

ISSUE NO:- 07/ 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.

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

www.mirror.co.uk 16 July 2020

DWP welfare reforms hit disabled 4 times worse as families lose '£1,200 a year'

A coalition of charities says the disabled are "bearing the brunt" of Tory cuts - and it's "simply disgraceful"

Disabled people have lost £1,200 a year on average in benefits on the Tories' watch, a damning study says today.

Research says they've been hit four times harder than non-disabled welfare claimants under cumulative cuts in the system since 2008.

Households with one disabled adult and one disabled child were worst off, with all benefit changes costing them £4,300 a year, according to the study for the Disability Benefits Consortium of 80 organisations.

DBC research chief Michael Griffin, of Parkinson's UK, said disabled people are "bearing the brunt of the disastrous changes to welfare."

He added: "This is simply disgraceful and cannot be allowed to continue.

"The Government must make urgent improvements to the application processes and assessment criteria, and resolve the flaws in **Universal Credit** before more people are denied the support they desperately need to live independently."

The study looked at a flood of welfare changes introduced since 2008 - including the benefit freeze, benefit cap, Bedroom Tax, Universal Credit and transfers to new benefits ESA and PIP. The vast majority were pioneered by the Tories after 2010.

Researchers modelled how much less claimants will receive per year by 2021/22, compared with if benefits had continued rising from their level in 2010 without the changes.

On changes to benefits alone, the study said disabled claimants will be £1,200 per year worse off on average by 2021/22, while non-disabled claimants will be £300 per year worse off.

Once Tory tax cuts, National Insurance reforms and changes to gross incomes are factored in, disabled claimants will be £870 per year worse off. But non-disabled claimants will be £288 per year better off on average, the study said.

The study said by 2023 there will be have been £38billion of total cuts in the benefit system - 63% of them shouldered by households with at least one disabled person.

The modelling was carried out by Landman Economics, and accompanied by 50 in-depth interviews with claimants by the Universities of East Anglia and Glasgow.

Epilepsy sufferer Sinead Webber, 28, said she was denied Personal Independence Payments (PIP) twice despite regular seizures.

The medical secretary from Cullompton, Devon - who won PIP both times through appeals - branded her assessment "harrowing, degrading, intrusive and disheartening".

Sinead, who has fallen on a knife and dropped a pan of boiling water due to seizures, said: "I had to rearrange this assessment three times due to seizures.

"She didn't seem to grasp the fact I would be having a better day during my assessment.

"I was also marked down for being articulate, which really upset me - essentially I needed to be incapable of speech for them to think I was disabled."

She added: "At times I even contemplated taking my own life."

Shadow Minister for Disabled People Marsha De Cordova said: "This major report is a damning indictment of the government's assault on disabled people's social security. According to this research, cuts have shockingly hit disabled people four times harder than non-disabled people. "And as the report highlights, with many people still to be moved to Universal Credit, there are even more cruel cuts to come for disabled people. The government must urgently stop the roll out before more damage is done.

"The next **Labour** government will rebuild our social security system, ensuring that disabled people are treated with dignity and respect."

A DWP spokeswoman said: "We know that disabled people and those with health conditions can face higher costs, which is why we're spending £55 billion this year on benefits to support them – more than ever before.

"Disability benefits are exempt from the benefit freeze and in many cases our reforms mean people will receive more money on average, with one million households gaining an average of £100 more on Universal Credit."

www.mstrust.org.uk 10 July 2019

Remyelination in MS – what progress has been made?

Background

Treatments for MS have come a long way over the last two decades. There is a growing list of drugs for relapsing remitting MS, with Ocrevus now approved for primary progressive MS and siponimod going through assessment by the European Medicines Agency. All of these drugs act by reducing the immune attack which causes inflammation and damage to the myelin coating around nerve cells in the brain and spinal cord.

