

Spelthorne Committee Access Now



info@spelthorneaccess.org.uk

www.spelthorneaccess.org.uk



Included in This Issue

- 2 *Heathrow Airport - 'Unacceptable' Levels Of Accessibility*
- 3 *How Disabled Travellers Still Faced Discrimination*
- 4 *Double Amputee Stuck At Gatwick When Wheelchair Is Broken*
- 5 *How The Ancients Invented Prosthetics*
- 6 *Disabled Ramblers*
- 6 *Share the Vision*
- 8 *Disabled Britain's Doing It for Ourselves Series*
- 9 *Being Grabbed, Pushed Or Touched Without Warning*
- 10 *What Does The White Cane Mean?*
- 10 *Braille Art Exhibition*
- 11 *Kew Gardens Walking Tours*
- 12 *Blind BBC Presenter Traps Attacker Who Stole His Phone*
- 13 *World-First Birth for Disabled Mother - Don't Lose Hope*
- 14 *Genetic Research 'Changed Our Son's Life'*
- 15 *Actor Warwick Davis – Dealing with your Child's Death*
- 16 *Targeted for Robbery? - Signs to Watch Out For*
- 16 *Woman With Epilepsy Told Valid ID 'Not Legal'*
- 17 *Saturday Opening Times at Community Centres*
- 18 *ACS 'Drop In' Hubs*
- 18 *Disability Empowerment Network – North Surrey & Surrey Wide*
- 19 *SCAN and SPSCD Forum News*
- 20 *New Year OBE for Alison Lyons – Sesame Access*

30th Anniversary Edition 12 – February 2023



Sponsors for Newsletters 2022-2023

Heathrow Airport - 'Unacceptable' Levels Of Accessibility <https://www.getreading.co.uk/news/reading-berkshire-news/heathrow-airport-slammed-unacceptable-levels-25738886>

The Civil Aviation Authority (CAA) has slammed some of the United Kingdom's top airports for having 'unacceptable' accessibility arrangements. Although it did recognise some airports - including Heathrow - had made improvements in recent months.

A seven-month review, that took place between April and October, looked at accessibility at the UK's top 16 largest airports. It looked at what improvements have been made, and what changes need to be brought in for 2023. The CAA says it aims to provide people with reduced mobility a 'standard of service to which they are entitled'. Earlier this year, it wrote to airports saying they needed to make improvements over summer.

Several airports were told to put action plans in place, which the CAA says saw a marked improvement in performance. In the earlier months of the reporting period, eight airports were ranked as 'very good', two had 'very good' and 'good' features, with Heathrow ranking among those who 'required improvement'.

Heathrow, along with Bristol and Leeds Bradford, are still deemed as needing improvement, the CAA says. Paul Smith, Director of Consumers at the UK Civil Aviation Authority, said: "The aviation industry has faced unprecedented challenges, but too many passengers at UK airports have been waiting for unacceptable amounts of time for assistance on arriving flights on too many occasions.

We strongly believe that everyone should have access to air travel, and we welcome the substantial improvements that airports have made for disabled and less mobile passengers. We will continue to consider whether we need to take further action where airports are not delivering an acceptable level of performance, and not showing sufficient and sustained improvements. We want to see immediate further improvements, as well as airports being well prepared to provide a high-quality service during next year."

Heathrow bosses say it has seen 1.3 million passengers who require support come through its terminals in 2023. They say the assistance level provided looks set to exceed their targets.

A Heathrow spokesperson said: "We are extremely disappointed by recent service levels which fall well short of our expectations. The challenges faced by the entire aviation ecosystem this year have set us back, but we are working to recover performance to ensure Heathrow is a welcoming and accessible airport for all passengers. We are committed to achieving this in partnership with our service provider, airlines and their ground handlers, working closely with the CAA and user groups."

How Disabled Travellers Faced Discrimination in 2017. But Has Anything Changed? – Edited from Guardian April 2017 www.theguardian.com/money/2017/apr/24/disabled-traveller-airlines-flying-discrimination-damaged-property?platform=hootsuite

Jenny Gumbrell was left housebound and unable to work for several weeks after returning from a trip to New Zealand in mid-February 2017. After her flight arrived at Gatwick she discovered that her portable mobility scooter was in pieces, having been apparently dropped from some height. It was declared beyond economic repair and, since then, Jenny, from Winchester, who has multiple sclerosis, had to fight to persuade Emirates Airlines to pay for a replacement.

Airlines are only obliged to pay passengers a maximum of around £1,200 when their luggage is lost or damaged. The threshold was set in 1999 by the Montreal Convention which harmonises compensation rules for international flights.

In Ms Gumbrell's case, the £1,094 eventually offered by Emirates covered less than half the £2,200 cost of a new scooter and it included £105 she was obliged to pay to courier the damaged vehicle to the manufacturer when Emirates insisted it be professionally assessed. Moreover, it required four weeks of chasing before the airline made the offer.

