

Issue 19 – Autumn 2022

DISCOVER

FREE



Electric Vehicles & Accessibility

What you need to know

Sustainable Warmth Fund

Grant funded energy & efficiency scheme

Winter wellbeing & support available

Reclaiming Our Futures Alliance

We must be the agents of change

Government's Cost of Living 'Sticking Plaster'

is no long-term fix

Plus interviews, local activities, reviews, your stories and more!

Welcome

Welcome to the 19th edition of *DISCOVER*, it's thanks to Cornwall Council's Wellbeing & Public Health Team we have been able to bring you this edition.

We know this will reach you at a time of real concern for the majority of us, with the rising cost of living, so our key message to our readers is please remember you are not alone. We, and many other organisations can provide assistance through this really tough time, whether that's grants, emotional support, activities or professional advice, and there is absolutely no shame in seeking assistance.

In this edition we bring you some great people stories, tell you all about the pros and cons of electric vehicles as we all look to contribute to preserving our planet, we hear from the 'Reclaiming Our Futures Alliance' on why we must be the agents of change. We welcome a new Strategic Director for Care & Wellbeing at Cornwall Council, learn of Samantha Renke's cost of living hacks as well as the sustainable warmth fund; for grant funded energy efficiency measures for your home.

There is the holiday support scheme for families on low incomes, and did you know about the all new Access Card to show your accessibility requirements at key events, or attractions? We hear from our Ukrainian colleagues on the impact on disabled people and the vital work they are doing in their war-torn country and about inclusive employment opportunities here. We explore people's stories on marijuana for medical use, and learn how the numbers of disabled people is set to grow significantly due to Covid. We have your poems, news (BSL recognised as its own language!) useful services, activities, support organisations and your enquiries.

Do please join our membership to stay up to date on our news and get *DISCOVER* delivered direct to your home, the form is inside the back cover.

As always, we wish you well, and we are here for you if you need us.

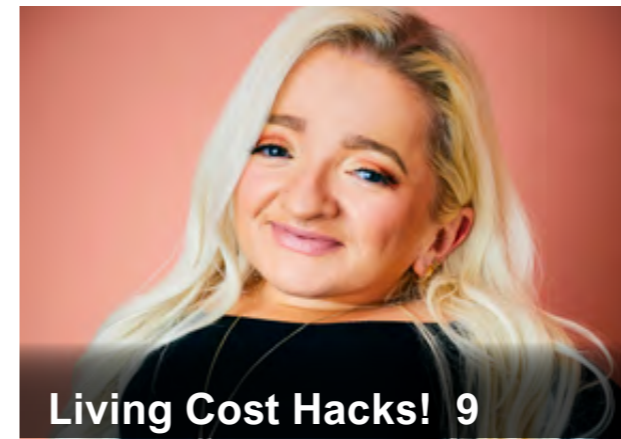
With very best wishes.

The dC Team x

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-  @CornwallDC
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Electric vehicles and accessibility



What you need to know

With over 345,000 electric vehicles (EVs) and in excess of 650,000 plug-in hybrids on UK roads at the end of October 2021, it's fair to say the nation is adopting the transition towards a cleaner means of travel. But how do EVs meet the needs of people with accessibility requirements?

Drivers with mobility challenges face hurdles that some road users wouldn't even think about. While cars are becoming increasingly accessible for all drivers there's still a noticeable gap between drivers who do and don't have a disability on British roads. A report by the Government stated that disabled adults in England made 28% fewer trips than non-disabled adults. The same study found that 38% of blue badge holders felt that the law does not do enough to prevent other road users from parking in blue badge spaces.

If you're interested in driving an EV, it's important to understand how to maximise the performance of your car to help you. We all know about the environmental benefits of driving vehicles which don't use an Internal Combustion Engine (ICE vehicles), but what are the pros and cons for drivers with accessibility requirements?

The Pros

A smoother ride

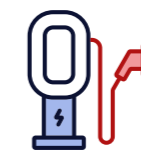
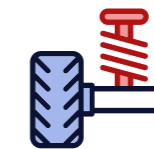
The clunky vibrations which can be associated with older Internal Combustion Engine vehicles are a thing of the past for drivers of EVs. This can be particularly helpful to drivers who have severe joint pain or similar conditions triggered by excess movement.

Non-grip charging

While charging an EV certainly poses a series of hurdles, it can at least be said that the process itself requires less time spent manually gripping, unlike in the case of a nozzle-fuelled Internal Combustion Engine vehicle. This is a major help to people with muscular issues, artificial limbs or any kind of joint pain.

Reduced noise

Likewise, any driver who is sensitive to loud noises, for example someone who has tinnitus, will enjoy the welcome relief of a quiet, battery-powered vehicle. EVs are actually so quiet that they often have to be fitted with external sound emitters to ensure pedestrians know a car is nearby. (EVs not using sound emitters pose a significant threat to people with sight loss as pedestrians).



Lower running costs

Figures show that it can be up to £756.44 cheaper a year to run an EV when compared to traditional engine vehicles, and allowances exist to further financially support disabled people.



The Cons

While the needs of drivers with mobility restrictions are being taken into consideration more now than ever before, there's still progress needed to ensure all cars are fully accessible. According to a report by The Scottish and Southern Electricity Networks (SSEN), some of the most commonly cited barriers for drivers with a disability are:

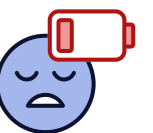
Charging accessibility

Charging points are often hard to access for people with mobility restrictions, while issues like the weight of chargers and access to them from parking locations can be an issue too.



Range anxiety and other psychological barriers

Range anxiety is the name given to the fear of an EV running out of power before reaching its next potential charging point. What's more, accessible charging points are not always clearly signposted, adding to the anxiety.



Upfront costs

While there's definitely long-term benefits in purchasing an EV, you may find the upfront costs of buying the car to be a little high. This could be either as a result of the value of the car itself, or the need to install an at-home charging point, or both.



A lack of information

Advice and support for disabled drivers is also sometimes hard to find. The same report found that most mobility impaired drivers will turn to generic motoring specialists for their information, even though these are usually limited in providing support for people with specific medical conditions.



The charging process

Reaching and handling the charge point itself has been cited as a real problem for a lot of drivers. Many find it heavy to hold, and find it a challenge to locate assistance when they need it. A recent survey reported that 41% of people found moving the charging cable to be difficult. 54% also said lifting the cable from the boot was a challenge.

Unbelievably, there is just one fully accessible charging point in the UK, representing 0.003% of all those available. Currently, only 25% of drivers with a disability feel comfortable driving an EV. If changes were made to the infrastructure of the charging system, that number would rise to 61%. Many find that EV charging zones can be quite hard to access, most often owing to the absence of dropped kerb access and a flat parking area with level access.

Possible solutions to charging barriers

As well as the additional support provided, drivers with a disability can also remain hopeful about a series of potential future solutions to the hurdle of charging. Some of the options include:

Car design changes

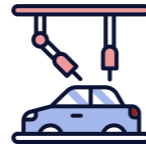
As motability issues continue to be discussed, it's the responsibility of manufacturers to guarantee enough is being done to accommodate all drivers. That means modifying cars to be accessible for everyone, with ample space for any necessary medical equipment. It could also see the charge point of the car swapped in accordance with the needs of the driver.

Changes to charge point designs

Points can be made lower and more accessible, while payment systems can also be streamlined to make the process as easy as possible for those with cognitive or visual restrictions.

Longer trial periods for drivers with a disability

While it takes time for any driver to get used to a new vehicle, the process can be even more challenging for someone who also has to balance driving with a disability. As such, they may need longer than what's offered to be able to make an informed decision.



Inductive charging

This futuristic technology allows for a car to be charged by being parked over a specific spot. Electricity is sent through the air at a gap of four inches to a coil, which is attached to the underside of a vehicle. This method requires precision in parking, but with the continued efforts being made to perfect self-driving cars, it could be a realistic option for all drivers in future.



Accessible adaptations

Just like traditional engine vehicles, EVs are capable of being fitted with a number of adaptations to make them more accessible to drivers. Here are some of the best options that can be added to your vehicle:

Hand controls

For example a push or pull device to help with accelerating and braking can be useful for drivers who aren't able to freely use the lower half of their body. These work fantastically for automatic gearboxes, which EVs exclusively use.

Pedal modifications

If you still want to use pedals as they are traditionally intended, you can extend them to reach up to your feet. This makes driving more comfortable and simple for drivers who cannot reach them at the standard distance.

Electronic accelerators

For people who aren't able to freely use pedals when driving, but also lack the strength to use a push and pull lever, there are a series of electronic accelerators available. These can be placed throughout different areas of your vehicle:

Trigger accelerator – You pull this forward to accelerate and push away to brake

Over ring accelerator – This is placed on the steering wheel, pushing down to accelerate

Under ring accelerator – This is put behind the wheel, with speed controlled by you pulling it towards the wheel

Ghost ring accelerator – This is also fitted behind the wheel, with the driver controlling speed by moving it from side-to-side.

Steering aids

If you have trouble holding or moving a traditional wheel, several steering aids are available, such as a ball which can be used in one hand to control the direction you're heading. Each steering aid will

come with a hand-operated brake device.

For more information visit:

www.autotrader.co.uk/cars/electric/ev-drivers-with-disabilities/



The Motability Scheme was set up to make it easier for drivers with a mobility restriction and carers to affordably and safely get behind the wheel of a car. Drivers are able to lease cars through the scheme, with a variety of expenses taken care of.

Benefits of the scheme include:

- A series of plug-in vehicles to choose from
- Insurance for up to three named drivers
- Maintenance, and repairs all covered
- Also, support for installing an at-home charging point.

You will be eligible to join the scheme if you receive any of the following:

- Enhanced Rate of the Mobility Component of Personal Independence Payment (ERMC PIP)
- Higher Rate Mobility Component of Disability Living Allowance (HRMC DLA)
- Armed Forces Independence Payment (AFIP)
- War Pensioners' Mobility Supplement (WPMS)

For all Motability Scheme Adaptation Installers in Cornwall visit:

<https://findadealer.motability.co.uk/adaptations/south-west>





CORNWALL



If you have a stay in hospital and have difficulties or barriers to returning home, then call us, our friendly professional team can:



Help to settle you in at home from day one, ensuring your comfort, safety and wellbeing



We can put in place longer term plans for shopping and prescription deliveries



Develop a support plan with you and take the pressure off, so you can focus on yourself



Assess if there is any equipment or adaptations you may need, to maximise your independence and source them



Ensure you have all the welfare benefits and extras you are entitled to, for maximising your household income



Deal with any concerns you have and provide grants for any items of home equipment needed



Arrange personal assistants or community carers, for daily support at home if required (whether short or longer term)



Absolutely anything else that's important to you!

If you are in hospital and would like to speak to a member of our team to arrange support, contact us, or you can ask a staff member on the ward to contact us on your behalf.



We are here to help and our service is FREE so keep our phone number in case you need us!

Hospital Discharge Team

📞 01736 697914

✉ Disability.cornwall@nhs.net

A service brought to you by disAbility Cornwall & Isles of Scilly
Registered Charity No: 1140925 Company Registration No: 07436153

Living cost hacks!

By Samantha Renke



Photo courtesy of Nicky Johnston

Samantha Renke

I am however not one to surrender!

Luckily for me, I was born to be a serial thrifter. I guess it was inevitable, I've turned into my mother, the Queen of a good bargain. In fact, I grew up being shrewd. I come from a very proud working-class background and my father, upon being made redundant from his long-term job back in the early 1990s taught himself a new skill of antiques dealing. More specifically how to bring clocks and pocket watches back to life. I even had my own antique stall aged seven.

But before I start rattling off a list of tips and tricks that could potentially save you a few bob, I want to make a few things clear. Firstly, and for full transparency, this isn't a sponsored blog. I'm not being paid for any of the products or items I'm going to mention or endorse. I have however already tried and tested them or will, without a doubt, be doing so in the future.

Secondly and probably most importantly, please remember that asking for help including going to food banks or claiming any form of benefits is nothing to be ashamed of. It is absolutely no sign of weakness either! I receive benefits and I also live in a flat that is owned by a housing association.

I'd be lying if I said that life is going pretty darn well for me. There are loads of wonderful things happening. I have a book coming out 'You Are The Best Thing Since Sliced Bread', my consultancy work is going from strength to strength and I'm working with wonderful people on a whole host of exciting future projects. But a lot of this is my Instagram life... shall we say. The parts that are going well I am open to sharing with the world.

I am however a human being and although I have much to celebrate, equally I'm experiencing one of the worst bouts of anxiety. Sleepless nights and restlessness, mostly fuelled, like many of us by the rising cost of living and in my case a whopping big bill for my social care.

I often feel as though there is little or no incentive to work or earn a decent living when you have a disability. The more you put yourself out there and assimilate into the 'abled' world the more we must pay out and fight for.

The way I see it is that we still live in a disabling world that at times can really suck! Disabled people are continuously left to fend for themselves, are undervalued, and discriminated against daily.

So, if something is available to us then grab it with both hands and do not look back! So please do yourself a favour and leave your pride and your ego for that matter at the door!

In fact, I spotted a guy in a very posh suit in my local Marks & Spencer and all of his food had yellow stickers (reduced price) on them, I glanced and smiled because I thought bloody good on you! Being thrifty is actually en-vogue. So here is my first hack, don't dismiss reduced items. Most supermarkets will reduce their stock in the evening or on weekends. I often find myself freezing goods such as bread and even blueberry muffins! It's important to note that not all products are suitable for home freezing so always check before you

put them in your basket. It's also tempting to buy reduced items just for the thrill of scoring a great bargain! However, my advice is to resist temptation and only buy what you know you will use.

Now you've probably all heard of eBay, but there are other online thrift platforms that are worth checking out. Facebook marketplace is a wonderful start, Vinted, Shpock and Depop (for cool kids) are all apps to sell and buy second hand items.

Washing your clothes on a low heat 30/40 degrees and popping a colour catcher sheet into your wash means clothes hold much longer and you'll be less tempted to buy new.

There are many apps whereby you can swap food products with your local neighbours. Like OLIO, you upload a picture and description of food products you don't want or have a surplus of, then you can swap with those in your local area. FOOD CLOUD, NOSH and NOWASTE are also ones to check out. Don't forget to sign up to Top Cashback (www.topcashback.co.uk) – they literally give you money back on your shopping.

Now I love my bargain stores, Poundland, Home Sense and B&M – but living in London means these places are hard to reach if you don't drive. So, I was delighted to find out about Cherryz (www.cherryz.com) – all your bargain store goodies delivered to your door. Plus, free P&P for new customers.

One thing I often forget to do is check for offers and discounts that are available to me as part of my membership cards like Boots. Always remember to check what offers you have and upload them onto your card or app before you shop.

I appreciate these tips and tricks seem like a drop in the ocean and won't be saving you thousands of pounds, but I truly believe that having a little more financial security starts with changing your mindset and tweaking your habits.

Every little helps, so I hope I've been able to help in some way. Message me on social media and tell me if you've checked out and used any of my recommendations!

Samantha Renke, @samantharenke

Cornwall Freemasons donate £94,000 to local charities

The Freemasons of Cornwall hosted their annual charity event in the ancient King Arthur's Hall of Tintagel Castle. Holding true to the freemason grand principle of charity, the Deputy Provincial Grand Master, Roger Cargeeg, presented 35 Cornish charities a total of £94,000.

A total of 130 people lined the regal hall to watch the Provincial Grand Lodge of Cornwall donate to a wide range of organisations, including The MS Therapy Centre, Cornwall Air Ambulance, and £1000 to Disability Cornwall & Isles of Scilly accepted by Patron and former three time Paralympian, David Wetherill.

David told *DISCOVER*: "It was truly an honour to accept the generous donation on behalf of Disability Cornwall, as Patron, I am in awe of all the tremendous work that everyone connected with our



David Wetherill and Roger Cargeeg in Tintagel Castle

charity is doing to support people, particularly as we move on from the pandemic. I am in admiration of all these charities and what they achieve every day to make life better for people. The generosity of the Cornish Freemasons makes a valued contribution to their work.

The Provincial Grand Lodge of Cornwall made us all feel very welcome and it was inspiring to hear first-hand some of the selfless stories which often go unheard or understated."

The Shiners give Ali a warm & fun welcome



Ali Bulman, Strategic Director for Care & Wellbeing, Cornwall Council

In August a great thing happened, the young adults from the Cornwall Accessible Activities Program (CAAP), known as the Time2Shiners, were invited to interview Cornwall Council's new Strategic Director for Care & Wellbeing, Ali Bulman, at New County Hall, on behalf of *DISCOVER*. A team of eight Shiners participated, supported by Director, Sandy Lawrence and some of the parents, and what a great interview it was!

Sandy set the scene explaining that CAAP supports 960 families with holiday activities and Time2Shine is a spin off for the young adults. The Shiners support all the events to gain experience, they attend conferences and go on trips. In Dublin they attended an event with 800 disability student nurses and feedback they had was: "When the Shiners walked in the room, it was like a ray of sunshine coming in."

Everyone, including Ali introduced themselves in Makaton, the questions began, and the first was an inquiry into Ali's background. She has worked in social care since age 15, at first as a volunteer and then as a staff member in a care home, working between Wales & England and Ali is a proud Welsh lady. Essentially this has culminated in her working in social care her whole life so far, most recently coming from Powys, where she had responsibility for children's services and adult social care.

"Originally I wanted to be a nurse, but my mum worked in social care and I realised that I didn't need to be a nurse to become somebody that can help and empower people, working alongside them to deliver what's really important to them."

Ali says: "I was drawn back to working in Cornwall because it's a beautiful place and Cornwall Council has real integrity and, the Chief Executive (Kate Kennally) is inspirational and aspirational for what the Council delivers for the residents of Cornwall. I was particularly attracted to some of the plans that have been put in place for delivering the outcomes for our population by 2050."

This getting to know each other conversation digressed beautifully discussing both Ali's and the Shiners' dogs, Formula 1, mountains in Wales, boxing, sheep, horses (with equine asthma), alpaca trekking and inviting Ali to their end of Summer festival at Hayle Rugby Club!

Sandy explained how the Shiners have developed and deliver their own training about what it's like to access health services as a young person with a learning disability. Ali felt this training would be great for the System Executive Group that brings all the people that are responsible for health and social care together.

