

*A VERY MERRY CHRISTMAS AND A
HAPPY NEW YEAR
FROM
STOCKTON MS GROUP*



December 2018 Bulletin

MONTHLY EVENTS

Drop-In:-

Greens Lane Methodist Church, Hartburn. We meet here 1pm to 4pm on a Tuesday. Alternative therapy is available on these days for those who enjoy or would like to try Shiatsu.

Shopping Online?

Buy items or book holidays through the Stockton MS Group web site and we will receive a donation. There are over 100 top retailers to choose from. It all helps raise funds for the group.

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TOMBOLA STALL

On Sunday 25th November 2018 Stockton Cricket & Rugby Club held a Christmas Table Top Sale. We were invited to hold a tombola.

We raised £132.90 on the day, Thank you to everybody who donated prizes and to the help I received on the day. **David Henderson**

We would like to take this opportunity to wish our members and their families a very merry Christmas and all the very best to you for 2019.

www.multiplesclerosisnewstoday.com 13 November 2018

Heavy Caseloads for MS Specialist Nurses in UK Compromise Patient Care, MS Trust Reports

Nurses who specialize in treating multiple sclerosis (MS) patients in the U.K. are handling heavier caseloads than recommended or preferred, resulting in patients going without the necessary care and support they deserve, the MS Trust reports.

Particularly, the 2018 report notes that newer treatments require more complex and careful monitoring. However, it found that each MS Specialist Nurse (MSSN) handles 379 patients on average, rather than the 315 the group considers a “sustainable figure.”

The October report, “MS Specialist Nursing in the UK 2018: Results from the 2018 MS Trust Nurse Mapping Survey,” builds on the MS Trust’s 2016 survey. It is based on data from responses by MS specialist nursing teams, or nurses with an MS-only caseload, across the U.K. In 2018, the Trust found that — although the number of whole-time equivalent (WTE, a unit of measure that converts part-time working hours into full-time equivalents) of MS specialist nurses (MSSNs) increased by up to 4% between 2016 and 2018 (from 241 to 250) — this increase “has not been rapid enough to counteract the lower sustainable caseload figure and increase in the number of people with MS.”

Currently, the recommended caseload for MSSNs is 358. But work by the MS Trust show that as patient care and demands on MS nurses changed, a lesser number is more suitable.

“The existing sustainable caseload of 358 people with MS for each WTE MSSN was recognized as too high. Work recently commissioned by the MS Trust ... recommended 315 as more realistic,” the report states.

Furthermore, a nearly a quarter of MS patients (more than 26,000 people) live in areas where caseloads are more than twice the recommended number. And, working on with an estimate of 127,000 total MS patients in the U.K., the Trust report found that 77 percent “live in areas where caseloads are in excess of 315 per WTE” nurse specialist.

This excess suggests MS patients there are missing out on proper care, and symptom and treatment management.

The report also found considerable variation in the degree of nursing provision across the U.K., with the most significant care shortages spotted in England and Scotland.

“The landscape has changed significantly since our last MS Nurse mapping exercise in 2016. We now have more disease modifying drugs being made available, more requirements for complex monitoring and many MS nurses carrying out non-specialist work,” Jo Sopala, director of health professional programs at the MS Trust, said in a news release.

“Whilst we welcome the increase in the number of nurses shown in the 2018 census, 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,” Sopala added. “As a consequence of this, the number of people with MS living in areas that don’t have enough MS nurses is growing.”

The Trust recommends that “between 61 and 105 new MSSNs” are needed countrywide to reach one nurse for every 315 patients.

“[A]lthough progress has been made in the last two years, there is still a lot more to do,” its report concludes.

www.mssociety.ca 14 November 2018

MS Society of Canada launches vitamin D recommendations for MS

The Multiple Sclerosis Society of Canada has launched evidence-based recommendations on vitamin D supplementation that can help people affected by MS make informed decisions about their health. These recommendations will provide information for at-risk populations and people diagnosed with MS as well as highlight comorbid conditions and toxicity associated with vitamin D supplementation.

Referred to as the “sunshine vitamin”, vitamin D is produced by our skin through sun exposure but can also come from other sources like supplements and diet (eggs, fish and fortified dairy products). Vitamin D works to help absorb nutrients, particularly calcium, and more recently vitamin D has been investigated for other health benefits.

Vitamin D is a hot topic in multiple sclerosis (MS) research and the association between vitamin D and MS risk, and vitamin D as a potential disease modifier has been the centre of considerable attention and public discussion for years. As research continues to advance to identify and strengthen the link between vitamin D and MS, the MS Society has developed recommendations that can help people affected by MS to make informed decisions about their health.

