

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"

Group Contacts

Carol 01642 617864

Web address:- www.stocktonmsgroup.org.uk
e-mail: info@stocktonmsgroup.org.uk

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NEWS UPDATE

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Benefits row as DWP criticised for refusing payments to dying man

A man whose terminally ill brother was refused disability benefits has accused the Department for Work and Pensions of being "shambolic and incompetent".

James Oliver, 49, could "barely walk" and was incontinent due to liver disease before he died on 9 April, his brother David Smith said.

But the DWP denied Mr Oliver Personal Independence Payments (PIP) after he scored zero points in an assessment.

The DWP said its procedures were followed correctly.

Several months after Mr Oliver's death in Hastings, one of his children found a letter inviting him to an appeal hearing about the decision.

Mr Smith said he had told the department his brother was dead and described the letter as "insulting".

The DWP said it was "very sorry for the distress caused" by the letter and it was "looking into this to prevent it happening again".

Mr Oliver had suffered chronic liver disease caused by alcohol dependency for several years, but his health took "a nosedive" in 2016 when his other organs became affected, his brother told the BBC.

"That left him barely able to walk," Mr Smith said, adding that it would take Mr Oliver two to three hours to walk 500m to the nearest supermarket.

"He had to stop every few metres for breath because he was gasping," he said.

"He had no control over his toilet habits and was so embarrassed. He'd go out and soil himself."

Mr Oliver applied for PIP - the benefit that is replacing Disability Living Allowance - in March 2018.

How does PIP work?

PIP is made up of two parts: the daily living component and the mobility component, according to the charity network Citizens Advice.

Each part can be paid at one of two rates, either the standard rate or the enhanced rate.

During a PIP assessment, a health professional will give a claimant a score between zero and 12 on a range of activities.

The rate you receive depends on the number of points you score - a higher number puts you on an higher rate.

The assessments are done on DWP's behalf by the private companies Capita and the Independent Assessment Services (formerly called Atos), which have come under **criticism for scoring claimants too harshly**.

Mr Oliver was assessed by a paramedic, who "gave him zero points on everything", which meant he did not receive the disability benefit, his brother said.

He applied for a review of the decision - called a mandatory reconsideration - but it was upheld in June 2018.

Doctors gave Mr Oliver 12 months to live last summer, according to Mr Smith, although the DWP said it only had a record of the diagnosis from March this year.

Currently, a terminally ill person only qualifies for fast-tracked access to benefits when their death is expected within six months.

But the government is **reviewing the rule** after the All-Party Parliamentary Group for Terminal Illness said it was "outdated, arbitrary and not based on clinical reality.

Without the benefits payment, Mr Oliver was not able to heat his home and he resorted to using a hot water bottle during the day to keep warm, Mr Smith said.

He said his brother "gave up" after his mandatory reconsideration was rejected and turned to alcohol.

"He just downed more or less anything he could lay his hands on at that point and it was the beginning of the end. We couldn't bring him back from that," Mr Smith said.

After collapsing on the way to the supermarket, Mr Oliver was taken to the hospital, where he was told he would soon die.

According to Mr Smith, his brother said: "I can't believe it I'm going to die and I'm still not sick enough to qualify for PIP."

March 2018 - Mr Oliver makes a PIP claim

May 2018 - His claim is denied

June 2018 - His mandatory reconsideration is disallowed

July 2018 - He appeals the decision

April 2019 - Mr Oliver dies

August 2019 - The DWP invites Mr Oliver to an appeal hearing in September

A Facebook post about Mr Oliver's death had been shared 107,000 times by Friday afternoon. Since writing the posts, Mr Smith says he has been "bombarded" by similar stories to his brother's.

A DWP spokesperson said: "Our thoughts are with Mr Oliver's family at this difficult time."

www.bbc.co.uk 30 August 2019

Blue badge permits: Shake-up 'will increase parking demand'

Councils must make sure there are enough disabled parking spaces to cope with the extra demand a blue badge scheme expansion will bring, the charity Scope has said.

