

*A VERY MERRY CHRISTMAS AND A
HAPPY NEW YEAR
FROM
STOCKTON MS GROUP
December 2017*



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.

Group Contacts

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NEWS UPDATE

MEMBERSHIP FEES

The yearly membership subscription of £5 is now due.

Payments can be made at the Drop-In, Social Evening or sent by post. All cheques made payable to Stockton MS Group please.

Payments by post can be sent to:-

Mr D Henderson
74 Windermere Road
Stockton-on-Tees TS18 4LY

Donation

We would like to say a huge thank you to Billingham Team Parish for their kind donation of £250 to the group. Continued support by local community fundraising is greatly appreciated, helping us continue to support all those affected by MS.

Make A Wish Campaign

Can we just remind everybody once again to help support the group by collecting the tokens from the evening gazette. Can you also try to encourage your family and friends to help collect the tokens too, as the more tokens collected, the more money we receive.

Thank you

If you should find any stories on MS that you think may be of interest to our members or would like to contribute to the Bulletin with jokes or recipes etc; then send your articles to: susan.oneill3@ntlworld.com or pass them on to any member of the committee.

DISCLAIMER

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

Paralympian Anne Wafula-Strike wins train toilet payout

A Paralympian has been compensated after wetting herself on a train when the disabled toilet was not working.

Anne Wafula-Strike, 48, was on a three-hour CrossCountry train from Nuneaton to Stansted in December with an out-of-order accessible loo.

The wheelchair racer, from Harlow, said train staff knew she needed to use the toilet but when they reached a station it was too late.

CrossCountry has apologised and made a confidential payment.

A CrossCountry spokesman said since what happened on 8 December, a "thorough review" had been undertaken.

He added: "While we have apologised for the events that day, a lot of good has also resulted from this, with the whole rail industry looking at ways to make Britain's railways a more accessible environment, alongside the Department for Transport's ongoing consultation on an Accessibility Action Plan."

The deadline for the Accessibility Action Plan's consultation ends on Wednesday.

Kenya-born Mrs Wafula-Strike, who is a board member of UK Athletics and has an MBE for services to disability sport, has said disabled travellers need the "support of the Government to hold transport companies to account".

Mrs Wafula-Strike had been returning from a UK Athletics board meeting when she needed to use the toilet and asked the ticket master if they could let her off at the next stop after seeing the out-of-order sign.

However, Mrs Wafula-Strike said there was nobody to help her at that station and on the way to the following station she "ended up wetting" herself, which was "humiliating".

Care workers 'exhausted' by staff shortage

A care worker in Northern Ireland has said she feels like a "workhorse" because a shortage of staff means she often has to work 80 hours a week.

Her comments follow a BBC investigation into the current state of social care.

It reveals that on one day this month, 88 people had to stay in hospital unnecessarily, due to a wait for a suitable home care package.

The Department of Health said care demand has risen "considerably" and it is reviewing its domiciliary workforce.

'Snapshot of situation'

The BBC's investigation also revealed that the longest wait for a patient for home care provision was 11 months.

However, the Southern Health Trust stressed that this was a highly unusual case where the patient required a specialist care package.

The second longest wait was in the Belfast Health Trust where a patient waited 104 days.

The average waiting time for a care package for people across the five health trusts during a three-month period ranges between three and 26 days.

These figures give a snapshot into Northern Ireland's adult social care system on just one day in the middle of November.

'Exhausted'

The home help worker, who wishes to remain anonymous, told the BBC that 37 house calls in 17 hours is not unusual.

"I feel like a workhorse at times," the interviewee said.

"You are physically and mentally exhausted because you are just working big hours all the time and even when you have given your last wee bit - they are still expecting you to go out and do a wee bit more - but that isn't recognised."

Domiciliary care is provided when a person who is living at home requires help with personal care, including practical household tasks.

It can involve helping the person wash, eat and take their medication.

A different care worker said that it was not unusual to work through a shift without taking any breaks for food or even to use the toilet.

"I was at work 17 hours and had seen 35 people - it was terrible," the woman said.

"The company was short staffed, the clients were back-to-back, I was constantly travelling between clients.

"I wasn't able to have a break - nothing to drink, eat or even a toilet break. That kind of day is pretty typical."

The workers' personal experiences highlight a social care system that is under considerable pressure due to the lack of domiciliary care staff across the five health trusts.

