 2018 where you set your own distance challenge to complete during May and raise sponsorship to support people living with MS.

Whether it is half a mile or 100 miles, you pick how far you want to go and do it your way! Walk, wheel, arm cycle, scooter, swim, run... it's up to you. Complete the distance in your own time over the month, track your progress and raise vital funds. You don't have to do it alone either, why not get your colleagues, gym class or family involved?

Sign up for just £15 and you will receive an MS Trust T-shirt, a personalised online page where you can track your progress and raise funds, and a certificate when you finish. If you don't know where to start, we'd love to talk with you about some of the different ways you could get involved.

- Visit [mstrust.org.uk/miles](http://mstrust.org.uk/miles) to sign up.

## Did you enjoy reading MS in Practice?

We hope to continue to bring you all the news and updates you need throughout the year. But we need your help to make sure we are hitting the right note.

A quick, five question feedback survey is now active on our website, so please go online to tell us what you liked, what you didn't, and what you would like to see more of in the future.

- Go to [www.mstrust.org.uk](http://www.mstrust.org.uk) and follow the links to take part or search #MSinPractice on Twitter

A selection of slides from the MS Trust conference is available to view online. Go to [www.slideshare.net/mstrust/clipboards/ms-trust-conference-2017](http://www.slideshare.net/mstrust/clipboards/ms-trust-conference-2017)

## SAVE THE DATE MS Conference 2018

4-6 November, Jurys Inn Hinckley Island Hotel

It's going to be another great event with an exciting, high-quality programme.

For further information visit the conference website [www.mstrust.org.uk/conference](http://www.mstrust.org.uk/conference)

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