

**ISSUE NO:- 03/ 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 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 16 February 2019

### Medicinal cannabis: Why has it taken so long to get to patients?

Medicinal cannabis was legalised last year but so far, virtually no-one in the UK has been able to access it.

Now, enough cannabis to treat 30 patients for a month has arrived in the UK from the Netherlands.

Three patients with prescriptions, all to treat chronic pain, will receive cannabis-derived medicines immediately.

Specialist **doctors have been able to prescribe cannabis since 1 November** - so what has taken so long?

#### The new law

The new law moved cannabis from schedule 1 under the Misuse of Drugs Regulations 2001 - meaning it had no therapeutic value - to schedule 2.

That category is for drugs which are controlled but have a recognised medical use and can be prescribed in certain circumstances.

Cannabis-based medicines can come in the form of whole cannabis flowers, oils or capsules, or a single compound which can be isolated and extracted.

The two main active ingredients in cannabis are cannabidiol (CBD) and tetrahydrocannabinol (THC) but a cannabis plant will contain hundreds of different compounds.

#### Prescribing

Medicinal cannabis is currently unlicensed so doctors can prescribe it only if a patient has a need that can't be met by licensed medicines.

Under the new rule, GPs are not allowed to prescribe cannabis-derived medicines. It has to be a specialist consultant, for example in neurology or paediatrics.

Even getting the right prescription pads has been a challenge according to Hari Guliani at Grow Biotech, a consultancy which has worked with both doctors and importers.

Prescribing cannabis is new to UK doctors and so it may take a while before they begin doing so, says Dr David McDowell, the pain specialist who prescribed cannabis for the patients receiving their medicines this week.

He described the current process as "tortuous".

The prescriptions are valid for 28 days and, at the moment, doctors are advised to prescribe a month's worth at a time.

One of Dr McDowell's patients, who is set to receive his first supply of medical cannabis, suffers from Crohn's - a painful inflammatory bowel disease. He said he had been prescribed opiates in the past, which, he said, had made his condition worse.

"It's a hard thing to do to yourself to put up with becoming addicted to opioids or putting up with the vomiting and nausea that come with immune-suppressing drugs," he said.

But, he says, the price for cannabis - £695 for one month's supply - "takes the edge off the good news", adding that he didn't believe it would be sustainable for him in the long term.

All the patients receiving cannabis this week are doing so privately.

NHS England said that cannabis-based products would be prescribed only where there was "clear published evidence of benefit" that couldn't be achieved by a licensed medicine.

It said that where necessary, NHS Trusts could meet the cost but, "the current position is that no cannabis-based products for medicinal use are routinely commissioned."

In October 2019, the National Institute for Health and Care Excellence (NICE) plans to publish guidelines concerning the medication, and the NHS will then use this to decide whether it will eventually fund the drug routinely for some patients.

### **Patients**

At the beginning of December, **Carly Barton is thought to have become the first person to be given a prescription for cannabis** but wasn't able to actually receive the drug because none had been imported.

She told the BBC last year that she had been buying cannabis "on the black market" instead of taking very strong opiates including fentanyl which she had been prescribed for pain.

Last month, Charlotte Caldwell, whose **son has a rare form of epilepsy** and became the centre of a campaign to legalise the drug for medicinal purposes, told the Times she had been able to pick up a dose of cannabis.

- **Campaigner's company sells cannabis oil**

It's understood that an individual supply was flown in from Canada - but this week is the first time a stock of the drug has been imported.

Other conditions cannabis might be prescribed for include multiple sclerosis and cancer.

### **Whole flowers**

At every stage of the process, getting cannabis-based medicines to patients is very tightly regulated, adding to the delay.

The first batch of legal cannabis has been shipped into the UK in the form of whole flowers, which contain more than one active pharmaceutical ingredient.

This also makes it more complicated to get approval than importing a single compound like, say, morphine.

While morphine is also a controlled substance, it has a well-established medical use, meaning processes are in place to import and regulate it.

This batch coming from the Netherlands has been grown at a specially regulated site for cannabis for medical purposes and the export has to be approved by the Dutch government. Importers in the UK need to apply to the Home Office for a licence to bring in the cannabis from overseas.

The whole process can take up to 28 days, so by the time it's completed, the prescription may have expired.

These delays are why companies involved in the process of importing medical cannabis say it's important to bring in a bulk amount.

The bureaucratic hurdles are all there for patients' safety, says Mr Guliani at Grow Biotech.

