

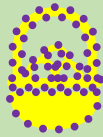
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1992 – 2023

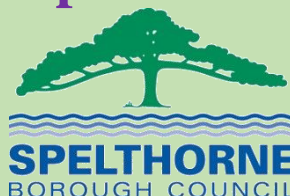


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## **Elmsleigh Centre Changing Places Facility**

The Elmsleigh Centre in Staines is delighted to announce that a new fully accessible Changing Places toilet facility has been installed and is now available to visitors with complex needs.

Changing Places toilets include a hoist, an adult size changing bench and generous space for a disabled person and up to two Carers.

Spelthorne Borough Council applied for a funding grant for £40,000 from central Government which covered the cost of installing the new facility which is located on the first floor of the Elmsleigh Centre and accessed via the lift by Costa Coffee.

Thousands of people with profound and multiple learning disabilities, as well other disabilities that severely limit mobility, cannot use standard accessible toilets. People may be limited in their own mobility so need equipment to help them or may need support from one or two carers.

Accessible toilets do not usually provide changing benches or hoists and are often too small to accommodate more than one person. Without Changing Places toilets, the person with disabilities is put at risk, and families are forced to risk their own health and safety by changing their loved one on a toilet floor.

It is now accepted and expected that everyone has a right to live in the community, to move around within it and access all its facilities, but for some people with disabilities the lack of a fully accessible toilet is denying them this right.

The Mayor of Spelthorne, Cllr Susan Doran opened the Changing Places facility on 23 February. She said: "We are pleased to have helped obtain the funding needed for this project. Changing Places toilets can make a dramatic difference to the lives of thousands of people who feel isolated in their homes because of the lack of appropriate facilities. It's a very simple thing but will make a big difference to many."

Gary Little, Centre Manager for the Elmsleigh Centre, said: "We believe this new facility will make the Elmsleigh Centre an even more welcoming and inclusive place to visit. Changing Places toilets have more room and specialised equipment which mean people with severe disabilities and their families can visit the town centre knowing their needs are catered for."

Ken Saunders, Chair of Spelthorne Committee for Access Now which supports people with disabilities, said: "A lack of fully accessible toilets can severely restrict people's ability to take part in everyday activities and robs them of their dignity. Just knowing

these facilities are available can take away much of the worry and stress around going out.”

For more information about Changing Places, including a map of facilities, visit [www.changing-places.org](http://www.changing-places.org)

Photo: Elmsleigh Centre Manager, Gary Little and the Mayor of Spelthorne, Cllr Susan Doran, at the Changing Places facility at the Elmsleigh Centre in Staines.



## **Walking For Health Scheme**

<https://www.spelthorne.gov.uk/walkingforhealth>

The Spelthorne Walking for Health Scheme is part of the National Walking the Way to Health Initiative that aims to improve health and fitness of more than a million people, especially those who are not physically active and want to become more active.

The Spelthorne scheme started in May 2003. Walks are designed for total beginners and are between one and three miles. The walks take place at least once a week in various areas of the Borough. All walks are led by volunteer walk leaders who have undergone the ‘walking the way to health’ training. There is always a front leader and back leader in order that all walkers can take part at their own pace.

Physical activity should not pose any problem or hazard for most people. In order to identify those who should seek medical advice before walking, you will be required to complete a short health questionnaire before taking part of the scheme.

To receive a form by post contact Leisure Services on 01784 446433 or download the form from the Council’s web site and bring it along to your first walk to hand to a walk leader.

### **Important walk information**

Please bring any medication you may need with you (eg inhalers) and let us know if there are any changes to your health. Wear comfortable shoes with good grip and support and loose fitting clothing, as this will allow you to move freely. Long trousers are recommended in case of nettles/thistles. Bring waterproof clothing in case of rain. Please note our walks are for adults only. If there is a café or pub nearby, leaders and walkers often stop for a drink and a chat after the walk. Everyone welcome.