Although these drugs can reduce damage to myelin, they can't stop it completely or repair damage that has happened. Your body can replace damaged myelin but this process is impaired in MS. Treatments which promote remyelination would offer the potential to delay, prevent or reverse disability and a great deal of research is exploring this. A recent review has outlined the progress made so far in understanding the biology of remyelination, what goes wrong in MS, some of the research problems that need to be tackled and the prospect for treatments in the not-too-distant future.

How does remyelination work and what goes wrong?

An important first step in developing treatments is understanding how remyelination works in health. The picture that is emerging is a complex interaction between different cell types and chemicals produced by the cells.

In the brain and spinal cord, cells called oligodendrocytes produce myelin which they wrap around nerve axons, like a Swiss roll. An important focus of research has been understanding the different steps that immature oligodendrocytes (oligodendrocyte progenitor cells, OPCs) go through before they can produce new myelin.

Large numbers of OPCs are seen in demyelinated MS lesions, so one theory is that remyelination fails because these immature cells are unable to mature into oligodendrocytes capable of making myelin. However, recent research using brain tissue from people with MS suggests that remyelination is mostly carried out by pre-existing and not newly matured oligodendrocytes. Another recent study found several types of mature oligodendrocytes and differences in the ratios of these subtypes in people with MS compared to healthy people. These two studies raise questions about how well the models used to research remyelination represent the process in humans.

Electrical activity in nerves has been found to stimulate remyelination, suggesting that intact nerve axons are necessary for successful repair. Perhaps related to this is the recent finding that access to a running wheel in a lab model of demyelination improved maturation of oligodendrocytes, the rate of remyelination and the proportion of remyelinated nerve axons. Combining physical activity with clemastine (see below) further enhanced remyelination. The debris left over from damage to myelin has been shown to inhibit remyelination so the clearance of debris by macrophages and the role of other cell types found in brain tissue, such as astrocytes and microglia, is another area of research.

Remyelination reduces with age and disease duration. This may have important consequences for designing clinical trials and deciding when in the course of MS remyelination treatments would be most effective. It may be possible to counteract some of the consequences of ageing – a recent study reported that in a lab model of demyelination, alternate day fasting or treatment with metformin, a type 2 diabetes drug which can mimic the effects of calorie restriction, can recalibrate ageing OPCs to remyelinate axons.

Remyelination clinical trials

The good news is that research is beginning to identify potential treatments which are being tested in clinical trials. However, one of the biggest difficulties for clinical trials is demonstrating that a drug is having an effect by promoting remyelination. Advanced MRI techniques and PET (positron emission tomography) scans are being developed. Another approach is to use evoked potentials to measure the speed of electrical messages along sensory nerves to the brain.

A protein called Lingo-1 prevents OPCs developing into functioning oligodendrocytes. Opicinumab blocks the action of Lingo-1, allowing OPCs to mature. In a phase II study of people diagnosed with optic neuritis, opicinumab improved transmission of nerve impulses in the optic nerve, suggesting that remyelination had occurred. A second phase II study used a combination of Avonex (interferon beta 1a) and opicinumab but found neither an improvement in disability nor a slowdown in progression. These results were disappointing, but further analysis suggested some improvement in a subset of the participants. It is now being tested in a further study as an add-on to disease modifying drugs in relapsing MS.

Another route to discovering candidates is through testing large numbers of molecules in laboratory models of OPC development. This approach identified clemastine, a drug normally used to treat allergies. In a phase II clinical trial in 50 participants with relapsing MS and evidence of long term damage to the optic nerve, clemastine treatment resulted in a small improvement in the speed at which nerve impulses passed along the optic nerve. There was a slight improvement in vision, but too small for this to be conclusive. The researchers were unable to show the repair on MRI scans and other measures of myelin. Clemastine is now being tested in a second phase II trial in people with acute optic neuritis.

The review lists further clinical trials of potential remyelinating treatments, including bexarotene, biotin and cell-based therapies, which have been completed or are underway.

