

ISSUE NO:- 05/ 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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Published by: Stockton MS Group, 74 Windermere Road, Stockton-on-Tees. TS18 4LY

NEWS UPDATE

Tombola Stall

Can we just remind everybody that in July of this year Stockton Cricket and Rugby Club will be holding their annual field day. We will be having a tombola stall. We are in much need of prizes, so if you have any, please contact David on 07999-849340

Safehands Holidays.

Safehands holidays provide short breaks for people with disabilities, their carers, families and friends.

They have two specially adapted hotels; one based in Blackpool and one in Llandudno.

If you would be interested in a brochure you can request one from any of the addresses listed below:-

e:mail:- caroline.sankey@safehandsholidays.co.uk

Website:- www.safehandsholidays.co.uk

Address:- Safehands Holidays Ltd, 2 Neptune Court, Whitehills Business Park, Blackpool, FY4 5LZ.

Tel: 0333 999 8888 Ext: 3305.

www.bbc.co.uk 1 May 2018

'I was stranded on a train in a wheelchair'

I have always lived in fear of being late - for work, school and friends.

As a wheelchair user, I get up at 5am for my carer to arrive to help me get dressed, often skipping breakfast to catch the 06:30 train to Waterloo.

I accept this as part of my responsibility. What I do not accept is being late for work because I have been left stranded on the train by platform staff who fail to arrive.

Unfortunately, I faced this exact situation on Tuesday morning's commute, stuck on the train for around 20 minutes - the longest in a catalogue of incidents **I have begun recording** over the years.

As train passengers departed I waited patiently, but no one came. Once it became clear that I had been forgotten, I was struck not by fear, but rather a familiar sense of frustrated resignation - taunted by the small yet insurmountable gap between the train and the platform.

Tired of being treated like a second-class citizen, today I decided, for the first time, to stream what was happening live. I did not do so for attention or sympathy, but rather to highlight the reality of travel as a disabled person.

South Western Railway, the train operator behind the service I was travelling on, apologised for the "unacceptable" incident and said an investigation is ongoing.

"We take accessibility seriously and want all of our customers to be able to use our trains safely and comfortably," the company said in a statement.

"We already work very closely with accessibility groups on our network to help us improve our services," it added.

However, it mirrored a near identical situation from 2016, where I was left desperately shouting for help after finding myself completely alone and unable to get to work.

- This occurred at the hands of a different operator - South West Trains - but the changeover did not affect staff.

Such humiliating situations are easily avoidable, especially since the train guard in this most recent case, who helped me on board with the wheelchair ramp, had called ahead to arrange assistance with the platform staff.

But many other disabled people have experienced similar situations, including my blind former BBC colleague **Lucy Edwards**, who also found herself forgotten by platform staff at a London station when reporting for BBC Radio 4.

Alan Benson, chair of accessibility pressure group Transport for All said: "The accessibility of our rail network is now well behind other public transport modes like buses.

"Railway companies (which all make handsome profits) have to stop treating disabled people as second class citizens."

The frequency of the problems point to a wider systemic problem in wider society's approach to disability.

In March, BBC security correspondent Frank Gardner **highlighted the widespread scale of the problem** after tweeting about his anger at the "casual disregard" from staff as he tried to disembark from an aircraft at Heathrow.

He said he felt his basic human rights had been denied after his wheelchair was "lost" by staff. And that is how I felt on Tuesday morning - helpless as the clock ticked down.

Faced with the prospect of guardless, automated trains, I fear for the future and ask that rail companies play their part.

I can accept that mobility takes longer as a disabled person, I can get up at 5am, I can skip my breakfast, but I cannot and will not waste my time.

www.bbc.co.uk 7 May 2018

How #HotPersonInAWheelchair is fighting hate on Twitter

A US YouTuber has inspired a Twitter campaign after she read a tweet that said: "Nothing sadder than a hot person in a wheelchair."

The tweet that got Annie Segarra so annoyed was actually four years old. It had been written by author Ken Jennings, known in the US for winning the classic TV game show Jeopardy! 74 times in a row - and pocketing more than \$2.5m (£1.85m) in the process.

Segarra, who tweets using the Twitter handle @annieelaine - adapted Jennings' tweet so it read "#HotPersonInAWheelchair", adding: "Cry about it, babe". She attached a photo to the tweet showed her in a chic outfit.