'Workforce gap'

A spokesperson for the Department said: "Demands on this vital service have grown considerably in recent years - not least in terms of the complexity of the needs being met.

"While clearly it is important that we respond to current needs, we must also look to the future and it is crucial that we develop new models of care to meet the challenges ahead."

They added that the department is finalising a domiciliary care workforce review and that initial findings demonstrate there is a gap in the workforce, resulting in pressure on services.

The review will set out a number of recommendations including commissioning, recruitment and career development and will contribute to the implementation of a health and social care workforce strategy which will be put to an incoming minister.

'Very frail'

The shortage is having a detrimental impact on staff, and it is also affecting patients and their families.

Moira Etherson, who is in her late 60s, is currently looking after her 97-year-old mother.

While a care package had been in place, with just a week's notice it was withdrawn by a private care company which told the family there was a shortage of staff.

That was four weeks ago.

"It's very, very tough. It is exhausting. My mother is very frail she needs a lot of help," Mrs Etherson said.

'Totally broken'

"My husband helps me to lift her but we haven't showered her in a month. We are just washing her, keeping her clean and comfortable."

Mrs Etherson, who lives in Maghera, County Londonderry, described Northern Ireland's social care system as "totally broken".

"I think the health trust would need to take back responsibility for care within the community," she said.

"I think they have delegated it, it's got out of hand. For private companies, it's been a race to the bottom and I just feel that the staff have left because of their poor conditions, and clients like my mother have been abandoned."

In a statement, the Northern Health Trust confirmed that the independent company providing the 97 year old's care had withdrawn it last month and since then, the trust has been trying to secure a package of care to meet her needs.

It added that the difficulty in securing care packages "reflects the demands on the sector in some geographical areas" and the trust acknowledged the impact and distress on the family.

Pay rates

A national report on the funding of older people's homecare across the UK reveals that Northern Ireland pays the lowest rate per hour.

According to the Homecare Deficit 2016, the average prices paid by the individual health trusts ranged from £11.42 to £12.96 per hour, with trusts paying rates which places them in the lowest quartile of all authorities in the UK.

Matters such as pay might be addressed if a Northern Ireland government was in place.

The ongoing political vacuum means that a report into social care in Northern Ireland, completed in May 2017, remains unpublished.

'Exploited workers'

However, the Department of Health confirmed on Monday evening that it plans to publish it within the coming weeks.

The BBC understands that the report is critical of some aspects of the system, including that workers are being exploited.

Asked if people were suffering under the current care system, Chief Social Worker Sean Holland said that it was a "system under pressure".

"I think suffering is a very strong word. There are certainly people who on occasion have to wait a period of time for the care that they have been assessed as needing," he said.

"But we are providing care to approximately 24,000 people and I think we shouldn't lose sight of the fact that if we were to go a generation back, many of those people would have to live in institutions or end their days in long stay hospital wards."

'Very concerning'

Meanwhile, none of the recommendations - included in a separate report entitled 'Domiciliary Care in Northern Ireland' by the Commissioner for Older People in 2015 - have been implemented.

The current commissioner, Eddie Lynch, said: "I would describe the situation with domiciliary care as very serious across Northern Ireland.

"Many older people are not getting their needs looked after. They are getting them assessed, but then the care packages aren't being implemented for a series of reasons and this is very concerning.

He added: "In particular, two years on from when a report was published from my office which outlined clear recommendations to government about what needs to happen, that report has yet to be implemented.

"So, older people across Northern Ireland are still in situation where they are not getting the care they deserve at home."

Viagra can be sold over the counter

Men will no longer require a prescription to obtain the impotence drug Viagra and will instead be able to buy it over the counter at pharmacies.

The decision by the UK Medicines and Healthcare products Regulatory Agency follows a public consultation.

It will be up to pharmacists to judge whether men over the age of 18 can safely be sold the little blue pills.

Manufacturer Pfizer hopes to get stocks of Viagra Connect (sildenafil 50mg) into UK pharmacies by spring 2018.

Experts say making the medication more widely available will help men who might not feel able to visit their GP about impotence.

The MHRA hopes it will stop some men buying unregulated medicines from websites operating illegally.

Mick Foy, MHRA's group manager in vigilance and risk management of medicines, said: "This decision is good news for men's health.

"Erectile dysfunction can be a debilitating condition, so it's important men feel they have fast access to quality and legitimate care, and do not feel they need to turn to counterfeit online supplies which could have potentially serious side-effects."

