

**ISSUE NO:- 10/ 2019**

# BULLETIN



## EVENTS

### Drop-In:-

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

### Social Evenings:

These are held at the Orthoptic Supplies, 176 Belasis Avenue, Billingham, TS23 1EY, on the last Wednesday of every month at 7pm.

### 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.

### Monthly Bulletin

"If you would like to receive this bulletin by email, then just send a request to [news@stocktonmsgroup.org.uk](mailto:news@stocktonmsgroup.org.uk).

Remember if you change your email address to let us know by sending a message to [news@stocktonmsgroup.org.uk](mailto:news@stocktonmsgroup.org.uk)"

### Group Contacts

Carol 01642 617864

Web address:- [www.stocktonmsgroup.org.uk](http://www.stocktonmsgroup.org.uk)  
e-mail: [info@stocktonmsgroup.org.uk](mailto:info@stocktonmsgroup.org.uk)

Published by: Stockton MS Group, 74 Windermere Road, Stockton-on-Tees. TS18 4LY

## NEWS UPDATE

www.bbc.co.uk 23 September 2019

### **Labour pledges free personal care for over-65s in England**

Labour is promising free personal care in England for over-65s most in need of it, so they will not have to pay for help with dressing, washing and meals.

Currently, state help with the cost of home or residential help is available for those with assets below £23,250.

Labour says the pledge, costing an estimated £6bn a year, will double the number of those not having to pay.

It would bring England into line with Scotland, where personal care is free for those with the most severe needs.

In his keynote speech to the Labour conference on Monday, shadow chancellor John McDonnell said the move would be funded out of general taxation.

A future Labour government would pass legislation to enshrine a right to free personal care for those most in need, consulting on "eligibility criteria to ensure this system works for all".

Labour said it would give more details of how it would be paid for in its election manifesto but the Conservatives said the opposition's already extensive spending commitments meant "there simply won't be enough money to pay for it".

In anticipation of a general election this autumn, Labour has already pledged this week to axe prescription charges in England and remove the charitable status of private schools as a first step to "integrating" them into the state sector.

But the leadership remains under pressure over Brexit, with delegates set to vote on a motion pushing for a clearer Remain stance in a future EU referendum if Labour wins power.

Prime Minister Boris Johnson has promised to solve the crisis in social care, which has bedevilled previous Tory and Labour governments due to its cost and complexity.

Mr McDonnell said cuts to care funding since 2010 had left a million people not getting the care they need and "87 people dying a day waiting for care".

Subsidising the cost of basic tasks such as getting in and out of bed and going to the toilet will enable more people to continue to live independently in their homes, he said.

#### *Analysis by Nick Trigg*

Free personal care is something campaigners have long been calling for in England.

Scotland has already introduced it and Wales and Northern Ireland each provide some level of universal entitlement. In Wales the cost of home care is capped, while in Northern Ireland the over-75s get it for free.

Both the Tories and Labour have been talking about reforming the system for over two decades - Tony Blair came to power in 1997 promising to look at it.

But neither has managed it. Why? The cost and complexity have proved to be insurmountable barriers.

What is more, how much impact the policy has depends on the threshold that is set for accessing it. Even in Scotland, Wales and Northern Ireland the bar for getting help is set very high. Only those with the most severe needs get it.

The devil, as always, will be in the detail.

Based on Scottish figures, Labour said the move could save those currently self-funding their care almost £10,000 a year while 70,000 fewer families would be liable for "catastrophic" lifetime care costs in excess of £100,000.

Removing the distinction between health and care needs, Mr McDonnell argued, will most help families of dementia sufferers, who face the highest costs and, in many cases, have been forced sell their homes to pay for care.

"I believe the right to dignity in retirement is a part of that right to health at any stage of life," he said. "The truth is our social care sector is a national scandal.

"The next Labour government will introduce personal care free at the point of use in England "Funded not through the Conservatives' gimmicky insurance schemes But, like the NHS and our other essentials, through general taxation."

