

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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Family Fun Day

At the field day at Stockton Cricket and Rugby club on Sunday 30th July we raised £267.

Thank you to the people who helped to prepare the tombola, and to those people who helped at the stall on Sunday.

Also, a thank you to everybody who donated prizes for the tombola

Bulletin Quiz

Can we please ask members that when participating in the monthly quiz, we need you to put your name and address on the answer sheet so we know who they are from.

Please send your answers to the bulletin quiz through the post.

www.bbc.co.uk 9 August 2017

'A lack of toilets led me to choose surgery'

Paralympian Anne Wafula-Strike had to wet herself on a train journey, last year, because the disabled toilet was out of order. Now, she hears from others facing similar problems. Marni Smyth has spinal muscular atrophy, and has used a power chair since she was three. She needs a hoist to get on to a toilet, and says finding disabled loos that could accommodate her needs became a daily struggle. "When I first went to university, I would avoid drinking as much as I could, because [otherwise] I needed to go home and leave a night out early," she tells Anne Wafula-Strike, in the Paralympian's report for the BBC's Victoria Derbyshire programme. "I'd need a hoist and plinth to get changed on, and they just weren't [available]." Two years ago, she took the step of undergoing surgery for which she had no medical need. She had a suprapubic catheter fitted, so she does not have to get out of her chair to go to the toilet. She says she knows others who have also had the operation, and it has "completely changed my life". "I'm so much healthier in general. I used to dehydrate myself. I wasn't drinking all day to avoid having to use the toilet," she says. The operation, however, can cause infections and complications. Marni says she "wouldn't change [the catheter] for the world", but still questions why it got to a stage at which she felt such an operation was necessary. "I kind of wish I didn't have to have it in the first place, if the facilities were there," she says.

'Crawl along the floor'

A 2014 government audit suggested as many as 40% of restaurants and a third of department stores still did not have appropriate toilets for people with disabilities.

This is despite businesses having a legal duty, under the Equalities Act, to make reasonable adjustments so their loos are accessible.

Anne Wafula-Strike doesn't have to look far to find other athletes that have experienced issues over toilet accessibility.

"It happens day in, day out. What's even worse is that some disabled toilets aren't even maintained," Emma Alexander says.

Gary Donald says he once went on a camping trip, only to discover the disabled toilet's ceiling had caved in.

"I just got off my chair, crawled along the floor and climbed up on to the able-bodied toilet. I'm often doing that," he says.

The lack of suitable facilities can also affect parents and carers, some of whom have had to change their loved ones on a toilet floor.

Lorna Fillingham - whose seven-year-old daughter Emily-May has severe disabilities - says:

"There are people out there changing people on toilet floors all day, every day - in towns and cities across the UK.

"There are people with very low immunities at risk of catching infections on toilet floors.

"There are people with feeding tubes, tracheostomies, all sorts of things you do not want to get dirty, which could actually kill somebody if they got an infection into it."

Lorna believes the answer lies with Changing Places toilets, which are designed for people with severe disabilities.

They are more spacious and contain specialist equipment, such as an adult changing bench and a hoist to help users out of their wheelchairs.

An estimated quarter of a million people in the UK require such facilities, but there are currently only about a thousand in place for public use.

A recent government committee recommended these toilets be made compulsory in large buildings that serve the public, but no legislation has been put in place to make that happen.

A spokesman for the Department for Communities and Local Government said "working with the disability sector, we're helping to make sure facilities improve for disabled people.

"This includes reviewing building regulations so new buildings are more accessible. We've also recently funded a website to help people find the nearest suitable changing facilities."

Anne Wafula-Strike describes the time she wet herself on a train as "one of the most humiliating experiences of my life".

She had been on a three-hour CrossCountry service from Nuneaton to London Stansted in December 2016 when she discovered the disabled toilet was out of action, with no prior warning.

The government's rail minister later assured her he was committed to ensuring no passenger went through the same ordeal. But it has happened since.

Chris Stapleton was on a Virgin Trains journey from London to Birmingham when he had to wet himself, after he found the disabled toilet broken.

He had booked his ticket six weeks in advance.

"I was angry with the train company's negligence, knowing that there was a wheelchair user needing that toilet potentially on that train," he says.

"There should have been a toilet ready and in working order."

Virgin Trains has since apologised to Chris, and says it has introduced measures to prevent such an incident happening again.

Cross Country has apologised to Anne.

Action plan

The Paralympian decided to return to the Rail Minister, Paul Maynard, to hear why Chris's experience had been allowed to happen.