Emirates finally agreed to fund the full cost of a new scooter after Ms Gumbrell contacted *The Observer*. *"We apologise for any inconvenience caused as a result of this,"* says a spokesperson. *"The comfort and wellbeing of all of our customers is of paramount importance, in particular customers with reduced mobility."*

In 2006 the European Commission introduced regulations which require airports to provide temporary alternatives if mobility aids are lost or damaged. However, passengers still complain of discrimination.

Campaigner Roberto Castiglioni set up the advice website Reduced Mobility Rights <https://www.reducedmobility.eu/> after attempting to fly with his severely disabled son. *"Access to air travel is not something people with special needs can take for granted because of the obstacles they meet getting onto a plane,"* he says. He advises travellers with mobility equipment worth over £1,200 to make a "special declaration of interest" when they book their flight. This is akin to an insurance policy covering the transport of goods worth more than the cap set by the Montreal Convention. It is illegal for airlines to deny this, but most airlines charge a fee, and it is only available on request and on a case-by-case basis.

WHAT THE RULES SAY

Under EU law airports and airlines are jointly responsible for

assisting disabled passengers to and from the aircraft and during a flight, provided they give 48 hours' notice of their requirements. This includes providing an alternative wheelchair if the passenger's chair is lost or damaged in transit.

Bizarrely, although airlines have to pay airports for that assistance, they are legally obliged to step in if the airport fails to provide the service. EC Regulation EC1107/2006, which enshrines the rights of disabled travellers, applies to all EU flights and aircraft. In 2014 the Civil Aviation (Access to Air Travel for Disabled Persons and Persons with Reduced Mobility) Regulations 2014 gave the UK regulator, the Civil Aviation Authority, legal powers to ensure airlines or airports comply with European regulations. Copy the following web link into your web browser if you wish to read the full article



Double Amputee Child Stuck At Gatwick Then Wheelchair Is Broken <https://metro.co.uk/2022/12/12/tony-hudgell-double-amputee-8-stranded-at-gatwick-for-five-hours-17921147/>

Tony Hudgell's £6,500 wheelchair was missing when he and his adoptive family landed at Gatwick Airport in the early hours of 12th December 2022 on a Jet2 flight from a 'magical' trip to Lapland to meet Santa.

After waiting for five hours for it with 'no help', it finally arrived – but it was 'twisted and bent'. The situation emerged despite his adoptive parents Paula and Mark pre-booking assistance. The family had already been hit by a 4.5 hour delay while travelling back to the UK as snow and ice hit the country.

Furious mum Paula tweeted about the 'appalling' situation, saying 'his wheelchair is his legs'. She tweeted a photo of a forlorn-looking Tony on an unused luggage conveyor belt at 3am. 'Appalled with @jet2tweets @gatwick_airport have been stranded for 3 hrs now with no wheelchair as its still on the plane', she wrote.

Tony was just 41 days old when he was assaulted by his birth parents, an attack which caused multiple fractures, dislocations and blunt trauma to the face, leading to organ failure, toxic shock and sepsis. He was left untreated and in agony for 10 days and was on the verge of dying before doctors at the Evelina London Children's Hospital saved his life. His injuries were so bad that both his legs had to be amputated. Tony has since been hailed as a hero after raising more than £1.8 million for charity.

A Gatwick Airport spokesperson has named the situation 'unacceptable' and apologised 'for the distress caused to the Hudgell family'. 'This is unacceptable and we have picked it up as

a matter of urgency with the airline, Jet2, and their ground handler, Menzies', they said. 'We experienced significant disruption last night and had to close the airport for a two-hour period for safety reasons.'

Jet2 replied on Twitter at 5.20am, saying they were 'incredibly sorry to hear of your experience'. They said they were contacting their team at Gatwick to solve the situation – but Paula replied saying it was 'sorted now but five hours too late as far as a wheelchair user needs ignored'. Metro.co.uk has contacted Jet2 for further comment..



How The Ancients Invented Prosthetics – *Edited from The Independent May 2017* www.independent.co.uk/life-style/health-and-families/healthy-living/severed-limbs-and-wooden-feet-how-the-ancients-invented-prosthetics-a7741996.html

We are living through an incredibly exciting period for prosthetics. A pioneering brain computer interface that will allow veterans to control artificial body parts with their minds was recently announced by researchers in Virginia in the US. Meanwhile, Newcastle University in the UK is developing limbs which “see” objects in front of them and react at speeds more comparable with the real thing.

Projects like these are steadily helping people with prostheses to move more naturally and easily than ever before. But what few people appreciate is just how far back this field actually goes.

Amputations and prostheses date back to ancient times, and saw advances that were heralded as no less life-changing then as they are today. Whether survivors in the ancient era were injured in battle by a blade, spear or missile, or in camp by frostbite or trench foot, their arms, legs and extremities were incredibly vulnerable. In Ancient Greece, they benefited from simple surgical amputations as far back as the late fifth or early fourth century BC.