But bringing cannabis into the country in larger amounts can mitigate these delays, meaning when patients' supplies run out there's stock available and they don't have to have a gap in their treatment.

www.bbc.co.uk 17 February 2019

### **Selma Blair opens up about MS: 'People with disabilities are invisible'**

US actress Selma Blair has spoken about her life with multiple sclerosis, four months after she was diagnosed.

"I really feel like people with disabilities are invisible to a lot of people," she told Vanity Fair magazine.

But the star, who appeared with a cane at an Oscars party on Sunday, added: "There's no tragedy for me. I'm happy.

"I don't know if I believed in myself or had the ambition before my diagnosis. And oddly now I do, and I don't know if it's too late."

MS is an incurable condition affecting the brain or spinal cord, causing vision, balance and muscle problems.

The actress is known for films including *Cruel Intentions* and *Legally Blonde*, and will star in Netflix's forthcoming sci-fi drama *Another Life*.

She said: "If I can help anyone be more comfortable in their skin, it's more than I've ever done before."

Blair revealed she had MS on Instagram last October. "It wasn't about announcing a dramatic diagnosis," she told *Vanity Fair*.

"I had no idea, for some reason, that news outlets would pick it up or anything. When they did, I was kind of uncomfortable.

"Then I was worried, thinking, 'Will anyone hire me?' I reconnected with so many people who thought I might drop dead soon!"

Those who got in touch included Amy Schumer, whose father has MS.

Blair's health has continued to deteriorate. "I also never thought I'd get this bad, to tell you the truth," she said.

She struggles with movement, memory, dressing and is struggling with her vision after a bad reaction to a high-dose glucocorticoid treatment.

### **'Fatigued joy'**

She says she now looks and sounds so different that it has changed her relationship with her seven-year-old son Arthur.

"He wants to be closer to my body more, and I can tell he wants to make sure I'm still here inside. I used to be so athletic with him. Now I fall in front of him.

"There's a humility and a joy I have now, albeit a fatigued joy."

She added: "I'm pretty much a nobody in Hollywood.

"But when I read comments on Instagram from people who were suffering, whether it was from MS, or anything, I thought, there's a need for honesty about being disabled from someone recognisable."

She is also keen to team up with a fashion designer because she says there's a lack of stylish clothing for disabled people.

"I would like to partner with someone like Christian Siriano on a line for everyone - not just people who necessarily need adaptive clothing, but for those who want comfort, too.

"It can still be chic. You shouldn't have to sacrifice style. Like, let's get elastic waistbands to look a little bit better."

Blair appeared on the red carpet for the *Vanity Fair* Oscars party on Sunday, using a black cane for support.

"A cane, I think, can be a great fashion accessory," she said.

[www.bbc.co.uk](http://www.bbc.co.uk) 4 March 2019

### **Social care 'national scandal and disgrace'**

It is one of the biggest domestic policy issues of our times - where should the balance be struck between the individual and the state's responsibility for paying for care in old age? A much-anticipated government policy paper for England has still not surfaced.

Experts are calling it a "national scandal" with services in parts of the country near collapse and millions of vulnerable people deprived of the care and support they need.

The document (known as a Green Paper) on the future of adult social care in England was first promised for the summer of 2017.

Delays and postponements followed and despite official guidance that it would appear in 2018, the paper remained unfinished and under wraps in Whitehall.

In January the Health and Social Care Secretary Matt Hancock told MPs he intended it to "happen before April".

But April is not far off and there is no sign of imminent publication.

### **Time is running out**

Sources indicate that hopefully the paper will emerge during April. But with the Easter parliamentary holiday there are limited dates for a launch.

The May local elections have thrown up another obstacle in the shape of "purdah" during campaigns. Traditionally, official policy announcements are not made in the weeks before polling day.

The Brexit debates and votes have made it harder for ministers to focus on domestic issues like social care, let alone decide a date for a policy launch.

The paper is a cross-government exercise and needs buy-in from Downing Street and the Treasury. There are thorny questions to be resolved and differences still to be ironed out.

So don't hold your breath. It may yet be a while before the document sees the light of day.

And this is causing increasing concern amongst both leaders in the social care sector and their counterparts in the NHS.

A group of health 15 health organisations has now written to the Prime Minister calling for action.

They note that it is unusual for one part of the public sector to call for more funding for another part.

Led by the NHS Confederation, the group argues that "social care is on the brink of collapse" and that 1.4 million older people in need in England now receive no help.

After a two year wait, they claim, it is time for the government to put things right.

### **Protecting the vulnerable**

The Green Paper will not contain long-term funding plans for local authority provision of social care.

They will come with the Treasury spending review which is due in the autumn. But the paper will address the question of an individual's responsibility for paying for care.