What does it mean?

This review shows that a good deal of progress has already been made, although there is still much to be done. The authors finish by identifying questions that need to be answered in order to build on this work:

- How well does remyelination in animals match the process in people with MS?
- What is the best way to measure remyelination in clinical studies?
- When would be the best time to start a remyelinating treatment?
- Which is the most appropriate group of people with MS for testing remyelinating treatments?

Cunniffe N, Coles A.

Promoting remyelination in multiple sclerosis.

Journal of Neurology 2019 Jun 12.

Multiple sclerosis: Dad walks daughter down aisle after standing frame study

A father with progressive multiple sclerosis (MS) says he was able to walk his daughter down the aisle after using a simple wooden standing frame to strengthen his muscles.

John Kendrick's mobility has been deteriorating for a decade.

Desperate to fulfil his promise to daughter Nicky, he volunteered for a study looking at whether standing frames could help people with MS.

"It meant everything," he said of being able to take part in her big day.

Mr Kendrick, 67, from Sparkwell in Devon, was diagnosed with the condition, which can affect the brain and spinal cord, 14 years ago.

He now has the secondary progressive form of the disease meaning it will get worse and there is no treatment that can help him.

"You either give up or you get on with it," he said of deciding to take part in the Plymouth University-led study.

"I was putting my hand up for anything... I was determined to take my daughter down the aisle when she got married and using this gave me the strength to be able to walk down the aisle with the help of my daughter and one crutch instead of two crutches."

Mr Kendrick said without the standing frame, which he uses while watching television in his living room, he would be "really struggling" and would not have been able to complete his fatherly duties.

"This is an amazing bit of kit. It is so simple yet it is so effective," he said.

Professor Jenny Freeman, who led the study, said it was aimed at those whose mobility had been restricted to only being able to walk up to 20m with crutches or a walking frame.

She said the results showed there was a significant difference between people who used the standing frame and those who just had their usual care.

"It is a really simple intervention and it is not costly at all," she said, adding that it had had a "tremendous" impact on the quality of life of many of the participants.



- Each frame costs £550
- Participants were introduced to the frames during two sessions with a physiotherapist
- They were told to stand for 30 minutes, three times weekly, over 20 weeks
- They were encouraged to exercise their upper body at the same time
- The study found the standing programme "significantly increased" motor function in people with severe progressive MS

Currently standing frames are only used "occasionally" in the NHS and it can be difficult to get commissioners to agree to purchase them, Prof Freeman said. She said she hoped evidence from the study would help make the frames more readily available for MS patients.

www.bbc.co.uk 16 July 2019

Disabled access: 'I gig in my wheelchair every week'

Jamil describes himself as an "avid music fan" - something that seems a bit of an understatement for someone who tries to go to at least one gig a week.

The 31-year-old from London who was born with cerebral palsy and uses a wheelchair says: "I won't let that stop me experiencing things."

And it hasn't. His favourite gig recently was The Cure - he says the goth rock band have still got it.

"They're veterans, they know what they're doing," he laughs.

Jamil travels all over London to concerts, usually accompanied by a support worker. It's not an option - he can't go without one.

One of the most recent gigs he's been to is British Summer Time, which took place last weekend in Hyde Park.

It's one of his favourites not just because of the music - which this year included Florence + The Machine, Blood Orange and Let's Eat Grandma - but because of how accessible it is.

BST recently won a gold award from the group Attitude is Everything, which works to improve access to live music for disabled people.

But the interpretation of what makes an event accessible can vary hugely from gig to gig.

"I've been to venues where they say 'Yeah, yeah, we're accessible,'" explains Jamil.

"And what they meant was they'll help lift my wheelchair up a set of stairs.

"Mainly it's things like accessible toilets... if they do exist, they'll be locked - they'll be used as store cupboards.

"The dimensions will be really tiny and my electric wheelchair is fairly big and I've had situations where I can't shut the door.