The pledge goes beyond what Labour promised in its 2017 election manifesto - in which it vowed to raise the minimum asset threshold for free care, cap the amount anyone has to pay during their lifetime and support free end of life care.

Under the current means-tested system, if an individual has assets worth more than £23,250, including property, they must pay the full cost of residential care without help from the council.

Those with assets above £14,250 have to contribute, but may get some help from state.

Labour, whose long-term aim is to provide free personal care to all working age adults, says support for over-65s will alleviate the pressure on the NHS by reducing delayed transfers of care from hospital and admissions to care homes and hospitals.

'Catastrophic costs'

Mr McDonnell also pledged to close the gap in social care funding - Labour has already pledged to spend an extra £8bn a year over five years - and give local authorities extra support to provide care so services are not outsourced to private firms.

The King's Fund think tank has estimated that free personal care could cost £6bn a year in 2020-21, rising to £8bn by 2030.

The organisation said Labour's announcement was a welcome step but "it is not the same thing as free social care, and some people would still be left facing catastrophic costs."

In its Spending Round earlier this month, the government announced a further £1.5bn in extra funding for social care and promised to look at giving councils more leeway to raise extra funds via council tax bills.

[www.bbc.co.uk](http://www.bbc.co.uk) 23 September 2019

## **Medical cannabis product approved for epilepsy**

The EU has approved for the first time the use of a medicinal cannabis product aimed at patients with two rare, but severe, forms of childhood epilepsy.

Doctors can prescribe Epidyolex - an oral solution of cannabidiol, which comes from the cannabis plant - if they think it will help sufferers.

It has been approved for use in the UK and other European countries, but the NHS does not currently recommend it.

But some parents want alternatives that contain a component not in this drug.

Last month, the UK's National Institute for Health and Care Excellence made an initial decision not to recommend prescribing Epidyolex, due to lack of evidence of long-term effectiveness.

Final guidance is due later this year.

The drug does not contain any of the psycho-active component of cannabis, a compound called tetrahydrocannabinol (THC).

Some parents, who have travelled to the Netherlands to buy cannabis medicines, feel the treatment will not help many children because it does not contain THC, which they argue has helped their children.

Epidyolex has been approved as a treatment option for children as young as two with Lennox-Gastaut syndrome or Dravet syndrome - difficult-to-treat conditions that can cause multiple seizures a day.

The medication, developed by GW Pharmaceuticals, will be used in combination with another epilepsy medication called clobazam.

### **What about other medical cannabis products?**

There are many different medical cannabis products. The use of ones containing THC was legalised across the UK in November 2018.

These treatments can be prescribed only by specialist doctors in a limited number of circumstances where other medicines have failed.

Few of these unlicensed prescriptions have been made on the NHS.

There are some other cannabis-based medicines that are licensed in the UK.

Nabilone is a medicine, taken as a capsule, that has been developed to act in a similar way to THC.

Doctors can give it to people having chemotherapy to help with nausea.

Sativex is a cannabis-based medicine that contains THC and CBD and is licensed in the UK for people with multiple sclerosis.

Recreational use of cannabis remains illegal.

### **What do experts say?**

Ley Sander, Medical Director at the Epilepsy Society and Professor of Neurology at University College London, said: "This new drug will bring hope for some families and EU approval feels like a positive step. Medicinal cannabis, however, still remains a medical minefield and there are many hurdles ahead.

"CBD was not recommended by NICE for prescription on the NHS. It is important that the pharmaceutical industry continues to work with the medical advisory body to ensure that drugs are cost effective and that its long-term effects are clear."

www.bbc.co.uk 8 October 2019

## **Caroline Wyatt: The fight to reverse damage caused by MS**

"I don't like to think of the future. It's such a big question mark. I just keep living in the present." Karine Mather was diagnosed with MS when she was 27, although she noticed the first symptoms much earlier.

It started off as a mental-health issue with anxiety and depression, she remembers. Later, she noticed she was starting to limp when she walked longer distances.

Karine began using a walker to help with her balance and stamina, and then a scooter when she could no longer walk very far.