More than 2,700 people liked the post from Segarra - who was diagnosed with Ehlers-Danlos syndrome (EDS) in 2014 and is now a wheelchair user.

It prompted some of her followers who are also wheelchair users to post photos of themselves with the same hashtag.

Australian para-athlete Robyn Lambird (@Robyn_Lambird) shared an image of herself wearing a white hoodie.

Segarra addressed the issue further on Facebook.

"We're here, we're hot, we deserve to feel hot, to be seen, to take up space," she posted.

"We deserve to use the mobility aids and any other device or assistance we need without shame.

"I think what's important here is that tweets stand the test of time. They still have the power to hurt and offend or anger years after posting when their author totally forgot what they'd originally said."

Meanwhile images using Segarra's hashtag kept coming. Diogo Martins (@rodas89) tweeted a picture of himself and his partner, both in wheelchairs.

"A hot woman in a wheelchair is in a relationship with a guy (who she states is hot too) in a wheelchair!" he wrote in the caption.

And Caitlin Goerlich (@CGoerlich) commented to Ken Jennings, the original tweeter, "Hey @KenJennings - I think you are very, very wrong."

She then posted photos of herself in prom dresses, casually at home and practising archery. Back in 2014 - when the original tweet was posted - California-based stand-up comic Billy Anderson (@BillyAndersonYo) tried to lighten the mood. He tweeted a posed-by-model image of a man in a wheelchair sweltering in a sunny garden.

"When @KenJennings tweeted 'Nothing sadder than a hot person in a wheelchair' pretty sure he meant it THIS way. #SoSad"

Ken Jennings hasn't responded directly to the most recent criticism to date.

www.bbc.co.uk 4 April 2018

Ministers outline plan for disabled people's air travel

New measures to improve air travel for disabled passengers are being considered by the government.

They could include a limit on the time passengers wait for assistance boarding and disembarking, and quicker reunions with their wheelchairs.

The issues faced by disabled flyers were **recently highlighted by the BBC's Frank Gardner, whose wheelchair was lost at Heathrow Airport.**

The government said it wants to ensure a "positive" flying experience.

Ministers are also talking to the aviation industry about developing priority storage for wheelchairs so that they can be returned to their owners quickly upon arrival.

They are also considering the removal of seats to allow wheelchairs to be used in cabins - allowing those who cannot transfer or who require specialist seating to travel - and to create space for disabled toilets

- Aviation minister Baroness Sugg said: "We have to do everything possible to ensure passengers are put at the very heart of our aviation industry and the flying experience is a positive one for everyone boarding a plane."

'I was once asked to get out of my wheelchair'

By Lucy Webster, BBC News

The issues these measures attempt to allay are all too common. As a wheelchair user, I have experienced so many problems that the mere thought of air travel causes a twinge of anxiety.

More often than not, my wheelchair is damaged. I have seen my precious motor (detachable, as the airlines like it) be flung with great force onto a pile of luggage, as if it were a bag of clothes and not my only means of independent movement.

I cannot go to the toilet on the plane as I need a personal assistant to help me and the cubicles are too small, so I have not taken a long-haul flight since I stopped travelling with my parents. I wonder if I will ever fulfil my desire to see, as an adult, the world beyond Europe. The plans announced today would go some way to making my experience better. But they do not tackle the most degrading part of flying: the attitude of ground staff and cabin crew. I was once asked to get out of my wheelchair, just to make security's life easier. That particular problem will not be solved by more rules.

Mr Gardner, who was kept waiting on a plane for almost two hours after landing at Heathrow in March, described the government's ideas as a "welcome step" but added "we're unlikely to see actual changes in near future".

He said there is "still a long road to travel".

"Many disabled people rely on essential equipment like wheelchairs for their own personal mobility," said Keith Richards, who advises the government on transport for disabled people. Mr Richards said that while wheelchairs are "too often treated in the same way as baggage" he welcomed the move to give them priority.

The government is due to publish its aviation strategy in early 2019.

www.theguardian.com 10 April 2018

A broken lift made me a prisoner in my home. But I fought for my disability rights

Many years ago, aged 16, I broke the law and was remanded in custody to await my trial. I was confined to my cell for up to 22 hours a day and only occasionally got to break the monotony of it all, strolling with my fellow inmates around the prison courtyard. Although my incarceration was short – I got a community service order and a fine – my loss of independence hurt. I vowed I would never return to jail.