Ali was asked what she plans to do to improve the transition process from children to adults services: "One of the things that is going to be key for me is

to make sure that our officers in adult social care are engaging with young people at the right time to really understand what's important for them and what matters to them, and make sure that we're supporting the planning for achieving that."

"You, as a group of young people have such a huge role to play in how we set our vision and strategy, and contributing what you want us to focus on, so we can make sure that we're getting this right for the young people that are coming behind you and learn from some of your experiences, so I was so pleased to be invited to meet with you today, it's going to be the best meeting I have all week that's for sure!"

There was much talk about adult and children services and Ali said she will be working hard with her teams to deliver the best they can in response to the needs identified. She appreciates there is always much to do, and upholding the morale of her team is important to her and would be key to that. "Everyone in Cornwall is working hard and wanting to do the right thing for the residents. I have a really dedicated team behind me supporting our stakeholders and I think there's something about working smarter, not harder and some of our policy positions need to be more flexible, open and enabling so that people can work in a in a different way."

Adult services in England have not been inspected by the CQC for well over 10 years, and those inspections are going to start in 2023. Ali feels that this will hold a mirror up to adult services in England.

The Shiners wanted to know why people can earn more 'flipping burgers' than they can working as a Personal Assistant, and Ali says it's tough when we are competing against so many other sectors, especially hospitality. Also, there seems to be no flexibility in hourly pay, for Personal Assistants working with people with higher level needs.

"When I was in Cornwall four years ago, I did some work around Direct Payments and personalisation but what I can see is that we now have a Direct Payment policy, which is quite restrictive and risk adverse, instead of being much more open and enabling and you're all nodding so, I'm sure you agree!"

"I've had some interesting conversations where people think that to do something in a more

enabling way is not within the policy, but we just need to change those conversations, because as long as it's not outside of the law, we need to be much more open about what we're providing them for. We have an hourly Direct Payment rate in Cornwall of £12.70 but where I've been working recently I got rid of a set rate. Instead, I'm more interested in what your current support plans look like and what are the costs of meeting those needs, making best use of resources for the Council, but also delivering what matters and what makes a difference for people. So I'm keen that we look at our Direct Payment policy very soon."

The Shiners raised the issue of not being able to pay their PAs mileage, as they live in areas with no public transport. Ali said: "We wouldn't pay PAs to come to you, but if they're taking you somewhere then we need to look at that as part of the review of the policy too. What's just as important is the practice, so that all our frontline staff know that policy has changed, I cannot promise anything right now, but I am absolutely promising to look at that and address it."

She talked of some planned work to develop the self-employed Personal Assistant market to help meet the massive care workforce challenges at the moment. "This is a different way of working in health and social care with a bit more flexibility and autonomy, and having a range of clients. So, we need to put that infrastructure around personal assistants to make sure they get the right support to operate and to attract new people to work in health and social care. I recently met with Humans Cornwall and we talked a lot around Cornwall developing a much more sustainable offer, through the Direct Payment process as well and we will be looking at how we put this into place. I'm really excited about that because I think that's what really matters to people. Whilst getting showered and dressed are critical, there are other things that are really important to people and we need to make sure that we're supporting them with those areas of their lives as well, so that's my ambition."

At this point the interview was disrupted by a welcome visitor, Kate Kennally, Chief Executive of the Council, who thanked the CAAP team for their work, and made a beeline for the French Fancies!

Asking the Shiners what they had learned about Ali so far, received an enthused response of she's Welsh, she loves dogs, she's funny, they feel she is going to change things for the better and everyone agreed they hope she is here to stay!

So back on it, one Shiner wanted to know why she has the same social worker as her grandad! Good



The Shiners pictured with Alison Bulman

question... "There are a number of different models that work across social work teams and in Cornwall, we have a generic team, so that will be the experience people have in the structure we have."

Kate added: "We want social workers that really know their localities, so they can link people into them, rather than saying I work with people with learning disabilities or a physical disability, or I work with somebody who's an older person. This is necessary because we want everyone to be a part of and engage with their community. I really want to see a 0-25 years social work service so that your social worker when you are up to 18 is the same one that you have in your 20s, because that period of being a young adult is where you are still working out what you want for your life, and actually that takes a bit of time. Our brains take up to the age of 25 to become fully developed, so that's why I want the 'Preparing for Adulthood Board' to say, let us have a single team that's working with our young people up to the age of 25."

Ali added: "This is so important because it gives that continuity through that transitional phase into adulthood."

The conversation moved to how the Council intends to improve services for young people when education services end. One Shiner is expected to be ready for employment at 20, post college,

but she isn't quite ready yet, especially having lost a year due to covid. For some young people, they may finish education age 25, but cannot find employment and in some cases end up regressing and struggling with their mental health due to this.

Ali said: "There is a lot of work going on at the moment as to how we make sure that we're having the right conversations with young people, and around connections with school and college careers advisers, we are looking at education officers for people up to 25 as well, where that's appropriate and wanted. There are also discussions around supported internships which will be rolled out as a pilot, but not until September 2023. We need to make sure that we get the right offer around supported employment and engage with local businesses to make sure we secure some of those opportunities for young people moving forward."

The Shiners spoke of some of their ambitions, maybe an extra six months at college, work experience in health and beauty, working in a soft play area, working at Waitrose, one Shiner already has his own radio show!

Ali offered the parents the chance to put some questions forward, and agreed to pick them up individually on the issues they raised.

There was talk of the point where Health Care Plans end and the planning that goes into them at

that stage. Sometimes this gets dealt with aged 18, and moving between children and adults services. Kate said: "The question is are the young people continuing to have good days after education and the plan finishes? Schools are supposed to track what's called a young persons 'destination'. What happens to that young person? Do they get a job? Do they go to college? What's the responsibility of that education provider to make sure that your son is also leaving that provision and excited about what their next chapter is going to be, rather than worried."

She added: "We no longer have the European Social funding (ESF), but now what Cornwall gets is called the Shared Prosperity Fund and that comes to Cornwall Council this year and it ramps up year on year. The priorities that have been set nationally are around people and skills and that is to replace the funding that was going into employment projects through the ESF. Quite a lot of work based support projects were ESF funded and lots of good things have gone with that, but the rules about what that money could be spent on was not locally set. So now we have the money in local control it's an opportunity to work out what we want - to keep going with some great projects or should we look at some of the gaps and how can we fill them? We need to get the right arrangements in place for transitions and the right relationships with all the different education providers, but also we can't recruit enough people in Cornwall, but we're linking up with employers, so together we can try and find out how we manage that gap because one statistic I am really not proud of at all in Cornwall, is the number of people with a learning disability who are known to adult social care that are in paid employment, which shows we are in the bottom 25% in the whole country."

"So what we've got is a number of different things going on, maybe not enough expectations of actually what our young people can achieve, and that's why being a Shiner is so important, to change expectations of families as well as employers and organisations. Playing it safe in terms of traditional day services for adults needs looking at, and actually the pandemic made us do this in terms of actually what that offer needs to look like, and I think we've got to work better with organisations such as the Job Centre too, so people are getting the right advice and are feeling confident about what it means for benefits and for money, and being able to do some of that longer term planning."

Sandy said we have some brilliant services supporting young people, and going through school, going to college, all can be well and

suddenly when that ends things are not good. She added: "We're not using those skills and that talent, so if we can work on that together, that would be brilliant. I think the quote here is teamwork makes the dream work and we want to say that our shiners are willing, able and want to work with you to improve things not just for themselves but for the cohorts that are coming behind them."

Ali said: "We can't do this without you that's for sure. I've really enjoyed my interview today and I'm hoping that this is a start of a relationship, not a one off kind of event where you guys hold me to account on the conversations that we've had today. The things that I've said, we're going to do, which involves all the things that Kate just mentioned, because I haven't come to Cornwall to deliver services to you that are in the bottom 25% of England, so we're going to be on a journey together from now on."

"We want to be a Council that walks with you as a family. We don't want the adult social services department to be replacing things, because we never could. What you as a family and our communities offer to each other, we want to support and enable that."

"So if you don't need us as much then you'll tell us, and we'll take a step back, but when you need us more, you can be confident that we'll be there. I want to see a greater emphasis on how we're actually working along with family members, how we're doing much more work on contingency planning, so we don't just put in a care package, that sort of stays there."

Kate added: "Family carers of young disabled people over the last 12-18 months have faced big pressures, due to social workers having to prioritise flow around the hospital, trying to reduce the ambulance queues and get people home, so there is a need to reset and reshape. We need a different set of relationships that are more about us being partners with you."

Ali closed the meeting thanking the Shiners for their work. "I really welcome the feedback on where we've got the individual pinch points at the moment. I know there are bigger issues and systems that need to be fixed, but if we can do this one by one then we can un-pick what's happening and understand why there are delays."

Celebrating Cornwall's people who care



Jane Johnson MBE and Vaughan Temby from disAbility Cornwall with award winner Dean Harvey.

The CAHSC Learning Partnership hosted yet another wonderful and glamorous evening in April at Tregenna Castle in St Ives, showcasing and celebrating the Care and Support sector in Cornwall.

'Big Ian Donaghy' keynote speaker and the evening's host works tirelessly to raise dementia awareness and combat loneliness, with 20 years teaching young people with learning difficulties, and nearly 10 years in the world of care. Ian entertained guests with a vocal performance of 'I'm still Standing' by Elton John, after an incredibly difficult two years during the pandemic, which saw care workers come under considerable pressure and be the backbone of support for many.

disAbility Cornwall & Isles of Scilly sponsor the CAHSC Excellence in Leadership Awards and this year we received three great nominees, they were Leah Marsh from Swallowcourt, Caroline Somerville from Bluebird Care and Dean Harvey from Pentreath.



'Big Ian Donaghy'

We were delighted to present it to our chosen winner, Dean Harvey, who is a BAME and mental health advocate, trainer and consummate professional. Dean has a wealth of evidence based knowledge, an extremely high value base, the highest level of integrity and pure passion, commitment and dedication for what he does. He inspires others and is a highly effective leader, training many in ASSIST (suicide awareness), cultural capability and much more. His nominators believe he has probably saved many hundreds of lives through this and the ripple effect of his work. His whole life is about improving the delivery of care and support and the incredible feedback from people he has supported or worked with, is testament to that.

His nominator said: "The reason I have nominated Dean for the excellence in leadership award is because he is a real true genuine leader and high quality care and support is a value he demonstrates by example. Dean has been integral in educating his team on the findings within the Racism report and pushing for proactive change, awareness and high standards. He is a leader and what a leader, manager or CEO should aspire to be."

Well done Dean, an incredibly worthy winner, we are so proud of you, your achievements and this duly deserved recognition.



Sustainable Warmth Fund

The Sustainable Warmth Fund is the new grant funded energy efficiency scheme from the Government. This fund aims to improve the Energy Performance Certificate (EPC) rating of your home with a range of energy saving measures. These measures will help with your heating costs, ensuring your home is warmer and improving your general health and wellbeing - essential in the current rising cost of living and energy crisis.

Cornwall Council are working in partnership with OVO Energy Solutions to deliver this scheme across Cornwall and the Isles of Scilly. It will run until March 2023 and aims to help around 400 homes – could your home be one of those?



Eligibility checklist:

- You or someone you live with must have a health condition, or be at risk of poor health, or be caring for a vulnerable person, or be children aged 19 or under, or be worried about their home being cold or damp.
- The total household income is a maximum of £30,000 gross (so before tax and any other deductions).
- Your home has an EPC of E, F or G (some D's can be accepted). If you don't know your EPC you can check it and find your energy certificate online at www.gov.uk, or we can check for you. We are required to use the EPC to find out if you can afford to keep your home warm.

List of potential measures available under this scheme:

- External Wall Insulation
- Cavity Wall Insulation
- Underfloor Insulation
- Loft Insulation
- Draughtproofing
- Double Glazing
- Air Source Heat Pumps
- High Retention Storage Heaters
- Solar PV

If you and your home are eligible, then a full house retrofit survey will be done in order to identify what measures would make your home as energy efficient as possible. You will be given the opportunity to tell us about any measures that you don't want to have, as well as those that you would prefer, before the retrofit survey is done. Our qualified retrofit assessors will then recommend the best measure or combination of measures for your home - so in other words, the ones that will result in the greatest improvement to your property's EPC score.

How do I apply?

To receive an application form or for more information, please get in touch:

rachel.garmory@cornwall.gov.uk
01872 323583
(Public Health help-desk)

If you are a landlord and want to discuss this, please contact Nicole Solomons at Community Energy Plus:

nicole@cep.org.uk
01872 308 930

The Sustainable Warmth Fund is delivered as part of the Winter Wellbeing programme: www.cornwall.gov.uk/winterwellbeing

What can't be installed?

We can't install any solid fuel, oil or gas measures under the scheme (but we can work on homes that currently have them).

What will it cost me?

If you are a home-owner or tenant then this will be free of charge. If you are a landlord then you will be required to pay one third of the total installation cost. The cost will vary depending on the type and number of measures to be installed, but an approximate cost will be provided after the retrofit survey is complete and before you sign any contracts. Landlords will be required to keep the property for a minimum of 5 years following installation, or re-pay the funding in full.



If you would like this information in another format or language please contact:

Cornwall Council, County Hall,
Treyew Road, Truro, TR1 3AY

e: customerservices@cornwall.gov.uk
t: 0300 1234 100

The universal ACCESS CARD



Martin Austin MBE at the The Ticketing Business Awards 2021

Nimbus Disability is a social enterprise run by and for disabled people and delivers various services such as training on the social model of disability, through to access auditing, but its main area of business is the Access Card.

Martin Austin founder of Nimbus, describes the Access Card as like no other, they translate your disability or impairment into symbols that highlight the barriers you face and the reasonable adjustments you might need.

Mark Briggs, Director of Partnerships at Nimbus told *DISCOVER*: "It's all based on your rights under the Equality Act and service providers responsibilities, to ensure that disabled people are not put at a disadvantage in participating in events such as live music or sports. The card and our partners have expanded over the years to see it being used at Buckingham Palace to Alton Towers. Once you are a cardholder and your needs have been assessed based on your application, it is used

to inform providers quickly and discreetly about the support you need and may gain you access to things like concessionary ticket prices and complex reasonable adjustments without having to go into lots of personal detail."

What is ground-breaking is the international reach of the Access Card, having been rolled out as far away as New Zealand. The locally operated Hapai Access Card works in exactly the same way and is led by a dedicated team in Auckland.

In 2019, Martin was named in the New Year's Honours list, receiving an MBE for Accessibility in the Tourism and Entertainment Sector and following that, the Access Card received the extremely prestigious Queen's Award for Enterprise, in the innovation category.

Mark said: "The next few months are going to be very exciting at Nimbus we will be unveiling so many new projects and partners, that will expand both the card and Nimbus's reach. One of these in

development is an ingenious way we will be able to use the concept of the Access Card and new digital technology to protect disabled people's parking. Much of the detail is still under wraps for the moment, but we are close to announcing our partnership with sector leaders in parking management and electric vehicle charging, which could be the answer to one of the most contentious issues for disabled people, the misuse of accessible parking bays."

You can apply for your Access Card now. It's just £15 for 3 years and you can see all the benefits of the card on their website.

www.accesscard.org.uk



Actress, broadcaster and activist Sam Renke brings you her no-holds-barred look at life and plenty of advice, which will inspire you to live boldly and follow your dreams.

We are made to think that what makes us human, our flaws, failures, and heartaches, are things to keep hush-hush. Being unapologetically imperfect is seen as something we should be embarrassed by. But what I've learned is that we all experience the same insecurities. We just aren't talking about it. Well, I'm here to break the silence.

For starters, I have way too many nipple hairs. I prefer the company of my pets to other people. And repeatedly I question am I normal? I was born with brittle bone condition and so far, I've broken my bones 200 times. But most of the hurdles I face don't come from my disability, they come from things we all experience.

In this book, I will share the lessons I have learned and why you should embrace your uniqueness as what makes you fabulous. We spend a lot of time living by others' expectations and it's only when you stop, that you start saying yes to life. Irrespective of who you are and the obstacles you might face, you can do whatever you want. Be free and unapologetically you. Samantha's book is available from Amazon on audio, audible, hardcover and paperback.



Photos courtesy of Nimbus

Pictured left to right: Mark Briggs and Martin Austin

The Memory Cafe Network



The Network is a place where anyone with memory loss whether diagnosed or not and their carer or family can engage and be supported.

The cafes are here to enhance wellbeing and quality of life and are a place for connections, social activity and support, acting as a lifeline for many.

Activities include music, dance, entertainment, exercise and important social time together. All cafes are welcoming and in most cases free!

There are two 'Wayfinders' working full-time with the Cornwall Memory Cafe Network, and each covers a different end of the county. They can provide advice, guidance, practical support, and referrals to services you may need.

There are memory cafes located all around the county!



Photo courtesy of Amy Findlater

West
Isles of Scilly

Mid

01736 697459
kirsty@disabilitycornwall.org.uk
www.cornwallmemorycafes.co.uk

In partnership with
disAbility
CORNWALL & ISLES OF SCILLY
Represent Include Support Empower

Hiding in plain sight



Not every disability is Visible.

There are a range of chronic illnesses and conditions that are not visible, but have a significant impact on daily living and the Hidden Disabilities Sunflower Scheme aims to overcome this and raise awareness. The Sunflower is now a globally recognised symbol for non-visible disabilities, also known as hidden disabilities or invisible disabilities.

These disabilities may include autism, chronic pain, and learning difficulties as well as mental health conditions, mobility, speech impairments, and sensory loss such as speech, sight loss, hearing loss, or deafness. They also include respiratory and chronic conditions such as diabetes, chronic pain, and sleep disorders yet these significantly impact day-to-day life. Although you may not be able to see these invisible impairments and conditions, they're still there.

Disability has often been characterised by the wheelchair user logo, yet wheelchair users account for less than 8% of all disabled people. Unless people see something such as a mobility aid, a guide dog or equivalent then they overlook the needs of that person.

People living with these often face barriers in their daily lives including a lack of understanding and negative attitudes. So some choose to wear the Sunflower lanyard to discreetly identify that they may need support, or just a little more time in shops, transport, or public spaces.

