

ISSUE NO:- 10/ 2018

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.

Remember if you change your email address to let us know by sending a message to news@stocktonmsgroup.org.uk"

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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

www.bbc.co.uk 26 September 2018

Electrical implant helps paralysed people to walk again

Three patients, all paralysed from the waist down, have been able to walk again after having an electrical patch fitted to their spinal cords.

Experts say the device, which is placed below the injury, helps lost signals from the brain reach the leg muscles.

US research teams at the University of Louisville and the Mayo Clinic, report the success in **Nature Medicine** and the **New England Journal of Medicine**.

One of the recipients says her life has been transformed by the technology.

Hope after accident

Kelly Thomas, 23, from Florida, is one of two patients at the University of Louisville who has been helped by the development, which has been combined with months of intense rehabilitation therapy.

She said: "Being a participant in this study truly changed my life, as it has provided me with a hope that I didn't think was possible after my car accident.

"The first day I took steps on my own was an emotional milestone in my recovery that I'll never forget, as one minute I was walking with the trainer's assistance and while they stopped, I continued walking on my own. It's amazing what the human body can accomplish with help from research and technology."

Jeff Marquis, who was injured in a mountain-biking accident, has also benefited.

The 35-year-old is now able to walk for himself with support either from a frame or from people on either side of him holding his hands.

A third patient, 29-year-old Jered Chinnock, was treated at the Mayo Clinic in collaboration with the University of California, Los Angeles.

He injured his spine in 2013 in a snowmobile accident. Since having the patch fitted he has been able to walk more than 100m with the support of a frame.

The patch does not repair the damage but circumvents it by stimulating nerves lower down in the spinal cord.

This appears to allow signals from the brain to reach the target muscles so the person can voluntarily control their own movements again.

When the stimulation was switched off again the conscious movement didn't happen. Neurosurgeon Dr Kendall Lee, who co-led the team from the Mayo Clinic in Rochester, Minnesota, said: "It's very exciting, but still very early in the research stage." Although there are many unanswered questions, including precisely how it works and who it might help, Dr Lee said: "It gives hope to people faced with paralysis." Other scientists have had success in the past with **mending spinal damage using cells**.

www.bbc.co.uk 28 September 2018

Disabled train users to get new 'life-changing' app

A "life-changing" app that can track disabled rail users in real-time will be rolled out nationwide.

The app will update station staff on where a passenger is at any point, useful in the event of a delay, change of platform or missed train.

Four rail companies are using an early version, with the full one to be available across Britain next autumn.

Paralympian Anne Wafula-Strike said the app would "empower disabled people to travel without any fear".

Currently when passengers with mobility problems book assistance, a print-out is given to station staff in the morning.

But when a change occurs there is no way to update the paper list, which can lead to staff being in the wrong place and causing some passengers requiring help to go without assistance at all.

The app, developed by Transreport for the railway industry, will allow users to create a profile, amend and cancel bookings and give staff live information to accommodate short-notice changes.

Mrs Wafula-Strike, from Essex, who won compensation after wetting herself on a train when the disabled toilet was not working, called the app "true inclusion".

She said: "Although passenger assistance usually works, I've had awful experiences when it has failed, so it's great to see the rail industry addressing this and planning to change and improve for the benefit of disabled people."

Disabled comedian Tanyalee Davis, from Norfolk, previously said she was "harassed and humiliated" for using a disabled space for her mobility scooter and called for an app of a similar type to be implemented.

She said: "We'll have more flexibility and spontaneity, but most importantly it'll help ease our anxiety because we can keep in contact in real-time with the people who are assisting us."

"If it works well, it will be life-changing."

Sarah Ward, from Shrewsbury, has been using a trial of the app since May and said it allowed her to be "much more flexible" with her travel.

Robert Nisbet, regional director at the Rail Delivery Group, which represents the railway, added: "We want everyone who has requested assistance to get the help they need, which is why we're investing in this pioneering technology that has the needs of our customers at its heart."

Alan Benson, chairman of Transport for All, said he was "pleased" the rail industry was improving the service it offered to disabled passengers.

He added: "Our team still hears regularly from disabled people sharing stories of rail passenger assistance going wrong."