Around the same time, orthopaedic surgery had refined to the point that prostheses were starting to become available as alternatives to staffs, sticks and crutches. We see this in the account of the Graeco-Persian War (499-449BC) about how the Persian diviner Hegesistratus, when imprisoned by the Spartans, amputated part of his own foot to escape his shackles, then procured a wooden replacement.

Egypt was using similar technology around the same period. Prosthetic toes made from wood or layers of fibre known as cartonnage have been recovered from burial sites, such as the one from a mummy near Luxor. They show signs of wear and tear, indicating that they were functional rather than purely cosmetic.

So when we see the latest prostheses giving veterans an

incomparable quality of life or helping athletes to achieve amazing things at the Paralympics, it is worth reflecting on the distance travelled. For the full article please enter the following link into a web browser:



Disabled Ramblers

The Disabled Ramblers is a small charity working across England and Wales to help make the countryside more accessible to people with limited mobility – which benefits everyone.

We Campaign

For the removal of man-made barriers such as steps, stiles, narrow gates and narrow bridges. We do not ask for tarmac everywhere.

We work with national bodies including:

Natural England, Natural Resources Wales, MOD,
Forestry Commission, National Trails, National Parks,
Areas of Outstanding Natural Beauty,
British Standards Institute, National Trust,
Joint Committee on Mobility for Disabled People,
British Horse Society and the Ramblers.

While we can offer advice, we don't have the resources to help with individual cases.

We Organise Rambles Designed For Mobility Scooters

We run 25 – 30 rambles each year, organised into groups of 3 or 4 in selected areas of the country. They are run from April to October, whatever the weather. All our routes are checked well ahead, with a written Risk Assessment, and are graded from Category 1 to 3, according to difficulty.

Our rambles take place in diverse areas of England and Wales. Click our Calendar of Rambles for more details.

<http://disabledramblers.co.uk/calendar/>

Our rambles are run over a variety of terrain which means that many rambles need the use of large mobility scooters such as the Trampler and the TGA Supersport but a few rambles can be done on 'shopping scooters' or sturdy, off-road capable, powerchairs.

If you have no suitable scooter of your own, we have four loan mobility scooters (Trampers) for hire – but only for use on our rambles by our members. Even if you can't ramble with us, please join and help support our work. Contact our Membership Secretary membership@disabledramblers.co.uk for further information.



Share the Vision' - <https://readingsight.org.uk/about-us/>

'Share the Vision' is a coalition of UK organisations that work together to improve the quality, availability and accessibility of library services for visually impaired and print disabled people. Our

partners include ASCEL, the British Library, Calibre Audio Library, ClearVision, Libraries Connected, and RNIB. Together we produce the Reading Sight website, which is a bank of resources to support anyone with an interest in helping people with sight loss to access reading and reading services.

Why we do it

One in eight people in the UK finds it difficult or impossible to access reading in alternative formats (large print, audio and braille).

Reading Sight

Reading Sight is a one-stop shop for people working in the libraries to find information that will help them to support visually and/or print impaired readers. This includes library managers, as well as front line staff, teachers and volunteers. Reading Sight promotes accessible reading and library services by providing information on:

- Accessible formats and the services that provide them
- How to join libraries and participate in reading groups and activities
- New developments in the world of accessible reading and reading technology
- Best practice for people working in libraries

Get in Contact

You can contact Share the Vision / Reading Sight via the following email address: info@readingsight.org.uk To keep abreast of news and developments in the field of accessible libraries and reading,



Spelthorne Para Sports Club



Aimed at young people aged 5-25 and their siblings, Spelthorne Para Sports Club provides opportunities to play a wide range of sports as well as offering sport specific coaching for those interested in developing skills. All sessions are overseen by enthusiastic volunteers although parents/guardians

are encouraged to stay on side during the sessions. No need to book - come and try - first session free!

Where - Spelthorne Leisure Centre, Knowle Green, Staines,

Cost - £3 a session (£2 for siblings) payable on the day.

When - 1st and 3rd Saturday each month 10:15-11:45am (term time) For more information please visit the council's web site

www.spelthorne.gov.uk/parasportsclub

Spelthorne Boccia Club

Boccia is a disability sport that is similar to bowls and petanque. The aim of the game is to propel leather balls, coloured red or blue, close to a white target ball (the jack).

It is played from a seated position and the ball can be moved with players' hands, feet or an assistive device eg a head or hand pointer.

Our club is aimed at people aged 16+ with disabilities (young people aged 14+ may join with an adult carer present)

Where - Spelthorne Leisure Centre, Knowle Green, Staines

When - Every Thursday 6pm - 6.55pm

Cost - £3 per week (no need to book, just turn up and join in)

For more information please visit the council's web site

www.spelthorne.gov.uk/boccia



Staines Shopmobility

making staines accessible

**Two Rivers (West Car park),
Mustard Mill Road,
STAINES, TW18 4BL.**

Telephone 01784 459416

The service will be available Tuesday to Saturday from 9.30am until 4.15pm, with the last equipment hire time of 3pm.