The Government estimates that one in five people in the UK have a disability. However, according to the Disabled Persons Transport Advisory Committee (DPTAC), it is impossible to know how many more people have a hidden disability.

However, there is still much to be done in tackling hidden disability discrimination. DISCOVER talked

to Marie Ralph, a disability rights campaigner from Newquay. Her eldest son has a complex mix of Autism, Tourette's, and various other diagnoses. Marie states that she and her family encounter hidden disability discrimination regularly, both 'indirect and direct'. "At least two to three times a week my son is refused entry to places because he is seen to be 'swearing' or acting in a manner that they're not used to."

There is legislation in place to tackle disability discrimination and the Equality Act (2010) requires service providers to make 'reasonable adjustments' to make services accessible and inclusive. The law gives fundamental rights to all disabled consumers of goods, services, and facilities and providers must not treat a person with a disability less favourably than someone without, as that would constitute discrimination. This also includes education and in employment. Yet, we often hear of attitudinal barriers in the community, and they can account for a considerable proportion of discrimination cases people may face.

Marie believes more should be done and the law needs to be far more robust and accessible for prosecution cases: "Currently, not many people will pursue cases, leaving the issue to compound itself. We also need far better and standard training and awareness on not just equality but equity for disabled people to ensure all can access as much as possible."

For more on Hidden Disabilities Sunflower Scheme:

www.hiddendisabilitiesstore.com

Support is available this Winter, we are with you

As the rising cost of living bites harder, please remember you are not alone, and there is no shame in asking for help. If you need a grant or a food bank voucher, support with home energy use, or if you need supplies such as blankets or hot water bottles, get in touch. These are going to be challenging and worrying times for us all, but please reach out for support, there are many organisations and support groups in Cornwall who are here to help and we are aware of resource available.

Call the DIAL or Carers Advice Line to check you are claiming all your entitlements to maximise your income. Contact Citizens Advice if you are already struggling with budgeting and debt. Community Energy Plus can support households trying to reduce their energy bills. There is also a 24/7

mental health crisis telephone number for anyone experiencing mental health issues, severe anxiety and depression.

You are not alone, please ask for help!

DIAL Cornwall: 01736 759500

Carers Advice Line: 01736 756655

Citizens Advice Cornwall: 0800 1448848

Community Energy Plus: 0800 954 1956

Mental Health Crisis Cornwall 24/7 support line:
0800 038 5300



MoneySavingExpert

Cutting your costs, fighting your corner

Do you follow Martin Lewis the money saving guy? If not, check out his website now and sign up for the free money saving email for top tips on everything!

How to fight soaring energy bills, bank switch bribes, the best life, car and home insurance, vouchers and coupons, energy prices and the best suppliers, offers, benefit checks and a 'how to budget' guide. 'Heat the human not the home' guide, best contracts for broadband, social tariffs, cheap/free sanitary products guide, water saving gadgets, help with school uniform costs, how to shop cook and save money, grants and assistance available, discounted prescriptions, checking your council tax band, the 'downshift challenge' for buying cheaper brands, top tips for reducing costs all round and so much more.

The website explains about getting 0% balance transfers on credit cards, driving more efficiently to save costs, how to haggle for the best deals, using trainee hairdressers for a cheaper cut, the 'speedy app' for end of day discounts in cafes and restaurants, debt advice, nifty tools to use larder leftovers, yellow stickers and when and where to find them. Sharing Wi-Fi or Netflix with neighbours,

getting paid for your opinion, becoming a property guardian to earn extra cash. You can't afford not to sign up!

www.moneysavingexpert.com

Council Tax Discount

You might be able to apply for a Council Tax discount or exemption if you or someone you live with is disabled and if you live in a larger property than you would need, if you or another occupant were not disabled. You also will be able to apply for a discount if you or someone you live with is classed as 'severely mentally impaired'.

You'll need to get evidence from a medical professional, such as your GP to prove your eligibility. You'll get a 100% discount if you qualify as 'severely mentally impaired' and live alone or any another adult in your household qualifies as 'severely mentally impaired' or is a full-time student. There'll be a 50% discount on the council tax bill if everyone else is disregarded.

If you live with someone who is classed as this, you will get a 25% discount if there are no other adults in your household or everyone else in your home is disregarded.

Vital work continues despite the tragedies of war



Ukrainian speakers at the DPO conference

Ukraine Disabled People's Organisations (DPOs) joined a special conference hosted online by disAbility Cornwall in June to share the struggle unfolding during the Russian-Ukrainian War.

Larysa Bayda, secretariat and Viktoria Nazarenko, general secretary from The National Assembly of People with Disabilities (NAPD), an umbrella organisation that represents approximately 120 DPOs in Ukraine apprised delegates on the impact on disabled people during the conflict and the humanitarian issues unfolding.

The NAPD is committed to responding to the needs of disabled people, including providing humanitarian aid like medication, financial aid, hygiene goods, and assistance with evacuating into safer areas of the country and abroad. They are advocating for the need for accessible air raid shelters and lifesaving information at both local, regional, and national levels. They have managed to arrange shelters that have helped up to 500 disabled people and their families so far, but more are needed. Since hostilities began in 2014, the NAPD has been urging the government to improve access to air raid shelters. Larysa said: "I live in Kyiv and sometimes we don't even go down to the shelter. We are getting accustomed to this."

Many people are forced to stay in their homes as they are 'not able to flee' due to their personal and accessibility needs and countless numbers of people have had to be accommodated in groups, due to a shortage of social workers and carers.

Disabled people have been housed at holiday resorts and mental health institutions, which have been put on the brink of catastrophe, due to staff shortages and over population, and essentials like medication are in short supply.

They say it's impossible to measure how many people with learning difficulties or physically disabled people may not be accessing humanitarian aid or have fully accessible information.

Many disabled people are left out in obtaining key information, especially in rural towns and

villages, as there is a lack of up-to-date computers and phones. They shared examples including how visually impaired people are left 'completely disorientated' during air raids, and how one deaf colleague, despite having no way to identify air raid sirens, was still out distributing food to disabled people who live on their own in the suburbs of Kyiv.

Over half of disabled people in Ukraine survive below the poverty line, receiving only £60 a month in disability benefits.

Ukrainian laws adhere to the UN Convention regarding the Rights of Persons with Disabilities. However, Viktoria said that on the ground, the reality is, these laws are not followed. Further, there has been an increase in non-disabled people administering DPOs which act as what she describes as 'pseudo protectors'. They speak good English and are experts at conveying information to influential organisations both nationally and internationally. This means they are effective at securing funding from both Ukrainian public institutions and international donors.

The NAPD say one of their main objectives is to increase the impact of DPOs on decision-making processes in Ukraine.

Larysa said: "Now is the time to organise teaching and learning for people with disabilities, and to arrange psychological treatment and healthcare. This is hard though as many people have lost their jobs and there is no funding available."

Funds are desperately needed now and the NAPD are calling on the international community to fund vital humanitarian aid. You can donate to support the NAPD's important work on the ground in Ukraine, by visiting the website below. Donations help provide financial assistance to disabled people, repair damaged infrastructure, and fund essential humanitarian aid such as food, medicine and hygiene products.

✉ office-naiu@ukr.net 🌐 www.naiu.org.ua

Inclusive employment opportunities in Cornwall

PROPER JOB is a new scheme offering adults with learning disabilities or autism a wide range of meaningful work-related opportunities.



Greater opportunities, better lives

Supporting adults with learning disabilities and/or autism into a range of person-centred work-related outcomes enabling them to live active and better lives



www.cornwall.gov.uk/properjob

The scheme was launched in June this year to coincide with the new PROPER JOB Café at County Hall in Truro. The café offers a range of work-related opportunities in a commercial environment but recognises that not everyone wants, or is ready, to move directly into full-time employment and may need support to help them on their journey towards reaching their goals.

The PROPER JOB team knew that people wanted alternatives to paid employment; alternatives that included training, volunteering and work experience. They also saw the need to develop access to supported internships and apprenticeships.

So, this new scheme offers people a job, with proper pay and proper conditions, giving an affectionate nod to the local phrase, often delivered with a thumbs up sign, to represent a job well done. Using the thumbs up symbol is also well-known as a 'like' on social media and it's the British Sign Language symbol for 'great'!

Area Manager for Cornwall Council, Clive Gaylard, told *DISCOVER*: "We wanted to create greater opportunities that support people to live better and more fulfilled lives. This new service is completely person-centred and combines two key elements - enterprise and employability. Our initial enterprise was the Ginkgo Café based at the One Stop Shop in St Austell, and alongside this we had Employability Cornwall - our supported employment service. We are very proud of our five trainees who have now progressed into paid employment, and we have plans to open another PROPER JOB Café at our Dolcoath Office in Camborne - so please do look out for further news on this. Our plan is to expand our enterprise model across Cornwall, to include a broad range of employment sectors."

So what do the PROPER JOB employees have to say:

Laura Keeper, 41 from St Austell says: "I really like working on the till and I like having my own money. It makes me very happy, cooking and working on the till, having a laugh and making new friends."

Gemma Rodcliffe says: "I enjoy it, I like working on the till and using the card reader"

Lauren Bryant after the initial launch event said: "It's been quite busy today, we do sandwiches, chocolates, drinks, things like that. I work behind the till and I serve drinks as well. I do like it here, I've made new friends and I do like my job."

Another critical aspect of PROPER JOB is to support employers and promote the value of employing people with a disability or autism.

Andy Virr, Cornwall Council Cabinet member for adults and public health told *DISCOVER*: "With any life-long disability it can be quite isolating and lonely and also tough on carers. Some of the more traditional approaches like day centres have a role, but wouldn't it be better if folks like this are fully integrated into our communities and working with local employers. It's great support for them, they make new friends, it's helpful for their families and it's a really positive contribution to that employer."

If you are or know of an adult with learning disabilities or autism and would like to find out more then please get in contact with the team. Or if you are an employer thinking about giving people an opportunity, the PROPER JOB team at Cornwall Council would love to hear from you.

✉ properjob@cornwall.gov.uk



**PROPER
JOB**

We offer a wide range of work-related opportunities which recognise that not everyone wants, or is ready, to move directly into full-time employment and sometimes need stepping stones to help them on their journey.



Courtesy of Cornwall Council

Channel 4's Disability Code of Portrayal



Pictured left to right: Sophie Morgan and Ade Adepitan

Channel 4 announced in July its plans to strengthen the representation of disabled people across all Channel 4 platforms.

The popular television network plans to introduce what it refers to as The Code, a pioneering initiative, being the only one of its kind in the media industry. It is a set of guidelines for both commissioners and programme makers, pledging measures like the commitment to seek disabled actors for disabled roles and the guarantee to represent people with disabilities as well-rounded characters who are shown to be more than just their conditions or impairments. Channel 4's Chief Content Officer Ian Katz said: "It's now time for a step change at Channel 4 across all our portfolio, in terms of both the quantity and quality of disability representation in our content."

The Code includes ten commitments:

They will commit to having a range of portrayal types for disabled people including 'incidental' where disabled people are incorporated without any direct comment on their disability; 'integrated' where people's disabilities are sometimes addressed when authentically relevant; and 'core' where people's disabilities are at the forefront of the narrative.

They will adhere to 'nothing about us, without us' (The United Nations Convention on the Rights of Persons with Disabilities) where disabled people

tell their own stories whenever possible; Channel 4 will seek disabled performers for disabled roles; and have empathy with, rather than sympathy for, people with disabilities. The television network aims to strike a reasonable balance between neither overplaying nor underplaying disabilities, meaning a person's disability will only drive the narrative if it is sincerely required. Conversely, Channel 4 states they will not gloss over or reject disability in their content if it is an integral part of a character, presenter or contributor.

Ian Katz adds: "This Code not only allows us to get into more engaging and knotty creative conversations around disability, but it also gives us a framework for accountability, for our production partners and our commissioning editors. It will ensure that they work with the best talent, on and offscreen, to allow us to deliver on it and make sure that we get to a higher standard of portrayal."

Channel 4 has built a long-standing reputation as an inclusive television network including giving fair representation to people with disabilities. The network has been the official broadcaster of the Paralympics since 2012, showcased hit series such as *The Last Leg* and *Born to Be Different*, and promoted broadcasting talent like Ade Adepitan, Rosie Jones and Adam Hills. Channel 4's new initiative goes to show its strengthening commitment to the representation of all voices.

www.channel4.com



IgniteYou is a Community Interest Company, founded in 2017 by Becci Gowers after she identified a need for accessible and affordable nutrition and dance delivery, particularly in low socio-economic areas, where she ran many dance classes. IgniteYou's ethos is about empowering people to take ownership of their health through fun, engaging and accessible workshops, classes and consultations.

Mainly delivering to people with additional needs, of all ages and from all walks of life, IgniteYou prides itself on seeing people as individuals rather than labels and ensures that every person is treated equally. A lot of the workshops are designed by the people, for the people, which creates an even greater positive outcome, as people feel they are being listened to and have a say in what is important to them.

There are three main strands to IgniteYou:

The Inclusive Dance Timetable

Classes for all ages and abilities in mainly street dance and music and movement, which is a more contemporary vibe.

The Hub Project

A creative place for adults with learning disabilities to harness the power of creativity and connection and there are plans for advocacy support to be added to this soon.

Keys4Health

A project focusing on nutrition, sleep, stress management and movement and why these are all so important for living your best life. This also includes 1:1 nutritional therapy.

IgniteYou has seen hundreds of people in their workshops and classes throughout Cornwall and they have received amazing feedback and witnessed people thrive over the years through engagement.

They say all this wouldn't be possible without their awesome volunteers, who themselves started from joining classes and workshops and are now trained volunteers. Becci told *DISCOVER*: "They are invaluable to all delivery as they have lived experience and can support IgniteYou in how best to move forward, as well as being so supportive to everyone who comes to the sessions".

From September 2022 projects will be run in Camborne, Redruth and Penzance.

If you would like to find out more about IgniteYou, they welcome people to get in touch, or check out their website for current timetables.

✉ becci@igniteyou.org.uk

🌐 www.igniteyou.org.uk





Get out on the water for some sightseeing, fishing and fun!

Wetwheels South West, based at the Falmouth Haven Marina has enjoyed a fantastic first year of operation. They tell *DISCOVER* they have had a tremendous amount of positive feedback and many returning customers, including families, groups and from organisations that support disabled people, or people who have a life limiting or terminal illness.

Their 325hp engine powered catamaran has disabled access direct from a pontoon at any tide and it operates 365 days of the year (other than for short servicing periods). It offers the opportunity for guests to go fishing and view the marine wildlife, including dolphins, seals, tuna, and even peek into their lobster pots to see if any crustaceans have visited.

Their fishing trips are very popular, for the complete novice or experienced fisherfolk and all equipment is provided, they even have an electric fishing reel, for people who have limited mobility. If you fancy a more leisurely trip, Wetwheels offer a gentle

cruise, either along the coast or up the River Fal and everyone gets the opportunity to drive the catamaran, there is a wheelchair access slope right up to the steering controls in the wheelhouse.

All of the crew are volunteers and many are from a lifelong maritime background and offer their time free, to bring smiles to faces and happy memories for guests.

At any time, they can accommodate up to three guests in wheelchairs, along with family members or care providers, to a total of 10 passengers and the wheelchairs are secured to the deck on specially adapted mounts, for comfort and safety.

The vessel is fully safety certificated and registered with the Maritime and Coastguard Agency and is licensed for passengers. All of the safety, lifesaving, and firefighting equipment is in place and serviced in accordance with National Maritime Legal Requirements.

Should the weather become less favourable, they are fully prepared with full body and wheelchair ponchos and fleece blankets. There is nothing guests need to take, other than a drink, a snack, sun cream and a hat in the warmer months, and of course, a camera!

Wetwheels South West is part of the Wetwheels Foundation which has been operational for 10 years and founded by Geoff Holt MBE. They are a not for profit community interest company, who enjoy the patronage of HRH The Princess Royal.

If you think your community or anyone you support may benefit from what Wetwheels offer, they invite you to get in touch. You can learn more by visiting one of their online media platforms, where you can see photographs, videos, and read reviews.

☎ 07889 275907 (Bookings)

✉ david.rogers@wetwheelssouthwest.co.uk

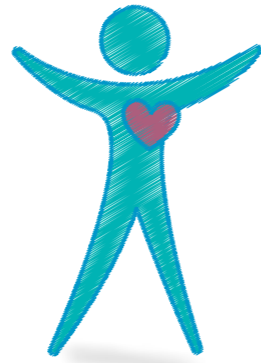
🌐 wetwheelsfoundation.org/locations/southwest

📱 @wetwheelssouthwest

📺 Wetwheels South West



Photos courtesy of Wetwheels South West



Why we're Proud to Care

Proud to Care Cornwall was set up in 2017, as part of a wider South West initiative, to raise the profile of social care, and highlight the amazing work carried out by our care workforce. We want to inspire people to work in a sector which provides job satisfaction, job security and career development.

It's no secret that we are in need of more recruits to adult social care. From personal assistants and care and support workers, to managers, there are regularly over a hundred job adverts for multiple vacancies on our website. These jobs are located in a range of settings, some in care homes, others in at-home care.

There are many misconceptions about a career in care. One of these is that a job in care won't lead to a career. This isn't true, Cornwall Council's CEO started her career in a care role, as did Kate Shields, the CEO of Royal Cornwall Hospitals Trust. Once you gain experience, there are lots of opportunities to specialise and progress.

There are many other benefits to a role in care, what we hear most often from care workers is that it's so fulfilling. You're directly making each day better for someone, just because you're there for them. Jobs in care are often flexible, enabling you to work around existing commitments. You don't even need experience to get your first job, free training is provided. You'll also get support from a friendly team - and most of all, the company of those you're caring for.

If you are an organisation looking to recruit, it's free to post jobs on the Proud to Care Cornwall site.

To make the leap into a career you can be proud of, visit www.proudtocarecornwall.org.uk/jobs for the latest vacancies.