He said the government was working on an "action plan" to improve accessibility on transport, which contained "a range of ideas that not just make sure that passengers get a better service on the day, but that we can work more tactically and more strategically to make sure more toilets are in service on trains in the first place".

"There are strict legal rules in place as to what threshold of achievement train operating companies have to achieve," he said.

"The Office of Road and Rail enforces that, and I've made very clear to them I want them to take this very, very seriously indeed."

Anne describes this as a "step in the right direction", but is keen to hear more details.

She says the issue is not simply about access to toilets, but about "access to all areas of life" - and ensuring people are not defined by their disabilities.

www.huffingtonpost.co.uk

7 August 2017

Treating Multiple Sclerosis: We Need To Address Gaps In Care And Conversations

Imagine you're 28, developing your career, relationships, trying to get on the property ladder and starting to make your way in the world. Then you're diagnosed with Multiple Sclerosis, the most widespread disabling neurological condition for young people around the world, for which there is currently no cure. That was me in 2008.

MS is an autoimmune disease of the central nervous system. The immune system becomes faulty and attacks healthy tissue in the brain and spine, eroding the protective covering of nerves and leaving them exposed and damaged. Nerve signals that enable the body to function are interrupted, causing a myriad of symptoms that can include vision loss, pain, muscle spasms, bladder/bowel issues, fatigue and mobility problems. People with MS have to live with a whole range of different symptoms. People are commonly diagnosed in their 20s and 30s, and around 100,000 people in the UK have the condition. I have the most common type of MS - the relapsing form, which is characterised by a relapse or "flare ups" that can last from a few days to several months. My symptoms have included loss of strength in my hands, numbness, muscle spasms and fatigue. You don't know when a relapse will occur, how long it will last, how severe it will be, what bodily function it will affect and if there will be lasting damage. MS is a constant life of uncertainty.

But nine years from diagnosis I've turned MS into a positive life change. I'm a campaigner and advocate for people with the condition and have done some amazing things as a result.

However, it hasn't always been easy and much of my advocacy and awareness-raising has been borne out of seeing gaps in services and support, something echoed by Sanofi Genzyme's recent Missing Pieces report. The report shows that there's still a serious lack of access to information and treatment for people with MS, even though the landscape has changed tremendously in the past decade, with more licensed therapies available and more services being developed. What is clear is that availability doesn't necessarily mean accessibility.

A key finding in the report is that people with MS are very concerned about potentially becoming disabled. Of people with MS surveyed as part of the report, 54% say they are worried and 45% say they are scared about future disability - this is something that really resonates with me. Despite this, the survey also revealed that 24% said that they were unaware that treatments which can reduce relapses and disability, exist. Plus, just half surveyed said that disability was discussed with their healthcare professional (HCP) at diagnosis. If these conversations aren't happening, how can treatment plans be established to meet patients' goals? Most HCPs surveyed said they were reluctant to discuss disability because they didn't want to make the patient uncomfortable. If we can't have that conversation with our HCP, who can we have it with? It's their responsibility to ensure that we're aware of what might lie ahead, so that we're able to plan for the future, whether that's to do with treatment choices, financial planning or anything else that may be necessary if disability was to develop. At the very least, HCPs should be signposting patients to information and support from other organisations.

Even more concerning is that about 75% of HCPs surveyed believe people with MS encounter delays in starting DMTs, with the main reason being lack of access to MS specialist neurologists. Therefore, even if patients have treatment goals, the UK care system does not necessarily enable them to be fulfilled. I believe that all people with MS should be given the choice to take any DMT they're eligible for, from the point of diagnosis. That choice shouldn't be limited by where they live, who their neurologist happens to be or which hospital they're seen at. Timely intervention and reducing the chance of developing long term disability not only allows for better quality of everyday living but also has a social, mental and financial impact on people's lives longer term.

Finally, the report calls for access to a multidisciplinary healthcare team, personalised care plans and regular reviews, in line with NICE Quality Standards for MS. I count myself lucky that I've had access to treatment, I'm regularly monitored and I have a proactive healthcare team that is approachable and easily accessible. This should be the case for everyone but, as at the moment, 36% of people in the Missing Pieces survey hadn't seen a neurologist in the past 12 months. Support, effective treatment plans and information is crucial for living a positive life with this condition and if there are gaps they need to be addressed, whether that's through education, policy change, or further training. I truly hope that this report prompts action to bring about these changes so that people with MS can live disability-free for as long as possible.