"This app, as part of a wider overall passenger assist, can really improve the journey experience of disabled and older passengers."

West Midlands Railway, London Northwestern Railway, Greater Anglia, and South Western Railway are currently trialling different parts of the app before the full roll-out across England, Wales and Scotland.

So when a high-profile civil servant is disabled, the press finds its sympathy

Andrew McDonald's case deserves attention of course, but most disabled people get a different reception when the benefits system casts them aside

I want to tell you about two very different disabled people, both going through Britain's benefit system.

"Disabled person 1" has Parkinson's disease and terminal cancer. The effects of the Parkinson's are so severe, he's about to undergo brain surgery in attempts to mitigate them. Still, he had his benefits stopped after assessors decided he was no longer ill enough for personal independence payments.

"Disabled person 2" has fibromyalgia – "Like the Incredible Hulk grabbed me, lifted me off the floor and flung me against a brick wall" – as well as a host of other conditions. For years she has bounced round the benefit system: tested, rejected, overturned at appeal, then tested again. Now she's about to be re-tested twice in the space of three weeks: once for PIP and then for her out-of-work sickness benefit, employment and support allowance. It means she could potentially lose all her income at once. "So what will I live on?" she says. "More to the point, where will I live? Once they cut ESA, that means rent will stop too. That means eviction and homelessness."

One of the two disabled people had their story picked up by sympathetic national newspapers this week, with broadcast journalists also respectfully discussing their plight. The other sent their story to me in the early hours of Saturday morning. She had already contacted her MP but with little hope of reply, she wrote to me too.

The difference? The first was a high-profile former civil servant, Andrew McDonald, who spoke out at the weekend over what he described as the "hostile environment" created by the system. The second was an ex-IT worker with no connections, struggling to get by on benefits.

It is not surprising that the experience of a former high-ranking civil servant would gain media interest and McDonald's case deserves attention. But the double standards can't have escaped many disabled people's notice: if McDonald fitted the mould of a typical "benefit claimant", he would likely have found himself experiencing a very different reception by the media. What thousands of disabled people in poverty have been saying for years about the "Kafkaesque" benefit system is apparently credible and important now a middle-class senior official is saying it.

It reminds me of the Grenfell victims, who warned before the fire about the safety risk of the cladding but were ignored as poor, migrant, and black people; or the women who talk relentlessly about sexism but it's only when a man says it that it's seemingly worth listening to. It is not enough to speak out about the harm being done to you. You have to be the sort of person those in power want to listen to.

Britain's benefit system runs on a sort of institutional gaslighting, in which disabled and poor people are simultaneously pushed into starvation, homelessness and mental health crisis, while their hardship is either repeatedly ignored or openly vilified. Think of the rightwing headlines distorting stats to bemoan "sick note scroungers", or the way some privileged commentators mocked the realism behind Ken Loach's *I, Daniel Blake*. It is not for lack of evidence; be it the rates of successful appeals (at last count 70%) or the behaviour of assessors, report after report backs up disabled people's accounts of ill treatment by a social security system that is meant to help them.

For an insight into the toxic culture of disbelief "welfare" claimants face, research this week found that almost half of disabled people fear being stripped of their benefits for being "too active". (If this fear sounds far-fetched, disabled people are routinely falsely reported for benefit fraud to the authorities for even going to the shops.)

A report by the Equality and Human Rights Commission to the UN this week warned that one in five disabled people are suffering “erosion of their rights” because they are disabled, and this can’t be seen as separate to the downplaying of disabled people’s suffering in the benefit system.

Given our place in the economy and society – as more likely to be in poverty, unrepresented and excluded – most disabled people have few means to influence debate or change policies. I’m writing this as one of the few disabled columnists working for a national newspaper. It’s not a coincidence that a media – or parliament – that is widely made up of white upper-middle-class non-disabled men don’t naturally listen to the voices of poor and disabled people. It’s surely an in-built bias as much as wilful exclusion: people are largely socialised to p The fact McDonald had been a senior civil servant but only became aware of the reality of benefit policy once he was affected, and the media’s reaction to it, are both clear arguments for better representation of marginalised groups in power. Get more people in positions of influence who actually experience the brunt of the policies being brought in, and these issues would be more likely to be addressed.