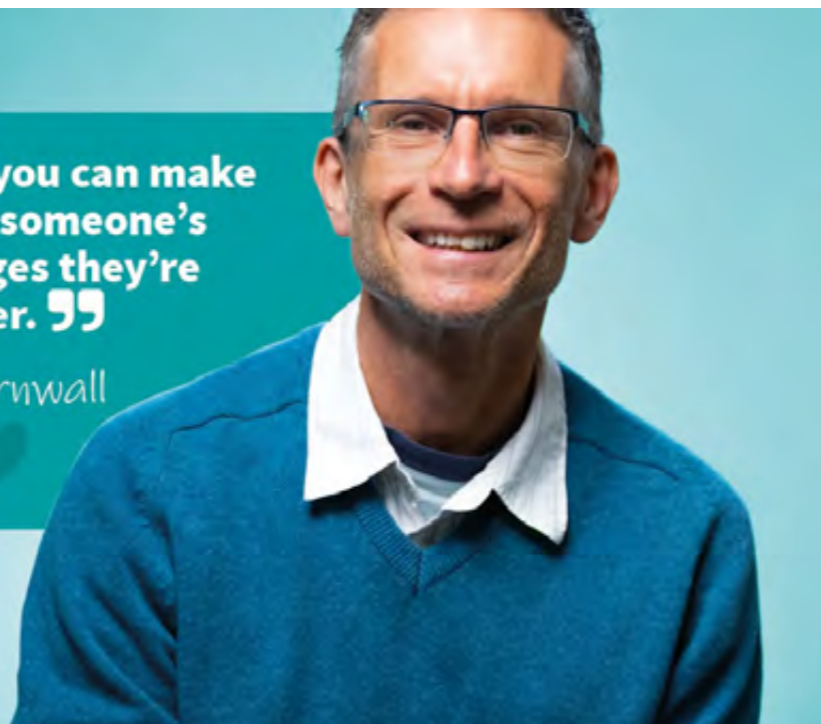
#BeProudtoCareCornwall

The work of Proud to Care Cornwall is part-funded through the European Social Fund (ESF).

www.proudtocarecornwall.org.uk/jobs

“I love the fact that you can make a real difference to someone's life or make any challenges they're facing that little bit easier.”

- Vaughan, DisAbility Cornwall and the Isles of Scilly



BuDS share their latest Covid insight

Buckinghamshire Disability Service (BuDS) formed an expert group to advise on the pandemic, including clinicians and statisticians with pandemic expertise.

They have produced over 250 articles which include a weekly risk assessment and they talked to *DISCOVER* about their findings, the future modelling and the significant increase of people with a disability which will not only have a considerable impact on Disabled People's Organisations in demand for support but how the long-standing disability issues around barriers, accessibility, attitudes and so forth, will be enlivened by being applied to a new group and in new contexts.

While BuDS is a locality based disabled people's organisation, their Covid risk response has had a national reach through associating with over 150 active project volunteers in 16 teams. Andrew Clark, Chair of their Trustees told us: “The virus has three major effects: it causes an acute illness in a minority of people who catch it, some of whom die, it causes acute post-infective conditions in a larger minority, and lastly, it causes long term disability to a significant minority.”

Andrew described that Covid infection is a lottery and it's impossible to predict who will get which level of illness or disability. However, it's well known that people who are already clinically vulnerable or extremely clinically vulnerable are much more likely to have an adverse outcome.

“In 2020 the NHS calculated there were 2.2 million clinically vulnerable people in England, but subsequent research suggests the number is much

higher, possibly around five million, which is around 7% of the population. Repeated infections increase the probability of an adverse outcome and in the past six months, it has become obvious to clinicians that the number of people developing acute post-infective conditions and long-term disability is much greater than first thought.”

“The virus mutates quickly to avoid protections from both prior infection and vaccination, it cannot scientifically be controlled or eliminated by a one-off vaccination programme as the Government claims. There cannot scientifically be any ‘herd immunity’ to Covid, it is a biological impossibility.”

As of June 2022, the UK was in the middle of the third Covid wave this year alone: Andrew explains that new variants will continue forever, as long as the virus is allowed to circulate freely. He maintains the only way to bring the pandemic under control is to provide a rolling vaccination programme, alongside measures to limit the spread of the virus, which he says is something the UK Government is politically unwilling to do. “Most independent scientific observers expect a pattern of future waves. This isn't a prediction, but an illustration. A crucial point to remember is that one wave overlaps the next, so that there is a constant high level of infections with regular peaks. This is the technical definition of a pandemic.”

Andrew says the strategic implications of the pandemic for Disabled People's Organisations (DPOs) are substantial.

“We have compiled a massive quantity of data to put together a series of forecasts and it's impossible to give hard figures as we are still trying to understand ‘Long Covid’ and its repercussions, but from a strategic perspective, the future will see hundreds of thousands, possibly millions more disabled people, due to Long Covid.”

“We expect between 600,000 and 1.9 million more disabled people by 2025 due to this alone. Many of whom will be of working age or younger, this means that their number and presence in society means that being disabled will become much more of a mainstream matter.”

What does this mean for DPOs? “For starters, DPOs will see a massive new demand for those services,



including befriending, advocacy and financial help. This will coincide with the real possibility that there may not be a corresponding increase in Government or voluntary sector funding. Without Covid, DPOs would have seen a more natural demographic increase in demand for services of about 1.5% by 2025. Covid now means that the mid-range estimate for an increase in demand sits at 10.5%.”

BuDS stressed that as being disabled becomes more mainstream, the long-standing disability issues around barriers, accessibility, attitudes, and so forth will be enlivened by being applied to a new group and in new contexts. “DPOs which support disabled people in work or into work are going to be especially busy. Pre-Covid, disability was primarily an age-related issue, with a minority of disabled people being young or of working age. Covid will change that position significantly, and a great many of the people disabled by Long Covid will be of working age.”

“For membership and voluntary DPOs, the influx of many more working age disabled people, many of whom will be furiously indignant, gives an opportunity to refresh and expand DPOs membership and volunteer base. For all DPOs, Long Covid gives a huge conceptual opportunity to break out of a minority group mindset and start positioning disabled people as a ‘normal’ group within society, rather than a marginalised minority.”

Even from a more practical standpoint, Covid will continue to affect DPOs as organisations and as employers. “Every DPO needs to make a decision about whether to allow Covid to control the organisation and its future, or not,” said Andrew. “A significant percentage of DPO’s staff will catch Covid-19, some of them repeatedly. Therefore, a significant percentage, possibly over half or three-quarters of your staff and volunteers will drop out of the workforce many of you have already coped with the deaths of staff/volunteers/service users, and that will be a recurring theme for the future.”

Andrew affirmed that Covid-19 is not turning into a mild, seasonal illness like influenza. It is, and will remain for the foreseeable future, a virus which will cause significant levels of both acute illness and long-term disability. DPOs and their staff, volunteers and people using services are all playing a numbers game in which Andrew declares is a ‘death by a thousand cuts’.

BuDS do have scientifically grounded advice to help organisations and employers mitigate Covid-19 infection and reinfection. Andrew explained that, “Covid is not going away. It is, therefore, our recommendation to all DPOs to consider an easy, affordable and practical alternative to



In June we sadly lost a very dear friend, this beautiful lady was Ann Georgina Le Hunte, a long-time member, friend to our staff, and wife of one of our Directors, George. For many years George and Ann have enjoyed doing our restaurant reviews for *DISCOVER*, checking out accessibility and enjoying some lovely meals around the county while doing so, the last one being the Red River Café at Heartlands featured here. Ann leaves her husband George and son’s David, Stephen and families. Donations in lieu of flowers were kindly gifted to disAbility Cornwall and the (stroke) Speakeasy Club. We send our heartfelt sympathies to Ann’s family and everyone who knew this lovely lady.

allowing Covid to run your DPO. It is the way that Buckinghamshire Disability Service has decided to run itself over the next few years. We call it ‘Covid-Careful’.” He added, “Covid-Careful is simply to use scientifically proven precautions to minimise the Covid-impact on DPO staff and service users. This includes establishing a Covid-safe office, where masks are not mandatory, but where constant fresh air is required and in circulation. In instances where there is a risk of contracting Covid-19, we advise DPO staff to wear FFP2 or N95 masks as they offer the most protection against infection.”

BuDS have changed the way they work to enable them to work just as efficiently and effectively, without losing necessary social interaction, while minimising risks. Andrew says this was not difficult nor expensive and BuDS are happy to share all their learning and plans with other DPOs who also wish to be Covid-Careful.

☎ 01494 211179

✉ info@buds.org.uk

🌐 www.buds.org.uk

Restaurant Review

Heartlands Red River Café

by George & Ann Le Hunte

Heartlands is a 19-acre Cornish Mining World Heritage Site, is a family friendly visitor attraction that embodies Cornish culture. It is at Robinson's Shaft, Dudnace Lane, Redruth, nestled just off the A30 in the mining heart of Cornwall. It is open from 9am till 4pm.

Heartlands is a charitable trust dedicated to providing a community hub which can be enjoyed by the local community and visitors from afar. It is a place where people can learn, explore, play, relax and enjoy eating at the Red River Cafe. It includes a mining museum and exhibition, diaspora gardens, and a giant adventure playscape for kids. All are completely free to enjoy.

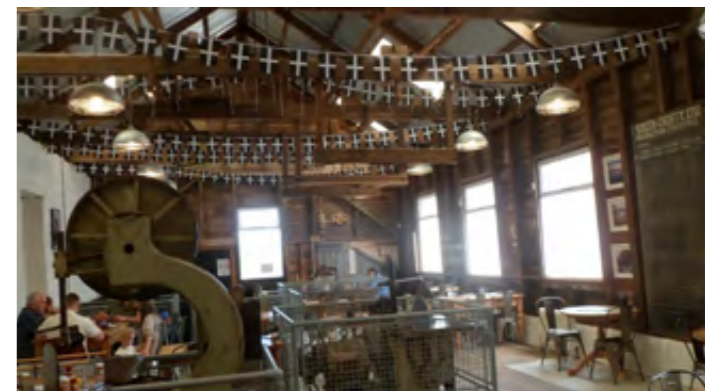
Heartlands is a disabled friendly site, all flat-surfaced, with blue badge car parking behind the Red River Café, an accessible toilet in the cafe and a Changing Places toilet by the blue badge parking.

The family friendly Red River Cafe gives a real taste of Cornwall. With a beautiful wooden beam ceiling and original mining features, the cafe is unique which makes it the perfect venue for a coffee, breakfast, or lunch.

The menus are created using fresh locally sourced ingredients, to provide imaginative but traditional Cornish food. They cater to dietary requirements so make sure the team is aware of any allergies when you are ordering.

For a cafe, the menu is extensive, to eat in or take away. Starting with a full, or small, Cornish Breakfast, with several vegetarian options. For lunch you can choose light bites including chicken nachos, pasties, soup, sandwiches, or a Cornish Cream Tea. The main menu includes fish and chips, salads, burgers, plus more, with side dishes. The menu also

Children's meals offering smaller portion sizes. The dessert menu has a great variety of ice creams, waffles, and cakes. There is also a wide selection of drinks available including milkshakes, alcohol, soft drinks plus tea and coffee.



Profits raised from the Red River Cafe and shop contribute towards the upkeep of the children's adventure playground, landscaped gardens, lawn, museum, engine house and maintenance of several Grade 11 and Grade 11* listed buildings.

It's a place worth visiting!

Government's cost-of-living 'sticking plaster' is 'no long-term fix'

by John Pring
Disability News Service

Hundreds of thousands of disabled people will each miss out on £650 in crucial support, because of the government's failure to target new cost-of-living funding at some of the groups most in need, disabled campaigners have warned.

Disabled people's organisations said the injection of £15 billion in grants and other funding that was announced in May – while welcome – would not solve the cost-of-living crisis for disabled people. And they said the new funding underlined the urgent need for a long-term fix for the social security safety net.

The chancellor, Rishi Sunak, has announced support for energy bills, as well as cost-of-living payments*.

People on means-tested benefits such as universal credit and income-related employment and support allowance (ESA) will receive £650, split across payments in July and autumn 2022, but people who only receive the contributory form of ESA** (or the contributory form of jobseeker's allowance) will not be eligible for this funding. All disabled people receiving disability benefits such as personal independence payment (PIP), disability living



allowance (DLA), attendance allowance, and their new Scottish equivalents, will also receive a one-off payment of £150 by the end of September.

Because the chancellor announced a series of flat-rate increases, people on lower rates of PIP, DLA and AA will receive a proportionally more generous payment than those on enhanced rates of the benefits. Domestic electricity customers in Britain will each receive a £400 grant, which will appear as a credit from energy suppliers from October 2022 onwards. And people of state pension age who already qualify for an annual winter fuel payment will receive an extra one-off £300 payment, from November 2022.

In addition, Rishi Sunak announced a £500 million increase for the Household Support Fund***, extending it from October until March 2023, bringing the total allocated to the fund to £1.5 billion. The Treasury said the package amounted to £15 billion in support, which was “targeted particularly at those with the greatest need”.

The Institute for Fiscal Studies described the package as 'genuinely big' and said: “The chancellor is engaging in some serious redistribution from rich to poor – albeit against a backdrop of rising inequality, while he had 'finally' produced funding targeted at benefit recipients.” Benefit claimants had been due to lose out significantly, with benefits rising in April by just 3.1 per cent, despite inflation over this year now expected to average 8 per cent.

Disabled people's organisations and grassroots groups welcomed the new funding but raised

significant concerns about how the money was targeted. Linda Burnip, co-founder of Disabled People Against Cuts, said: “While we welcome the additional funding that has been made available, we are very concerned that those receiving contribution-based social security payments have been excluded from this extra funding to help meet their needs. No doubt this is a sly move by government to try to force people to claim universal credit instead.”

Michelle Maher, from the 'WOWcampaign', said that those on contributory benefits, such as the contributory form of ESA, would not receive the £650 grant, despite the huge cost-of-living increases they were facing. Many of them, like her, were still on low incomes, and qualify for free prescriptions and help with their council tax, even if their incomes and savings were not low enough to qualify for means-tested benefits. She pointed out that she and 290,000 other claimants of DLA and PIP who do not qualify for specific means-tested benefits were already set to lose the right to receive the Warm Home Discount (WHD) later this year, which will mean losing out on £150. She questioned why someone with the wealth of the chancellor – who has three homes – should receive £1,200, with a £400 fuel grant for each of his three properties, compared with just £400 for her and most other disabled people.

Maher said that many disabled people feel pain when they are cold, while essential impairment-related equipment often needs electricity. She said: “We have no choice. I myself can't cook, because

it's dangerous due to a severe tremor. I also can't physically shop around all the different shops for bargains. My choices are limited. Do I hand back the Motability car which gets me to hospital and doctors' appointments, and lose the freedom that allows me? Do I stay cold, find the cheapest, unhealthy microwave food, cutting fruit out of my diet?”

“We are the groups on legacy benefit who didn't get uplifts during the pandemic; we got zero support. We are the group with Covid still hanging over our heads like the sword of Damocles. We're not the group who mishandled the pandemic, giving billions out to fraud, cronyism and a £1 billion tax cut for bankers. We're the invisible, the second-class, the othered.”

* For further details, see government information on its Energy Bills Support Scheme and its cost-of-living support

** Contribution-based benefits are not means-tested and are available to those who have paid enough national insurance contributions

*** The Household Support Fund is distributed by councils in England through small payments to help “vulnerable households” meet costs such as food, clothing, and utilities

Our professional and friendly advisers are here to support you Monday to Friday 9am - 4pm



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T
01736 759500
M
07522 970336
E
advice@dialcornwall.org.uk

Credit: Cornish Pixels

We are Cornwall Mind and we're here to help

When you're managing a mental health problem, or supporting someone who is, having access to the right information and support is vital.



We believe no-one should have to face a mental health problem alone. We listen, give support and advice, and fight for those who need our help.

Our vision is for people to live and work in a county that promotes good mental health for all and treats people positively, fairly and with respect. We collaborate with the National Mind to make sure their pioneering campaigns, information, and research make a difference in Cornwall. Although we're affiliated with Mind, the national charity, Cornwall Mind is an independently registered and funded charity dependent on fundraising and donations, to continue our vital work in the community.

Our wellbeing service supports people to help build resilience and reduce the onset of mental health problems. We offer a range of recovery focused groups and activities and work with people to support them in achieving their goals and engaging in their local communities. We rely on our amazing team of volunteers to help us deliver our services and support our day-to-day work.

Working with our community networks, we also offer a range of one to one Outreach Support projects, working individually to empower people to access the solutions they need for recovery,

independence, and progression towards happy, healthy lives.

Ensuring that people with lived experience of mental health are involved and influence the ongoing development of Cornwall Mind is very important to us.

We work hard to understand the needs and experiences of people with mental health problems. This drives everything we do, and, wherever we can, we actively seek opportunities for people with lived experience of mental health.

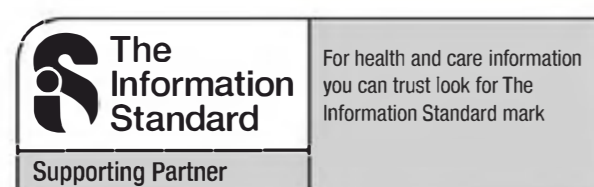
Our award-winning mental health radio show 'A Space To Speak Your Mind' in collaboration with Source FM, provides an opportunity for people to get involved and have their say. Through the radio show we can listen to, understand, and act on the views and opinions of as wide a range of people with experience of mental health problems as we can.

To refer to our services or find out more about volunteering or fundraising please get in touch.

📞 01208 892 855

✉ info@cornwallmind.org

🌐 cornwallmind.org



**INVESTORS
IN PEOPLE**

Gold

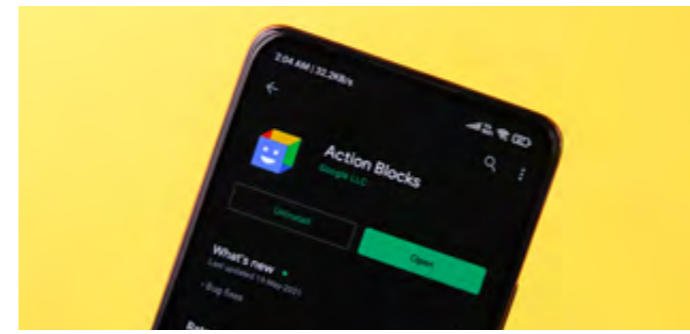


Digital Inclusivity:

Disruptive technologies helping people in the workplace

According to the World Economic Forum, over 1.3 billion people live with some form of disability, many of whom work in an office or work from home. Advancements in technology can offer larger economic benefits and greater inclusion increasing job opportunities.