I never did, but the onset of multiple sclerosis, and severe disability, meant I went back to that waiting cell, metaphorically speaking. I've still got a room with a view, but this time it's with a life tariff. Doing this type of "bird", for me and countless others living with a chronic disease, can be hard labour. I count myself lucky, though. Soon after diagnosis I became homeless and went to the local council for help. A few months later they awarded me a flat. My mobility was manageable to start with but over the decade I lived there, the steps up to my flat became too much. My special needs elevated me to the highest band on the transfer list. When a self-contained adapted apartment became available nearby under the management of a housing association, I moved in.

I've lived there for eight years now. My disease has continued, confining me to a wheelchair and now affecting my whole body. I can still get out, thankfully, if my energy levels allow. It's a bit of a lifeline, a chance to share a conversation, an opportunity to feel part of something. However, living on the first floor of a housing block, I have a new incarcerator, whose reliability is often very poor – the lift.

Recently it broke down – again. It was motionless for 10 days. The landlord and lift engineers were quick to blame each other – no one was prepared to take responsibility, leaving me reliant on the goodwill of my neighbour. My problem, though, does not appear isolated. A quick search on Google reveals many others marooned in their flats because of sub-standard services.

A chronic shortage of accessible housing in the UK means that an estimated 1.8 million people with disabilities – 56% of whom are homeowners – are often unable to leave their homes, and many are desperate for alternative accommodation. The case of Richard Chrimes, who has to crawl through his front door because his wheelchair does not fit through the front door of his two-storey house, was recently featured by the BBC.

He has to drag himself along the ground to get to his car. After several years he's still waiting for a home that both he and the council agree is appropriate.

I could have sat there and taken the broken-down lift, but why should I? I've done enough time already! As far as I'm concerned, the broken lift infringed my human rights. It stripped me of my independence. So I refused to pay my rent for the period it was out of order and sought compensation for the inconvenience caused. I also made a local councillor aware of my predicament, including him in the "round robin" email correspondence with the housing association. He informed the landlord and me that the lift's inaction may have broken the 2010 Equality Act. The news seemed to tip the balance. Soon after the lift was fixed, both myself and my neighbour (who is also disabled), received compensation of more than £500 as settlement. Everyone in the same predicament should think about taking a similar stand. We all have a voice and it is there to be heard. When those voices are amplified, they make a difference – otherwise nothing changes. This was a point of principle, a line I was prepared to hold, whatever the cost. The lift has worked fine since, fingers crossed. Hopefully the payment means a lesson has been learned and any future malfunction will be treated with more urgency.

Future building forecasts and an ageing population mean many more people who become less mobile could be forced to live in properties that ultimately imprison them - little provision is being made for their long-term needs.

It should be enshrined in law that new developments have more accessible housing. It makes sense.

www.bbc.co.uk 6 April 2018

Labour urges rethink on mortgage benefits

Labour has warned that vulnerable people may struggle to pay their mortgages because of benefit changes.

About 90,000 people on certain benefits claim support for mortgage interest (SMI) but from Friday the benefit will be replaced by government loans.

Figures suggest 27,000 SMI recipients - 51% of those contacted - say they will not take up the loan.

Labour says there is a risk elderly people may cut back on essentials like heating rather than take the loan.

The new state-backed loan, secured against the mortgaged property with interest added each month, would not have to be repaid until the property is sold or transferred to someone else.

'Halt this change'

The government says it is reasonable to ask someone who has received help towards their mortgage to repay it, as their home is likely to increase in value.

But shadow work and pensions secretary Margaret Greenwood said: "Even at this late stage, the government could and should think again and halt this change."

She added: "It is worrying that the government seems determined to push ahead with this change despite the risk of it causing real hardship for people on low incomes."

"Many of the people who claim SMI are elderly or disabled, and it is extremely concerning that pensioners might try to cope without the loan by cutting back on essentials like heating."

The government is set to spend about £161m on SMI in the year 2017-18. As of 21 March, they had successfully contacted 54,000 people by telephone and tried to contact a further 31,000, as a follow-up to a letter explaining the change.

Of those contacted, 51% - about 27,000 people - had said they intended to decline the offer of a loan, 13,000 said they would accept it and 14,000 said they were undecided.