It’s hard not to think that if officials were on the social housing list or applying for universal credit, council homes would be plentiful and assessments would be humane and competent. As it stands, the McDonald furore shows not only how broken our benefit system is, but something altogether more disturbing: some disabled people are just worth more than others. Put less value on a person’s life and voice if they are black, disabled, female or poor.

www.bbc.co.uk 13 October 2018

Universal Credit: Chancellor pressured over welfare system

Chancellor Philip Hammond is facing increasing pressure from Conservative MPs to find extra funding for Universal Credit in his upcoming budget.

Tory MP Heidi Allen told the BBC some 30 colleagues had expressed concerns about the flagship welfare system.

Reports say 3.2 million households could lose £48 a week under the system, which merges six working-age benefits.

The work and pensions secretary has admitted it could leave some worse off but defended the system.

Esther McVey said the most vulnerable would be protected, and people could take on more work to increase their income.

The government has set aside £3.1bn to help people affected by the transition to Universal Credit. However, there are still fears families will face hardship.

And the architect of the system, former work and pensions secretary Iain Duncan Smith, has said it needs a further £2bn cash injection to enable it to work properly.

Currently being phased in across the UK, Universal Credit is aimed at making the benefits system simpler and more flexible - so people who are able to work are rewarded for doing so. It has been criticised for running over budget and causing delays to people's payments, but the plan is to move all existing benefit claimants on to it next year.

Analysis by Matthew Cole, BBC political correspondent

With two weeks until the Budget, calls for the chancellor to address concerns about Universal Credit are growing.

Which raises two questions: Will he stump up some cash? And if so, where will he find it? Philip Hammond has hinted he could raise taxes... and possibly cut relief on pension contributions.

But whilst that might appease those worried about Universal Credit, he could end up angering "low-tax Tories" elsewhere in the Parliamentary party.

Clearly, he has a tough balance to keep all sides of his party happy.

But if the chancellor decides against including cash in his Budget for the flagship welfare reform, the government might face trouble in the Commons next month.

Votes are scheduled on measures connected to the migration of claimants onto Universal Credit - which could be an opportunity for unhappy MPs to rebel.

Maria Amos, from Liverpool, **told BBC Radio 4's PM programme** she had had to wait five weeks to get her payment, which had led to feelings of hopelessness.

"I was so frightened," she said. "I didn't know how I was going to cope.

"I [asked], 'can you explain this to me', but they didn't. They [just said] it is the way the system works.

"[In that time] I got behind with my rent by over £400 [and] I wasted away."

Ms Allen, a member of the work and pensions select committee, told BBC Radio 4's Today programme: "Significant numbers of colleagues on my side of the House are saying this isn't right and are coming together to say the chancellor needs to look at this again."

Mr Hammond, who will announce his budget at the end of the month, has hinted he could target tax relief on pension contributions to find extra funds, calling the measure "eye-wateringly expensive".

'More losers than winners'

Torsten Bell, director of the Resolution Foundation - which has carried out numerous studies on the benefit - said the purpose of Universal Credit was a good one, aiming to simplify welfare and make sure people were not losing money by returning to work.

But he told Today: "The problem is that a benefit that was meant to do that... has then had cuts added to it [**by former chancellor George Osborne in 2015**], and it now means there will be more losers than winners."

Ms Allen said she wanted her party to have the "political nerve" to remove the triple-lock protection for pensions, which she said cost the government £3bn a year.

The triple-lock sees the state pension rise in line with wages, inflation or by 2.5% - whichever is highest.

'Sound principles'

The warning from Tories comes after a number of senior political figures attacked Universal Credit this week, including former Conservative Prime Minister **Sir John Major** and former Labour premier **Gordon Brown**.

A government spokesman said ministers were listening to concerns but defended Universal Credit, stressing it was based on "the sound principles that work should always pay and those who need support receive it".

Labour leader Jeremy Corbyn has said he would stop the nationwide roll-out immediately and propose a "more comprehensive system."

Doctors can prescribe medical cannabis from November in UK

Doctors will be able to prescribe cannabis products to patients from 1 November, the Home Secretary Sajid Javid says.

The new regulations apply to England, Wales, Scotland and Northern Ireland.