In a world of constant advancement in artificial intelligence amongst other disruptive technologies, *DISCOVER* reports on the latest digital tools that provide equal opportunities in an office environment.



Google Action Blocks

Action Blocks makes it more convenient to carry out routine actions, whether it is calling a work colleague or opening a calendar. You can set up these actions through the app, where they appear as literal images or widgets on your phone's home screen. A simple touch on the Action Block triggers the action. The app can also speak, so it's helpful for people with communication needs.

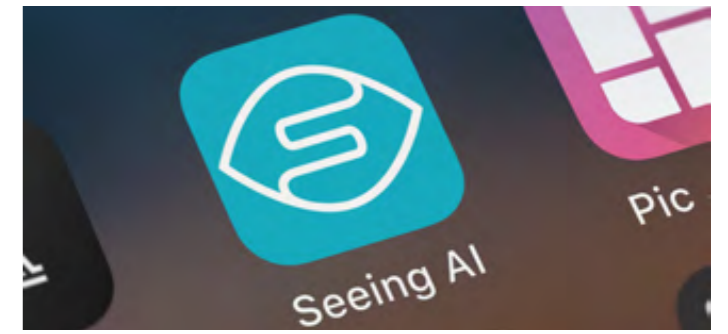
It's available on Android phones in English, French, Italian, German, Spanish, Portuguese, and Japanese via the Google Play App Store.



Zoom Transcripts

The video communications app 'Zoom' was one of the fastest-growing virtual meeting apps in the last few years. It recently matched Microsoft Teams and Google Hangout by integrating live captioning to aid people with hearing loss during online meetings. An additional feature enables users to obtain a transcript of a recorded meeting after it has finished.

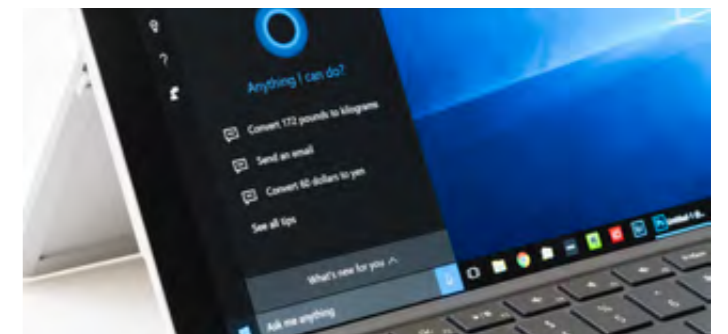
Recorded transcripts with similar applications have been known to not produce the most accurate of transcripts. However, with Zoom transcripts, there is the added function of 26 third-party transcription apps that have been approved for use. These can be found on the company's app marketplace. Zoom is available on Windows and macOS computers, and on Android and iOS devices.



Seeing AI

There is an estimated 253 million people worldwide that are either blind or have sight loss. This app really adheres to Microsoft's mission which is to empower every person on the planet to achieve more and the 'Seeing AI' app is essentially a talking camera app. It describes the visual world through harnessing artificial intelligence and active human-computer interaction. The app uses your smartphone's camera to audio-describe the environment around you. Multiple tasks can be completed with it, including reading out handwritten texts and computer documents. An additional experimental feature is that Seeing AI can identify people you know, describing their appearance and how they seem to be feeling (through their facial appearance).

Currently available in English and seven other languages, it will also describe images in other apps like Twitter and WhatsApp. The application is available on iOS devices.



Windows Speech Recognition

'Windows Speech Recognition' allows for the ability to control your PC through a voice-only option, without needing a mouse or keyboard. You can accomplish commands like 'open search', 'double-click an item' and 'switch to an open app'. If you want to unlock the potential of windows speech recognition, use the command, 'what can I say?', to find out a plethora of new voice commands. The application is available on Windows 10 and 11 computers.

Leanne's Poem

I'm lying on the sofa, just staring at my boy...

He's on YouTube again, watching a clip of a toy...

As I lay there watching what he's doing; a smile upon his face..

I think about how life could have been, my head starts to race..

I wonder what he would be like, if the autism wasn't there..

If he was able to talk and didn't need a wheelchair..

If he didn't have hypermobility and rumination syndrome...

If he didn't require special equipment in the car, at school and home..

I wonder what food he'd eat, if his diet wasn't so restricted..

I wonder if he would play the Xbox and like his brother, be addicted..

I wonder how his voice would sound and what questions that would bring..

What his favourite music would be and what songs he would sing..

I wonder what his favourite school subject would be.. or if he'd like school at all...

I wonder whether he'd be in a club or team.. karate, parkour or football..

I wonder whether he'd have lots of friends or have just one or two..

I wonder if his favourite colour would be yellow, red or blue..

I wonder what he would argue with his brothers about..

And whether he'd be the calm one or if he'd scream and shout..

I wonder what he would get excited about, or look forward to..

Where he would request to go, or what he'd like to do..

Thoughts running through my head.. I get carried away..

Thinking about what he's like now and what he could've been some day..

I'm saddened by my thoughts, my heart.

aches a little too..

Because his disability restricts everything that he can do..

Then he looks at me and smiles and those thoughts vanish from my head..

"As long as he is happy" - that's what I have always said..

I wonder why I'm even wondering; what if's are a negative thought..

And I remind myself of the incredible things in life, that autism has brought..

I'll never know how Jaxon would be, if the autism wasn't there..

I stop wondering and remind myself, I actually don't care.

I smile back at my gorgeous son; reminded of the joy he's brought..

"I'm lucky to have him, just as he is" - that was my final thought..

I reached over to kiss him on the cheek, like I do all the time..

Feeling lucky to be this boys' Mum and feeling proud that he is mine.

©Leanne Spargo - May 2022

I am a single Mum of 3 boys:

Cody age 14, Jaxon age 12 & Dexter age 6



Film Review

by Ruary Marshall



The documentary film Untethered explores the relationship between three-time Paralympian blind sprinter, David Brown, and his running guide Jerome Avery and their build-up to the Tokyo Paralympics in 2020. With the Tokyo games ever closing in on the duo, the film opens by picturing them visiting New York on a trip in search of inspiration. While visiting the 'Big Apple', David explains how he and Jerome have come a long way, running together as a duo for over seven years and participating in athletic tournaments including London 2012 and Rio de Janeiro 2016, attaining a gold medal in the 100 metre sprint in the latter.

He describes the importance of synchronicity with regard to blind sprinting: "We have to be, you know, locked in, Jerome has to be fast enough to be comfortable in guiding, and I have to be fast enough in order to win!"

The sprinting duo are more than training partners and there is a segment of the film where Jerome describes the sheer size of the Brooklyn Bridge as they take a trip on a New York ferry, to which David replies: "I didn't even realise the ferry was moving!" It is a crisp cinematic documentary with camera shots showing intimate details, like David gripping onto the ferry's rope fence, evoking how David's other senses are heightened.

Next, is an effortless camera transition showing David gripping onto a device called a tether, a small piece of rope that helps blind runners and their guides stay aligned in the sprinting lane. It covers David's entry into athletics, with interviews from his former school coaches, explaining how at first, although always an exceptional athlete, David found it hard to accept he was losing his sight.

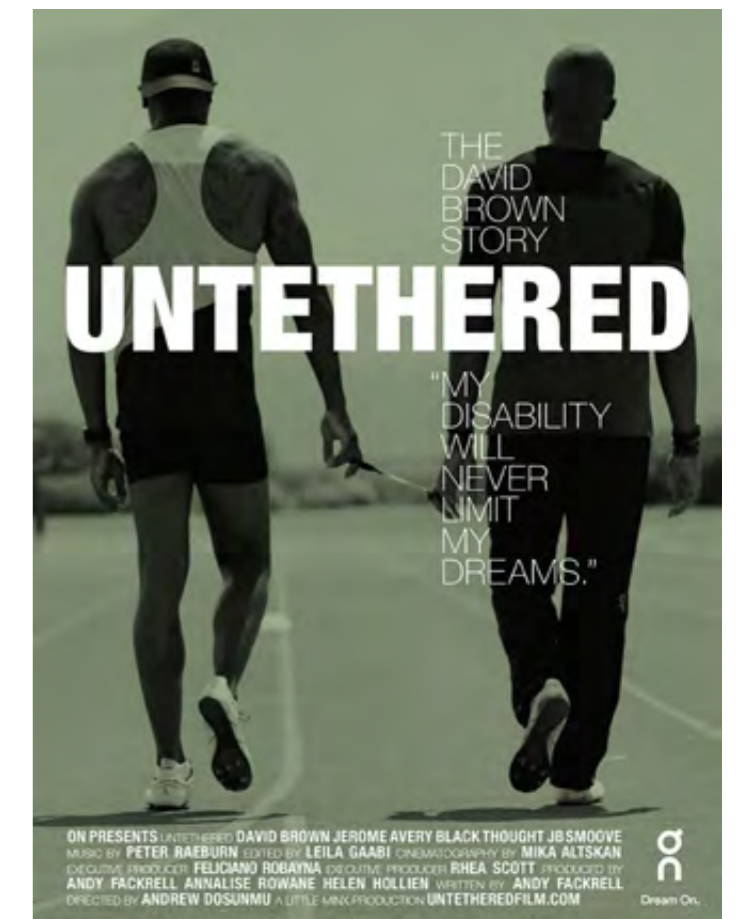
David was diagnosed with kawasaki disease, which led to glaucoma and complete blindness by the age of 13. One coach adds that David's perception of his body and movement increased with this, as he excelled at sports like sprinting and goalball, which is a mixture of tennis and football, for people with sight loss. What the coaches convey is that sports for disabled people is more than simply an activity, it is an opportunity for them to challenge

themselves, build confidence and become a part of a team.

David is inspired by people overcoming disability, which he describes as: "Getting up, doing something and staying active"

The documentary is 21 minutes long and is shot entirely in black and white, using several pictures showing David when he was young and when he had a vision, a simple yet striking juxtaposition.

The film ultimately has its narrative arch to a final poignant message. Jerome Avery was not actually selected to be David's guide for the then upcoming Tokyo Paralympics in 2020, and yet how, for that tournament, they become untethered. This film was more about David finding meaning through sprinting and his relationship with his running guide Jerome, rather than the focus being Tokyo 2020.



Your Enquiries

to the Cornwall Disability Information & Advice Line Team

Get in touch...

☎ 01736 759500

✉ advice@dialcornwall.org.uk

✉ I'm a carer and getting increasingly worried about the rising cost of everything. At the same time, I don't want to restrict the enjoyment I get travelling around Cornwall with the person I care for, as we greatly enjoy getting out and about visiting places and doing shopping. I've heard from other people that carers can sometimes get discounts for certain things and don't know what's available in the local area for activities or even buying stuff nationally. Any tips or advice would be gratefully received.

Carer, Liskeard Area

Yes, a range of discounts can be found if you have the time and energy to look around in the right places. It doesn't hurt asking at places you visit whether they do offer carer discounts or concessions. Some places will offer free entry if the person who requires care buys a ticket. Some popular local places which offer concessions include the National Maritime Museum, Trebah Garden and the Cornish Seal Sanctuary. A full list can be found on the Support in Cornwall Website (www.supportincornwall.org.uk), search under 'free and discounted entry for carers in Cornwall'. Some places will require proof of your caring role.

There's no single place that will show you every offer that's available but the internet can be a good resource, if you are mindful that some websites are better than others! Try to look for those that don't require any kind of membership fees. If you Google 'discounts for carers', you should get a selection of websites that offer different things. Cornwall Carers Service Advice Line can provide a Carers Passport which gives you recognition locally as an unpaid carer and in the future might be linked to a number of small discounts with local organisations. (01736 756655) They can also give you further help if you are struggling with finding online information.

✉ I am thinking of using my rail card and planning a trip to Cornwall by train to stay in the Newquay area. I'm a wheelchair user so I know there will be some challenges, and I would like to be able to enjoy the beach too. Have you got any suggestions that can help me?

Visitor staying in Newquay

If you need assistance (for example help getting on or off a train, with your luggage, or if you require ramps for a wheelchair), contact the train operator in advance where possible:

- > Great Western Railway – Assisted Travel (for most routes in Devon and Cornwall)
visit: gwr.com or call the Passenger Assist Team on 0800 197 1329.

All train operators carry wheelchair ramps on board their trains. Station or on-train staff can help wheelchair users to board and disembark. You can find out the maximum dimensions and other information for taking wheelchairs and mobility scooters aboard via their websites. Please note that Great Western Railway asks users of larger mobility scooters to register for a permit.

National Rail Enquiries 'plan assist' can be contacted on 0800 0223720

Visit Cornwall's website has some useful information; there is a map of Cornwall showing accessibility of Cornwall's beaches and where Beach Wheelchairs are available for hire along with options to search for accessible accommodation and attractions throughout the county. www.visitcornwall.com

If you don't have access to the internet, please contact DIAL Cornwall on 01736 759500 who can help.

✉ I'm an unpaid carer for my 86 year old husband. I'd love a break from my caring role but don't know how to go about this. I'm also worried about something happening to me while I'm away and not being able to get back to care for my husband.

Unpaid carer seeking respite

The Respite Association offer carers a week long self-catering holiday in Penzance, or North Wales, if you'd like to travel further away. The holidays are for the carer with friends or family. The cared for are not included as these holidays are designed to give the carer a break from caring. They also provide grants to pay for someone to look after the person being cared for which can be provided in the home, by a suitably qualified person or organisation, or away from home by a suitable organisation. You can apply directly via their online form at www.respiteassociation.org or by contacting the Cornwall Carers Advice Line on 01736 756655 for more support.

They can also provide you with a free 'Emergency Carers Card', a plastic card, the same size as a credit / debit card which fits easily into your purse

or wallet. This card gives reassurance to carers who are concerned about what would happen if they were taken ill, in an accident or if another emergency stopped them from getting back to the person they care for, and ensures the person they care for will receive support whilst remaining in their own home until the emergency is resolved or until other arrangements can be made.

To receive an Emergency Carers Card contact Cornwall Carers Advice Line on 01735 756655 with details of two people who can provide care should anything happen to you, or you can complete the online application form directly from the website www.cornwallcarers.org.uk. The card will be issued to you within 1 week, has a unique reference, and the telephone number of professional advisers who can access details of your nominated people which are held on a secure database. Adult Social Care will provide support free for the first 24 hours should your nominated people be unable to help at the time of contact. You can still request a card to identify you as an unpaid carer even if you don't have anyone to take your place.

Beneath the Tracksuit, Robert's story

Robert Gillett from Bodmin, shares his battle with Relapsing Remitting Multiple Sclerosis, from coming to terms with the condition at a young age, to channelling his adversity into touching poetry. He is the embodiment of inspiration for many around the world, sharing his words with over 5,000 Facebook followers and now a book: *Thoughts of a Warrior: Beneath the Tracksuit*

Robert tells *DISCOVER*: "In March 2014 I froze at work whilst fitting a kitchen, I had symptoms that resembled a stroke and I had so many different tests and several MRI scans to get a definitive diagnosis. I felt like it took forever, but we got there in the end, finally I was diagnosed with Relapsing Remitting Multiple Sclerosis, commonly referred to as RRMS, in March 2015."

The beginning of my journey was slow and my symptoms didn't give me too much hassle for the first few years. I had a lot of strange symptoms and my hand would randomly curl shut and when fresh air brushed across my skin, it would feel like fire. Symptoms like this would only last a few weeks or so, but it was very unpredictable and rather scary.

Then, in January 2019 I had a relapse that would change my life significantly. I was on the most intense treatment available (Lemtrada) and it didn't work for me. The relapse left me with a dropped foot, persistent neuropathic pain, my body became weak and heavy and my balance was absolutely terrible. I now use a walking stick and need to use a mobility scooter for any sort of journey, because I haven't got the strength or stamina to keep going.

As a 30 year old man, this was so difficult to comprehend. I'm a father, a husband and a very



Reading live poetry at the Merlin MS Therapy Centre

active man. To have these difficulties happen to me, so unexpectedly, brought me into a very rough time with depression, which is also such a hard fight. I'm in and out of episodes of depression and living with Multiple Sclerosis only made this worse.

I started seeing a counsellor to help with my mental health and he suggested I write a thought diary to help put my pain somewhere. I did this for a little while, but it wasn't really working, I would go back and read it through and it would make me feel worse. So, I put my emotions into poetry instead. This was different, this was good. I was creating art; I was creating something positive out of my pain. I'd find myself writing a lot and this was really

giving me a way of explaining the way I was feeling. When someone would read my poetry, they would have a clear understanding of the way I felt and the problems I was facing.

My wife suggested that I could share my poetry, she said it could help people, raise awareness, and inspire others to reach out. She suggested it could also help other people have a better understanding of what MS is and what it's like living with it.

I said no at that time, I didn't want to share it, this is my thought diary, my thought process, and my raw emotions. I didn't want to share it with the world. Would you share yours?

After a while, I came round to the idea that this could help other people. When I was diagnosed, I wish there was some way I could have had a better understanding, so maybe this could help others and if it helped one person, it would have been worth it, so I started to share and I created a Facebook page called 'Beneath the Tracksuit'.

MS is an invisible illness and I always wear tracksuits, and no one can see the struggle that goes on beneath it. So, Beneath the Tracksuit made sense. I only planned for my friends and family to see it at first, but the following began to grow faster than I expected and my poetry is shared all around the world now. I have people from America, Australia, New Zealand, South Africa and all over the UK messaging me. People thank me for helping them emotionally and mentally. I have carers messaging me too, thanking me for helping them understand what their loved ones are going through. This is a response that I wouldn't ever thought could have happened. My pain is helping so many people, it's very surreal. I've been writing about my struggles, mostly in my bed and they have been read all over the world, helping and supporting other people with MS!

"My pain is helping so many people, it's very surreal"

After about six months of Beneath the Tracksuit doing well, I thought about putting these poems and some of my story into a book. It was difficult writing a book but I got there eventually, I released "Thoughts of a Warrior: Beneath the Tracksuit" on Amazon and I turned my pain and my struggle into a book. When I started writing, this was never on the cards, I just used poetry to help with my pain and now I have written a book which is sold worldwide. I am so proud of what I managed to achieve and it showed me that anything is possible. Out of my pain came so much light and positivity!