As of Friday, people with hidden disabilities in England are now also eligible to apply for blue badges.

Scope welcomed the move but said if spaces are scarce, the badges "are not worth the paper they're printed on".

The Local Government Association said councils regularly review parking.

Currently, **about 2.35 million people** with physical disabilities in England have a blue badge.

Blue badge holders are allowed to park in spaces which might be restricted to other drivers, for example parking on yellow lines for up to three hours, for free in pay and display bays, or in spaces designated "disabled".

Under Friday's change - which is the biggest shake-up of the blue badge scheme since it was introduced nearly 50 years ago - people with hidden disabilities, such as dementia, autism or anxiety disorders will also be eligible to apply for the permits.

However, not everyone with hidden disabilities will qualify for a badge, as it will still be up to local councils to decide if an applicant meets the eligibility criteria.

'Life-changing'

The change has been widely welcomed by charities, including the head of the National Autistic Society, who called it a "huge relief".

"A blue badge can be life-changing," said Tim Nicholls, from the charity, who said many autistic people are often so anxious they may find it hard to leave the house.

Ceri Smith, policy and campaigns manager at Scope, also welcomed the move, saying it would make a "real difference" to disabled people with invisible impairments.

However she added: "But in order for it to work, it's vital that councils issue blue badges to people who are newly eligible to apply.

"More also needs to be done by councils to ensure that there are enough allocated blue badge spaces near shops and amenities to meet increasing demand."

'Not enough spaces... and mouthful of abuse'

Sarah Tranter, 52, from Stourport-on-Severn, has had fibromyalgia - a long-term condition that causes pain all over the body - since 2008. She got her first blue badge five years ago after she was diagnosed with breast cancer.

She says she has mobility issues and cannot walk far, while her son has autism which causes "debilitating" anxiety.

"It is very difficult to get a blue badge, so anyone lucky enough to have one absolutely needs and deserves one," she says.

"There aren't enough spaces, however; that is something that really needs addressing.

"Even those that are available get taken up by non-blue badge holders... usually fit young men in my experience.

"If you say anything you get an aggressive mouthful of abuse."

Meanwhile, blue badge holder Rebecca, from Oxfordshire, says the change is important and positive, but adds she already finds it hard to find disabled spaces as they are often full.

"Ultimately the consequences of there not being enough spaces is that I sometimes have to park in regular spaces, which makes it challenging to get my wheelchair out of the car as there is not enough space," she says.

Earlier this week, Scope responded to figures from company Confused.com claiming many UK councils in charge of parking provisions have not planned to extend their number of blue badge spaces.

Ms Smith said: "With spaces already scarce, it's extremely worrying that so few councils have prepared for the expansion of the blue badge scheme, despite knowing it was coming for months.

"Councils need to up their game to ensure blue badge holders can actually use them."

Charity Disabled Motoring UK, which campaigns for disabled drivers and blue badge holders, warned the increase in demand "may undermine the entire scheme and render it not fit for purpose".

"The end result may mean it will let down the people it was originally intended to help as well as disabled people with hidden disabilities," **it said in a statement.**

"The charity predicts that when the number of blue badge holders increases from August 2019, we will be contacted more and more by disabled people who find their blue badge completely meaningless as they will be unable to find adequate parking because it will be so oversubscribed.

"We implore all local authorities and private parking operators to take this change seriously, review their disabled parking provision and stress the importance that they all enforce disabled parking properly so that disabled bays are kept free only for genuine blue badge holders."

'Not just councils'

Last year, 859,000 blue badge permits were issued in England, a decrease of 3.2% compared to the year before.

Earlier this year, Essex County Councillor John Spence said the new rules could lead to a 20% increase in the number of applications in Essex - putting further pressure on stretched disabled parking provision.

The Department of Transport, launching the expansion of the scheme on Friday, said councils will get £1.7m in the first year of the programme, to help with the expected spike in applications. But it added that councils may need to review parking provision to increase the number of spaces available.