### **Facts about walking**

- health professionals recommend that you should participate in at least 150 minutes of moderate physical activity every week
- a 'brisk' walk should make you breathe a little faster and feel warmer
- the intensity should feel comfortable and you should be able to talk

## Walking can

- make you feel good and give you more energy
- help reduce stress and help you sleep better
- reduce blood pressure
- help to manage your weight

## Why walk?

- it's a chance to meet new people and make friends
- almost everyone can do it
- you can do it anywhere and any time
- there is very little risk of injury
- it is free and you don't need special equipment
- you can start slowly and build up gently

## Become a Volunteer Walk Leader

The Spelthorne Walking for Health scheme would not be possible without our amazing volunteers. From volunteer walk leaders and assistants to admin and promotion roles, our volunteers do a fantastic job in supporting and developing the scheme. We are currently looking for more volunteers to help lead the walks. We provide all walk leaders with full training and support. No previous experience required, just a willingness to help and to share a passion for walking.

If you are interested in becoming a volunteer Walk Leader or would like more information on our walks, please contact Leisure Services on 01784 446433 or email [leisure@spelthorne.gov.uk](mailto:leisure@spelthorne.gov.uk)



## 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 16 April 2023 11am-12pm**

### Forthcoming Community Well Being Tours

<https://www.kew.org/kew-gardens/whats-on/community-wellbeing-walks> **Wednesday 5 April 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 12 April 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 16 April 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](mailto:discovery@kew.org) or Telephone 07341 114533.



## Being Disabled Costs Me An Extra £13,000 Each Year

<https://metro.co.uk/2023/03/02/ive-worked-out-that-being-disabled-costs-me-an-extra-13000-each-year-18360562/>

Shani Dhanda is a broadcaster, social entrepreneur and award-winning disability specialist. She was born with a rare genetic condition called Osteogenesis Imperfecta, commonly known as Brittle Bones Disease. It means that bones break without any trauma, and she is just under four feet tall, about the height of a four-year-old.

But another, perhaps less obvious, side effect of her condition is how difficult it has been finding meaningful employment. In a recent article for Metro she said *'When I was 16, and looking for a part-time job while I was in college, I applied for over 100 roles and got nowhere. Someone flippantly told me that I didn't actually have to work and that I could rely on disability benefits instead.'*

*It's a big misconception that when you experience a disability or live with a health condition or impairment that everything you may need, such as equipment or welfare support, is really easy to get, and there's lots of it as if it's all being handed out like sweets. And plus, I didn't want to do that. I couldn't understand why I was being encouraged to rely on benefits when I could work and contribute to society.*

*I kept applying, but it wasn't until I removed any mention of my condition from my CV and cover letter that I was first offered an interview. And back then, I had no idea just how much it was going to cost me. Because, regardless of if you work or not, the economic impact of experiencing disability or living with a health condition is significant, and we are far more likely to be poorer than the rest of the population. It's why we're disproportionately affected by the cost-of-living crisis and cannot absorb the increase in the prices of goods and services.*

*Disabled people are twice as likely to be unemployed and have to*

*apply for 60% more jobs before they find work. And even disabled people who do secure employment are typically paid less; the disability pay gap rose to 17.2% in 2022, meaning disabled people are paid £3,731 less than non-disabled people per year based on a 35-hour working week. This equates to working 54 days of the year for free.*

*In recognition of these increased costs, the government provides disability-related financial support through benefits, tax credits, grants and concessions – but the money doesn't come close to meeting the true amount of the extra costs we face.*

*It's one of the reasons I work with businesses and brands to transform the experience for their disabled employees and customers. And it's why I've campaigned tirelessly to raise awareness of the extra costs disabled people face for years.*

*But I'd never totalled up my extra costs until now – and I was shocked at the number. Can you imagine being able to part with over £13,000 every year, just to be able to carry out basic, and essential tasks?*

*I want to live in a society where employers value diversity and understand the wealth of talent disabled people can add to an organisation. I want to see social tariffs for energy and gas implemented for vulnerable users like disabled and older people, along with a real-terms uprate in welfare support that actually meets the extra costs we face.*

*I've created an app called Diversability Card to help disabled people save money on everyday products and services, which I hope to launch this year. Because being disabled cannot continue to cost the earth. Join the waiting list at <https://www.diversabilitycard.co.uk/>*



## **Boy Hears His Family After Cochlear Implant Surgery**

<https://www.dailymail.co.uk/news/article-11772947/amp/Moment-four-year-old-boy-hears-family-time-getting-cochlear-implant-surgery.html>

In a video originally shared to TikTok, a mother of three posted footage of her four-year-old son Sawyer hearing his family's voices for the first time after receiving cochlear implants.

Christina Lenglin's son had been diagnosed with Pendred syndrome, a genetic disorder that causes early hearing loss in children. In the footage she shared, the giggly young boy is scene after undergoing cochlear implant surgery in Ontario, Canada.