Mr Javid decided to relax the rules on when cannabis products could be given to patients after a review into medicinal cannabis earlier this year.

This followed an outcry over Alfie Dingley and Billy Caldwell being denied access to cannabis oil.

The parents of the two young epilepsy sufferers said the product helped to control their seizures.

Alfie's mother, Hannah Deacon, welcomed the move, saying: "We urge the medical world to get behind these reforms so they can help the tens of thousands of people who are in urgent need of help.

"I have personally seen how my son's life has changed due to the medical cannabis he is now prescribed."

Professor Mike Barnes, the medical cannabis expert who secured the first long-term licence for its use for Alfie, encouraged doctors to embrace the changes to the laws on prescribing medicinal cannabis.

An initial review by chief medical officer Dame Sally Davies concluded there was evidence medicinal cannabis has therapeutic benefits.

The Advisory Council on the Misuse of Drugs (ACMD), which carried out the second part of the review, then said doctors should be able to prescribe medicinal cannabis provided products met safety standards.

It recommended cannabis-derived medicinal products should be placed in schedule two of the Misuse of Drugs Regulations 2001.

Cannabis has previously been classed as a schedule one drug, meaning it is thought to have no therapeutic value but can be used for the purposes of research with a Home Office licence.

Lower Fatigue Reported by MS Patients after aHSCT in Canadian Study

A small group of multiple sclerosis (MS) patients with aggressive disease, who were treated with hematopoietic stem cell transplant in a clinical trial, reported a drop in their fatigue levels that researchers suggested was likely due to lesser inflammation.

The study, "Autologous hematopoietic stem cell transplantation improves fatigue in multiple sclerosis," was published in the *Multiple Sclerosis Journal*.

Immunoablation — the wiping out of the immune system — with high-dose chemotherapy, followed by its rescue with autologous hematopoietic stem cell transplantation (aHSCT) has proven to be an effective way of treating inflammatory activity in the central nervous system of MS patients. However, the treatment's effect on fatigue, a common MS symptom affecting as many as 90% of all patients, has not been examined.

Researchers in Canada aimed to assess fatigue in MS patients before and after aHSCT treatment.

Their study looked at data from a Phase 2 clinical trial (NCT01099930) in which MS patients — with ongoing relapses and progression despite the use of disease-modifying therapies — went through this aHSCT procedure. Patients were followed regularly afterward, and every six months for three years completed a self-reported fatigue questionnaire looking at seven specific measures.

The Multiple Sclerosis Council for Clinical Practice Guidelines recommend the use of a scale called the modified Fatigue Impact Scale (mFIS) for assessing the degree of fatigue experienced by MS patients. mFIS is composed of 21 questions and is a modified form of the more elaborate 40-question FIS.

In total, the study analyzed data from 23 patient, resulting in 148 FIS measurements over the three years.

At baseline, most patients (20) had high mFIS scores that ranged between 30 and 46.5, with a median score of 36. The higher the mFIS score, the worst is the fatigue level.

At a six-month post-treatment follow-up, mFIS score ranges dropped to a median 25.5, declining further to a median score of 23 at the study's end. This represented a significant drop in fatigue measures with a 36% reduction in mFIS score.

Four patients had a reported 100% reduction in their fatigue scores at three years post-aHSCT. The researchers also reported that the improved FIS scores correlated with younger age and lesser disability at baseline (study start), "as well as increased independence as evidenced by a return to gainful employment and even driving," they wrote, suggesting a positive change in social well-being.

In fact, at the end of the study, "seven patients came off disability and gained employment, which was associated with a lower median mFIS score of 16 compared to those who were unemployed at the end of the trial who had a median mFIS of 32," they wrote.

Driving was associated with a lower total mFIS score, and four patients gained valid driver's licenses at the study's end.

Overall, the study showed that 78% of the patients analyzed (18 out of 23) reported lesser fatigue following aHSCT treatment. This reduction was most likely linked to reduced levels of inflammation following treatment, the researchers said. This suggests that active inflammation contributes to MS fatigue, a finding that is consistent with previous studies.

"The use of aHSCT in patients with aggressive MS has been shown to halt all ongoing detectable CNS inflammatory activity with the potential to drastically change the disease course," the study states.