I read my poetry at my local open-stage events where I teamed up with some other artists. We then created an event to raise money for the MS Therapy Centre in St. Austell and it was very successful and it's something we are all very proud of.

Who knows what the future has in store for any of us, but we try and keep trying and we'll do the best we can in life with what we have. I'll continue to write, and I'll continue to share. If it helps one person, then it'll be worth it.

Thoughts of a Warrior: Beneath the Tracksuit is available on Amazon.

You can find Robert's blog on his Facebook page and read one of his poems overleaf:

f @Beneaththetracksuit

*Beneath
the
Tracksuit*



Sick of being sick

I am so sick of being sick,
My body,
My brain,
My mental health,
They can't handle it.

This persistent pain,
It's annoying me,
The not being able to walk,
It's depressing me,
The way I switch from positive to negative,
Is constantly confusing me.

I need help,
I need out,
I'm ok on the surface
But beneath,
Inside I'm in doubt,

I can't escape this disease,
All I do is fight,
Always!
Morning!
Noon!
Night!

Why can't I just be me?

Why can't I just go back?

Why take my abilities?

I'm really struggling to handle that.

I'm trying to go on,
Trying to live through another day,
Keep finding the strength to continue,
I don't see another way.

©Robert Gillett - May 2022



CORNWALL CARERS SERVICE

SUPPORT FOR PEOPLE WHO CARE



01736 756655

A Whole Age Service

 hello@carersadvice.org.uk


www.cornwallcarers.org.uk
www.kernowyoungcarers.co.uk



A Carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a condition that affects their mental or physical wellbeing or an addiction cannot manage without their support.

This includes helping with chores and tasks like cooking, cleaning, communication, moving around, shopping, washing, taking medication, managing money or appointments.



The service delivers a range of high quality support for unpaid Carers of all ages throughout Cornwall including:

Emotional support, information, advice and guidance, statutory assessment, access to grants, community support, carer specific training and dedicated support for all carers (including young carers and young adults).

KERNOW YOUNG CARERS SERVICE

Kernow Young Carers Service meets the needs of young carers and young adult carers, age 4-25 yrs.

We offer:

- Practical support, information, advice, and guidance.
- Activities and workshops.
- Social interaction, peer support and help to provide a break from the caring role.
- Training and support for schools.
- 1:1 support.
- Help to access grants to meet a range of needs that help to reduce the impact of your caring role.



Our Partnership is made up of DisAbility Cornwall IOS, Barnardo's, Age UK CIOS, Promas CIC and CRCC as the Lead Partner.

A Creative and inspirational partnership of like-minded organisations supporting unpaid informal Carers caring for a loved one.

New BSL 999 emergency service

A new innovative mobile application will be a welcome technology enabling thousands of deaf people to report a 999 emergency in their own language (BSL)



The mobile application called '999 BSL', was released in June 2022 and it is an emergency video relay service which will help thousands of deaf people, who have always had to rely on others, or use a text-based system.

It is an easy-to-use service, the person in need of the emergency service simply goes on the app or website and presses 'Call 999 Emergency Now'. Within a few seconds, they will be put through to a BSL interpreter who can give them guidance in the same way as a generic 999 call responder.

This new service offers deaf people more independence as previously, deaf people would have to text the emergency services on 999, but this service is only available if you have registered for the service in advance.

James from Hayle, who is the magazine designer for *DISCOVER*, has been profoundly deaf since

birth, says: "I have spoken to various emergency respondents over the years and asked them, 'how would I get hold of you because I can't phone 999?'. Usually, they just hand me a business-type card that contains numbers and details that don't offer a quick emergency response."

"When I found out about the new 999 BSL app, I was overjoyed and relieved that there is now a straightforward emergency service that I can use comfortably if needed. All I have to do now is press the 999 BSL App and connect to a BSL respondent that can understand me and my needs. The app gives me peace of mind."

999 BSL is available on Apple and Android phones as a downloadable application. There is also a desktop online version, available via the link below.

www.999bsl.co.uk

Inclusive improvements for our hospitals

The Cornwall Disability Alliance which incorporates 10 partner organisations has been working with the Royal Cornwall Hospitals Trust to influence and shape the new works at Treliske, West Cornwall and St. Michaels hospitals, to ensure that new buildings and developments are fully accessible and inclusive for everyone. This resulted in bringing together an Accessibility Advisory Group to meet regularly, review plans and provide advice and guidance, enabling co-production of the design of the new developments with their Strategic Estates Team. The pan-disability group comprises of representatives with lived experience, and they are now about to embark on improving some of the existing challenges such as accessible parking.

Carolyn Garman, Communications Lead for the Strategic Estates Team at RCHT told *DISCOVER*: "Feedback from colleagues tells me just how useful this group is, and there is growing momentum and belief in the work we are doing, I am extremely committed to continuing to raise awareness and the profile of the group across the Trust."

In the last six months the group have visited one of the new wards, provided valuable insight to the teams on general use of the new buildings including use of colour, signage, and suggested a pilot to have Makaton signage throughout one of them. There has been a review of the importance of bed positioning, improvements made to the layout of washing and toilet facilities, introduction of the use of the ADI Roommate to some of the accessible toilets, discussions on the layout of furniture, the need for subtitles on TVs, hearing induction loops, the types of intercoms which are inclusive, and colour contrast on switches and plugs! The group visited during the construction and design phase, and it was a great learning opportunity for the estates team to watch and understand how some of their patients have to navigate their way into and around the hospital environment.

Steve Paget MBE, a member of the advisory group said: "It is so refreshing to hear that our main hospital is now actively engaging with disabled people and that healthcare provision will become that bit more inclusive as a result. An important move towards co-produced solutions is always welcomed."



The Accessibility Advisory Group at the Royal Cornwall Hospital



There is much more to learn and improve but these small, positive steps have already helped to build trust between the hospital and the Accessible Advisory Group, providing a firm foundation for the ongoing partnership to ensure that the Trusts' estates are making improvements towards fully accessible infrastructure for patients, visitors and staff.

Cornwall Disability Alliance

www.cornwallvsf.org/our-alliances/our-alliances/disabilities-alliance



Join Our Social Movement

Who might join us?

We are a dedicated team committed to supporting people at times of real need.

We will take you through our speedy onboarding process and then, you will receive a real-time notification via the Humans App when there is a need in your community, and you can accept the job if the time is right for you. No obligation to work if the time is not convenient for you.

You can join us as employed or self-employed, whatever suits you! We can help with guidance and advice on how to set up as self-employed too.

Anyone with great values and compassion is welcome to join us, subject to references, right to work and a clear DBS check.

Sign up now or for a chat first, feel free to contact Jan, our Care Quality Lead, she is waiting to sign you up!

T: 01736 697904
E: jan@humanscornwall.co.uk
W: www.humans-cornwall.co.uk

So far, members include business people, OTs, nurses, former unpaid carers and people from all walks of life.

We have a back-office team here to support you while you are out undertaking work in the community.

- People in employment looking for extra hours maybe evenings or weekends.
- Retired people who still have more to give.
- Parents who need to fit work in around nursery or school hours.
- Students looking for work in the holidays.
- People who feel that a career in supporting others, aligns with their moral compass.

Reclaiming Our Futures Alliance: We must be the agents of change



Mark Harrison

Reclaiming Our Futures Alliance (ROFA) mission is simple; to defend disabled people's rights and campaign for an inclusive society. ROFA is a collective of disabled people and their organisations in England, allied together to create a united voice.

ROFA believes that due to the mismanagement of the government, disabled people must be self-determinists and Mark Harrison, head of ROFA emphasises that 'change starts from us, we must be the agents of change'. He told *DISCOVER*: "It is a tribute to those who founded our movement in the 1970s and before, that we have the rights we have. However, our rights are going backwards since the UK Government signed and ratified the United Nations (UN) convention. The historical exclusion and discrimination that we fought against is coming back."

Mark says that life for 13.3 million disabled people living in the UK is getting worse, not better. "Disabled people are experiencing retrogression against most, if not all the articles of the UN convention and we are twice as likely to live in poverty and be unemployed. Daily barriers, exclusion and poorer outcomes in all areas of life are increasing. Hate crime against disabled people is up by one-third. This is combined with austerity inflicted by our government which disproportionately falls on disabled people and there is a huge reduction in statutory support including social care." With such obstacles for disabled people in society, Mark stated he was 'proud' that ROFAs member group Disabled People Against Cuts (DPAC) reported the UK Government to the UN. This resulted in the UN establishing a special investigation using the 'Optional Protocol'. Something Mark welcomed as he says: "Our government is the only government that's been investigated for human rights abuses against its disabled population."

There is no doubt that Covid-19 disproportionately affected disabled people, but to what extent? "In Covid, not only did our government refuse to have BSL signers at the daily bulletins, so deaf people

could not access the information, but there was a lack of access to services like food, health and social care. There is an internal war going on in the UK, from our government against disabled people. It feels like we are the enemy within. We have seen the erosion of our rights, services closed, and there were Care Act 'easements' that meant disabled people had 'do not resuscitate' put on their medical records in hospitals against their will, or were not even consulted. Further, there has been a lack of support, particularly around social care and people in mental distress. This dire situation has led to structural inequality, where 60% of the deaths in the pandemic were disabled people when they are less than 20% of the population."

ROFA conducted a research project funded by The National Lottery in cooperation with Inclusion London which looked at the situation facing disabled people's organisations (DPOs). The project mapped out the DPO sector in England, which had 96 DPOs completing an in-depth survey and 60 DPOs taking part in a series of focus groups.

Mark discussed the key research findings: "What we found was that many DPOs went out of business over the last 10 to 15 years. This is because they were under resourced, and they did not have any ongoing commitment regarding funding from the government at local or national level. This was heightened when austerity measures were implemented. Services were cut and were taken back in-house by local authorities, and awarded to non-DPOs because they were undercut either by private businesses or disability charities who bid lower in order to win the work."

"There was a lack of capacity and resources to build staff and member skills to provide the right training and support, to develop new leaders, particularly amongst young disabled people. And to grow our influence to reach new generations of disabled people into our membership."

Mark says it is paramount to keep innovating: "I think it's very clear here in the UK that all the changes that have been made, including access to public transport, accessible buildings, and mainstream schooling for disabled children... all those changes have come out of campaigns led by disabled people. Sometimes within the law... and sometimes through civil disobedience! And it's thanks to these innovations that disabled children can live mainstream lives. It's not until these children grow up and reach the employment market, that they suddenly find out that there are barriers against being disabled, not due to their impairment, but due to disability discrimination based in society."

ROFAs findings state that the statutory support from

government services has disappeared not to be replaced, and that's had an enormous impact on our capacity and why the DPO sector is fragmented and isolated. There is next to no capacity for collaboration, shared learning, networking or to have a collective voice at a regional or national level. Mark emphasised that this is an issue, as it has always been something at the 'heart' of the DPO movement. He continues: "Not having the infrastructure or the funding to be able to do that, depletes our ability to serve our staff, our members, and the wider disabled population. Another issue is that our movement is getting older and dying off. To bring in younger generations requires a conscious effort, but we are lacking the capacity to bring in the next generation of disabled people. The focus needs to be on young disabled leaders from all communities to revitalise our movement."

There is a lack of knowledge of the social model of disability, yet it's so important and at the heart of our ability to create change, is an understanding that disability isn't about us... it's not about our impairments, it's about turning the spotlight around. The focus should be on the discrimination, the barriers that we face in daily life.

DPOs face certain external challenges, one of which is funding. Mark said, "No resources have flowed to us, while the UK government have continued to fund charities for disabled people that are run by non-disabled people and are part of the problem for us, not part of the solution. It feels like our world is going backwards. So, it's really important that we unite together, to become a stronger fighting force. But also, that we articulate our uniqueness better. I believe that funders, at local, regional and national levels don't really understand disability equality, or the power of DPOs to create change." Mark finishes by saying: "Change started from us, and this will continue to be the case."

✉ info@rofa.org.uk

🖥 www.rofa.org.uk



An alliance of Disabled People & our organisations in England

What Can Citizens Advice Do For You?

citizens advice

Citizens Advice Cornwall is an independent, local charity that's been around for over 80 years, helping people find a way through the problems they encounter in life.

All our services are free and confidential and provided by fully-trained advisers who live in the local community and understand the problems people face.

We're here for everyone, regardless of income, race, religion, age or disability and we never judge you, whatever your circumstances.

Most people come to us about issues related to benefits claims, housing, debt, employment, discrimination, relationship breakdowns and consumer problems but whatever your query, we'll try and find a way to help you.

When you come to Citizens Advice, either at one of our drop-in sessions at our offices across Cornwall, or by phone, you'll speak to an adviser who'll take the details of your case and decide to deal with it straightaway, or, if necessary, make an appointment for a more in-depth chat.

We'll look at all the various options you have for getting on top of your problems – such as appealing a PIP (Personal Independence Payment) decision, trying to get your money back from a company or making sure you have the information you need if you're in an abusive relationship or in debt.

We also run a range of projects to tackle some of the root causes of problems we see. These include energy programmes to help you with your energy bills (applying for home energy efficiency grants, help reducing bills if you're on a low income or showing you simple ways to reduce energy consumption).

We also have projects that will help you budget and take control of your finances, so you can start



saving and build a more secure future for yourself and your family.

We have specialist teams that can help you if you're a victim of crime, domestic abuse or loan sharks and we can also represent you in court if you're being unfairly evicted by your landlord. All this good work is made possible through grants and public donations and our superb volunteers.

We welcome volunteers from all walks of life, whether young or older, able-bodied or disabled and from all social backgrounds.

There are lots of different roles available and full training and supervision is given. We even have free tea and biscuits and your travel costs are met in full!

As well as advisers, who work on the frontline, we also rely on a team of admin workers, community fundraisers and people who volunteer for our research and campaigns unit. We also recruit volunteer board members from time to time.

So, if you ever need help or have time to help, please contact Citizens Advice. We're local and here for everyone, you just need to get in touch.

To contact Citizens Advice:

📞 ADVICE to 78866, we will call you back within 10 working days.

📞 08001448848

🖥 www.citizensadvicecornwall.org.uk

Let's Innovate

The benefits of Technology

As American filmmaker Godfrey Reggio stated, "It's not that we use technology, we live technology". Technological advancements have become ever more varied and applicable for people with communication and learning needs.

With an estimated 14.1 million disabled people within the UK that means a significant number of the population could benefit from the latest applications that can offer accessibility and inclusion. Empowering people in everyday life.

Signia Active hearing aids

An estimated 6.7 million people in the UK are thought to have mild to moderate hearing difficulty and could benefit from using a hearing aid. The Signia Active hearing aid looks to tap into the evermore dynamic hearing aid private market.



This multi-use gadget can stream music, answer phone calls, and enhance your hearing through high resolution Bluetooth technology. The battery is rechargeable and has an accompanying mobile application.

With a sleek modernised design, the Signia hearing aid revolutionises assistive technology. Inbuilt smart software amplifies other peoples' voices over background noise.

Signia has released two different models. The budget friendly Signia Active, which offers all the features described above, but only targeted to people in need of a hearing aid in noisy situations. Additionally, the Signia Active Pro, the premium model guarantees what Signia describes as the 'full hearing experience'. Designed for people with mild to moderate hearing loss.

www.signia.net/en-gb/

Pictello

Pictello is the ultimate storytelling app. Whether you want to create your own engaging diary or make a vibrant visual schedule for a loved one. Pictello integrates visuals, text, and voiceover for the ability to create social stories.



This app will help develop the user's writing, spelling, and speech. This is possible due to the in-built word prediction and a voice dictation technology. This app is used by people with autism, cerebral palsy, downs syndrome, selective mutism, and more.

This app is very accessible for people with limited literacy. It includes auditory instructions, speak as you type, and a playback feature to see what has been written. Text can be emphasised through word-by-word highlighting which helps to understand word and sentence structure.

The app is available in 35 languages and offers alternative app themes designed for cortical vision impairment. Available on iOS only.

www.assistiveware.com/products/pictello

Let's Demonstrate

Aipoly Vision:

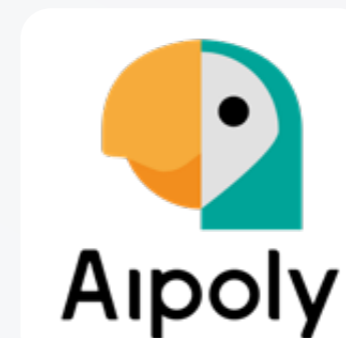
Vision AI for people with sight loss

Aipoly Vision is an 'object-and-colour' recogniser app.

Users simply need to point their phone at any object. The

app will then identify objects within the users surrounding and narrate what their phone is pointing at. The app is revolutionary for people who are blind, visually impaired, or colour-blind. It is available in 26 languages, recognises over 900 different foods, and different texts, and includes an advanced list of over 200 colours. All in real-time and not requiring an internet connection. Available on Android and iOS.

www.aipoly.com



Prologuo4Text

Prologuo4Text is a text to speech application that enables people that otherwise cannot speak up, to have their say and empowers everyone to express themselves. It uses word and sentence

prediction technology to predict what the user will say next. Simply start texting via the application and prologuo4Text will vocalise what you have written. Grouped phrases will appear in the suggestions section on the screen for convenience. The app is user-oriented through its single screen layout, making it easy to use.

An accessible app for people with autism, cerebral palsy, and amyotrophic lateral sclerosis. Available with 130 voices across 18 languages, on iOS only.

www.assistiveware.com/products/prologuo4text

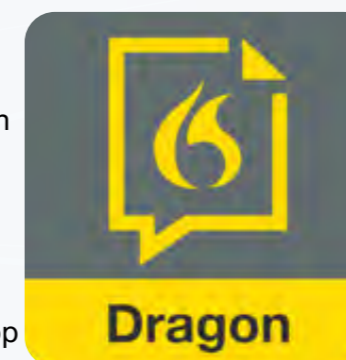


Dragon Anywhere

Dragon Anywhere is a professional-grade dictation app with high recognition accuracy. The app enables users to speak instead of writing up documents. Users can speak on the app for any length of time

and edit and share documents directly from their mobile devices. There is also the option to sync documents effortlessly with the desktop version. Available on Android and iOS.

www.nuance.com/en-gb/dragon



Cozi (Shared calendar & lists)

Cozi is a family scheduler app, designed to manage everyday to-do lists, activities, and appointments all in one calendar. Perfect for families and carers, the app allows you to colour code your calendar and filter by each individual. There is the ability to set reminders and coordinate everyone's schedules seamlessly. Available on Android and iOS.

www.cozi.com



Payroll & Managed Accounts Service Cornwall and IoS



We offer affordable services to take the strain and leave you free to live your life, your way.