As the sound levels on his devices are turned up for the first time, the child begins to grin ear-to-ear, prompting his emotional mother to say, 'That's the biggest smile I've ever seen him do.' Big sister Rosie, is beyond thrilled to welcome her brother to the world of

hearing, and [we as] parents are also elated to have the magical opportunity to communicate verbally with [our] son,' she wrote.

Rosie asks her parents if the operation will change Sawyer's life, and her mother says it will, 'for the better, maybe.' Sawyer, said Christina, 'courageously braved the surgery and now happily tackles the journey to learn how to hear and understand English.'

Both Sawyer, and his baby brother Tucker, were diagnosed with Pendred syndrome and though the Canadian government pays for the first set of cochlear implants for each child, replacements, which are needed every five years, are not covered by the country's socialized medical system. According to the family, cochlear implants for both boys will cost some \$30,000 CAD - about \$22,300 USD - every five years.

Christina told Storyful, where the video was also shared, that she would like if her son's story helped highlight the issue of access to hearing surgery and access to American Sign Language.

'We will have to choose between ASL or speech therapy; neglecting either his speech learning or neglecting respecting his Deaf culture,' she said. The family has launched a GoFundme page for Sawyer and his younger brother's future surgery and implants. '[We] are so proud of his resiliency and adaptability- we all hope we can help make a change,' said Lenglin.



## **Designer Alters Father's Jackets for Dialysis Treatment**

<https://www.independent.ie/world-news/and-finally/woman-in-awe-of-viral-reaction-after-adding-zips-to-fathers-dialysis-jackets-42369635.html>

A fashion designer based in San Diego has said she was "in awe" after going viral by crafting six jackets for her father with zips in the sleeves so he doesn't get cold during dialysis treatment.

Mina Fox, 28, posted photos to her Twitter account that showed her father, Sean Shelton, 53, proudly standing in the newly-altered jacket which will stop him feeling chilly while he receives treatment for kidney failure.

Ms Fox's tweet, which said Mr Shelton "liked them so much" he made her create six more, quickly accrued more than 170,000 likes and over 4.4 million views from users who praised the idea.

"It's really touching, I had no idea that I would make such a big impact on the internet," "I'm still shocked, I don't even really have the words for it... I'm just in awe. "Dialysis is still new to me, so hearing stories about what other people went through... It really touched me. "Reading these stories really made me cry a lot – like all day."

Mr Shelton, his daughter explained, has been on dialysis since

November 2022. It is a procedure to remove waste products and excess fluid from the blood when the kidneys stop working and requires a needle in the arm – where Mr Shelton will now have a zip handy to keep him warm.

Ms Fox was flooded with comments heralding her work, with many suggesting she should sell the designs. While she said she wants the jackets to remain “as accessible as possible” and would not “feel right” about selling them, Ms Fox has offered users a tutorial explaining how she made the jackets. “Hopefully it gets around and helps a lot of people out there.”



## 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 of each month 10:15-11:45am (term time)

For more information please visit the council's web site

[www.spelthorne.gov.uk/parasportsclub](http://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](http://www.spelthorne.gov.uk/boccia)



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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](mailto:stainesshopmo@gmail.com)

[www.stainesshopmobility.com](http://www.stainesshopmobility.com)

[www.facebook.com/stainesshopmobility](https://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.**



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## **Changes to Parking Meters Will Isolate Elderly & Disabled** <https://inews.co.uk/news/scrapping-traditional-pay-display-parking-meters-isolate-elderly-disabled-people-critics-say-2174374>

The expansion of cashless systems for parking payments threatens to isolate elderly and disabled people critics say as more councils turn away from traditional pay and display machines.

Bromley Council is one of the latest local authorities to modernise its parking payment facilities with the RingGo service. The system means that motorists can no longer use cash to pay for parking. Instead they must download the RingGo app, or call or text to pay. Anyone without a mobile phone can call and pay in advance from a landline, but this does not guarantee them a parking space on arrival.

Councillors who oppose the expansion, which will result in all other forms of payment being axed, say the move will prevent some vulnerable people from using their cars in the area. Cllr Alison Stammers of independent party Chislehurst Matters, said:

“Fundamentally, it will stop some residents being able to use their cars if they need to park in a Bromley car park, or they will have to rely on others to help them pay, so losing much-valued independence and adding to loneliness and isolation, and potentially mental health issues. The scheme definitely disadvantages elderly people who have not embraced and do not feel confident about embracing mobile technology,” she added.