Another important finding is that patients with depression showed lesser improvement in their mFIS and physical FIS scores, leading the researchers to suggest that "depression can exacerbate fatigue, regardless of disability."

Overall, the team concluded that MS patients in the study "had significantly less fatigue on average after aHSCT," and that these findings "may serve to better understand the contribution of ongoing CNS [central nervous system] inflammation to fatigue peculiar to MS."

But the researchers emphasized that further studies into aHSCT and its benefits in MS are needed, given the small patient group analyzed here, the lack of a control group, and the different technical approaches to aHSCT treatment.

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

Lying around, pondering the problems of the world, I realized that at my age I don't really give a rat's ass anymore. If walking is good for your health, the postman would be immortal. A whale swims all day, only eats fish, drinks water, but is still fat. A rabbit runs and hops and only lives 15 years, while a tortoise doesn't run and does mostly nothing, yet it lives for 150 years.

And they tell us to exercise? I don't think so. Now that I'm older, here's what I've discovered:

1. I started out with nothing, and I still have most of it.
2. My wild oats are mostly enjoyed with prunes and all-bran.
3. Funny, I don't remember being absent-minded.
4. Funny, I don't remember being absent-minded.
5. If all is not lost, then where the heck is it?
6. It was a whole lot easier to get older than it was to get wiser.
7. Some days, you're the dog, some days you're the hydrant.
8. I wish the buck really did stop here, I sure could use a few of them.
9. Kids in the back seat cause accidents.
10. Accidents in the back seat cause kids.
11. It's hard to make a comeback when you haven't been anywhere.
12. The world only beats a path to your door when you're in the bathroom.
13. If God wanted me to touch my toes, he'd have put them on my knees.
14. When I'm finally holding all the right cards, everyone wants to play chess.
15. It's not hard to meet expenses. . they're everywhere.
16. The only difference between a rut and a grave is the depth.
17. These days, I spend a lot of time thinking about the hereafter . . . I go somewhere to get something, and then wonder what I'm "here after".
18. Funny, I don't remember being absent-minded.

A young boy went up to his father and asked him, "Dad, what is the difference between 'potentially' and 'realistically'?"

The father thought for a moment, then answered, "Go ask your mother if she would sleep with Brad Pitt for a million dollars."

Then ask your sister if she would sleep with Brad Pitt for a Million dollars.

Then ask your brother if he'd sleep with Brad Pitt for a million dollars. Come back and tell me what you learn from that.'

So the boy went to his mother and asked, "Would you sleep with Brad Pitt for a million dollars?"

The mother replied, "Of course I would! We could really use that money to fix up the house and send you kids to a great University!"

The boy then went to his sister and asked, "Would you sleep with Brad Pitt for a million dollars?"

The girl replied, "Oh my Gawd! I LOVE Brad Pitt I would sleep with him in a heartbeat, are you nuts?"

The boy then went to his brother and asked, "Would you sleep with Brad Pitt for a million dollars?"

"Of course," the brother replied. "Do you know what a million Bucks would buy?"

The boy pondered the answers for a few days and then went back to his dad.

His father asked him, "Did you find out the difference between 'potentially' and 'realistically'?"

The boy replied, "Yes, 'Potentially', you and I are sitting on Three million dollars."

"But 'Realistically', we're just living with two hookers and a queer."

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 actor portrayed Samuel Johnson, writer of the first dictionary, in Blackadder the Third?
- 2/ What are the three given names of Prince George of Cambridge?
- 3/ Which English author created the priest-detective 'Father Brown'?
- 4/ BHD is the IATA code for which UK airport?
- 5/ Who stood in as host on the first episode of Have I Got News For You following Angus Deayton's departure in 2002?
- 6/ How much is the purchase price of Old Kent Road in the London version of Monopoly?
- 7/ Who was the sixth wife of Henry VIII?
- 8/ In which century was William Shakespeare born?
- 9/ Who is the alter-ego of Sir Percy Blakeney?
- 10/ Which female singer's name is an anagram of 'Presbyterians'?

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/ Shrek 2/ Memory 3/ Derbyshire 4/ Heal the World 5/ Chopin 6/ American Flag
7/ Alton Towers 8/ Hydrogen 9/ Reading 10/ Portugal