The Gazette 24 July 2017

MS care has come a long way...so why have so few British patients benefited?

Major breakthroughs in the development of the effective drugs can seem like the holy grail for anyone involved in the treatment of – or who is affected by a chronic illness. But however groundbreaking, they're of little use if they don't reach the people they're intended to help – and experts are warning that this is the situation with MS (multiple sclerosis) in the UK right now.

LIFE-CHANGING POTENTIAL

More than 100,000 people in the UK have MS, which causes the immune system to attack myelin, the protein covering the central nervous systems, resulting in lesions or 'scarring' mainly in the brain and spinal cord. Symptoms can be complex, including pain, numbness, stiffness and spasms, poor vision, speech and balance problems. Strength and mobility, plus things like bowel and bladder function can also be affected, and a lot of MS symptoms are 'invisible', such as crushing fatigue, memory problems and the impact of mental health.

There are different type, but the majority diagnosed have relapse remitting MS (RRMS), where people experience a relapse or 'attack' of symptoms which lasts for a certain length of time, before symptoms ease off – either partially or completely – for another stretch of time. However, while unpredictable and variable from one person to the next, MS is considered progressive and can be very debilitating and cause varying degrees of disability.

The development of disease modifying treatments (DMTs) has transformed the landscape of MS treatment. Where once, major disability seemed like a cruel inevitability for many, now, where suitable, drugs offer the potential to significantly reduce the amount and severity of relapses, and delay the progression of disability.

Currently, 11 DMTs are approved for use by the NHS. But only 21% of UK MS patients receive DMT'S – one of the lowest rates in Europe. Nearly a quarter (24%) aren't even aware that treatments could help delay disability, and 74% of healthcare professionals (HCPs) believe patients face delays starting DMTs.

MISSING PIECES

The figures are highlighted in Sanofi Genzyme's newly published 'The Missing Pieces' report, which identifies gaps not only in access to treatment, but overall in the communication between patients HCPs and MS specialists.

When Trishna Bharadia was diagnosed in 2008, aged 28, there were fewer licensed DMT's than today – but she was deemed eligible for some of those that were available.

"I was offered DMTs at the point of diagnosis" says Trishna, now 37 and a campaigner and MS Society UK and Sue Ryder ambassador.

"However, I'm fully aware not everyone's offered them or has access to all treatments. It's something I don't think should be happening and I actually find it appalling that one in four don't even know that DMT's could help delay disability. Everyone should be given the information so they're able to make an informed decision."

GAPS IN CONVERSATIONS

Though lucky to have been offered DMTs early, Trishna, from Buckinghamshire, says she "wasn't offered guidance and support as to where to go for reliable information about these drugs".

She and her own family did their own research about side-effects and efficacy. "It was a big task," she says, "at a time when we were also trying to come to terms with this life-changing diagnosis."

Amelia Southard, 44 from Devon, thinks things have improved a lot since her MS diagnosis in 2003. She tried some of the early DMTs but didn't find them effective. Now, she takes one of the newer ones – "a daily tablet, whereas the others all involved injections or infusions of some sort".

"There is so much more available [now] and patients, in my experience, are given much more choice in their treatment," she says. And despite her ups and downs with drugs over the years, and relapses ("I use two crutches and a wheelchair to get around these days,") Amelia feels certain that DMTs are important.

"It's massively important; it can mean the difference between having some sort of quality of life or not. It hasn't been the case for me, but I know it can mean the difference between orking or not being able to work.

Or of having some sort of social life or hobbies versus being housebound. It really can make that sort of difference...

Not necessarily for everyone, but hasn't everyone got the right to try and see if they work?"

TRICKY TOPIC

But what if the options being presented? According to the Missing Pieces report, HCPs say Disability is 'routinely discussed' with newly diagnosed patients 69% of the time – but just 50% of patients says this was the case for them.

Half of the HCPs agree there's a reluctance to discuss disability, mainly because 'they felt it was not appropriate', and not wanting to make the patient feel 'uncomfortable'.

Amelia notes that her experience in this regard has been positive – "I have a brilliant consultant neurologist who is very straight talking".

For Trishna, it's not just the quality of communication that's important, but ensuring conversations take place frequently enough, too: "It wasn't until a couple of years after my diagnosis that I even knew there was such a thing as a specialist MS neurologist," she says. "This upset me because I'd have liked to have had the choice from the point of diagnosis to transfer to a specialist MS centre if I'd wanted to."