Caroline Abrahams, charity director at Age UK, said: “It’s important that everyone can park near services, appointment venues and amenities, but the fact is that not all older people have a smartphone or a credit card, nor the ability to easily use automated services on a landline, so the parking opportunities for anyone in this position are increasingly limited. “If they have mobility issues as well, then it can be even worse, shutting them out of town centres and other busy areas if they depend on using their car but have no prospect of parking it. We are a long way away from a world where digital tech can help everyone, and public bodies and businesses running parking services should recognise this.”

In defence of the changes, Cllr Nicholas Bennett, executive councillor for transport, highways and road safety, said parts of Bromley had “successfully operated without pay and display machines for some years” and the council was following many other boroughs who switched to cashless payments.

Peter O’Driscoll, managing director, RingGo, said: “Large sections of the population need to rethink their preconceptions about seniors. Rather than assuming they are against or fearful of technology, we must understand their needs and provide appropriate support.”



## **Diagnosed With Life Changing Disorder Aged 21**

<https://www.mylondon.news/news/health/man-21-diagnosed-life-changing-26410424>

A mum-of-two. whose son was diagnosed with a rare genetic disorder at age 21 has called for early years screening for the heart breaking disease. Vivienne Clark's, 73, son, Scott, was diagnosed with adult-onset metachromatic leukodystrophy (MLD) just weeks before his graduation - at age just 21.

MLD is a rare hereditary disorder that causes fatty substances to build up in cells and is life-limiting. Scott, now 50, slowly declined, and Vivienne demanded Scott was referred to a neurologist. After multiple tests, including CT and MRI scans, Scott was diagnosed with MLD.

Scott now lives in a care home, as Vivienne is unable to look after him herself, but he spends time with the family on weekends and

"loves a Sunday roast". Vivienne Clark, Chair of MLD support UK, from Learnbay, Kent, said: "That day our normal life came to an abrupt end. "I have to say that his brother who was a donor is also a carrier, and he still feels guilty. Once a sibling is diagnosed they automatically test the parents and other siblings. "There is a huge guilt, and all the families suffer terribly, the guilt of knowing that one of your children is going to die and the other one is going to survive is awful. I was lucky that my other son was just a carrier and he didn't have the disease."

Vivienne is calling for the UK to implement early screening to prevent children from dying from MLD. She said: "The point is we have a treatment that stops MLD it is criminal not to test children and to let them die because we are not testing.

Scott was at the University of Bristol to study History and planned to go into politics. At the age of 21, his family started noticing changes in his personality and noticed he became forgetful. After a year of slow deterioration, Scott was referred to a psychiatrist. Vivienne said: "Scott was expected to go on and do a PhD after university but that was not to happen as his cognitive decline had already started. It took us two years to get the diagnosis, they assumed it was psychiatric schizophrenia. By the time we got the diagnosis he had already deteriorated."

Scott was diagnosed with adult-onset MLD in August 1995 after spending a week at the Royal Free Hospital, London, for tests. After his diagnosis, Vivienne started doing research into bone marrow transplants and managed to get Scott a transplant - replacing damaged blood cells with healthy ones. Vivienne said: "Scott's elder brother, Russel, turned out to be a perfect 6/6 match which saved a lot of time. The transplant took place in February 1996, just a week after Scott's graduation from the University of Bristol and just before his 21st birthday.

"It was a traumatic year – never underestimate how dreadful a bone marrow transplant can be. However, it was Scott's only hope and he signed the consent form himself for the treatment to go ahead." Scott continued to deteriorate but began to stabilise six months after the transplant. Unfortunately, his body rejected the transplant and in 1998 he had to have a stem cell transplant again from his brother Russell, 53.

Vivienne said this was Scott's "last chance". The stem cell transplant was a success but Scott developed acute Graft vs Host Disease (GvHD). The condition occurs after a transplant and affected Scott's skin and liver - Scott is still suffering from chronic GvHD but the condition does not affect his general health or life.