Pharmacists will decide whether treatment is appropriate and can offer advice on erectile dysfunction, usage of the medicine, potential side-effects and whether further consultation with a general practitioner is required.

Viagra Connect will not be sold to:

- those with severe heart disease or at high risk of cardiovascular disease
- those with liver failure
- those with severe kidney failure
- men taking certain medicines that could cause a bad reaction when combined with Viagra

Men who are sold it will be advised that they can take a 50 mg tablet an hour before having sex, but should not use more than one pill a day.

Sildenafil is already available on NHS prescription free of charge.

Erection problems

Most men occasionally fail to get or keep an erection.

This is usually due to factors such as stress, tiredness, anxiety or drinking too much alcohol, says NHS Choices.

Men should see their GP or go to a sexual health clinic if erection problems keep happening because it can be a sign of an underlying health condition, it advises.

The MHRA received 47 responses to its consultation, with 33 in support of making viagra available off prescription and one 'unsure'.

The 13 that did not support the proposal included eight pharmacists. Some were concerned that customers might withhold medical information from staff in order to get the treatment. Risk of abuse or misuse of the drugs was another worry.

In reaching its decision the MHRA judged that the benefits of permitting Viagra to be sold without a prescription would outweigh potential risks.

Denise Knowles, psychosexual therapist and counsellor at Relate, warned that taking a pill was not a sticking plaster for relationship problems.

"Many of the people I have spoken with have a misconception that it will give them a stronger erection or add to their desire. But it's not there to enhance prowess.

"It's not a magic pill that will cure problems in a relationship."

Disability plan will help a million people into work, ministers say

Plans to get one million more disabled people in work over the next 10 years have been set out by the government.

Ministers say the new strategy will help those with disabilities keep their jobs and progress in their careers.

The new measures include widening the number of people who can issue fitness-to-work notices and additional training for mental health professionals.

Labour's Debbie Abrahams said benefit cuts had already pushed more disabled people towards poverty.

'Tackling injustices'

The pledge comes after **ONS figures from June 2017** suggested that disabled people were twice as likely to be unemployed as non-disabled people.

About 80% of non-disabled people are in work compared with just under 50% of disabled people.

- Prime Minister Theresa May said a person's life and career "should not be dictated by their disability or health condition".

"Everyone deserves the chance to find a job that's right for them," she added.

"I am committed to tackling the injustices facing disabled people who want to work, so that everyone can go as far as their talents will take them."

The government says in the past four years 600,000 disabled people have found work.

However, the disability charity Scope says progress is too slow.

The new strategy includes:

- Measures to provide access to personalised support for those with mental health issue
- Extending "fit note" certification - which details how a condition affects someone's ability to work - beyond GPs to a wider group of healthcare professionals, including physiotherapists, psychiatrists and senior nurses
- Reform statutory sick pay

The 10-year plan builds on a green paper published last year which pledged to halve the so-called disability employment gap.

Employers' attitudes

The government hopes the changes to the fit note system will improve the identification of health conditions and treatments to help workers get back to work quickly.

But some disability activists say the problem lies in employers' attitudes. Mik Scarlet, an inclusion specialist, says he chose to be self-employed after some "disastrous attempts" at getting work.

"Employers have little idea of how beneficial disabled employees can be to a workforce," he said.

"They also don't understand that creating flexible inclusive work systems improves the working environment for all."

BBC disability correspondent Nikki Fox said it was not the first time the government had pledged to get more disabled people into work.

However, she said "the employment gap between disabled and non-disabled people has not significantly changed for some years".

Labour's shadow work and pensions secretary, Ms Abrahams, warned the government's plans "hinted at" further cuts.

"The Tories' cuts to social security support are pushing more and more disabled people into poverty," she said.

"The Tories have already hit disabled people who are not fit for work but who may be in the future in the work related activity group.

"I hope they are not going to now target the most disabled people in the support group, as their green paper hinted at."

www.bbc.co.uk 3 December 2017

Children's commissioner may consider legal action over Universal Credit

Scotland's children's commissioner has said he may consider legal action over the Universal Credit rollout if it further disadvantages young people.

Bruce Adamson said poverty was the biggest human rights issue facing children in Scotland. He told the BBC reforms to the benefits systems could be resulting in some children going without basics like a warm home and hot meals.

The UK government said Universal Credit was helping people improve their lives.

A spokesman for the Department for Work and Pensions said the system was "working" and that as a result of Universal Credit people were "moving into work faster and staying in work longer than under the old system".