Payroll

We deliver a complete, professional and friendly service for people who employ their own PAs. All you need to do is advise the hours your PAs work each month and we produce their pay slips and an employer summary for your records.

We act as your agent with HMRC and will process all aspects of payroll including monthly RTI submissions, end of year returns, starters & leavers, P60s, statutory payments and holiday calculations. We also provide a fully comprehensive pension support service at no extra cost.



Managed Accounts

We can receive your care and support budget direct from the local authority or NHS and make all the necessary payments on your behalf, as well as fulfilling any auditing requirements. We also offer this service if you self-fund your own care and support.



A service brought to you by disAbility Cornwall & Isles of Scilly

Contact our friendly & professional team:

✉ hello@pamas.org.uk

☎ 01736 751929

Medicinal Marijuana

DISCOVER explores the medical use of cannabis for people with long-term health conditions and its questioned legal status.

We share poignant case studies about how cannabis in its variety of forms helps people.

Humans have consumed plant-based drugs, including cannabis, for medicinal purposes for thousands of years, but through a series of laws passed between the 1920s to the 70s, the Government made cannabis illegal for recreational and medical use. When cannabis and cannabis-based products reach the headlines, the two primary chemicals from the cannabis plant called cannabinoids make the point of contention. Tetrahydrocannabinol (THC), the chemical that makes a person feel 'high', and cannabidiol (CBD), the chemical compound that does not make you feel intoxicated but has been shown to relax people's anxiety, pain, and movement disorders*. In 2016, The Medicines and Healthcare products Regulatory Agency (MHRA) stated that properly licensed CBD oil can be sold freely if it is used for medical purposes. Since then, a plethora of high street retailers like Boots, Holland & Barrett and B&M have been selling CBD products.

THC has considerably more red tape and legal barriers attached to it. Therefore, smoking cannabis is still strictly prohibited. However, in 2018, the use of certain cannabis-based products that include THC have been rescheduled and legalised for medicinal use. These cannabis-based products and treatments are only prescribed on rare occasions, through a specialist doctor at a hospital, not through a local GP.

Sativex

One such drug is called Nabiximols, otherwise branded as Sativex, developed by UK company GW Pharmaceuticals. It is a mouth spray used to treat muscle stiffness and spasms that affect people with multiple sclerosis (MS).



According to the MS Society, about seven out of ten people with MS who experience this and are prescribed Sativex, see their symptoms reduced by 20%, with four in every ten people prescribed seeing a 30% reduction in these symptoms.

But how readily available is Sativex within the United Kingdom? In England, it's only available if all other treatment is ineffective, and the person's condition is 'moderate to severe'. In Wales, it has been available since 2014, and in Northern Ireland, it's accepted by the Health and Social Care Board, but the Scottish Medical Consortium is yet to approve its use.

What makes Sativex a legally contentious issue, is that it contains high levels of THC and the MS Society states that it can cause some less desired effects including dizziness, headaches and a dry mouth.

But with seven out of every ten people with MS seeing their symptoms significantly reduced, many would like to see the cannabis-based drug more readily available. Some names have been changed in the following case studies for obvious reasons.

Emma's Sativex Story

Emma from The Lizard told *DISCOVER*: "I was diagnosed with MS age 18, but according to a clinical trial I was on for medical cannabis, I've likely had it since childhood. I attended Marie Therese House in Hayle as an outpatient for physiotherapy for my spasticity and I became a regular inpatient, twice a year for five days of intensive therapy and a review."

"The Doctor would try me on a drug for spasticity on Monday and by Wednesday I would have to stop taking it because of extreme side effects. Over the next ten years plus, I tried every spasticity drug available on the NHS, every time with extreme side effects. I have never done drugs well and I'm always on the list of one in ten get 'blah blah!' It was concluded this was because I had a high metabolism. Unfortunately, in the cannabis clinical trial, my pills were a placebo. I couldn't find out the results for the other candidates that received the real cannabis medication." She added: "I first read about Sativex a couple of years ago in the MS research papers which is specifically for spasticity. It was available only in Wales then but after a lot of campaigning, it was eventually available across England."

When Marie Therese House stopped seeing outpatients for the maintenance of their condition, Emma said she was simply told to 'self-maintain.' Further bad news ensued, as a clinical trial by a leading researcher proved conclusively that continued physiotherapy made no difference to the progress of the disease. She claims the NHS jumped on this as an excuse to stop all maintenance physiotherapy for her condition. The researcher said the NHS decision was an unexpected consequence and she was 'sorry the NHS had reached their own conclusions'.

Cynthia Benz, a leading MS physiotherapist says: "Physiotherapy on a regular basis is thought to be the most effective, as it focuses on keeping the limbs working as normally as possible, reducing the severity of muscle spasms and helping to prevent contractures, which is when paralysed or unused muscles start becoming permanently shortened."

Due to Emma's MS developing into secondary progressive, she now has contractures and spasticity, and has to spend £70 an hour on private physiotherapy. She is also attending the pain clinic for Botox and steroid injections that she says are painful. "If I could just try Sativex, the drug I've been refused, it might just work for me, get me out of pain and more mobile, who knows without trying it." She knows a great many people who have MS that smoke cannabis on a regular basis for pain relief. Something Emma is not willing to do as she

is asthmatic and doesn't want to risk longing for a cigarette again.

In January 2022, her MP contacted Dr Paul Cook, chair of NHS Kernow, the then clinical commissioning group for Cornwall and the Isles of Scilly. He said there were no barriers in place that stop suitable people from being prescribed Sativex if they met the criteria. However, the prescribing of it is only permitted by a 'neurologist who has the specialist expertise.' This means that a GP may not initiate treatment with Sativex and any amendments to this requirement would need to be made by the Medicines and Healthcare products Regulatory Agency (MHRA), not NHS Kernow. Emma's MP's caseworker contacted the neurology department at Royal Cornwall Hospital to ask about the issues relating to the prescription of Sativex in Cornwall. The neurology department replied by saying that there is a lack of infrastructure to effectively prescribe Sativex, hence the poor take-up.

Epidyolex

Epidyolex, is another cannabis-based drug that is legal, it's a highly purified liquid containing CBD developed by GW Pharmaceuticals. Unlike the diluted 'over the counter' CBD oil that you can purchase in popular shops like Holland and Barrett, Epidyolex is an NHS drug that is prescribed by a specialist for patients with rare forms of epilepsy. Like Sativex, it's heavily restricted and only prescribed in rare circumstances.

Casey's Epidyolex Story

Casey was born with epilepsy but was initially thought to have cerebral palsy, although she was never given a formal diagnosis. Her parents are strong advocates for CBD to be freely and easily available. They told *DISCOVER*: "Casey was born starved of oxygen in 2009. No formal diagnosis was ever given but she was having hundreds of seizures a day.

CBD was amazing for Casey and we first started in 2015 on 'CBD Brothers' oil. Once she had settled on the right dose, having just two drops a day under her tongue, the results were amazing. She was seizure free for over nine months. It also had a good effect on her mood, she started to be clearer and even started talking again. Her consultant could see the improvement and was very supportive." However, Casey had a setback and was taken to Bristol Royal Infirmary For Children, where no CBD could be administered. Her parents said, "When she came home, she continued to have a few seizures, but nowhere as many as she had before CBD. We paid for the CBD oil out of Casey's PIP care allowance, it was £116 a bottle but it lasted for months. We had tried so many different prescribed

pharma medications that didn't help, we would have given our last penny for this oil. It was really important as she had the kind of seizures (infantile spasms) that damage the brain and development."

"When the cannabis medication finally became available on the NHS, the criteria was so strict. There was a lot of confusion about who was eligible, it seemed to us that only the high profile children whose parents had been on the TV or radio were prescribed the drug. There was no hope for us. So in 2020, we decided to go private."

They turned to the Sapphire Medical Cannabis Clinic, the first private, stand-alone CQC registered cannabis clinic in the UK, where Casey was immediately prescribed CBD oil. Her seizures were getting worse as she got older, but her parents say they were prepared to pay whatever it took to help her. "We had received the CBD oil from the clinic but hadn't administered it as she was a bit 'chesty'. We didn't want to try anything new until she was better and back to her 'baseline'. Unfortunately, she quickly got much worse and died of pneumonia aged 12, before we could even begin the new regime. We were prepared to continue to pay for this private treatment as she was on a clinical trial and the price was greatly reduced. This medicine should be freely and easily available on the NHS. Parents shouldn't be forced to do what we had to do for our darling little girl. We all saw how much CBD oil helped Casey to live a happy life for 12 years, despite being given just weeks to live at birth."

Casey's parents are one of many people *DISCOVER* has spoken to, that support the use of medical cannabis for neurological conditions like epilepsy; emphasising that these drugs should be readily available and free of charge. Many argue that medical cannabis is more effective and does not have, as Casey's parents put it, the 'diabolical' side effects of the pharmaceutical drugs currently available for prescription.



In 2020, the UK Government's Advisory Council on the Misuse of Drugs conceded that the scheduling of Epidyolex 'may need to be reviewed again in the future'.

Smoking Cannabis

With the discussion around the availability of Sativex and Epidyolex only going to grow, the broader conversation around smoking cannabis being legalised for medicinal use is frequently drawn into question.

Mark's Smoking Cannabis Story

Mark from Newquay, is on the autistic spectrum with severe attention deficit disorder (ADHD). When asked how smoking cannabis helps, he told *DISCOVER*: "I knew from a young age that I wasn't the same as other kids. I struggled in my first year of school." After a lot of pressure from Mark's family and MP to get him medically assessed, he was finally diagnosed with ADHD by the NHS. His family said, "Following the diagnosis, we were sent to the Royal Cornwall Hospital where we were offered the drug 'Ritalin' so we did some investigation and discovered Ritalin is not a nice drug. We were advised against it by professionals we trusted and instead we saw a homeopath who prescribed Chamomile pills." After taking the pills, Mark's teacher said he was a different child in class. Furthermore, his mum said that after four and a half years he finally slept through the night.

Fast forward to Mark's teenage years, his friend gave him the chance to smoke cannabis. Mark said, "I couldn't believe how good it made me feel. To this day, I still smoke cannabis as I feel like it helps to balance out and calm my mind. I can concentrate, I feel less anxious and much less agitated." When Mark became a dad, he said he stopped using cannabis for a year, but his wife said the effects of his ADHD returned, which she said was hard to cope with. Mark now measures out his

cannabis into a weekly pill container to help him effectively 'self-medicate'.

A neurological psychologist who worked closely with Mark claimed it's a shame that cannabis is illegal. He said that for people like Mark, cannabis can normalise their brain and reduce the negative effects of neurological conditions like ADHD. DISCOVER learned there are now pilot schemes providing cannabis cards in the UK for users to carry to prove legitimate medicinal use, which then should mean it is unlikely to make it to court, and if they do, these cases are usually dropped. This is most notably true whereby a patient presents a card at court with a condition and is in receipt of a private prescription. It is said there is currently no way of identifying these people before emotional distress has been caused and public resources wasted. They claim it is an opportunity to create a benchmark for change and to decriminalise cannabis for vulnerable people to prevent the possibility of obtaining a conviction. Some doctors have been known to recommend cannabis cards to patients.

Mark wants cannabis legalised for people like him. He claims it was not addictive but admits that there was an issue with mixing cannabis with nicotine, as the nicotine can become addictive.

The legal status of the medical use of cannabis will no doubt continue. Recent years have witnessed high-profile government figures like former Health Secretary Jeremy Hunt and former Home Secretary Sajid Javid, support the use of medical cannabis through reviews and changes to the law. Although it's classed as a Class B drug under UK law, carrying a maximum prison sentence of 5 years if a person is caught in possession, many police forces will now simply administer a warning if it's your first time caught, or fine you if it is deemed a small personal use amount.

Public opinion is certainly shifting on it, especially regarding cannabis that is deemed for medical use. In a recent survey by Hanway and Savanta ComRes, in early 2022, 55% of UK respondents reported being in favour of legal and regulated cannabis sales to over 18s, while 27% of UK respondents reported being opposed and 16% stated neither support nor oppose**.

According to the NHS, there are risks to using cannabis that contains THC, including psychosis, when used continually for some people, as well as dependency. Although scientists believe that dependency on medical cannabis, when administered by a specialist doctor, is very small***, cannabis that is not bought or dispensed through a certified specialist doctor is illegal and can be dangerous, as the ingredients and strength are not known.

Disclosure: This article was produced for editorial use only and all opinions expressed should not be taken as advice nor are they the opinions of DISCOVER or disAbility Cornwall. We do not endorse the use of illegal drugs.

* VanDolah HJ, Bauer BA, Mauck KF (September 2019). "Clinicians' Guide to Cannabidiol and Hemp Oils". *Mayo Clinic Proceedings*. 94 (9): 1840–1851. doi:10.1016/j.mayocp.2019.01.003. PMID 31447137.

** www.hanwayassociates.com/news-opinion/recreational-europe-report-launch

*** www.nhs.uk/conditions/medical-cannabis/

#Phone a Friend

A recent report showed that nearly half of Cornish residents reported feeling lonely. We've all been more isolated over the last two years, but for a lot of people loneliness is their normal life. This can have a huge impact on people's mental wellbeing and it's even been shown that loneliness is as bad for your health as smoking and drinking alcohol.

Connecting with others is one of the 'Five Ways to Wellbeing' and a way to give mental wellbeing a boost. Whatever your age or situation, it's important to stay in touch with friends and family.

While we all carry phones, it's becoming less common for people to use them to talk to each other. These days we are more likely to send a text message, or post an update on social media, which isn't the same.

This is why the Public Health Team at Cornwall Council have launched a campaign to get people across Cornwall to #PhoneAFriend.

They are challenging everyone to pick up the phone and call someone; an old schoolmate, a relative, a friend from work, anyone who might be lonely.

If you're on social media, why not post about taking on the challenge and then tag three friends and challenge them to do the same. Don't forget to tag it #PhoneAFriend!

The fight to find an inclusive workplace for Chris

By Lynn Brittle

My son Chris, age 20, wants to work and be part of society, he wants friends in the workplace and he needs a purpose for getting up in the morning, but while he has been fortunate enough to get workplace experience, both paid and unpaid, mainly due to us fighting for opportunities, liaising with employers and even once going to work with him to give him the guidance needed to learn a job, he still remains unemployed due to his learning difficulties.

We are seeing the word 'inclusivity' in recruitment materials more and I would love to think that many modern working environments can be accessible to all, with some reasonable adjustments. However, from personal experience, this is not the case. The challenges faced by disabled people trying to enter the labour market, particularly people with learning disabilities, needs addressing.

It seems employers would rather leave a role unfilled than offer a reasonable adjustment leaving disabled people facing an uphill battle to break down barriers. It's also evident that companies put profits before people and we should all be questioning if the labour market is as inclusive as it should be.

Chris's first experience of working was a Saturday job as a kitchen porter at a farm restaurant aged 16, and the joy of getting his first wage was worth the effort it took to get him the job! Unfortunately, he developed Epilepsy, meaning it became unsafe for him to be in the kitchen until his condition was controlled, something that's perfectly understandable.

However, while we agreed that after six months of being seizure-free, he could return to work, that didn't transpire. They said: "Chris can be quite difficult to keep on task and takes some management time when he is here." I do appreciate that he does not work at a fast pace and requires more management than most, but as a large company that prides itself on being 'local', and with



Chris Brittle in his workwear

it being owned by a prominent family, I did expect that a few hours work for a local lad trying to be economically active would not have been too much to ask. They could have offered him another role in the business after all.

Alongside studying at college, Chris volunteered one day a week at a foodbank as part of an initiative

aiming to enable people to gain valuable skills for future employment. Unfortunately due to the pandemic, it was halted, and when businesses began to open again, the foodbank was inundated with volunteers who were previously on furlough, meaning Chris was not required. Why have someone slower and steady... when you can have fit, active, clever volunteers!

We've sent multiple job applications over the years, but after failed judgment assessments and constant correspondence asking for reasonable adjustments we had no success. When we finally managed to get him an interview at a supermarket, we got him prepared and were feeling confident, but before we had even had time to drink our tea in the café, he was out of the interview. We feel sadly, he was brought in just to tick a box regarding meeting the criteria to interview a disabled person.

There's been occasions where we would apply for a job and get rejected but find the job vacancy still being advertised and unoccupied weeks later! Once, Chris came out of an interview, and I enquired what they'd asked him: "what are you good at?" which received a reply of computer games and writing horror stories! Maybe if they had added... 'in the workplace'... they may have got a better answer!

One summer we managed to secure Chris a job litter picking at a holiday park. Initially, it was a disaster and after only one week, the owner called to say he was taking one hour to do what should take three hours and hanging around reception chatting. Fortunately his dad came to the rescue, going to work with him for a week and showed him exactly what was required. That was all it took and there were no problems once he was given the direction he needed. In fact, he was so well-liked we found out that the maintenance men had offered to pay his wages so that he could stay on! We were proud he held down that job for the whole summer.

Another time I approached a manager at a local café and they kindly offered a kitchen job and Chris loved it, he felt part of a team and enjoyed having a wage. However when the busy season began, Chris refused to go to work, as he said he couldn't cope with the pressure. I explained to them that he wasn't coping and he was moved to pizza box construction and litter picking and this was just what he needed. A steady repetitive job with no pressure, he could go at his own pace while listening to his music. He thrived and got on well with the team, continuing to work there until the end of the summer.

Unfortunately, the café went under new management and while I continued to try and get him back there this summer, I keep getting brushed off with: "I'll have a word with the manager when

he's not busy". There are only so many times you can ask before you get the message.