To develop these recommendations, the Society convened a panel of scientific and clinical experts as well as representatives from other national MS Societies and an individual living with MS to discuss the available evidence on the link between vitamin D and MS. Fruitful discussions between the panel of experts led to the development of evidence-based statements which formed the basis of the recommendations.

The MS Society recommendations provide information about the general role of vitamin D in the human body as well as reference the Health Canada recommendations, including sources of vitamin D. The purpose of these recommendations is to provide the suggested daily intake of vitamin D for various populations affected by MS including the at-risk population (children and adults with a biological relative diagnosed with MS), and individuals diagnosed with MS. In addition to the recommended daily intake of vitamin D, information on maintaining vitamin D levels is provided. Vitamin D levels are measured through a blood test. Comorbid conditions such as osteoporosis and vitamin D toxicity are also discussed in the recommendations.

The Society has launched two versions of the recommendations: a detailed [scientific version](#) geared to healthcare providers and researchers, and a [laypersons version](#) for the general public.

The recommendations support healthcare providers and policymakers by providing a detailed assessment of the evidence on vitamin D and its role in MS to help with clinical practice and inform public health policy.

Due to the rigor used in their development and comprehensiveness, the recommendations are endorsed by [The Canadian Network of Multiple Sclerosis Clinics](#) and [The Consortium of Multiple Sclerosis Centers](#).

The association between vitamin D and MS is still an area of considerable research. Research funded by the MS Society has added to the growing evidence on the link between vitamin D deficiency and MS, including MS risk and how vitamin D deficiency may affect the course and severity of the disease. The MS Society is committed to supporting research on factors that may contribute to the risk and progression of MS, including vitamin D. Until more evidence becomes available on vitamin D and MS, we encourage individuals with MS who are exploring options regarding their health to maintain ongoing consultation with their healthcare team.

multiplesclerosisnewstoday.com 15 November 2018

Ocrevus Helps Preserve Hand and Arm Function in PPMS Patients, Trial Data Show

Treating [primary progressive multiple sclerosis \(PPMS\)](#) patients with [Ocrevus\(ocrelizumab\)](#) can help to preserve strength and function in their hands and the arms, analysis of data from a Phase 3 trial found.

The research, "[Ocrelizumab reduces progression of upper extremity impairment in patients with primary progressive multiple sclerosis: Findings from the phase III randomized ORATORIO trial](#)," was published in the [Multiple Sclerosis Journal](#).

A gradual loss of function and dexterity in the upper extremities — the hands and the arms — is common to all MS patients, but thought to be particularly prevalent in those with progressive disease. Given the importance of upper extremity (UE) use to these patients, particularly those with walking and gait limitations, maintaining hand and arms function is key to a quality life, employment, and independence.

Doctors and researchers need to assess UE function in patients to monitor disease progression and evaluate the potential benefit of [treatments](#).

Despite being a commonly used measure of MS disability, many consider the [Expanded Disability Status Scale \(EDSS\)](#) less than adequate in assessing a patient's upper extremities, particularly in progressive MS.

The [Multiple Sclerosis Functional Composite \(MSFC\)](#) was designed to address EDSS limitations by including quantitative assessments of ambulation, UE function — using the [Nine-Hole Peg Test \(9HPT\)](#) — and cognition.

The 9HPT consists of a container with nine pegs, and a wood or plastic block with nine empty holes. A seated patient picks up the nine pegs and, one at a time, as quickly as possible places them in the holes. Then, again as quickly as possible, the patient removes the pegs from the holes, returning them to the container. Time needed to complete the task is recorded.

[Ocrevus](#), marketed by [Genentech](#), is the first disease-modifying treatment approved in the [U.S.](#) and the [E.U.](#) for both PPMS and relapsing MS.

A randomized, double-blind, and placebo-controlled Phase 3 trial, ORATORIO ([NCT01194570](#); study funded by [Roche](#), which owns Genentech) enrolled 732 PPMS patients, ages 18–55.

Treatment with Ocrevus led to [lower rates of disease progression](#), as assessed at 12 and 24 weeks based on EDSS, the [timed 25-foot walk](#), brain lesion volume, and total brain volume loss. Now, in an exploratory analysis, researchers looked specifically at the effects of Ocrevus on UE dysfunction in these patient.

In the 120-week ORATORIO trial, the 9HPT was administered at baseline (study's start) and every 12 weeks thereafter. Both hands were tested twice, the dominant hand first. Goals analyzed included changes in the time needed to finish the 9HPT, and the proportion of patients with confirmed progression of 20% or greater in this peg test — the usual threshold for clinically meaningful change in this test.

Researchers analyzed results of the entire patient group, as well as in patient subgroups: those with an abnormal or impaired (more than 25 seconds) 9HPT score at baseline compared to those with a normal score (25 seconds or less), and patients with an EDSS score of 6.0 or greater, corresponding to significant walking impairment and needing at least a cane to walk any distance.