## News from SCAN's Archive – 2020

### Supermarkets Failing To Provide Accessible Toilets

[www.muscardystrophyuk.org/press-releases/most-supermarket-chains-arent-providing-enough-fully-accessible-toilets-for-disabled-customers/](http://www.muscardystrophyuk.org/press-releases/most-supermarket-chains-arent-providing-enough-fully-accessible-toilets-for-disabled-customers/)

Disabled people and their families are being excluded from things as simple as shopping because some of the UK's largest supermarkets and retailers do not have a fully-accessible Changing Places toilet.

Changing Places are needed by a quarter of a million disabled people in the UK, for whom standard accessible toilets are not suitable. But Muscular Dystrophy UK's research into provision at supermarkets shows that Waitrose, M&S, Aldi, Lidl, Iceland and Co-op do not have a single registered facility.

Tesco, which partnered with Muscular Dystrophy UK earlier this year to roll out facilities at stores where there is the greatest need, is leading the way with 48 registered facilities and more due to be installed later this year and in 2020. Asda has registered seven, Sainsbury's three, and Morrisons one.

Muscular Dystrophy UK, which co-chairs the Changing Places Consortium, has also found that:

- Less than 0.1% of retailers have a fully-accessible Changing Places toilet. There are currently 80 registered Changing Places toilets in supermarkets and other shops across the UK
- Some of the UK's best-known shopping areas don't have a registered facility. The nearest to the world-famous Oxford Street, for example, is at Great Ormond Street Hospital, nearly two miles away
- 40% of the top 50 ranked shopping centres in the UK do not have a registered Changing Places toilet. There are 92 Changing Places toilets in total
- Some counties, including Bedfordshire and Lincolnshire, do not have a single registered Changing Places toilet in a shopping centre or shop. There are also no Changing Places toilets in any Greater London retailers



### NHS England Deal For Cystic Fibrosis Drugs

[www.england.nhs.uk/2019/10/nhs-england-concludes-wide-ranging-deal-for-cystic-fibrosis-drugs/](http://www.england.nhs.uk/2019/10/nhs-england-concludes-wide-ranging-deal-for-cystic-fibrosis-drugs/)

NHS England announced in October 2019 that it has secured a definitive agreement to make available all three of their UK-licensed cystic fibrosis medicines. This means NHS patients will now have full access to Orkambi, Symkevi and Kalydeco, and around 5000 people may now take up these

treatments. There is no cap on patient numbers, and each and every patient in England who might benefit can now get these treatments, free on the NHS. Clinicians will be able to begin prescribing these drugs within 30 days.

Announcing the agreement, NHS Chief Executive Simon Stevens said: “The UK has the second highest prevalence of cystic fibrosis of any country in the world, so today is an important and long hoped for moment for children and adults living with cystic fibrosis. “That fact also means that any drug company wanting to succeed commercially in this field needs to work constructively with the NHS.

Meindert Boysen, director of the Centre for Health Technology Evaluation at NICE, said: “We are pleased an agreement has been reached between NHS England and Vertex that brings these medicines to patients. It is also welcome that the company will now re-engage with the NICE process.



## How Therapy Pets Can Help Children In Need

[www.independent.co.uk/health\\_and\\_wellbeing/therapy-pets-children-animal-health-dog-llama-a9204116.html](http://www.independent.co.uk/health_and_wellbeing/therapy-pets-children-animal-health-dog-llama-a9204116.html)

Whether they are fluffy or furry, studies suggest that contact with animals has significant benefits for the mind.

Ben\* is a young resident at one of Calcot Services for Children’s ([www.csfc.co.uk](http://www.csfc.co.uk)) residential care homes called The Lodge. The homes are based in Berkshire and Hampshire. Each of the homes uses pet therapy to help the children heal emotionally and emerge into the world more confidently with a greater degree of trust in others. He a shy child who couldn’t bear the gaze of another human, whether child or adult

But now, he was slowly but most certainly and surprisingly coming out of his shell as he reached forward again to caress the tufty mane of Lola, a five-year-old alpaca. His eyes sparkled as Lola bobbed her head towards his arms looking for more affection. Ben gazed lovingly at Lola and told her she was a ‘good girl’.

Weeks later he started to trust his surroundings more and even started to speak to people, other children and adults too. He opened up and started healing and learning to live life on life’s terms.

Another organisation, the charity Parent and Child Together North East ([www.pactne.co.uk](http://www.pactne.co.uk)) a supported housing project for vulnerable families, based in a semi-rural location on the edge of Darlington, County Durham also deploys animals in therapeutic ways.