All equipment is to be returned by 4.15pm.

stainesshopmo@gmail.com

www.stainesshopmobility.com

www.facebook.com/stainesshopmobility

Membership Charges

Membership is available on a daily or annual basis. Please contact manager for details

Holiday Hire

Wheelchair- Overnight, Weekend, Week, Fortnight - maximum hire period of 6 weeks.

A Cash Deposit Of £50 Is Required.

Scooter - Overnight, Weekend, Week, Fortnight - maximum hire period of 4 weeks.

A Cash Deposit Of £100 Is Required.



Freedom

Accessibility

Independence

Confidence

**Charitable
Incorporated
Organisation
(CIO) 57628**



Disabled Britain – Doing It for Ourselves Series

Disabled Britain: Doing It For Ourselves, was a week-long series in July 2022 across the Daily Mirror's print and digital platforms,

showcasing the lives of disabled people and the issues important

to us. The articles have been conceived by disabled people, written by disabled people, and photographs - where possible - taken by disabled people.

Being Grabbed, Pushed Or Touched Without Warning Is Terrifying When You Can't See'

<https://www.mirror.co.uk/news/uk-news/being-grabbed-pushed-touched-without-27376323>

Visually impaired activist Dr Amy Kavanagh says she gets unwanted 'help' from people almost every time she leaves the house - and here explains why you must ask first.

I'm standing at the traffic lights, my Guide Dog Ava is by my side, and I'm waiting to cross the road. Suddenly a hand clamps my arm. I'm dragged into the traffic, but it's not safe, I can't hear the crossing beeps. Car engines roar around me, a scooter screeches, horns beep.

I struggle against the stranger's grip, but they won't let go, only holding tighter. Ava is next to me, confused and trying to keep up. I'm firmly shoved onto another pavement. The hand relaxes and a voice says "there you go love!". I'm disorientated, my heart is pounding, my arm hurts and I don't know where I am. Being grabbed, pushed or touched without warning is terrifying when you can't see. It doesn't feel helpful.

I was born visually impaired, so I've learned to navigate the world differently. I've memorised pavements with my feet, bumped my white cane around London and now I put my trust in a four-year-old golden retriever with a passion for carrots and escalators.

Like 93% of registered blind people in the UK, I have some useful vision. I can't recognise my own mother six feet away, but on a good day I might be able to read a zoomed up text on my PC. However, on a bad day nothing exists beyond dark shapes and bright light.

The world isn't built for blind people, so if something isn't accessible I often have to rely on strangers. Most of the time total strangers are amazing, kind and supportive. Even when someone has shoved me onto the wrong bus, people say, "oh they just want to be nice!" This is why I started a campaign #JustAskDontGrab.

Stop assuming disabled people are incapable. If you have good intentions then listen to us, we can tell you what assistance will be most useful. Disabled people are obviously the experts in our bodies and needs. So why is it so difficult to understand that disabled people deserve to choose how and when we accept help? The message is simple, if you think a disabled person needs help, just ask, don't grab!



What Does The White Cane Mean? *Edited from RNIB.org.uk*

Over one-third of blind and partially sighted people said that they sometimes, frequently or always experience negative attitudes from the public in relation to their sight loss especially when using a white cane.

The White Cane Explained

RNIB want to increase awareness with the general public, to help blind and partially sighted people feel more at ease when using their canes. To do this, they've created a simple infographic that demonstrates what the different types of cane are, and what you'd use them for.



Low But Useful Vision

The symbol cane is held in front to indicate that the person is partially sighted. It's particularly useful in busy places.



To Find Obstacles

A guide cane is held diagonally across the body and then used to find obstacles in front such as kerbs or steps.



To Show You Have Low Hearing And Vision

The Red and White banded canes of all types indicate a hearing impairment as well as sight loss.



To Avoid Obstacles For Those With No Vision

A long cane is rolled or tapped from side to side when walking, to find and avoid obstacles.

For more information visit the RNIB website at

www.rnib.org.uk/cane-explained



Braille Art Exhibition – Power of Touch

<https://www.mylondon.news/news/zone-1-news/visually-impaired-man-forced-carry-25806317>

Clarke Reynolds was born partially sighted in his right eye. As a teen, he was diagnosed with kidney problems and had to leave school as he was really ill and got treated at St Helier Hospital in Sutton, South West London. He wanted to always better his life but challenges kept throwing themselves at him. Clarke has never been able to see in a straight line but that didn't stop him from getting his degree in modelmaking in 2006.

When he eventually got a job as a dental modelmaker, he suddenly started noticing a dark shadow in his left eye. He was sent to the hospital and that is where he was 'brutally' told that he was going blind in his other eye.

Clarke, who now lives in Portsmouth but has worked in different parts of London throughout his life, added: "The doctor sat me

down, looked at my eyes, then asked 'do I drive?' I said 'yes' and then he said 'hand your license over, you're going blind'. That's how you're told, it's like ripping a band-aid off. Being blind has been my life so I never felt like it was the end of the world.