As previously shown, treatment with Ocrevus reduced the risk of confirmed progression of 20% or greater in 9HPT time for both hands at 12 and 24 weeks, both in the overall patient population and in patients with abnormal 9HPT times at baseline. Similar differences were found at higher confirmed progression thresholds (25%, 30%, and 35%, meaning higher UE disability).

Data further revealed a “significantly improved” change in 9HPT time from baseline to week 120 in patients treated with Ocrevus compared to those given placebo. This benefit was consistent in 9HPT and EDSS subgroup analyses.

Overall, “findings from this analysis showed that ocrelizumab [Ocrevus] mitigated progression of UE impairment in patients with PPMS using the 9HPT,” the researchers wrote.

The team also noted that Ocrevus' benefits in PPMS need to be determined in wheelchair-confined patients, for whom maintaining hand-arm function is of utmost importance.

Roche, together with a steering committee, is responsible for the trial's design and its data analysis.

www.bbc.co.uk 3 November 2018

The feeling that end-of-life carers won't admit to

When Brittany Fortner speaks about her dad Kendall, her voice cracks.

Kendall, who died four weeks ago, was not yet an old man. At just 53, he made it abundantly clear he wasn't ready to go.

In life his strength and resilience made him a formidable, inspirational character. But in dying, his stubbornness was hard to navigate.

An incident in his final days left Brittany with feelings which many family carer-givers experience - but few admit to.

Her confession highlights the emotional complexities of caring for someone at the end of their life.

She's not alone. Looking after ill relatives is a task which many will face, as populations live to increasingly older ages.

More than 90 million Americans currently care for family with chronic conditions, while in Britain, informal care at home for people aged over 65 is predicted to increase by 87% by 2032.

Kendall Fortner was first diagnosed with throat cancer two and a half years ago. He received treatment but after two remissions, the family knew it was terminal in October 2017.

"I would describe him as a visionary. He really made a difference. We did everything together - he was a wonderful father and we were all really close to him," Brittany, 32, explained shortly after her dad died.

In September she spent 10 days in the family home where Brittany's mum Carol, a nurse, was caring for him, along with Brittany's siblings Terra and Christian.

By then Kendall was so weak that he couldn't stand, and Brittany sat with her dad, sometimes chatting to him, but mostly just spending time together.

"When I arrived, he could still recognise me. He wanted to hold my hands, which we did for several hours, while he drifted in and out.

"At some point he said he wanted to sit 'presidential style' in his chair. He gathered us together to tell us how much he loved us and how proud he was. He gave us all a hug. He was so ill that this took 10 minutes."

Kendall's sleeping was erratic and, still awake one early morning, Brittany asked him to take his morphine so they could sleep.

"I looked him in the eye and told him I loved him, and he said it back to me. I didn't know it, but that was the last time he was aware enough to know who I was. He became comatose and we thought that was it."

Two days later Kendall woke up. That's when the confusion started.

"He started talking like he hadn't in months - he hadn't been very chatty because of the tumour," Brittany explains.

Kendall couldn't recognise his surroundings. "He said we had to get him out of there. He wanted to go outside and tried to get out of the chair, which was very dangerous."

Trying to calm him down, Kendall's family found his shoes and put them next to him.

Kendall had been prescribed very strong painkillers to manage the throbbing pain from his tumours, and not eating was causing serious bone and muscle ache. But the medication, coupled with his body beginning to shut down, was making him delirious and confused.

Character changes, delirium, confusion and agitation are normal, but usually extremely difficult for family members to manage, as highlighted in a recent Reddit post about families losing patience or lashing out at relatives.

These periods of "great confusion", when he seemed nonsensical, scared Brittany. But as well as alarm, her feeling of frustration - even irritation - became palpable.

"As his child, it was so hard to see this man who had been so intelligent that you could ask him anything, starting to babble.

"I depended on him for advice. When I was a grown adult, I even had to tell him to stop buying my car insurance. He just wanted to take care of us.

"To switch from that to him being so dependent, was truly heartbreaking.

"Suddenly he said, 'I figured it out. I'm not mentally with it'," Brittany says.

Kendall refused to take any more painkillers. "We kept trying to offer him medicine. He would firmly say no and clamp his mouth shut."

This began a cat and mouse game of balancing Kendall's deteriorating health with his wishes to remain mentally present.

This reaction is common, especially in younger patients who feel medication is something they can influence in the face of losing so much control of their lives, explains Jane Kaschak, a nurse at Valley Hospice in Ohio.

"One of the hardest things for a family care-giver is deciding when the benefits of medication are worth the burden on the patient. It's a fine line to walk," she says.