"So I've had to get someone to stand outside while I do my business."

Jamil says that if he really puts time and effort into planning around a gig, "most of the time" he can go.

"I used to go to Babyshambles' secret gigs when I was a teenager. They were in people's flats, so I've done all kinds of things."

But seeing live music gets pricey - and can be even more so for someone in a wheelchair.

"Just by the virtue that you have to get more transport. Accessible public transport is getting better but it's still not where it needs to be."

Double the cost

More than 3 million disabled people went to a live music event in the past year and disabled music fans make up 11% of the live music audience, according to government statistics. Jamil finds those statistics surprising considering he often has to buy two tickets: one for him and one for his support worker, which can double the cost.

Complicated and expensive ticketing is something disability rights groups are aware is a **major barrier to those with disabilities**.

"Usually a disabled person will get a free companion ticket because they can't attend without somebody being with them," Jamil explains.

"But that depends on the venue or the individual promoters.

"So sometimes you have to pay and that's an extra cost before you've even left the house."

Jamil wants more festivals to have a straightforward ticketing process, helpful and knowledgeable staff on site, and big enough loos.

And a good, well-positioned accessible viewing platform is always a bonus.

"Being able to get into the venue - if there's a wide enough entrance and exit, if there's any stairs. All these things you have to consider," he explains.

"But if those things are sorted then you can wind down and enjoy it just like everybody else."

www.dailymail.co.uk 6 July 2019

Multiple sclerosis sufferers Colette and Lucy were losing mobility in their limbs and faced a lifetime of disability... until stem cells brought their condition to a halt

Every day, Lucy Preston goes swimming in the clear waters of a lake near her home in the picturesque Cumbrian town of Keswick.

She can't believe how lucky she is, not least because, until recently, swimming was something she didn't think she'd ever do again.

The 36-year-old, who works in marketing, has multiple sclerosis, a condition in which the immune system attacks the brain and spinal cord, gradually leading to mobility, balance and cognition problems. Lucy was diagnosed in 2012.

'It was a tough time,' she recalls. 'But finding out lit a fire under me. I quit my high-pressure job and moved from **London** to Cumbria because I needed to be surrounded by nature.

At first, treatment kept her symptoms at bay but in 2016 she lost the use of her right leg. 'I couldn't tell where I was placing it, so it was hard to walk,' she says. 'I felt drained and my whole right side was numb.

I was told that my disease was highly active, which meant I would become disabled more quickly, and the drugs weren't working.'

So it is nothing short of remarkable that today Lucy has a new lease of life, and is facing a future without the threat of disability.

Her disease has been halted in its tracks thanks to a radical new treatment – a stem cell transplant. 'My partner calls me "Lucy 2.0",' she laughs. 'It's like I'm a new version of me. It's hard to describe what a change the treatment has made. The fog has lifted. I have a future now, which I didn't think I'd have.'

WINNING THE WAR... THANKS TO LIFE'S BUILDING BLOCKS

Stem cells are often called the building blocks of life, and scientists are increasingly convinced that treatments that harness their power will revolutionise medicine, providing therapies for everything from cancer to blindness and even paralysis.

These so-called master cells have an astonishing power to transform into any kind of cell. They are able to reproduce endlessly and are integral in allowing our bodies to grow and heal.

One of the most promising areas of research involves their use in the treatment of MS. The illness, which affects about 100,000 people in the UK, occurs when the immune system turns inward and attacks the nerves and their protective coating. This causes inflammation, ultimately affecting the brain and the spinal cord.

In some patients, flare-ups are followed by periods of remission, while others experience gradually worsening symptoms.

Treatment has mainly involved drugs that help dampen the immune system, easing discomfort. But what they could not do until now is halt the disease itself.

The new procedure, known as an autologous haematopoietic stem cell transplant, or AHSCT, involves harvesting the patient's own blood and bone marrow, and extracting the stem cells from them, before wiping out the body's immune system using a high dose of chemotherapy.