Clarke always had an affinity for being an artist and even after losing his sight, he didn't let that deter him. He continued: "Nobody in my family is creative but I always wanted to be an artist. I visited a gallery in Portsmouth at the age of six and that changed my life. I knew I always wanted to be an artist from then.

"Being blind, I didn't let that stop me so I studied and learned braille three years ago. Someone gave me a Perkins Braille typewriter and I started to learn it. Then I started thinking, this is an art form in itself.

Over the last three years, he has been exploring braille as an art form with bigger dots and now, Clarke has created his own exhibition, 'The Power of Touch'. It features 26 works of decoding braille pieces depicting his life through three different series. People have been encouraged to engage with the art in a similar way to how blind and visually-impaired people would, by wearing special glasses donated by the charity, The Vision Foundation.

He added: "I want people to go and see my art, no matter what age and feel like a child again. I want my art to be accessible to everyone and I want to be an inspiration to school children. Helping teach them about braille and sight loss. There's a school in London called Kings Cross Academy who have said they've named their Year Six class after me. I can only see my art through interaction and engagement from people.

"Kids don't have filters about asking me questions the same way adults do. There shouldn't be a stigma around being blind but it feels like there is and I want to break that. I want to be a role model for future generations of visually impaired children growing up and hopefully believe they can make it.

"Every day is different for me, people say I don't look blind. If it's quite bright, the second the light hits my eyes, everything goes black. I work in a lot of colours and have a memory for colour more than anything. I love being blind and I love what I've been doing. I get to wear my braille suit which people always want to touch. I'm just trying to live the best life I can be with the limitation that society has put on me.



Kew Gardens Walking Tours for People Living with Dementia, Sight or Hearing Loss (incl. BSL) and Community Well Being.

Kew have started their walks around the beautiful setting of Kew Gardens that are designed to be accessible for people living with

dementia, sight or hearing loss and for Community Well Being.

All walks start from Victoria Gate and last around 60 minutes. The walks are led by their volunteer walk leaders. Support workers, friends or family are very welcome and will also receive free entry to the Gardens. Please Check with Kew for any changes to the schedules

Forthcoming BSL Tour Dates

<https://www.kew.org/kew-gardens/whats-on/monthly-british-sign-language-tours>

Sunday 12 February 2023, 11am-12pm

Sunday 12 March 2023, 11am-12pm

Forthcoming Community Well Being Tours

<https://www.kew.org/kew-gardens/whats-on/community-wellbeing-walks>

Wednesday 1 February 2023, 11am to 12pm

Wednesday 1 March 2023, 11am to 12pm

Forthcoming Dementia Friendly Tour Dates

<https://www.kew.org/kew-gardens/whats-on/health-walks-for-people-living-with-dementia>

Wednesday 8 February 2023, 11am to 12pm

Wednesday 8 March 2023, 11am to 12pm

Forthcoming Sensory Tour Dates

<https://www.kew.org/kew-gardens/whats-on/sensory-guided-walking-tours-for-visitors-with-sight-loss-and-their-carers>

Sunday 12 February 2023, 2pm to 3pm

Sunday 12 March 2023, 2pm to 3pm

Walking tours have a limit to the number people who can participate for any of their Events and Walking Tours so it is essential that you register in advance for ALL walks and events at Kew. Email discovery@kew.org or Telephone 07341 114533.



Blind BBC Presenter Traps Attacker Who Stole His

Phone <https://www.mylondon.news/news/zone-1-news/blind-bbc-news-presenter-phone-25842113>

Blind BBC News presenter, Sean Dilley, nearly had his phone stolen but took matters into his own hands. He wrote: "A man on a bike just SNATCHED and stole my iPhone from my hand, wrong blind person, wrong day. Jumped on him, safely detained and got my phone back.

"I took a running jump and dive on the thief and knocked him off his bike and onto the floor, advised him that he was detained and called @metpoliceuk on 999.

I absolutely could have continued to detain the gentleman, but I got my phone back and I actually didn't want to risk injuring him. I

had him safely, detained on the floor, with my body weight across his legs and his wrists held to the floor."

Mr Dilley's tweets were met with an outpouring of concern and support from his followers. One person wrote "On the bright side, he's going to think twice before picking on another person with disabilities.

Mr Dilley, whose Twitter account says he is the Project lead for the BBC's Reframing Disability Programme, followed up his tweet showing he was still in some good spirits after the incident, replying to a tweet, he wrote: "I mean, how would I know but I strongly suspect he targeted me because he saw that I'm blind. I bet he wasn't expecting to be jumped on, and detained."

Phone thefts in London have been on the rise with Metropolitan Police figures showing in November there were 8,972 robberies of mobiles in London.

A Met Police spokesperson said: "Police were called on 27 December to reports of an attempted robbery. Officers attended and it was reported that a man was approached by a person on a bike who attempted to steal his phone. The suspect left the scene enquiries are ongoing to locate him.