In a statement, the Local Government Association - which represents councils in England and Wales - said the availability of spaces for blue badge holders was not just down to councils as there was also "significant private provision of parking".

"Councils know that blue badges are a vital lifeline for disabled people which help them get out and about to visit shops or family and friends and many have already been approving badges for people with non-physical disabilities," the LGA said in a statement.

"Councils regularly review parking provision in their areas, including both public and private, in order to help meet the needs of the public, including those with blue badges.

"Overall provision will depend on private operators, council resources as well as competing demand for road space and public land."

www.bbc.co.uk 12 September 2019

JK Rowling donates £15.3m to Edinburgh MS research centre

JK Rowling has donated £15.3m to support research into neurological conditions at a centre named after her mother.

The Anne Rowling Regenerative Neurology Clinic at the University of Edinburgh was established with a £10m donation from the Harry Potter author in 2010.

Her latest gift will help create new facilities and support research.

Anne Rowling died aged 45 from complications related to multiple sclerosis (MS).

The centre is an integrated care and research facility focusing on MS and neurological conditions with the aim of bringing more clinical studies and trials to patients.

Neurological conditions studied at the clinic include motor neurone disease (MND), Parkinson's and dementias.

'Matter of pride'

The university hopes the donation, which includes Gift Aid, will create a global legacy that will have a lasting effect on patients and their families.

Ms Rowling said: "When the Anne Rowling Clinic was first founded, none of us could have predicted the incredible progress that would be made in the field of regenerative neurology, with the clinic leading the charge.

"It's a matter of great pride for me that the clinic has combined these lofty ambitions with practical, on the ground support and care for people with MS, regardless of stage and type; I've heard at first-hand what a difference this support can make.

"I am confident that the combination of clinical research and practical support delivered by Professor Siddharthan Chandran and his exemplary team will create a definitive step-change for people with MS and associated conditions."

Personalised medicine

Prof Chandran, director of the clinic, said: "Our research is shaped by listening to, and involving, individuals who are living with these tough conditions.

"The Anne Rowling Clinic's vision is to offer everyone with MS or other neurodegenerative diseases, such as MND, the opportunity to participate in a suite of clinical studies and trials.

"This incredibly far-sighted and generous donation will unlock the potential of personalised medicine for people with MS in Scotland and further afield."

University vice chancellor Prof Peter Mathieson said they were "immensely honoured". "This inspiring donation will fund a whole new generation of researchers who are focused on discovering and delivering better treatments and therapies for patients," he added. The university set up a Centre for Multiple Sclerosis Research in 2007, which has also received support from Rowling. Ms Rowling's story of the boy wizard Harry Potter began as a story written in Edinburgh cafes while she was living on benefits. It became a multi-billion pound worldwide franchise based on seven novels describing Harry's adventures at Hogwarts School of Witchcraft and Wizardry. According to the Sunday Times Rich List, Ms Rowling has an estimated fortune of £750m. She has already given away many millions of pounds to various charities.

www.kentonline.co.uk 28 August 2019

Kent and Canterbury Hospital robotic legs trial helps Steve Barnes walk daughter down the aisle

A dad achieved his dream of walking his daughter down the aisle at her wedding thanks to a robotic legs trial.

Steve Barnes is one of 20 patients involved in a trial at the Kent and **Canterbury** Hospital using a robotic exo-skeleton to help people with progressive conditions - such as multiple sclerosis - re-learn how to walk again.

The 59-year-old travelled from his home in Reading to Canterbury to take part in the trial and set himself the target of being able to walk with his daughter Coral down the aisle on her wedding day - rather than using his mobility scooter.

Mr Barnes said: "At the start of the trial I could only stand for 30 seconds.

"At the end they asked me to do it for two minutes, and those two minutes were effortless. I am sure I could have gone on and done more.

"I was also able to balance while looking over my shoulder and reaching forward while standing – it felt quite revelatory being able to do these things."