Only those with assets below £23,250 receive local authority help with care costs. This includes the value of a house if the care is in a residential facility.

Historically, this has left some families having to sell a house to cover the costs of looking after a parent in a care home.

It is possible to defer these bills until after the parent's death but the property may need to be sold then to repay the local authority.

One solution is to cap lifetime social care costs and this was government policy until 2017 when the idea was shelved.

Matt Hancock, in a letter to the Prime Minister leaked to the **Daily Telegraph**, warned that plans for such a cap at around £100,000 could cost taxpayers billions of pounds and would only benefit a small number of better-off families.

In an interview with LBC radio, Mr Hancock was asked if people would in future still have to sell their houses to fund social care.

He described this as "an injustice" and dropped a strong hint that the current means-tested system was due for a major shake-up, with the burden spread across all taxpayers.

The Health Secretary has already talked about ideas for new forms of levy or taxation to cover future social care costs.

This could involve a state-backed insurance scheme which those in work are automatically enrolled into, along the lines of the workplace pension scheme introduced after government legislation in 2008. Opting out would be possible.

Another possibility is higher National Insurance contributions, or a special levy, to be paid by the over 40s with the proceeds ring-fenced for social care.

The latter idea was proposed by three Commons Select Committees so has the advantage of cross-party support.

When it comes, the green paper will have a series of ideas and there will then be a consultation process.

It will no doubt be a weighty and important document, but with questions rather than firm proposals.

Those seeking answers and solutions to this vital domestic policy issue may have to wait a while yet.

Scotland provides free personal care for the elderly. Wales has a weekly cap on home care and Northern Ireland has free care for over 75s at home.

www.bbc.co.uk 13 March 2019

### **'I was 25 when I was diagnosed with multiple sclerosis'**

"We need you to come to the hospital immediately. We think you might be having a stroke." I was sitting on my sofa at home alone when I got a phone call from my doctor that I'll never forget. I started freaking out - I had just been to see my doctor to try and work out why I was experiencing strange symptoms. I'd been making repeated unforced errors and having extreme headaches.

At the time, I was training as a volunteer police officer, while working full-time in insurance. After that call I was rushed to hospital for tests, but it would take three months from that day for doctors to confirm what was wrong with me.

I grew up in Norwich, where I still live today. My mum is a nurse and my dad works in the NHS in a managerial role. My parents separated when I was about three, so I lived at my mum's with my older brother. I was fully in both my parents' lives and they were fully in mine.

Having been quite a shy boy who was bullied growing up, I started to come out of my shell at college. I made more friends and decided to do some volunteer policing and see how I got on. I became **a special constable** (or "Specials") - which is essentially an unpaid police officer. You get trained to do the job voluntarily and you work alongside regular police officers. Eventually, I was doing about 50 to 60 hours a month as a Special, even after I got a full-time job in insurance.

I dealt with many things that people probably wouldn't normally see in their daily lives - everything from fatal car crashes to minor domestics. It was quite physically and emotionally demanding work, but I absolutely loved every second of it.

It was when I was out with a group of mates one day that I first noticed something was wrong. We had just finished a competitive pool match in the local league we play in when, out of nowhere, I got this blasting migraine - like nothing I've ever experienced before. It knocked me out. I was in so much pain. My mates asked if I needed a lift home, but I decided to drive myself and thought I'd just lay down and sleep it off. It'll be alright, I thought. Nothing to worry about. I was fine the next day, but, over the next couple of weeks, I started noticing that I had been making unforced errors - like when I was typing out documents at work. I knew that wasn't normal, and when I fell over one day, which was unlike me, I decided to get it checked out once and for all. I went to the doctor as a precaution thinking it would be fine.

My doctor started off by checking my reflexes with a little hammer, knocking it on certain areas on my knees and my arms to see how they reacted - the reflexes on my right-hand side were heightened, which can be a **symptom** that something is wrong. My balance was way off too; I was leaning much more to my left.

She said she was going to need to speak to a neurological specialist for some advice, and sent me home. Within half an hour, I was sat on my couch alone at home when I got that call telling me to come into the hospital immediately.

When I got there, I was in a bit of a daze because I wasn't sure what was going on. They put me in a little room and my mum eventually came and joined me. It helped having her there - she was really supportive and calm.

After a few hours they told me the words that would change my life forever: "We've looked at your scans and think you might have multiple sclerosis". I was shocked and scared because I didn't know what it was or what might happen next.