World First Birth for Disabled Mother - Don't Lose Hope.

<https://www.standard.co.uk/news/health/hira-ahmad-london-mother-birth-bruck-syndrome-b1046767.html>

Hira Ahmad, from Wandsworth, London, gave birth to her daughter Dua on January 29 2022 despite having Bruck syndrome – a condition with fewer than 50 recorded cases worldwide which means she has brittle bones, restricted growth and uses a wheelchair.

The 28-year-old, who grew up breaking bones so regularly she was taken to a hospital every three months, wants to share her story to inspire other mothers with physical disabilities. "People doubt you... they will say 'you won't be able to have a baby, it'll be very difficult for you'," said Mrs Ahmad, an insurance officer at Wandsworth Council. "But I just want to put out there that no matter what, don't lose your hope.

"I want my baby girl to go out there and explain to people that my mum is someone who had Bruck Syndrome and is a wheelchair user full time, she's got brittle bones, but she still managed to deliver me in the safest way. "I want her to look up to me and have that inspiration from her mother."

Mrs Ahmad praised the care she received at St George's Hospital in London, stating that doctors talked her through every stage and listened to her input to help tailor her specialist care. "I was very worried about the whole pregnancy itself because I'm quite a petite

person and being in a wheelchair just brings more terror,” Mrs Ahmad said.

Mrs Ahmad said caring for Dua has been “difficult” over the last year and she has been helped by her mother and husband. She said she always had “hope” she would be able to have a child after a doctor told her at 12 years old that she would be able to get pregnant, but knew it would be difficult to do so.

Professor Khalil, consultant in obstetrics and maternal foetal medicine at St George’s Hospital, said “Hira’s story is hugely inspirational and I know all of the clinical team involved in her care are all so pleased with such a fantastic outcome,” We all wish Hira, her husband and baby Dua good health and happiness for their future.”

Jacqueline Totterdell, chief executive at St George’s, Epsom and St Helier Hospital Group, also congratulated Mrs Ahmad, adding: “Our foetal medicine team are highly skilled specialists seeing patients referred from all over the UK, but it’s particularly heart-warming to hear such an inspiring story from someone in our local community benefiting from the services we provide.”



Genetic Research ‘Changed Our Son’s Life’

<https://www.standard.co.uk/news/health/dna-nhs-writing-b1046738.html>

Sarah and Rob Everitt had spent years trying to get a diagnosis for their son, Owen, now nine, after noticing he was not hitting his milestones as a baby. He was eventually diagnosed with a very rare condition – resistance to thyroid hormone due to defective thyroid receptor Alpha – when he was four after taking part in the 100,000 Genomes Project.

This programme of work has enabled quicker diagnoses and is changing the face of healthcare by reading the DNA of tens of thousands of people.

Owen’s condition, caused by a genetic fault, affects how the cells throughout his body use the hormone thyroxine, which plays a role in digestion, heart and muscle function, brain development and bone health. Thanks to the 100,000 Genomes Project, Owen can now take thyroxine tablets and his health is much improved.

By the time that Owen was one he could not sit up properly, had no words and was not crawling or walking. Mrs Everitt said: “As well as not hitting milestones, he had bad reflux, bad constipation, absolutely no energy and he was pale and would just fall asleep all the time.”

Owen’s diagnosis was only discovered when he was being investigated for another condition, a rare anaemia. A consultant suggested he take part in the 100,000 Genomes Project in the

hope of finding a definitive answer.

After an anxious two-year wait, the family were recalled to be told scientists had found something in Owen's DNA that indicated a problem with his thyroid receptors. Only six people in the UK have been diagnosed with Owen's condition, with only around 30 cases reported worldwide.

Mrs Everitt said: "What they told us, changed Owen's life and it changed our lives. Owen's treatment is simple – he just takes a thyroxine tablet every morning and has regular check-ups to look at things like metabolism and bone density. Mrs Everitt said getting a diagnosis for Owen, had also saved the NHS money.

Owen continues to have some speech problems and learning difficulties and medics are unsure exactly what the future holds. But, Mr Everitt said: "He's in mainstream school, which had been a concern when he was little, whether he would be able to go.

Sometimes it's a struggle for him but he holds his own there." "Not everybody will want to have these screening tests and that's fine. "But Owen didn't get treatment until he was four and a half. We think, without it, where would he be now?"



Actor Warwick Davis – Dealing With Your Child's Death

<https://www.standard.co.uk/showbiz/warwick-davis-death-first-born-son-lloyd-dwarfism-complications-willow-disney-plus-b1050040.html>

The Harry Potter and Star Wars actor, 52, has recently spoken about how he and wife Samantha were left devastated after losing their first born son Lloyd, who died just nine days after being born in 1991 due to complications from dwarfism, which he inherited from both of his parents.

"I think it brings you closer together, or something like that. But it's an experience I wouldn't wish on anyone. It's devastating," Adding: "You do learn to live with it.