The families who live there are vulnerable for a variety of different

reasons, including challenging home lives. The charity provides comfortable family homes and support includes parenting training, counselling, advice and guidance, and recreational and occupational activities. They live in well-equipped wooden cabins and enjoy plenty of space and fresh air as well as the company of goats, alpacas, chickens and a dog.

Mick Sutcliffe, operations manager of the project, says the families all enjoy the company of the various animals but it's the dog (a rather portly schnauzer called Schubert) who has the most therapeutic impact on the families. "Everyone knows him, plays with him, talks to him ... and feeds him," he says.

Whether a dog, goat or alpaca, the unconditional love and companionship of an animal can bring enormous therapeutic benefits. The remarkable journeys of the children and young people in the care of organisations that are investing the time and other resources in mining this rich therapeutic seam are surely testament to that.

*Marie Carter is the Editor of Pets Magazine (www.petsmag.co.uk), a digital magazine for pet-owners.*



## **Challenging Hearing Loss Stereotypes**

[www.booktrust.org.uk/news-and-features/features/2019/november/samantha-baines-on-challenging-hearing-loss-stereotypes-in-her-book-harriet-versus-the-galaxy/](http://www.booktrust.org.uk/news-and-features/features/2019/november/samantha-baines-on-challenging-hearing-loss-stereotypes-in-her-book-harriet-versus-the-galaxy/)

Comedian and author Samantha Baines has written a super-fun adventure for children (*Harriet Versus the Galaxy*), with a character (Harriet) who happens to be hearing impaired – and with a hearing aid that proves to be a bonus!

Harriet discovers that her hearing aid translates alien languages when she finds a creature from out of space under her bed. Harriet uncovers a few more surprising things too and is charged with protecting the planet from the Munchas, who eat things like socks, pens and, even, knickers!

Samantha Baines was just 30 when she noticed a peculiar whooshing noise in her ear. An actress and stand-up comedian, Baines first heard the sound at the Edinburgh Festival Fringe in 2016. "It was like a whirring noise or a tiny animal rustling around.

Following months of anxiety I went to the Doctor and was told I had tinnitus. I think it's so important that all children see themselves represented in books. When I discovered I needed hearing aids, I was an adult. Even so, I felt alone and "other", like it would hold me back in my career and social life. In contrast, three years on, I can honestly say that getting a hearing aid is one of the best things that ever happened to me. Sometimes out of challenge comes the most incredible people and experiences. I

have realised that myself and I wanted Harriet's story to represent that, too”

I think it's so important that all children see themselves represented in books. Sometimes out of challenge comes the most incredible people and experiences. I have realised that myself and I wanted Harriet's story to represent that, too.

Being an ambassador for both Action on Hearing Loss and the British Tinnitus Association has been incredible, and I have got to meet so many people who have had similar experiences to mine. But adults were always asking me if I could recommend any books or films for children that mentioned hearing loss. I personally couldn't list any, so I decided to create one.

It was so important to me that Harriet's hearing aid doesn't hold her back. It's actually a bonus. I wanted the book to be a fun adventure that everyone can enjoy first and foremost with an awesome little girl with a hearing aid and her non-binary friend who aren't defined by being "different". They are defined by their personalities and skills in saving the planet.



**Disabled Workers Paid Less Than Other Workers** – *Edited from The Independent November 2019*

[www.independent.co.uk/news/business/news/disabled-workers-paid-less-work-gap-tuc-a9184061.html](http://www.independent.co.uk/news/business/news/disabled-workers-paid-less-work-gap-tuc-a9184061.html)

According to the analysis, disabled workers earn on average £1.65 an hour less than non-disabled workers. People with disabilities are also less likely to be in work, facing barriers to accessing employment, said the union organisation.

Around half of disabled people are in work, compared to more than four-fifths of non-disabled people, a gap of almost 30 per cent, said the TUC. The TUC said its research indicated that disabled people effectively work for free for the last 57 days of the year, so they stop getting paid from today.

General Secretary Frances O'Grady said: "Everybody deserves a fair chance to get a job with decent pay. Being disabled should not exclude you from choosing to work, and it should not mean you are put on a lower wage.

James Taylor, of disability equality charity Scope, said: "Everyone should be doing their utmost to close this gap as quickly as possible.

"One million disabled people want to work but are denied the opportunity. "The next government must commit to halving the disability employment gap, which has been stuck around 30 per cent behind for over a decade."