The stem cells are re-injected, 'rebooting' the immune system. It means nerve cells no longer come under attack, preventing MS from progressing.

In a recent study, 110 patients were split into two groups. Of the 55 patients who received the stem cell treatment, just six per cent had relapsed after three years. In contrast, of the 55 patients given standard multiple sclerosis drugs, 60 per cent suffered a relapse.

Professor Basil Sharrack, consultant neurologist at Sheffield Teaching Hospitals NHS Foundation Trust, says: 'If you treat the right patients – those with a lot of inflammation and aggressive disease – early enough, you will not only arrest the illness but also prevent further, permanent damage to the brain and spinal cord.'

IT'S NOT A CURE – BUT IT CAN HELP

The Mail on Sunday caught up with Lucy at a park in Manchester where she was meeting fellow MS patient – and stem cell transplant recipient – Colette Beecher, 50. The pair seem to be a picture of health as they share their stories.

Currently, AHSCT falls short of a cure for multiple sclerosis. The treatment can't undo damage to the nerves or help them heal, so patients who have already lost mobility are unlikely to regain it. But both Lucy and Colette, an occupational therapist from Sheffield, have seen huge improvements since undergoing the procedure. Colette was diagnosed in 2011, after suffering pins and needles in her hands, and vision and co-ordination problems.

She says: 'Because of my job, I knew the symptoms of multiple sclerosis and diagnosed myself before it was confirmed by a neurologist. And I knew the disabilities I might face, which was scary.'

'My disease was aggressive and the drugs weren't working. Two years after diagnosis, I'd lost strength in my left side and was finding it hard to open shower bottles or butter bread, and my walking was becoming very impaired. It felt like my knee would give way.'

'I saw a documentary that mentioned AHSCT and asked my neurologist if I could have it.'

Colette underwent the treatment in 2016. 'Eight months later, I realised that one of my main symptoms – tingling down my spine – had disappeared. And my leg has stopped giving way underneath me. My scans show no further signs of active disease, which is amazing.'

BUT THERE IS A BIG DOWNSIDE...

As the chemotherapy drugs strip away the immune system, patients are left vulnerable to infection and must stay on an isolation ward for two weeks after the procedure. There is a small chance the treatment itself could kill.

Although Lucy suffered from extreme nausea, depression, lost 1st 8lb and her hair fell out during treatment, she says she doesn't regret having it for a second. 'I haven't had a single relapse since,' she says. 'I still have residual problems – weakness and numbness in my right side – but touch wood, this is as far as the disease will go.'

Colette, who is due to marry next year, lost her hair but otherwise had a less gruelling experience. She says: 'The treatment has been so liberating – worth more than gold. I also have far less concern for the future.'

Professor John Snowden, consultant haematologist at Sheffield Teaching Hospitals NHS Foundation Trust, says: 'This is a game-changer in the treatment of MS.'

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!

The following are all opening lyrics by the band Queen – but can you identify which songs they have been taken from?

- 1/ Fear me you lords and lady preachers...”
- 2/ “She keeps Moët and Chandon in her pretty cabinet...”
- 3/ Ooh, you make me live...”
- 4/ I’d sit alone and watch your light...”
- 5/ “One man, one goal...”
- 6/ While the sun hangs in the sky and the desert has sand...”
- 7/ “Every drop of rain that falls in Sahara Desert says it all...”
- 8/ “Sometimes I get to feeling, I was back in the old days long ago...”
- 9/ Is this the real life?”
- 10/ I’ve paid my dues time after time...”

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/ Lady Ga Ga 2/ Eclair 3/ Olympic Marseille 4/ Tasmainia 5/ Red Poppy 6/ Glasses
7/ Virginia Wolf 8/ Paris 9/ Branch Davidan 10/ Goodbye Yellow Brick Road