Eventually, over time, you're able to better understand why it happened and can come to terms with it a bit more. But you never get over it."

They later lost another baby boy to miscarriage several years after Lloyd's death. They decided to name this son George.

They are now parents to daughter, Annabelle, 25 and son, Harrison, 19 (who also both inherited Dwarfism from both their parents). "I think the losses shaped our family dynamic. We love Annabelle and Harrison more because they're here with us," he reflected.

Despite their heartbreak, he said that they are "grateful" for the short time that they had with their sons.

If you have experienced a bereavement and would like to speak with someone in confidence, contact Cruse Bereavement Care via their national helpline on 0808 808 1677.



Targeted for Robbery? - Signs to Watch Out For

The Safeguarding Hub - which shares home protection advice and information across the UK - previously said: "Between us, we have a fairly extensive knowledge of burglary.

We have spent many hours speaking to distraught victims, visiting crime scenes and dealing with burglars. We have actually seen and experienced these symbols being used by criminals. This is not to say that this is a common practice between bands of thieves, for most burglars work alone.

"We do not want to scaremonger and we can say confidentially that the use of these symbols is very rare. But, if you are a caregiver to an elderly or vulnerable person and spot strange marks outside their home, do you really want to dismiss it out of hand without just ensuring that the symbol is legitimate?"

Security firm Keytek has also highlighted the issue saying: "These 'robbery markings' or 'burglar signals' are basic sketches and forms that are supposedly used as a 'code' to determine whether a house is worth targeting.

These illustrations are also supposed to indicate to other thieves what type of person lives at the property, such as whether the residents are vulnerable, elderly, or live in a single-family home."

It added: "Chalk is the main material burglars use as it is easily removed and not as noticeable as materials such as spray paint markings outside the house.

As well as burglar chalk signs, burglars mark houses with almost anything they can; it may be a small blob of paint or a piece of string tied around a lamppost."



Woman With Epilepsy Told Valid ID 'Not Legal'

<https://metro.co.uk/2023/01/05/woman-asked-for-id-at-club-claims-she-was-discriminated-against-for-not-having-driving-licence-18044768/>

Cerys Fletcher, 21, has epilepsy so cannot hold a driving licence — meaning she uses a Validate UK ID card, an alternate card used to prove ID.

Cerys says half of the party — there to celebrate a friend's 21st — arrived at the venue at 6:40pm on January 1, 20 minutes ahead of their booking. The doorman asked for ID when they got there. "I handed him my ID and he glanced at it, and he said we do not accept this," she continued. "He said it's not a legal ID. "I've got

my bank cards out and a bright yellow slip of paper. That says I'm epileptic with my name and date of birth on. He still would not accept it."

Eventually, Cerys and her mates found another bar to celebrate the birthday, but she says she feels like she 'ruined' the event. In response, Peaky Blinders' management stood by its Challenge 25 ID policy. They also said they issued the group a full refund for the £90 deposit they paid.

A spokesperson said: "In line with the conditions on our premises licence, Peaky Blinders operates a policy, which requires patrons who look under the age of 25 to produce valid photographic ID. "We have since been in touch with the lead Booker who has explained to us that she missed these policies when booking. We have also provided them with a full refund."

The company that produced Cerys' card, Validate UK, ceased trading in 2021. However, CitizenCard**, the de facto replacement for Validate UK has confirmed that previously issued cards remain valid. That's provided they contain a PASS hologram which is not damaged, which Cerys' card does.

*** CitizenCard is an official UK ID / proof of age card recognised as such by the Home Office, the Chartered Trading Standards Institute and almost all UK retailers and public transport providers including UK airlines.*

The adult 18+ photo ID card displays the police and the Security Industry Authority logos and all CitizenCards bear the PASS hologram. A Standard application costs £15 and takes 21 days (card posted by Royal Mail 2nd class); an Urgent application costs £30 and takes 1-2 working days (subject to verification; card posted by Royal Mail Tracked 24 - next day delivery).



Spelthorne Community Centres Open On Saturdays

Spelthorne Borough Council is opening Community centres in Ashford and Shepperton on Saturdays until the end of February

The council hopes the six-day service will provide a boost to those most worried about the increased living costs and financial pressures.

Councillor Maureen Attewell, chair of Spelthorne's community well-being and housing committee, said: "A lot of our elderly residents are facing a worrying winter, with a significant proportion of their pension being spent on energy. I am really proud that our staff have stepped forward to extend the opening hours of the community centres and offer a warm and welcoming place where members can have a good lunch and meet with their friends, without having to worry about the heating.

The centres will be open from 10am to 3pm. Families are asked to book a place at their centre before visiting.