**Multiple sclerosis (MS)** is a condition where your immune system starts attacking the protective shell around your nerves. It's not clear exactly what **causes** MS - there are suggestions it could be genetic, or that outside factors like teenage obesity or smoking could be to blame. The symptoms vary from person to person - you can have one sufferer who gets tired easily, and then another who is completely debilitated by pain and fatigue.

More than **100,000 people** in the UK have MS – among young adults, MS is the most common condition affecting the central nervous system. It's nearly three times more common in women than men, and is usually diagnosed when people are in their twenties and thirties. Last year, the actress Selma Blair (star of Cruel Intentions) **went public** with her condition, showing the drastic effect on her walking and speaking.

The doctors needed to do a **lumbar puncture**, where they put a big needle into your spine and take out some cerebrospinal fluid, so they can test it to see if you have a **number of different MS indicators**. I'm absolutely petrified of needles and, I'm not going to lie, it was absolutely agonising. It took them six tries to get the fluid.

Three months would pass after this test before I would get my diagnosis. The wait was quite difficult initially, as I took some medication which had a bad effect on my mental health, and my mum had to take time off work to nurse me.

I was alone when I got my final diagnosis from the doctor. By then, I'd done some research and was being very logical about it all - almost cutting off my emotions and thinking, "Right, let's focus".

Straight after I got the news I went to see my dad, whose office was in another part of the hospital.

He was on the phone at the time - and looked at me as if to say, "Everything OK?"

I just stood there, in shock, and cried.

Dad got straight off the phone and gave me a massive hug, saying, "We'll crack on and we'll sort it".

I called my mum straight after. She was at work and they sent her home early because she was so upset.

I think it was hard for my parents because they understood more about MS than I did from seeing how it affects people through their work.

I'm lucky to get a lot of support from my family. I still live with my mum - she is essentially my carer - even though she has a full-time job. When she comes home she cooks my dinner and helps me to make my bed and tidy my room. My mum is my rock.

It took a while for it to sink in that my MS would change everything. At 25, you don't expect to get that kind of diagnosis. Most people at that age are going out having fun, doing stuff like going to the cinema, bowling, you know, just out for a laugh.

I get really fatigued. Some people think, "Oh, that's tired". But that isn't it. The best way to describe it is, if you've been at a full day's work and then you've gone to the gym for four hours - that's fatigue. I can wake up with that feeling, having done nothing.

The type of MS I have is **secondary progressive** - meaning your symptoms gradually get worse. This is different from **relapsing remitting**, where people have attacks of symptoms which fade away for periods - 85% of people with MS in the UK are diagnosed with this type.

Within three months of diagnosis, I was walking with a stick.

I'm in permanent pain with my right leg. I have constant headaches, issues with my vision and with my balance. I just feel rough all the time. On good days, I can move around and do things like nip to the shop with a walking stick aid. On bad days, all I can do is lie in bed and give my body time to sort itself out.

I stopped work when I got my diagnosis. Giving up my insurance job was hard, but giving up my role in the police was heartbreaking. It was my dream job and I loved it, and the police did offer to accommodate me and looked at getting me a desk job. But as a Special, you're primarily meant to be frontline, and the unpredictable nature of my illness meant I just couldn't commit to it anymore.

The saddest moment for me was handing my uniform back. I went in and met with the chief inspector of Norfolk police and handed everything over - my uniform, my body armour, baton, the works. And that was it. I felt defeated, in a way, even though I knew it wasn't my fault. I have lost some friends because I haven't been able to go out as much as I did before. But I've stayed close to some of my friends from the police and I try to make sure I socialise as much as I can. I see some of my friends playing pool - we catch up and have a bit of a moan while playing.

It's through playing pool that I met my partner. After my diagnosis, I didn't really think about relationships - I was too busy focusing on my health.

At first, I felt like I didn't want to risk having a family because **there is a chance** MS could be passed on genetically. While it isn't directly inherited, it's estimated you have a 2 to 3% chance of developing it as a sibling or child of someone with MS.

But then I met my partner - she's a mental health nurse and that helped her understand my MS. Soon after we met, we got pregnant and we now have a son, Leonard. I can't describe how it felt when I first picked my son up for a cuddle - it was the best feeling on the planet. I nearly cried my eyes out.

I've always been mentally strong, but he's made me feel more positive about the future. These days, I look at my condition like I can't decide what my body does, but I can decide how I deal with it. I've just got to crack on and try and make the best out of it as possible.

And with Lenny in my life, I've got a lot to look forward to.

[www.gov.uk/government](http://www.gov.uk/government) 21 February 2019

### **Regulations have been laid before Parliament to increase certain National Health Service charges in England from 1 April 2019.**

In the 2015 spending review, the government committed to support the Five Year Forward View with £10 billion investment in real terms by 2020 to 2021 to fund frontline NHS services.