## **Ben Elton's Admission About Ableist Slurs In 'The Young Ones'** [www.independent.co.uk/voices/ben-elton-ableism-the-young-ones-scope-25-cerebral-palsy-a9208911.html](http://www.independent.co.uk/voices/ben-elton-ableism-the-young-ones-scope-25-cerebral-palsy-a9208911.html)

It's hard to believe it's been 25 years since Scope, the disability charity, got its new name. Particularly when you think about how much has been achieved since that very proud day in 1994, which I was honoured to be a part of.

That name change meant a lot to me. It was part of the steep learning curve which I'd been on regarding the casual prejudice and discrimination disabled people experienced on a daily basis.

Of course, I cringe to even write this now and the only plea in mitigation I can offer is that my intention had been that the joke would be on the character of Rick, which was so brilliantly played by the late, great Rik Mayall. I had hoped that he'd look a fool for offering such a tired and witless playground insult as if it was some brilliant Oscar Wilde-style put down.

The letters I received from the parents of kids with cerebral palsy opened my eyes to the reality of what I'd contributed to.

The Young Ones was hugely popular with young people at the time and was much quoted in the playground. In our wretched naivety and thoughtlessness, Rik and I had legitimized the use of the word "spastic" as a term of abuse. Any satirical subtlety that I'd hoped for had been lost in the thoughtless cruelty of the playground.

Words matter and language has consequences. You'd think that I, as a writer and a drama graduate, would have known that. But – as I have learned over the years – there really is no limit to the thoughtlessness (often well-meaning) that non-disabled people can show to disabled people. In writing that line in *The Young Ones*, I proved that I am no exception to that rule.

The upside of this story was that, a few years later, I was able to use the experience in my second novel *Gridlock*, which featured two disabled people as its heroes.

The whole novel was in fact inspired by a chance encounter with a young man who had cerebral palsy. I only met him once, and I'm not even sure I ever even knew his name, but he helped to further open my eyes to my own unconscious prejudice and in doing so, he planted the seed of one of my most successful novels.

I wonder if he's reading this and recalls the encounter? If so – thank you brother! I owe ya!

I started imagining a brilliant mathematician whose cerebral palsy led people to making the fatal mistake of underestimating him! Geoffrey, the campaigning eco-scientist of *Gridlock* was born.

While writing the novel, I thought and read a lot about disability and continued to think about all that underestimated potential. I



got so enthused about it that I made the other hero of the book a young woman who has paraplegia.

The story was about traffic-induced urban paralysis (Gridlock!) and I figured a girl who had to deal with the issue of urban mobility every second of her life, while fighting to have access to the stuff the rest of us take for granted, might prove a fittingly astute and inventive comrade for Geoffrey.

The other result of that stage door meeting was that I decided to join what was then called the Spastics Society. I wanted to lend my support to disabled people in any way that might be useful, and I also knew that I would personally learn and grow from the experience.

My association with the charity has taught me so much about that power. Language defines attitude and all too often disabled people are held back by negative attitudes in all areas of life, including work, education or just trying to have a decent night out. That needs to change.

And part of that change means putting our hands up and recognising where we've made mistakes, and then doing something about it. That's why I'm sharing this with you.



**Hope From Implant To Deliver Drugs** - *Edited from Independent March 2019*

[www.independent.co.uk/news/health/parkinsons-cancer-treatment-valve-drilled-skull-drugs-a8798266.html](http://www.independent.co.uk/news/health/parkinsons-cancer-treatment-valve-drilled-skull-drugs-a8798266.html)

A ground-breaking implant which allows drugs to be pumped into the brain could “massively expand” the treatment of neurological disease, strokes and cancer, scientists have said.

The valve system, which is screwed into the side of the skull, was developed by Bristol researchers as part of a landmark trial drug trial funded by Parkinson's UK.

Trials are already under way for a system delivering potent chemotherapy drugs directly in children and adults with incurable brain tumours, minimising the damage to other areas of the brain.

Once implanted, the only visible part of the system is a small port seated just behind the ear. At each treatment session, the pump system is sterilised and screwed into the port, drugs are delivered via fine piping running over the surface of the brain to probes which route to the targeted parts.

Researchers were hoping GDNF, a chemical produced naturally in the body which has been shown to help restore nerve damage, could regenerate neurons if pumped directly into the putamen – a Brazil nut-sized structure in the midbrain affected in Parkinson's and responsible for producing dopamine, the key neurotransmitter

that is essential for coordinating movements as well as memory formation.