"I got to the stage where the wheelchair became quite liberating, and gave me back a sense of freedom again. Now I rely on the power-chair full-time because I can't stand by myself any more."

Now Karine and her wife, Sarah, have had to give up their full-time jobs.

Karine was forced to stop working as a customer service adviser at a bank because she could no longer fulfil the physical demands of work and Sarah gave up working as a data analyst so she could take care of Karine.

Now 34, Karine retains the use of just one hand, and suffers pain, stiffness and spasticity in her body that has got worse as the disease has progressed.

"It feels like a fist clenching all the time. And I have days when my mind is cloudy and I miss out words and sentences."

Both remain upbeat but the financial, as well as the emotional, impact of MS has been huge. Karine's MS is the type known as "primary progressive", or PPMS, which meant that for the first years after diagnosis, no disease-modifying treatment was available.

One new drug - Ocrevus, or ocrelizumab - was recently licensed for early PPMS in the UK but came too late to help Karine.

Now the MS Society is launching an ambitious "Stop MS" appeal, aiming to raise £100m to fund research over the next decade into treatments that can stop the progression of disability in MS. Since being diagnosed with MS in 2015, after many years of symptoms, I've been looking for anything that might help slow or even stop the progression of my MS, which affects the nerves in my brain and spinal cord.

I last wrote about my MS after travelling to Mexico for an autologous stem cell transplant (aHSCT) in 2017.

Sadly, despite initial improvements, I'm now back to where I was before: slowly but surely getting worse.

The only improvements that have endured are the lifting of some of the crushing brain fog I had before HSCT and less hesitation in my speech.

For both, I am eternally grateful, as they mean I can continue to work at the BBC, in the job I love.

However, I have no idea how long this reprieve will last.

The fatigue that had long been my worst symptom is now back with a vengeance, so that staying awake throughout a busy working day remains a challenge.

That MS fatigue did lift for a few months, and it felt miraculous. I awoke every day refreshed.

But then it returned, and I awake after eight full hours fast asleep feeling as if I haven't been to bed at all.

The ageing process - including menopause - has almost certainly been a factor in the worsening of some symptoms.

Ageing cells repair less well, and with my faulty immune system apparently determined to keep stripping away the myelin sheath that should protect my nerves, I'm less able now to repair the damage than I was when the disease first began to affect me in around 1992.

Since 2016, I've had to walk using a stick to aid my balance. It is sparkly-topped; an effort to make the accoutrements of disability just a little more cheery.

Dizziness is now a constant companion. It rarely goes away, making car travel or even buses a nightmare. Just turning my head too fast can make me stagger or fall over.

And for the past year or two, my right foot has begun to drag along the ground thanks to foot drop, meaning that I trip more often because I can't fully raise it.

I am always grateful to the strangers who kindly stop to help me up from the uneven pavement when I do fall.

Perhaps most worrying for me is that my right hand no longer works as it used to, catching on the computer keyboard as my outer fingers drag lazily along the keys, sullenly refusing my brain's command to lift.

In the mornings, both my hands and my feet are numb and frozen, then painfully full of pins and needles before warming up enough to be usable a few hours later.

When I wake, I wonder how long it might be until these hands and feet barely function at all, and quickly push that unwelcome thought away.

I'm well aware how very lucky I am that the progression of my MS has been relatively slow - at least until recently. I've learned how better to conserve energy for the things that really matter, though I still chafe at how little I manage to achieve.

Having enough energy to cook a meal from scratch on a day off is a cause for rejoicing. I'm still learning how to save up enough energy for family and friends, and not use up all of my much-depleted ration for work or research.

I have had to face the fact that I have now probably gone from the relapsing-remitting phase of MS (for which a dozen or so treatments exist) into the secondary progressive phase, for which there is currently no treatment licensed in the UK to stop the relentless progression that will affect so many of the 100,000 or more of us living with MS here.

But that may be about to change.

Anna Williams, professor of regenerative neurology at the University of Edinburgh, is looking at how the brain responds to MS damage and how the fatty myelin sheath under attack in MS can be restored more efficiently.