The following centres will open on weekends:

Saturday February 4th 2023 - Greeno Centre in Shepperton

Saturday February 18th 2023 - Greeno Centre in Shepperton

To contact the Greeno Centre, call 01932 246173 or email

Greenocentre@spelthorne.gov.uk

Saturday February 11th 2023 - Fordbridge Centre in Ashford

Saturday February 25th 2023 - Fordbridge Centre in Ashford

To contact the Fordbridge Centre, call 01784 243880 or email

fordbridgecentre@spelthorne.gov.uk



North West Surrey Drop-In Hubs

Addlestone – 2nd and 4th Wednesday of each Month

KnapHill – Every Monday

Shepperton – 1st and 3rd Wednesday of each Month

Surrey Downs Hubs

Epsom - 1st and 3rd Tuesday of each Month

Hersham - 2nd and 4th Monday of each Month

Leatherhead – Every Friday

To contact Action for Carers Surrey, Telephone 0303 040 1234

Email CSAdmin@actionforcarers.org.uk Text 07723 486730

Web site www.actionforcarers.org.uk



Disability Rights UK (DRUK)



Disability Rights UK

Disability Rights UK Helplines

Our helplines are operating as normal:

Personal Budgets Helpline

Opening hours: 9.30am-1.30pm on Tuesdays and Thursdays

Telephone: 0330 995 0404

personalbudgets@disabilityrightsuk.org

Disabled Students Helpline

Opening hours: 11am-1pm on Tuesdays and Thursdays

Telephone: 0330 995 0414 students@disabilityrightsuk.org

Welfare Rights Helpline for Member Organisations

Opening hours: 10.30am-12.30pm Tuesdays and Thursdays

Telephone: 0203 687 0779 ken.butler@disabilityrightsuk.org

PLEASE NOTE – *The news Bulletins received from **Disability Rights (DRUK)** and the **Surrey Adult Social Care Information & Engagement Team** are now being distributed as enclosures with each monthly SCAN Newsletter.*

Please email me on info@spelthorneaccess.org.uk for more copies of these enclosures



Disability Empowerment Network – North Surrey & Surrey Wide

Administration and management of the Disability Empowerment Network (DEN) meetings is arranged by the Surrey Coalition of Disabled People (SCDP)

All Empowerment Meetings Continue To Be Held Via Zoom unless otherwise noted

North Surrey Meeting Dates 2023 - covers the areas of Runnymede, Spelthorne, Woking & Surrey Heath.

Monday 6th March 2023, 1pm-2.30pm,

Surrey Wide Meeting dates for 2023

Monday 13th March 2023, 6pm

For more information, please contact:

involvement@surreycoalition.org.uk or Tel/SMS 07492 249 513 for details of how to participate in meetings remotely.



SCAN and Spelthorne Physical, Sensory & Cognitive Disabilities Forum (SPSCDF)



The meetings bring together service providers and users to influence the solutions to any problems or access issues

encountered by people with physical, sensory and cognitive disabilities.

For further information about the forum or to send your news or reports email info@spelthorneaccess.org.uk or visit SCAN's web site <https://www.spelthorneaccess.org.uk/news/scan-news/spscd-forum/>,

Hybrid meetings continue in the Goddard Room at Knowle Green The next meeting will be on **26th April 2023** beginning at 12 Noon.

This meeting will be in the usual format, with updates of Forum Reports from Service providers to the disabled community followed by SCAN's reports.



Alison Lyons, Sesame Access, Awarded OBE – Extracts from www.sesameaccess.com/

Alison Lyons, Sesame's Director of Commercial Development, has been awarded an OBE in the 2023 New Year's Honours list. The OBE was awarded for services to the Department for International Trade and people with disabilities.

Alison Lyons said "I am very honoured to have been awarded an OBE in the 2023 New Year's Honours list. This OBE belongs to everyone at Sesame Access.

Alison's father Charlie founded Sesame Access in 1996 after a friend commented that his wife, who used a wheelchair, couldn't get into the London art gallery that was a Grade I Listed Building, with steps up to the front door.

The first Sesame lift was installed in Merchant Taylor's Hall, Threadneedle Street in 1997. This lift is still working. Sesame has now installed their lifts in more than 200 buildings across the world. Their International clients include Sydney Opera House, Seattle Space Needle, Qatar National Library, Sotheby's and Christie's Auction Houses Paris and Apple Stores.

In November 2016 they were presented with The Grant of Appointment by the Lord Lieutenant of Surrey signed by The Queen and The Prime Minister.

Charlie (and Alison) were then invited to Buckingham Palace to be presented with The Queens Award for Enterprise.

The company also hold an Independent Living Design award and a Millennium Product marquee awarded by the Design Council in testament to the creativity of their products.

Alison will collect her OBE at Buckingham Palace before July 2023



While every care has been taken in the compilation of information included in this newsletter, no responsibility is accepted for any loss, damage or inconvenience caused because of any inaccuracy or error in an article that has not been independently substantiated. The inclusion of information does not imply any endorsement or any association with a contributor's services or products.

If you no longer wish to receive this newsletter or any other correspondence from S C A N, please send your request to 'Unsubscribe' to the email address on the front page of this newsletter or send to the return address on the reverse of the envelope.