Forty-one participants in the trial, published in the journals *Brain* and the *Journal of Parkinson's Disease*, were randomly allocated to receive GDNF and or a placebo infusion. For nine months each participant had their movement, speech and other traits scored in Parkinson's tests. The second half of the trial saw all patients receive the drug for a further nine months.

Over each year sufferers are expected to see around a one point decline, but patients receiving GDNF actually saw their scores improve by around four points in the first nine months, and nine points over all. But disappointingly for those hoping GDNF is a cure, this was only marginally more than those receiving the placebo.

"We've shown with the Pet scans that having arrived, the drug then engages with its target, dopamine nerve endings and appears to help damaged cells regenerate or have a biological response," said Dr Alan Whone, who led the trial at Southmeads Hospital. "This represents some of the most compelling evidence yet that we may have a means to possibly reawaken and restore the dopamine brain cells that are gradually destroyed in Parkinson's," he added.



### **North West Surrey Drop-In Hubs**

**Addlestone** – 2<sup>nd</sup> and 4<sup>th</sup> Wednesday of each Month

**KnapHill** – Every Monday

**Shepperton** – 1<sup>st</sup> and 3<sup>rd</sup> Wednesday of each Month

### **Surrey Downs Hubs**

**Epsom** - 1st and 3rd Tuesday of each Month

**Hersham** - 2<sup>nd</sup> and 4<sup>th</sup> Monday of each Month

**Leatherhead** – Every Friday

To contact Action for Carers Surrey, Telephone 0303 040 1234

Email [CSAdmin@actionforcarers.org.uk](mailto:CSAdmin@actionforcarers.org.uk) Text 07723 486730

Web site [www.actionforcarers.org.uk](http://www.actionforcarers.org.uk)



### **Disability Rights UK (DRUK)**

#### **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](mailto:personalbudgets@disabilityrightsuk.org)

## Disabled Students Helpline

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

Telephone: 0330 995 0414 [students@disabilityrightsuk.org](mailto: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](mailto:ken.butler@disabilityrightsuk.org)

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

*Please contact me if you wish to receive these enclosures by sending a text message (with your name and postal address) to 07859 639025.*

*If your preference is for an electronic copy then please email me on [info@spelthorneaccess.org.uk](mailto:info@spelthorneaccess.org.uk) or use the 'Contact SCAN' form on [www.spelthorneaccess.org.uk/](http://www.spelthorneaccess.org.uk/)*



## 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 22<sup>nd</sup> May 2023, 1pm-2.30pm,**

### Surrey Wide Meeting dates for 2023

**Monday 15<sup>th</sup> May 2023, 6pm**

**For more information, please contact:**

[Involvement@surreycoalition.org.uk](mailto: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.

We receive reports from a number of local groups and service providers.

Send your news or reports to [info@spelthorneaccess.org.uk](mailto:info@spelthorneaccess.org.uk) or fill in the 'Contact SCAN' form on our website pages at [www.spelthorneaccess.org.uk/](http://www.spelthorneaccess.org.uk/)

Our next meeting will be on **26<sup>th</sup> April 2023** starting at 12 noon and be Hybrid - held in person at the Goddard Room, Council Offices Knowle Green and via zoom

Further details for Spelthorne's Physical, Sensory and Cognitive Disability forum are on SCAN's web site at [www.spelthorneaccess.org.uk/news/scan-news/spscd-forum/](http://www.spelthorneaccess.org.uk/news/scan-news/spscd-forum/)



## Donations for SCAN's Newsletters

The post pandemic demand exceeded expectations. We have secured funding for the second year of printing the new format paper copies of the newsletters, until March 2024

The future of the project will be dependent on new sponsorship as demand for paper copies continues to evolve.

Sponsorship and membership subscription packages are available to any individual or organisation interested in supporting SCAN and the newsletter project – please use the contact options below for information about making donations.

If you have news that you would like included in the newsletter or on our web site, or to be reported at the quarterly meetings, please send an email to [info@spelthorneaccess.org.uk](mailto:info@spelthorneaccess.org.uk) or fill in the 'Contact SCAN' form on SCAN's web page where you will also find more details about SCAN's work [www.spelthorneaccess.org.uk/](http://www.spelthorneaccess.org.uk/)



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