"We have to look at ways to stop the nerves dying," she says. "We want to be able to try to limit that either by keeping the nerves alive, or keeping them working better."

Repurposing existing drugs to help with remyelination should prove the quickest route to therapies for progressive forms of MS, because creating and licensing new ones is a much lengthier and more expensive process.

Prof Williams still sees patients at the Anne Rowling Clinic of Regenerative Neurology in Edinburgh, named in memory of the Harry Potter author J K Rowling's mother, who had MS. (The author this year donated £15m for research at the unit.)

"At the moment, with PPMS or SPMS, we can always give relief for pain or stiffness but we won't change the course of the disease.

"So for those patients, to slow or stop or reverse the disease can only be done with more research, and money is critical for research."

The biggest trial yet in the UK for patients with secondary progressive MS is the [MS STAT2 trial](#), conducted by Prof Jeremy Chataway for the UCL Queen Square Institute of Neurology in London.

The trial is still recruiting at 30 centres across the UK to look at whether simvastatin, a drug used to treat high cholesterol, can slow or stop disability progression. If so, it has the potential to become one of the first disease-modifying therapies for people with secondary progressive MS. And perhaps most encouraging of all, Prof Robin Franklin and his team at the Wellcome-MRC Cambridge Stem Cell Institute recently published research suggesting a common diabetes drug - metformin - could hold the key to stopping disease progression in MS.

Costing just a few pence per tablet, metformin appears to have an ability to restore cells to a younger, healthier state and encourage myelin regrowth.

The next question is whether it works in people as well as it does in the lab.

Prof Franklin says: "This is a drug that's well tolerated and widely available. There is every reason to believe that the effects that we have seen - which have been so spectacular - will translate into humans.

"This is the great frontier of MS therapy. We're good at stopping the inflammation in MS. What we're not so good at doing is repairing the damage. All this work has given us some real hope that this medicine will reverse the damage done by MS."

I certainly feel rather more hopeful than I did.

I've changed as much about my lifestyle as I can - prioritising sleep, eating healthily, largely giving up alcohol, doing yoga and stretching every day, and cutting back on stress, be that reporting from war zones or attending too many BBC meetings.

But I'm all too aware that time is against me as my ageing brain and body struggle to repair the damage done in their lengthy continuing battle with my own immune system.

My hope now is that these trials will show good enough results in the next few years for at least one or two of the drugs to be rapidly approved for MS so they can help people like Karine and me before it's too late.

I ask Karine what she makes of the current research. She is suitably succinct.

"I'm sitting here with just the one limb working and I'm thinking - quicker, please."

## Wheelchair user 'forced to wet himself' after buses fail to stop

A wheelchair user says he was "forced to wet" himself when he was left at a bus shelter for an hour.

Ryan McDade said he was passed by three Pronto buses in Mansfield, Nottinghamshire. The 20-year-old said he felt "dehumanised" by the drivers and that the experience was "humiliating".

Bus operator Stagecoach East Midlands wrote to Mr McDade to apologise after reviewing CCTV footage adding "we do not condone this type of misconduct".

Mr McDade had spent time in Mansfield on Friday and was trying to return to Portland College, a residential specialist college near Ravenshead.

The musical theatre student, who has cerebral palsy, said: "We were waiting about an hour and in that time three bus drivers just drove past, one of them even opened the door to the bus and just said 'no'.

"We were waiting so long that I was forced to wet myself, which is really humiliating.

"There was a lady sitting next to me, I cannot tell you the embarrassment."

Mr McDade suffers from curvature of the spine, and therefore cannot use public disabled toilets. 'It's disgraceful'

He said it was the first time he was "point-blank refused" entry on a bus, but he said there was space in the wheelchair area of the buses.

"It was dehumanising, getting on a bus [as a wheelchair user] is a nightmare," he said.

"The bus is my way of having independence, so if somebody were to say 'you can't get on the bus' like they did on Friday, it's like somebody's taking away that independence."