NICE recommends people with MS have access to an expert multidisciplinary team and a comprehensive review of their treatment and care annually – but a recent MS Society survey found 36% of patients hadn't seen a neurologist within the past 12 months.

Of course, MS is unpredictable – which can also make disability a tricky topic to discuss, as there might be concerns around causing undue anxiety, for instance.

POSTCODE LOTTERY

Some HCPs have also highlighted that it's difficult to have a conversation about disease progression and potentially helpful treatment – if access to that treatment is not as readily available as they and the patient might then hope, and this may come down to funding, services and facilities at local levels (many DMTs need to be administered by specialist nurses in hospital).

The MS Society's recent My MS, My Needs survey found big disparities in services in different areas of the UK. A recent follow-up (involving over 11,000 patients – one of the biggest MS surveys ever done) found access to DMTs generally, has improved over the last three years – yet the UK still has among the worst rates in Europe.

"All people with MS should be given the choice to take any DMT they're eligible for from the outset. That choice shouldn't be limited by where they live, who their neurologist happens to be or which hospital they're seen at," says Trishna.

"Reducing the chance of long-term disability not only allows for better quality of everyday living, but also has a social, mental and financial impact on people's lives."

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

Over in the U.K. a very pretty young speech therapist was getting nowhere with her "Stammerers Action Group".

She had tried every technique in the book without the slightest success. No-one was improving.

Finally, thoroughly exasperated, she said "If any of you can tell me, without stuttering, the name of the town where you were born I will have wild and passionate sex with you until your muscles ache and your eyes water.

So, who wants to go first?"

The Englishman piped up. "B-b-b-b-b-b-b-irmingham."

"That's no use, Trevor," said the speech therapist. "Who's next?"

The Scotsman raised his hand and blurted out "P-p-p-p-p-p-p-p-aisley".

"That's no better. There'll be no sex for you, I'm afraid, Hamish."

"How about you, Paddy?"

The Irishman took a deep breath and eventually blurted out " London ."

"Brilliant, Paddy!" said the speech therapist and immediately set about living up to her promise.

After 15 minutes of exceptionally steamy sex, the couple paused for breath and Paddy said, "-d-d-d-d-d-d-d-d-erry"

Ralph and Edna were both patients in a mental hospital. One day while they were walking past the hospital swimming pool, Ralph suddenly jumped into the deep end.

He sank to the bottom of the pool and stayed there.

Edna promptly jumped in to save him. She swam to the bottom and pulled him out.

When the Head Nurse Director became aware of Edna's heroic act she immediately ordered her to be discharged from the hospital, as she now considered her to be mentally stable.

When she went to tell Edna the news she said, 'Edna, I have good news and bad news. The good news is you're being discharged, since you were able to rationally respond to a crisis by jumping in and saving the life of the person you love. I have concluded that your act displays sound mindedness.

The bad news is, Ralph hanged himself in the bathroom with his bathrobe belt right after you saved him. I am so sorry, but he's dead.'

Edna replied, 'He didn't hang himself, I put him there to dry...

How soon can I go home?

An Engineer dies... and goes to Hell. Dissatisfied with the level of comfort, he starts designing and building improvements. After a while, Hell has air conditioning, flush toilets and escalators. The engineer is a pretty popular guy.

One day God calls and asks Satan, "So, how's it going down there?"

Satan says, "Hey things are going great. We've got air conditioning and flush toilets and escalators, and there's no telling what this engineer is going to come up with next."

God is horrified. "What? You've got an engineer? That's a mistake - he should never have gone down there! You know all engineers go to Heaven. Send him up here! "

Satan says, "No way. I like having an engineer on the staff. I'm keeping him."

God says, "Send him back up here or I'll sue."

"Yeah, right," Satan laughs, "and where are you going to get a lawyer?"

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/ The song Luck be a Lady features in which musical?
- 2/ Port Said is in which North African country?
- 3/ Which country is known as the Pearl of Africa?
- 4/ Which vitamin is also known as pantothenic acid?
- 5/ Who was the eldest of the Marx Brothers?
- 6/ Kodiak Island is in which US state?
- 7/ In which year did Henry VIII become King of England?
- 8/ Who wrote the book Catch-22?
- 9/ Who was president of Vietnam from 1945-54?
- 10/ Granadilla is another name for which fruit?

Name:

Address:

Send Completed Forms To:
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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/ New Jersey 2/ Sheffield 3/ The tongue 4/ Water 5/ Beyoncé 6/ Eighteen 7/ Farfalle
8/ Bashful 9/ Witches 10/ Mary Poppins