She advises care-givers to think about how they want their own death to be, adding that hospice care in America can help people struggling with end-of-life care.

When the morphine lost its effect, Kendall's clarity of mind returned. Brittany's mum Carol could do things like reading aloud to him, a tradition the couple had performed for decades.

"As a nurse, I feel strongly about the individual's right to self-determination, but I knew he was in pain despite his denial," Carol explained.

Kendall spent the following day sleeping in fits and starts, as the family tried to manage his wishes and symptoms.

Not normally a man with a quick temper, Kendall became enraged when he was too weak to drink from a glass, and instead needed liquid squirted into his mouth with a plastic syringe.

"His anger was shocking to see. He said we were babying him but he was so weak," Brittany explained.

The family didn't agree about what they should do. Brittany's mum wanted to keep administering medicine, but Brittany's brother thought he had had too much.

"We didn't want to force him, but we would see him coming down from a bit of a high, and to see his frustration and anxiety during those moments was horrible," says Brittany.

"As much as possible, I would respect his wishes. However, as his cognitive ability declined, his quality of life took precedence over his wishes," Carol explains.

"I felt bad for praying he would just go to sleep in the middle of the night when he was so combative and I was so exhausted."

"It's a moral line," adds Brittany. "We knew his wishes were not to have it but he was in such bad shape when he didn't take it.

"We just had to try to support him without making him angry at us."

In the end the family reached a compromise. If Kendall was alert and refused medicine, they didn't force him to take it. But when he was asleep, they administered the painkillers.

Brittany eventually had to return home to Arizona for work, and spent their final night together observing and sitting with her dad. "I had real feelings of frustration and guilt about how to care for him in those last days," she says.

When Kendall died two days later, Carol said the most difficult emotional response was guilt, particularly as he "fought so hard to hold on to life".

"I felt guilty for medicating him such that I knew I had sedated him, but I knew it was in his best interest."

For Brittany, the experience made her realise that she wants her loved ones to know exactly what her wishes are regarding medication.

"I don't feel I'll be able to make a competent decision under the influence of pain and medicine.

"I want to try to make it clear, so no one is questioning what I want."

CHRISTMAS JOKES

What kind of music do elves listen to? Wrap.

What is a snowmans favorite breakfast? Ice Crispies.

Why didn't the skeleton go to the Christmas party? He had no-body to go with.

Who hides in the bakery at Christmas? A Mince Spy!

What says 'Oh Oh Oh'? Santa walking backwards!

What do you call a greedy elf? Elfish.

What do zombies eat with their Christmas dinner? Grave-y.

Who delivers presents to baby sharks at Christmas? Santa Jaws!

What did one snowman say to the other snowman? Can you smell carrot?

Whats the best Christmas Present? A broken drum - you can't beat it.

Which of Santa's reindeer has bad manners? Rude-alf!

Why did Santa put a clock in his sleigh? He wanted to see time fly!

What does Santa suffer from if he gets stuck in a chimney? Claustrophobia!

Why does Santa have three gardens? So he can ho, ho, ho.

What do you get if you combine Santa and a duck? A Christmas Quacker!

What do snowmen eat for lunch? Iceburgers!

Why are Christmas trees so bad at sewing? They always drop their needles!

What happened to the thief who stole a Christmas Advent Calendar? He got 25 days!

What is a skunks favorite Christmas song? Jingle smells!

DISCLAIMER

Articles in this Bulletin are meant for the sole purpose of information only and do not necessarily reflect the views of the committee.

MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you do not answer all the questions, send in those you have answered – you could still win!

- 1/ Which Russian word beginning with the letter B means great or large?
- 2/ The car in the Knightrider series was called KITT. What does this acronym stand for?
- 3/ What kind of storm is an HABOOB?
- 4/ Name the three seas that surround North and South Korea
- 5/ According to the most famous legend, what was the last song played by the band aboard the Titanic?
- 6/ What is the English equivalent of the Welsh word "Popty Ping"?
- 7/ Where in the human body is the LUNULA located?
- 8/ Which country with a land mass of 9.6 million square kilometres has just one time zone?
- 9/ Which male tennis player lost a record four US Open singles finals in 1976, 78, 80 and 81?
- 10/ The following words are from which song:- His welfare is my concern, no burden is he to bear

Name:

Address:

Send Completed Forms To:
Mr D Henderson
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Cleveland TS18 4LY

All entries to be received by the next social. The winner will be drawn from entries received with the highest number of correct answers.

Answers to last quiz:

1/ Chicago 2/ Jupiter 3/ Journalism 4/ Harry Kane 5/ J R R Tolkien 6/ Survivor 7/ Three Lions 8/ John F Kennedy 9/ Aphrodite 10/ Tom Hiddleston