The controversial measure, which is being rolled out across the UK, brings six existing benefit payments into one.

It faced criticism over claims some people had to wait six weeks for their first payment, contributing to a rise in debt, rent arrears and evictions.

Chancellor Philip Hammond announced changes aimed at speeding up claim times in his autumn budget last month.

Mr Adamson said he was engaging with ministers, from the both the UK and Scottish governments, about the impact the benefit changes were having on the human rights of children and young people.

He called for "political leadership" on the issue, but said he could not rule out the possibility of legal action in the future.

'Basics of life'

In an extended interview broadcast on **BBC Radio Scotland on Sunday**, the children's commissioner said: "Poverty is the biggest human rights issue facing children in Scotland at the moment.

"And there's a number of issues around the way in which Universal Credit is calculated and how it is paid. But this leads to a much, much deeper issue. We are talking about the rights of children and the right to benefit from social security.

"We are talking about things like having a warm and secure place to live, having regular hot, nutritious meals and also the ability to access things like transport to get to school and to enjoy social and cultural activities that we know are so important to their development."

Asked if there was any prospect of legal redress in Scotland, Mr Adamson said: "While we don't have the Convention on the Rights of the Child within our domestic law yet, we do have the Humans Rights Act which brings in the European Convention on Human Rights and the courts look very closely if a state falls below that minimum standard required, where the state fails to provide those basics of life.

"So certainly if children in Scotland aren't getting those basic things then legal action may be the way to take this forward. But it's not the best way."

He added: "We really need political leadership here and we need to make sure that we are never in a situation where children are going without the basics that they need."

The DWP spokesman said no-one who needed support had to wait six weeks.

He added: "In December, claimants can request an advance of up to 50% of their first payment and a further 50% in January if they need it, repayable over 12 months.

"Universal Credit lies at the heart of our commitment to help people improve their lives and raise their incomes. It provides additional, tailored support to help people move into work and stop claiming benefits altogether."

Speaking on the BBC's **Sunday Politics Scotland programme**, Brexit Minister Mike Russell said he thought the Scottish government would be "very sympathetic" to potential legal action against Universal Credit if it infringed the human rights of children.

He said: "The approach of the UK government on social security and welfare is truly appalling. It is impoverishing people. It is leading to despair.

"I think anybody who is standing up against that and arguing for a practical resolution, to what are awful, ideological problems being brought by the Tories, I think deserves all the support he can get."

On Saturday, a day of action, organised by the Unite union, saw demonstrations staged at various locations around Scotland protesting against changes to the benefits system.

www.radiotimes.com 23 November 2017

Caroline Wyatt talks to Mark Lewis about his search for a miracle cure for MS

Mark Lewis likes to win. Perhaps he even lives to win. The 52-year-old "super-lawyer" certainly relished squaring up to News Corp, representing the family of Milly Dowler and many other victims of the News of the World phone-hacking scandal. His successful fight led to the closure of the paper and the award of record damages to his clients. But Mark's latest battle is for himself, and his health, against the multiple sclerosis that is slowly shutting down his body, nerve by nerve.

"My life is like an egg timer that the sand's dripping through – and the sand's nearly finished," is how he describes it.

That's why he travelled with his partner Mandy and Channel 4 cameras to the Hadassah Medical Center in Jerusalem this summer to take part in a trial of a new stem-cell treatment, testing the effectiveness of injecting stem cells directly into the cerebrospinal fluid that surrounds the brain and spinal cord, as opposed to a vein.

His early symptoms, at the age of 23, included visual disturbances ("like looking through an ice-cube") and extreme fatigue. Aged 24, just as his then (now ex) wife was pregnant with the first of his four daughters, he noticed what felt like a bee sting on his wrist. He was eventually sent to a neurologist. After a brain scan, the father-to-be was told brusquely that he had MS. Over the years Mark's condition has worsened. By 2004, his difficulties with walking meant that he needed a disabled badge for his car so he could park near his destination. However, passers-by kept ringing the council to report him as a fraudster "because I didn't look disabled. People expect you to dribble when you have MS." He doesn't dribble, but due to the progression of his illness, the veteran and vintage car fanatic can no longer drive.

As we sit and talk at his London office, our walking sticks rest against opposite walls. Mark's right hand has lost so much function that he can no longer put on his socks on his own, meaning that Mandy, his partner for the past two years, is also in effect his carer, a relationship at the heart of the documentary.