A Department for Work and Pensions spokesman said: "People who sign up to the loan will continue to get help with their mortgage interest and it is only repayable if there is available equity when the property is sold.

"If people decide to decline the loan now but change their mind in future the loan can be backdated so, in effect, there would be no break in payments.

"We have already contacted everyone currently in receipt of SMI to explain the change but we are making sure people have time to review the documents, obtain advice and consider their options."

www.theguardian.com 10 May 2018

Now disabled people face a kind of internment. Just ask Edith

In 24 hours' time, Edith will no longer be able to get out of bed. The 30-year-old has multiple sclerosis, and relies on council-funded care assistants to help her live in her two-bed adapted flat in Hitchin, Hertfordshire.

For 18 months, she has managed with only a couple of visits a day: one at 7am, to enable her to get up for work as a chartered accountant, and another at 8.30pm to help her get out of her wheelchair and back into bed. After years of saving hard for her first home and moving out of her parents', it was meant to be the start of Edith's life. But in February her care agency struck a blow: owing to staff shortages in her area, they would be ceasing their contract, and giving social services 90 days' notice. Three months later, with barely a day until her carers leave, the council hasn't found her a replacement.

Edith is terrified. "Carers helping me out of bed every morning are the fundamental life support which everything else in my life depends on," she says. "And now it feels like the rug is being pulled out from beneath me."

Hertfordshire county council (HCC) says the care agency delivering Edith's support served notice because it doesn't have anyone else in need of support in the area, but that they're continuing to look for other care agencies before the notice period ends. HCC adds that some new care slots have already been offered, but ask Edith what the times were and it's little wonder she turned them down: a 9.30am wake up and 6.45pm night call. That would mean getting up half an hour after she's meant to start work and being back in bed 15 minutes after she typically gets home. Forget going for a drink with friends: she'd be in bed for 14 hours every day. "My housebound 90-year-old grandpa wouldn't accept that," she says.

Edith repeatedly tells me her social worker is doing her best, but in a social care climate of underfunding and staff shortages, she may as well be trying to squeeze blood from a stone. As Edith puts it: "There just aren't enough carers. The system doesn't work."

As vast budget cuts see people with disabilities and older people lose their support to eat, wash, and leave the house, the care sector is "in crisis" because of severe staff shortages. Low pay, zero-hours contracts and poor conditions means staff are leaving while councils and care homes struggle to hire and retain qualified carers. The drive for outsourcing public services in recent years, championed by Conservative and New Labour governments alike, only exacerbates this. To get a picture of the scale of the staffing shortage, on any one day, there are 90,000 vacancies for social care jobs in England, according to research by Skills for Care in 2017.

This will only worsen after Brexit as the care sector faces a future without the contribution of its largely European migrant workforce. With no carers found, Edith's social worker has come up with increasingly desperate solutions, including asking Edith's bosses to alter her working day around her care call hours.

"This isn't shift work. I'm an accountant," she says. Edith tells me she cried as soon as she heard the latest plan: putting her into a care home. If no agency can be found in time, she has been told she'll have to leave her own flat and move into an unnamed residential institution. "I feel like I'm being threatened into accepting a care package which will strip me of my life and just leave me surviving," she says.

Edith is far from alone in this. I reported in March how disabled people are increasingly being threatened with being "interned" in care homes owing to unprecedented underfunding in the system. I'm increasingly hearing from campaigners and charities that they're assisting disabled people who are being encouraged by authorities to go into an institution as a "solution" to their poor care packages, despite being in their own homes for years.

Suggest that a non-disabled person live like this and there would rightly be outrage. And yet someone like Edith, with her whole life ahead of her, is expected to waste her days in bed or a care home. It's reminiscent of attitudes to disability that were said to have died out before Edith and I were even born: that people with disabilities are "not normal", and as such don't need a career, social life or family.

Friday evening is the last time Edith's carers are scheduled to help her. As time runs out, she has been ringing around care agencies herself, but with no luck. She has even written to her MP for help. The stress would be tough for anyone, but with Edith's MS, it's brutal – she's increasingly fatigued and weak, and pain has developed down her right arm. In her worst moments, she says, she thinks perhaps quitting work, cancelling all plans, and lying in a care home might be preferable to this fight. As we finish talking, I ask her what she'll do on Saturday morning if her carers don't come. "My social workers said we'll have to start looking for care homes."

www.bbc.co.uk 21 May 2018

Motability boss's pay 'unacceptable' say MP committees

The £1.7m salary paid to the chief executive of the firm which runs the Motability disabled car scheme is "totally unacceptable," say MPs.