Alongside this, the government expects the NHS to deliver £22 billion of efficiency savings to secure the best value from NHS resources and primary care must play its part. This year, therefore, we have increased the prescription charge by 20 pence from £8.80 to £9 for each medicine or appliance dispensed. To ensure that those with the greatest need, and who are not already exempt from the charge, are protected we have frozen the cost of the prescription prepayment certificates (PPC) for another year. The 3-month PPC remains at £29.10 and the cost of the annual PPC will stay at £104. Taken together, this means prescription charge income is expected to rise broadly in line with inflation.

Charges for wigs and fabric supports will also be increased in line with inflation.

Details of the revised charges for 2019 to 2020 can be found below.

#### **Prescription charges**

- Single charge: £9
- 3-month PPC (no change): £29.10
- 12-month PPC (no change): £104

8  
**Your Jokes**

A young ventriloquist is touring Norway and puts on a show in a small fishing town. With his dummy on his knee, he starts going through his usual dumb blonde jokes. Suddenly, a blonde woman in the fourth row stands on her chair and starts shouting, "I've heard enough of your stupid blonde jokes. What makes you think you can stereotype Norwegian blonde women that way? What does the colour of a woman's hair have to do with her worth as a human being? Its men like you who keep women like me from being respected at work and in the community, and from reaching our full potential as people. Its people like you that make others think that all blondes are dumb! You and your kind continue to perpetuate discrimination against not only blondes, but women in general, pathetically all in the name of humor!" The embarrassed ventriloquist begins to apologize, and the blonde interrupts yelling, "You stay out of this! I'm talking to that little git on your lap."

\*\*\*\*\*

While riding my Harley, I swerved to avoid hitting a deer, lost control and landed in a ditch, severely banging my head. Dazed and confused I crawled out of the ditch to the edge of the road when a shiny new convertible pulled up with a very beautiful woman who asked, "Are you okay?" As I looked up, I noticed she was wearing a low cut blouse with cleavage to die for... "I'm okay, I think," I replied as I pulled myself up to the side of the car to get a closer look. She said, "Get in and I'll take you home so I can clean and bandage that nasty scrape on your head." "That's nice of you," I answered, "but I don't think my wife will like me doing that!" "Oh, come now, I'm a nurse," she insisted. "I need to see if you have any more scrapes and then treat them properly." Well, she was really pretty and very persuasive. Being sort of shaken and weak, I agreed, but repeated, "I'm sure my wife won't like this." We arrived at her place which was just few miles away, and after a couple of cold beers and the bandaging, I thanked her and said, "I feel a lot better, but I know my wife is going to be really upset, so I'd better go now." "Don't be silly!" she said with a smile, while unbuttoning her blouse exposing the most beautiful set of breasts I've ever seen. "Stay for a while. She won't know anything. By the way, where is she?" "Still in the ditch with my Harley, I guess."

\*\*\*\*\*

A Greek and an Italian were talking one day, discussing who had the superior culture. Over coffee, the Greek says "Well, we built the Parthenon." The Italian replies "We built the Coliseum." The Greek retorts "We Greeks gave birth to mathematics." The Italian, nodding, says "But we built the Roman Empire ". And so on and so on until the Greek comes up with what he thinks will end the discussion. With a flourish of finality he says "We invented sex!" The Italian replies "That is true, but it was the Italians who included women."

# 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/ Where in the world would you expect to find a car with the vehicle registration code 'V'? .....
- 2/ How many sides has a heptadecagon? .....
- 3/ What was the name of the character played by John Travolta in the film 'Pulp Fiction'? .....
- 4/ Which was the first James Bond film to feature Roger Moore in the title role? .....
- 5/ 'Suncrisp', 'Golden Russet' and 'Braeburn' are all varieties of which fruit? .....
- 6/ In which country would you find the coastal resort of Lara Beach? .....
- 7/ In which century was the first 'Grand National' horse race? .....
- 8/ The letters of the word 'allergy' can be rearranged to form three other seven-letter words. Can you find all three of them? .....
- 9/ Which celeb has children named Daisy, Boo, Pamela, and Petal Blossom Rainbow? .....
- 10/ What is the Japanese word for goodbye? .....

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/ The old curiosity shop 2/ Dudley 3/ Joseph Stalin 4/ Jungle Book 5/ Algeria 6/ Avon 7/ George III 8/ Homer 9/ Lyndon B Johnson 10/ Gambling, Casinos