"I come across as a grumpy Victor Meldrew – without the charm," Mark smiles. "You see me coping – badly – with disability."

Mark's journey has been similar to my own. I travelled abroad for treatment earlier this year in the hope of halting the accelerating damage caused by my relapsing-remitting MS, which first appeared not long after I turned 25. In January, just ahead of my 50th birthday, I went to Clinica Ruiz in Puebla, Mexico for a stem-cell transplant known as HSCT, a higher-risk, more radical treatment that's being used for MS more often now after proving successful for many patients with blood cancers. It involved having four rounds of chemotherapy to kill off the malfunctioning T and B cells, followed by an infusion into the veins of my own stem cells to shorten the length of time I had to spend without a working immune system.

Nine months later, I'm still focusing on regaining my strength. After my transplant, I was exhausted but full of hope because after the chemotherapy, and for around two months, I could feel that the MS was no longer attacking me. It appeared to have gone into remission, along with much of the pain in my eyes, joints, hands and feet.

Best of all, my mind felt sharp for the first time in years without the brain fog that had plagued it for so long. But in April, I was struck down with the most severe migraines I've ever experienced as the MS crept back, bringing with it all the old symptoms and, worst of all, the cognitive dysfunction. My concentration and ability to focus dwindled again, and while the migraines no longer arrive daily, they return with dismaying frequency.

I'm often told, though, that I "look very well". Giving up alcohol and stressful, sometimes 18-hour working days, as well as prioritising sleep, walking and yoga, has probably helped my overall health. And I remain an optimist. My new immune system will take until around the end of 2018 to build up to full strength. Perhaps by then, it will be able to prevent fresh and irreversible damage to my nerves until a permanent cure is found.

Mark, too, lives in hope. In the documentary, we watch as doctors use a four-inch needle to inject Mark's stem cells back into his cerebrospinal fluid. Within two hours of the first injection there's an almost miraculous improvement in his right hand and leg. He's in tears as he telephones the friend who helped him take part in the trial. Sensation returns to his hand and, triumphantly, he shows that he can grip a bottle of water again. Yet now, many of those initial improvements have disappeared, although the bee sting pain in his right wrist has diminished. As I leave his office, we rather shakily shake hands. "The day after the first stem-cell injection, I had a 60 percent improvement. If the trial is successful, I'll keep on going with it," he tells me. Make a special dinner for two with these inspirational recipes

Mark strikes me as both brave and bolshy, but does he ever have days when he's tempted to give up hope? He admits that he does have moments of self-pity: that sense of "why me?" Yet "if I were to die tomorrow, I've closed down the News of the World, I won the biggest settlement ever, so I can say I've had an impact. I've done something with my life," he says with absolute certainty. "But I'm sure MS will be cured."

I hope he's right.

JOKE

When God was making the world, he was particularly proud of Lancashire: some of the best beaches in the country, the best rugby league & football teams, the most pleasant people, good agricultural land, some of the best musicians and poets. He was so proud he showed Lancashire to St Peter. The saint said to God: "But it's just too perfect. Surely you've built in a fault somewhere."

"Aye," said God, adjusting his cap, "Just look at their neighbours to the east!"

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/ The song 'Happy Xmas (War is Over)' was written by John Lennon and Yoko Ono in protest against which war?
- 2/ Which famous company began a TV advertising campaign featuring 'Christmas Caravans'?
- 3/ In the famous Christmas movie Home Alone, by what name do burglars Harry and Marv refer to themselves?
- 4/ In countries such as the United States and Germany, it is tradition to hide a decoration on the Christmas tree in the shape of what type of fruit?
- 5/ What song does Billy Mack record in the film Love Actually in hope of reaching Christmas number one?
- 6/ What traditional Christmas beverage is made from mulled cider and begins with the letter W?
- 7/ What type of chocolate based dessert derives from an old Christmas tradition that involves a fireplace?
- 8/ How many different types of birds are mentioned in the 12 Days of Christmas song?
- 9/ How many Sundays occur during the period of Advent?
- 10/ True or False: Holly berries are poisonous?

Name:

Address:

Send Completed Forms To:

Mr D Henderson
74 Windermere Road
Stockton-on-Tees
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/ One Canada Square 2/ Theatre Royal, Drury Lane 3/ Victoria 4/ 1986 5/ Yellow 6/ 1961
7/ Canada 8/ Stephanie Cole 9/ Jamie Dornan 10/ Oda Mae Brown