The exo-skeleton at Kent and Canterbury Hospital is designed to build core and leg strength. It also "walks" them forward and back slowly which allows them to consciously focus on these muscles to improve balance, mobility and strength.

Steve was able to practise the exercises at home ahead of his daughter's wedding to fiancé James last Saturday.

He said: "It was really emotional – the night before the wedding, my daughter gave me some socks with the words 'slow and steady' on and the date.

"I didn't want to let her down and even that morning the registrar said we might have to think about using the scooter as my legs were hardly functioning but I was able to do it and it was brilliant.

"The whole day was fantastic but the fact I was able to walk her down the aisle it was the icing on the cake."

If the hospital can bring in more units then it could go some of the way to helping patients across the UK.

Though partly charity funded, they cost in excess of £100,000.

Dr Mohamed Sakel, one of the trial's leaders, said: "We have the opportunity with this trial to help people make a real difference to their lives.

"The machine takes away the risk of falling and the fear that accompanies it and allows people to become confident in a safe environment.

"They can retrain their muscles and build up their strength so they are able to realise the benefits outside of the machine as well.

Link Between Lemtrada, Mortality More Common Than Previously Reported

Treatment with Lemtrada (alemtuzumab) is associated with the death of patients with relapsing-remitting multiple sclerosis (RRMS) more often than previously reported and appears to be most common during the first month, according to a European review.

The study, "Adverse events with fatal outcome associated with alemtuzumab treatment in multiple sclerosis," was published in the journal BMC Research Notes.

Lemtrada works by inducing a marked decrease in the levels of immune T cells and B cells, which are involved in MS mechanisms, followed by a gradual recovery starting one month after treatment. Although considered safe, reports suggest that this RRMS therapy is associated with severe and possibly fatal adverse reactions resulting from complications such as the bacterial infection listeriosis and alveolar hemorrhage (bleeding into the lungs' tiny air sacs).

Such reports prompted a team from Norway to conduct a systematic search for data on deaths following treatment with Lemtrada, marketed by Sanofi Genzyme, using the European database EudraVigilance on suspected adverse reactions linked to medicines.

The search, conducted in November 2018, included reports from clinical trials and real-world clinical practice. Immunosuppression, infection, or enhanced inflammation soon after treatment, as well as secondary autoimmunity reactions months later, were among plausible consequences of taking Lemtrada, according to its known safety profile and biological effects. Ten fatal adverse reactions, nine among females, were identified as being most probably related to Lemtrada. Six of these cases had not been previously reported. All 10 patients were adults and died after receiving at least one treatment cycle. They ranged in age from 34 to 47 (data missing in one patient).

Nine cases were deemed probably caused by Lemtrada, with six of these patients dying within one month after receiving just one treatment infusion.

Five patients died from infection or multiple organ failure and septic shock. One patient (a woman) died from intracerebral hemorrhage after developing hypertension (high blood pressure). As it occurred soon upon treatment, and as Lemtrada has been linked with early strokes, this fatal case was also considered probably associated with the therapy.

The other three patients (all women) who died probably due to Lemtrada experienced secondary autoimmunity — reappearance of active B cells — eight to 18 months after the last infusion. One of these patients died from autoimmune hepatitis (inflammation of the liver), another from autoimmune hemolytic anemia (abnormal red cell breakdown), disseminated intravascular coagulation (blood clots blocking small blood vessels), and septic shock, and the third from brain hemorrhage and immune-mediated thrombocytopenia (low platelet count), which did not resolve with corticosteroid therapy.

The investigators disagreed substantially on two cases. One, ultimately considered possibly related to treatment, had a report of agranulocytosis — severe reduction in levels of granulocytes — 17 months after the second course of Lemtrada, followed by colitis (inflammation of the colon), pneumonia, and death due to multiple organ failure.

The second patient, who had aggressive MS, started to experience epileptic seizures a few days after taking Lemtrada, followed by pneumonia, sepsis, and colon bleeding, dying after 40 days. As the patient's status epilepticus was considered more likely caused by MS, causality between treatment with Lemtrada and death was deemed unlikely.