The remuneration package of Mike Betts has grown by 78% from £954,000 in 2008.

Motability said Mr Bett's pay was based on a comparison with FTSE 250 firms.

The Treasury and Work & Pensions committees found funds of £2.4bn were also being needlessly hoarded. The National Audit Office would look into the issues raised, the government said.

"The Secretary of State has stated that Motability provides an extremely valuable service to disabled people but the levels of executive pay and financial reserves are concerning," a spokesperson for the Department for Work and Pensions added.

The Motability scheme arranges cars for disabled people in exchange for some of their state disability allowance - their Personal Independence Payment benefit.

Motability Operations - the firm which runs the scheme - is a monopoly which faces no competition.

The two Parliamentary committees say that the government needs to explain why state assistance for the firm - in the absence of competition - is an appropriate use of public money.

'Totally out of whack'

Frank Field MP, chair of the Work and Pensions Committee, said that Mr Betts' pay is over ten times what the Prime Minister earns.

"The levels of pay pocketed by its executives and the cash reserves it is hoarding are totally out of whack with reality of its position in the market," he added.

Mr Field said that Mr Betts' pay is over ten times what the Prime Minister earns.

Nicky Morgan MP, chair of the Treasury Committee, said the "high levels of executive pay and significant financial reserves are difficult to square with the honourable objectives of the scheme".

"It seems that Motability may have lost its way," she added.

Motability Operations has denied having built up "spare" money and says it has provided 4.5 million vehicles to disabled people and their families since its 1977 launch.

On chief executive Mike Betts' pay, the firm said it was "reviewed against the market to ensure that it is both competitive over the long term and to make sure that any rewards are related to performance especially in relation to the quality of service provided".

www.yorkpress.co.uk 21 May 2018

Disabled toilets at York Racecourse to be kept locked after investigation allegedly found traces of cocaine

DISABLED toilets at York Racecourse will be put under lock and key after an investigation by a national newspaper allegedly found traces of cocaine in bathrooms.

An undercover journalist reportedly found traces of the drug using a swab in two disabled toilets in the Country Stand area on the Thursday of the three-day Dante Festival.

A spokesman for York Racecourse said the site aims to be as accessible as possible for all racegoers but will now have to put disabled facilities under lock and key

A spokesman for York Racecourse said the site aims to be as accessible as possible for all racegoers but will now have to put disabled facilities under lock and key.

He said: "On a balanced judgement between speed of access versus the potential for abuse, the racecourse had previously decided that these specific disabled toilets should not be operated only by a special key (known as a radar key). However given the zero tolerance policy, these locks will now be fitted to these toilets.

"Taken at face value, the investigation reports no evidence of drug taking, despite wide spread testing, in either any of the main toilets nor any of the disabled toilets in the Grandstand and Paddock enclosure, where we understand approximately twenty swabs were taken."

Security measures at the meeting, which attracted about 40,000 visitors, included sniffer dogs, assistance from North Yorkshire Police officers, bag checks, toilet monitoring and more than 300 specially trained stewards.

The spokesman said no incidents of anti-social behaviour were reported and added: "The issue of drugs is a major concern for society as a whole, racecourses as with other venues are part of that wider society, not separate to it.

"York Racecourse remains committed to offering an enjoyable and safe experience to all its customers and does not condone the choice of a few individuals to break the law."

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

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/ What does the abbreviation 4G stand for in relation to mobile communications?
- 2/ What star sign would you belong to if you were born on October 29th?
- 3/ What year did England and Wales become unified with Scotland?
- 4/ What type of tree produces conkers?
- 5/ What was the name of the first Scottish man to be voted European Footballer of the Year?
- 6/ How many days did the Falklands War last?
- 7/ Who is the author of Peter Rabbit?
- 8/ What is the largest planet in our solar system?
- 9/ How many players are there in a baseball team?
- 10/ Which famous poet wrote 'An Ode to a Nightingale'?

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/ Elephant 2/ Jerusalem 3/ Hiroshima 4/ Diabetes 5/ Skin Disease 6/ Bicycle 7/ Observer
8/ Wolf 9/ Taxidermy 10/ Predictions