Ceri Smith, policy and campaign manager for disability charity Scope, said: "It's disgraceful that Ryan had to endure this horrendous experience.

"Public transport should serve everyone in our society, but disabled people are being let down every day."

Stagecoach East Midlands operates the Pronto bus service.

In a written response to Mr McDade's complaint, the company said it offered its "sincere apologies to Ryan".

It added: "Two of our staff have failed to comply with the company's policies in respect of both stopping for passengers and disability awareness."

The drivers will be "interviewed under the company's formal disciplinary procedure".

A spokesperson for the operator added: "We are very disappointed that Ryan was let down on this occasion.

"We have also spoken directly to Ryan's mother to apologise."

### DISCLAIMER

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

## YOUR JOKES

A car hit an elderly Jewish man. The paramedic says, "Are you comfortable?" The man says, "I make a good living."

-----

I just got back from a pleasure trip. I took my mother-in-law to the airport.

-----

I've been in love with the same woman for 49 years. If my wife finds out, she'll kill me!

-----

Someone stole all my credit cards, but I won't be reporting it. The thief spends less than my wife did.

We always hold hands. If I let go, she shops.

-----

My wife and I went to a hotel where we got a waterbed. My wife calls it the Dead Sea .

-----

My wife and I revisited the hotel where we spent our wedding night. This time I was the one who stayed in the bathroom and cried.

-----

My wife was at the beauty shop for two hours. That was only for the estimate. She got a mudpack and looked great for two days. Then the mud fell off.

-----

The Doctor gave a man six months to live. The man couldn't pay his bill, so the doctor gave him another six months.

-----

The Doctor called Mrs. Cohen saying, "Mrs. Cohen, your check came back."  
Mrs. Cohen replied, "So did my arthritis!"

-----

Doctor: "You'll live to be 60!" Patient: "I AM 60!" Doctor:  
"See! What did I tell you?"

-----

A doctor held a stethoscope up to a man's chest. The man asks, "Doc, how do I stand?"  
The doctor says, "That's what puzzles me!"

-----

Patient: "I have a ringing in my ears. " Doctor: "Don't answer!"

-----

A drunk was in front of a judge. The judge says, "You've been brought here for drinking."  
The drunk says, "Okay, let's get started."

-----

A man called his mother in Florida. "Mom, how are you?"  
"Not too good," said the mother. "I've been very weak."  
The son said, "Why are you so weak?"  
She said, "Because I haven't eaten in 38 days."  
The son said, "That's terrible. Why haven't you eaten in 38 days?"  
The mother answered, "Because, I didn't want my mouth to be full in case you should call."

-----

A Jewish man said that when he was growing up, they always had two choices for dinner - Take it or leave it.

-----

A Jewish boy comes home from school and tells his mother he has a part in the play.  
She asks, "What part is it?"  
The boy says, "I play the part of the Jewish husband."  
The mother scowls and says, "Go back and tell the teacher you want a speaking part."



# MEMBERS COMPETITION

The monthly quiz will now just be for fun only with the answers as always at the bottom of the following month's bulletin.

- 1/ Which country has the longest coast line? .....
- 2/ What is the most populated country? .....
- 3/ What is the capital of the Philippines? .....
- 4/ What is the smallest county? .....
- 5/ Which country has the highest waterfall? .....
- 6/ In which country is Mount Fuji located? .....
- 7/ In which country is the Cape of Good Hope .....
- 8/ What country has the highest number of active volcanoes? .....
- 9/ The Sierra Madre Oriental is a mountain range in which country? .....
- 10/ Where was the hottest temperature ever recorded? .....
- 11/ Which of these countries uses the Shilling as its currency? .....
- 12/ Which country has three national capitals? .....

## Answers to last quiz:

1/ Girls Aloud 2/ Gerry and the Pacemakers 3/ Twisted Sister 4/ Thunderclap Newman  
5/ Guns and Roses 6/ Rolling Stones 7/ Deacon Blue 8/ The Beach Boys  
9/ Manic Street Preachers 10/ 3 Dog Night