Seven other cases were also deemed unlikely to be related to Lemtrada. Their causes of death included suicide (two patients), cancer (two), and status epilepticus (one). The remaining cases were newborns who died one day after induced labor and whose mother was treated with Lemtrada during pregnancy.

Overall, "fatal adverse events related to treatment with alemtuzumab [Lemtrada] occur more frequently than previously published in the literature, and seem to be most common during the first month after treatment," the researchers said.

Cautioning that the frequency of deaths in people treated with Lemtrada cannot be calculated because the number of patients on this therapy is not disclosed, the team added that “patients, physicians, and regulatory authorities should be aware of the serious risks associated with [Lemtrada], which must be weighed against the high and durable clinical efficacy.”

These findings were shared with the Pharmacovigilance Risk Assessment Committee of the European Medicines Agency, prompting a safety review of Lemtrada and a restriction of its use in patients with continuing flare-ups despite at least two prior disease-modifying therapies (DMTs), those ineligible for other DMTs, and patients benefiting from this medication.

www.msscociety.co.uk 14 August 2019

Ageing and myelin repair

As our bodies age, muscles and joints can become stiff, making everyday movements more difficult. New research, which we've part-funded, has shown the same is true in our brains. This age-related 'brain stiffening' has a significant impact on the function of the brain's stem cells. Researchers at the Wellcome-MRC Cambridge Stem Cell Institute studied the brains of young and old rats to understand how ageing affects a type of stem cell called oligodendrocyte precursor cells (OPCs).

OPCs are important for repairing myelin – the fatty coating that surrounds our nerves which is damaged in MS. In MS, and as we age, this repair process slows down. OPCs stop responding and myelin damage builds up.

'Rejuvenated' stem cells

To find out whether the changes to OPCs are reversible, researchers transplanted OPCs from older rats into the brains of younger animals. Remarkably, the older brain cells were rejuvenated, and began to behave like younger cells.

To understand why this happened, researchers developed materials in the lab that had a similar softness to either young or old brains. They used these to grow and study the rat brain stem cells. Dr Kevin Chalut, who co-led the research, said: “We were fascinated to see that when we grew young, functioning rat brain stem cells on the stiff material, the cells became dysfunctional and lost their ability to regenerate, and in fact began to function like aged cells. What was especially interesting, however, was that when the old brain cells were grown on the soft material, they began to function like young cells - in other words, they were rejuvenated.”

The role of Piezo1

The researchers think this might be caused by a protein called Piezo1, which helps cells sense whether their surrounding environment is soft or stiff.

Professor Robin Franklin, who co-led the research with Dr Chalut, said:

“When we removed Piezo1 from the surface of aged brain stem cells, we were able to trick the cells into perceiving a soft surrounding environment, even when they were growing on the stiff material. What's more, we were able to delete Piezo1 in the OPCs within the aged rat brains, which lead to the cells becoming rejuvenated and once again able to assume their normal regenerative function”.

DISCLAIMER

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

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.

Identify the musical pop groups from the cryptic clues given.

- 1/ Is this a compromise on "Men only"?
- 2/ One of the cast of "The Good Life" perhaps, using devices to regulate the beat
- 3/ A female relative in a bit of a tangle
- 4/ Actor Paul storms in and gets applause
- 5/ Firearms and floribunda will lead you to this US group
- 6/ According to the saying, these do not amass small flowerless plants
- 7/ A religious servant who is a bit down in the dumps
- 8/ What you might say to your two young sons if they asked "What is the best feature of Bournemouth?"
- 9/ Ravers on a box at Hyde Park Corner
- 10/ A poodle, an alsatian, a beagle and Paul McCartney for instance

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/ Black 2/ Middle 3/ Dali 4/ Alarm Clock 5/ Cologne 6/ 1939 7/ The ear 8/ 100 9/ Polish 10/ Elephant