By far our biggest disappointment was our most recent experience, where we applied for a 'yard operative' role at a builders merchants, their advert did state they are 'driving to be a truly inclusive employer' and want people to be 'confidently their authentic selves', also displaying a 'Disability Confident committed' (government scheme) logo on their website. A lovely lady got in touch, and after discussing Chris and his abilities and needs, it was agreed that he would go there for his work placement with his work coach, as part of his Supported Internship course at college, which they said, would lead to paid employment in the future.

Chris was part of that team for six months, and his work coach said he was making great progress and gaining confidence. During the last month, his coach took a step back and let Chris be independent, which he reports he did brilliantly. So, with my hopes running high, I enquired about employment. The response I received: "The ideal would be to enrol Chris onto our Level 2 Trade Supplier Apprenticeship, on a part-time basis." Sadly, the outcome of that was 'due to budget constraints' they could not take him on, yet the next day, low and behold... they were advertising for a yard operative. There is support available for Chris in employment, as he has an EHCP and I did explain this.

How can an 'inclusive employer' not make reasonable adjustments and give a young person that's been with them for six months an opportunity?

I expressed my disappointment and urged them to remove the statement of 'inclusivity' from their website, on the premise they were not prepared to make reasonable adjustments. To my surprise, I discovered that is exactly what they did, and rather than listen, embrace, and act on their statement, they chose to remove it!

Chris can of course work, but needs a job that plays to his strengths and support to understand his role. There are plenty out there, if employers were just willing to make some reasonable adjustments. Of course Chris doesn't have to work, he could live on benefits for the rest of his life, but he doesn't want that, neither do we as his family, and apparently, neither does the government. He has a lot to offer and wants an opportunity to be part of our society, so why are we not enabling this?

The Time2Move Holiday Programme by Active Cornwall

Fun, funded, inclusive activities for all children in Cornwall during the holidays



Ensuring every child in Cornwall has access to fun, inclusive and healthy activities during the holidays, is a key aim of a funded programme run by Active Cornwall.

The Time2Move Holiday Programme launched last year with great success, supporting tens of thousands of young people in the county, with a particular focus on helping families on low incomes.

Tim Marrion, Manager of Active Cornwall, said: "It is great to be working on such an important intervention to address the inequalities we have in Cornwall for children and young people. We know that a third of all children are classed as inactive and hopefully with programmes like this, we can address this and improve both their physical and mental wellbeing."

The Time2Move Holiday Programme is committed to ensuring that activities are accessible for all. As such, it is working closely with Parent Carers Cornwall (PCC) to support children with a special educational need or disability.

A representative will speak to parents directly about the needs of their child to ensure they are met when attending sessions. Parents and carers are asked to speak to a PCC representative at least one week in advance of any planned sessions.

Funding has been confirmed to roll out the nationwide initiative for three years in Cornwall and

all children are welcome to attend. The sessions are free for families on benefit related free school meals, via a code that can be accessed on the Time2Move Holiday Programme website. There's a small cost for families who don't receive financial support, with every child attending receiving a free healthy meal.

Providers run a wide range of activities, from football to water sports, from arts, crafts and dance to adventure playgrounds, during the summer, Christmas and Easter holidays.

The team is always looking for new providers to support the programme – with funding offered to support the delivery of activities.

📞 01872 323335

✉ time2move.holidayprogramme@cornwall.gov.uk

🌐 www.activecornwall.org

Contact Parent Carers Cornwall

📞 07706 021016 or 07706 021018

✉ t2mpcc@outlook.com



Jamie's Clint the Kidney campaign

Programming director and presenter of Rewind Radio, Jamie Reed, on his passion for radio, overcoming his transplant, and his 'Clint the Kidney' campaign.

Jamie, 42 years old from Penryn, had always dreamt of a career in radio and starting out on student and hospital radio stations, he has gone on to present programmes and news bulletins to millions of people across the country over a 25 year career.

With an equivalent passion for music, Jamie also started an events company, 'DJ in Cornwall' but it was impacted by the pandemic, so he started streaming parties online and hosting virtual quizzes. After receiving a digital service licence via Ofcom, Jamie collaborated with his friend and business partner Richard, officially launching the Rewind Radio station in 2021. Jamie told *DISCOVER*: "Our aim is to return to traditional local radio, which has become more formulaic, with many local stations using some national or all national content, but Cornwall is different, it has a different identity and that is reflected in everything we do."

Whilst spreading good music and vibes across the airwaves and internet sphere, Jamie has lived with Alport Syndrome since the age of three. People with this condition usually have impaired kidney function, eye sight and hearing loss. "Thankfully my eyesight is fine, but my hearing is a bit rubbish due to years of being a DJ. I have been on a range of medications for most of my life to help protect my kidney function." Despite a gradual decline in his kidney function over 20 years, Jamie recalls it was in 2018 the word 'transplant' was first mentioned. After a visit to Derriford Hospital, the south west's leading transplant hospital, he was placed on a waiting list. He adds: "At the time of receiving my transplant I was at 8% function and just a few days away from being put on dialysis."

Jamie was lucky he has a supportive group of family and friends, many of whom offered to donate and came forward to be tested to see if their kidney would match. "Derriford matched me with one of



them, I can't say his name because he wants to stay anonymous, but he is amazing. Mentally it was really tough as lots more appointments came up with the hospital, more blood tests and explaining to my children what was going on."

"We had some very honest and frank conversations."

The Covid lockdowns and periods of isolation hit Jamie hard, both mentally and physically. He says: "I knew my body was now starting to struggle, especially since my first and second transplant dates were postponed due to Covid spreading through the hospital and members of my family catching the virus. However, 'third time lucky', I had the operation on the 16th of December (my eldest daughter's birthday)."

Although Jamie felt extremely drained before the kidney transplant due to the strict monitoring of food types needed pre-operation, he describes how after the operation he felt so awake and alive. "My brain was whirring at a thousand miles an hour, but my body was a little slower to catch up." The ordeal gave him another level of appreciation for the doctors and nurses that supported him on the ward. "Thanks to them I was home after just five days (the UK average is around 10 days post-transplant),

which also meant I didn't miss Christmas with my family, although I wasn't allowed near the cooking, which really frustrated me!"

"The love and support around me makes me emotional, even writing this."

Jamie's passion for spreading positivity led him to create the 'Clint The Kidney Campaign', Clint referring to the name he has given his new kidney. "It's to raise awareness of the amazing teams that work in Cornwall and Devon and to raise funds to support patients who are not as lucky as myself". According to Kidney Care UK, the UK's leading kidney patient support charity, approximately 3,000 kidney transplants take place every year in the UK, but around 5,000 people are still waiting. This demand and the prolonged waiting list for kidney transplants puts tremendous pressure on hospitals and of course, leaves many patients in a constant waiting game. Jamie says he is planning to endure the four peaks challenge next year, a gala dinner and a world record attempt involving Rewind Radio station!

"Kidney disease is a silent killer and most people don't realise they have a problem until it's too late; even though I had a diagnosis, I didn't notice my function dropping because my body adapted to it." Jamie describes the symptoms of Kidney Disease as weight loss and poor appetite, swollen ankles and hands, shortness of breath, tiredness, blood in your pee, and an increased need to pee particularly at night. Despite Jamie's condition, he told *DISCOVER* how amazing he feels now and how he is preparing for the fitness tasks and challenges ahead!



Jamie Reed

Photo courtesy of Dave Scoffin

Rewind Radio:

✉ studio@rewindradio.co.uk
 🌐 www.rewindradio.co.uk

Find out more about kidney disease:

🌐 www.kidneycareuk.org

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Visit our website on your phone or tablet and you will be prompted to download ECC as an App to your home screen. You can search and rate a business by type, accessibility features, or location.

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www.better.org.uk/leisure-centre/cornwall/st-ives



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01726 223344
staustell@gll.org
www.better.org.uk/leisure-centre/cornwall/staustell-leisure-centre



Newquay Leisure World

Newquay Leisure World is Cornwall's go to place for ultimate family fun. There is everything you need to ensure a day of fun all in one convenient site. There's plenty of parking and the centre is easy to reach using public transport. There is a trampoline and soft play park filled with fun features offering everything you need to keep the smiles flowing for the whole family. There is also a swimming pool and a 45 station gym.

01637 853828
newquayleisureworld@gll.org
www.better.org.uk/leisure-centre/cornwall/newquay-leisure-world



Truro Leisure Centre

Truro Leisure Centre offers quality, affordable fitness facilities and leisure activities to help keep you active and lead a healthy lifestyle. Refurbished in the autumn of 2017, the gym holds 25 top of the range Technogym™ equipment stations and offers the perfect space to enjoy your workout. There is a 25m pool and a learner pool catering to all abilities.

01872 261628
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Finally, BSL is a recognised language!



The British Deaf Association (BDA) spearheaded the BSL Act Now campaign whose goal was to create greater recognition, equality and inclusion for BSL users by lawfully acknowledging BSL as a language. Many people were therefore delighted when the British Sign Language Bill was passed into law and came into full force in June 2022. This means BSL is officially a recognised language in England, Wales and Scotland!

The campaign has been a year in the making, with the campaign gathering support from several other high profile deaf voluntary, community and social enterprises including the Royal Association for Deaf people (RAD), Signature and Institute of British Sign Language.

Other than just the recognition, the Act will warrant government departments to report on how they are advocating and facilitating the use of BSL and provide guidance to government and non-ministerial public bodies on how to serve the needs of people who use BSL as their primary language.

David Buxton, Chair of the British Deaf Association told *DISCOVER*: " We are extremely pleased that the UK Parliament has finally listened and at last recognised British Sign Language as a language of Great Britain, after 19 long years of waiting. Today is an historic day for the Deaf community in the UK.

British Sign Language is Britain's fourth indigenous language, after English, Welsh, and Scottish Gaelic. It is only right that BSL be accorded the same

status and legal protection.

While today is a day to celebrate, we are aware that this marks the first step on the long path towards providing truly equal access to public services, information and opportunities for Deaf BSL signers in Great Britain.

We hope that the legal recognition of BSL will encourage many more people to learn British Sign Language and go on to become interpreters, bilingual professionals and allies of the Deaf community. BSL can bring us all together as a society.

We believe the key to the success of the Act will be the full inclusion and input of Deaf BSL signers from the start of all decision making, policy development, funding and support mechanism processes. We will still continue to fight for a stronger BSL Act that should include a statutory register of BSL Interpreters and BSL Teachers, free BSL training and support for families of deaf children at home and bilingual education.

We look forward to working collaboratively with the Government to implement the progress of the BSL Act 2022."

✉ bda@bda.org.uk

🌐 www.bda.org.uk/contact



Winter Wellbeing

FIRE SAFETY

Make sure you have at least one smoke alarm fitted at each level of your home and that they are tested regularly.

Always have a clear escape plan so everyone knows what to do in the event of a fire, especially during the night.

Take care when cooking. Keep your oven in clean working order as a buildup of fat can ignite and catch fire. Double check the oven is turned off after use.

If you are using an electric blanket, store it carefully to prevent damaging the internal wiring. Unplug the blanket before you go to sleep and always follow the manufacturer's instructions.

Washing machines and tumble dryers should have a single plug to themselves. Tumble dryer filters should be cleaned after every use.

Regularly check for damage on electrical goods and replace any damaged cables or plugs.

Always extinguish candles before leaving a room and make sure they are in suitable holders.

Do not smoke in your property. Always use child resistant lighters and keep matches out of the reach of children.

Make sure all internal doors are closed overnight as they act as a fire block for up to 20 minutes.

Be aware that paraffin-based creams are highly flammable. Change and wash bedding to avoid saturation, cover your furniture to avoid contamination and never use paraffin-based or oil-based creams on your skin if you are using oxygen, or if you smoke.

KEEPING WARM

Set your heating correctly. Your living room should be between 18–21°C and the rest of your home a minimum of 16°C. When you are in bed you can use a hot water bottle or electric blanket to keep you warm. The Cornwall Fire & Rescue Service can check electric blankets as part of a home fire safety check, which you can book with them.

Wrap up warm. Remember to wear coats, hats, gloves and scarves when you are outdoors, however do try and stay indoors during a very cold period. It's best to wear several thin layers of clothing in order to keep the warm air trapped in between them. If you get wet, change into dry clothing as soon as possible.

Keep active. Try to move around once per hour and do not sit down for long periods of time as even light activity will help to keep you warm.

Check on older friends and neighbours in winter. Make sure they are warm enough, especially at night and they have stocks of medicine and food so they do not need to go out during very cold weather. If you are worried about an older neighbour, contact Cornwall Council.

EATING WELL

Have a hearty breakfast. Winter is the perfect season for porridge and eating a warm bowl will help boost your intake of starchy foods and fibre which give you energy. Oats also contain lots of vital vitamins and minerals.

Eat more fruit and vegetables. As tempting as it is to fill up on comfort food, it's important you stick to a healthy diet and five fruit and veg portions per day is recommended. Winter veggies such as carrots, swede, parsnips, turnips and potatoes can be mashed and made into soups, stews and casseroles, which are perfect meals for the whole family and keep immune systems strong. There are some great recipe ideas on: www.bbcgoodfood.com

Drink more milk. Colds are common in winter, so it is important to keep your immune system healthy. Milk and dairy products such as cheese, yoghurt and fromage frais are great sources of protein, vitamins A and B12 and calcium. Choose semi-skimmed milk instead of full fat and low-fat plain yoghurts.

Drink more hot drinks. Hot drinks accompanied by hot food will make you feel warmer for longer.

REDUCING ENERGY COSTS

Turn lights off when they are not needed and upgrade all lights to LED bulbs.

Switch appliances off at the plug instead of leaving them on standby.

Seal draughts around doors and windows using draught excluders.

Set your water thermostat to 60°C. If it is higher than that you are wasting money.

Close your curtains at dusk and make sure heat from radiators can circulate. If curtains are long enough, place the lower edge behind the radiator so heat doesn't escape through the windowpane.

Ensure your walls and hot water cylinder are insulated. Wash your clothes at 30°C and try to dry outdoors as much as possible.

VEHICLE SAFETY

Do not drive in icy and wintry conditions unless absolutely necessary.

You should always aim to ensure you have your car serviced ahead of winter. The cold causes a lot of problems, half of which could be prevented by regular checks. Some garages will offer free winter car checks.

During cold weather, the car battery suffers a reduction in output. A battery should last about five years. If you're not in a position to replace it but it needs it, then carry jump leads in your boot.

Top your engine coolant up with anti-freeze to a mix of half water and half coolant. Your local garage should be able to help you with this.

Check your lights. Make sure they are all fully functioning and clean, essential on dark mornings and evenings and in the event of an emergency.

Carry a winter breakdown kit. Include a torch, hi-viz jacket, high energy foods and drinks, de-icer, ice scraper, shovel, first aid kit and spare clothes and a blanket.

Check your breakdown cover. This is essential for all vehicles and especially important in winter, so you will not end up stranded in the cold.

CARBON MONOXIDE

Carbon monoxide is a colourless, odourless and tasteless gas which is produced when fuels such as gas, oil, coal and wood do not fully burn. Make sure you have a carbon monoxide detector if you have a cooker, heater, boiler, gas, open fire or log burner that uses any of the above fuels.

Make sure you have your gas appliances checked annually by a Gas Safe registered engineer. Check their ID cards on both sides to make sure they are competent to carry out the work.

Read and follow all instructions that accompany a fuel-burning appliance.

Never use a gas oven / grill to heat your home, even for a short time.

The symptoms of carbon monoxide poisoning include headaches, dizziness, tiredness and nausea. Symptoms can be mistaken for the flu, viruses and even food poisoning. Never ignore symptoms, particularly if more than one person in the home is feeling them.

USEFUL CONTACTS

Cornwall Council

Tel: 0300 1234100

Email: customerservices@cornwall.gov.uk

www.cornwall.gov.uk

Cornwall Fire & Rescue Service

General Enquiries: 0300 1234232

24hr Fire Safety Advice: 0800 3581999

Email: fire@cornwall.gov.uk

www.cornwall.gov.uk/fire

Flood Line

Tel: 0345 9881188

www.cornwall.gov.uk/flooding

Gas Emergency Services

Report a gas leak

Tel: 0800 111999

South West Water (24hr Emergency)

Tel: 0344 3462020

www.southwestwater.co.uk

Western Power Distribution

Report electricity power failure

Tel: 0800 6783105

www.westernpower.co.uk/power-cuts/report-a-power-cut

Community Energy Plus

Tel: 0800 9541956

www.cep.org.uk

DWP

Tel: 0800 1690190

Do you qualify for the Priority Service Register?

Gas and electricity suppliers are obliged to offer a range of FREE services and additional benefits to support their most vulnerable customers.

The free services listed in this guide are available to all mains gas and electricity customers who meet the eligibility criteria.

You can ask to be added to your supplier's Priority Service Register if any of the following applies: you are of pensionable age; you have a disability; you have a long term health issue; or, you have a hearing or sight issue. Registering should provide you with the following free services:

Password scheme

You can arrange to have a secure password with your supplier, so you can feel confident any callers are genuine.

Meter reading

If you have difficulty reading your meter your supplier can arrange to read your meter more regularly and supply more accurate bills.

Moving and changing meters

If your meter is difficult for you to access or reach your supplier will look into moving it to a more convenient location. This move should be free of charge.

Free gas safety check

You can arrange to have a free safety inspection of all gas appliances and pipework.



COMMUNITY
ENERGY PLUS

Alternative bill recipient

If you would find it helpful, you can nominate someone else to receive a copy of your gas or electric bill. The responsibility for paying the bill will still be yours, but your nominee can help you manage your account.

Alternative bill formats

Your bill can be made available to you in a more convenient format, such as large print, braille or talking bills.

Notification of service interruptions

If you rely on heating for a health condition or have medical equipment dependent on your electricity supply, you can be notified in advance of any planned disruption to your supply.

Adapted controls

If you have difficulty using your gas controls, specially designed adapters may be available to help.

How to apply

Joining your energy supplier's Priority Services Register should be fairly simple but you will need to contact them to apply. A relative, carer or advocate can also do this for you, or you can contact Community Energy Plus for further assistance.

Warm Home Discount Scheme

Social tariffs, which are provided by energy suppliers to ensure that their most vulnerable customers access their cheapest energy prices, are being replaced with the Warm Homes Discount Scheme. This provides eligible customers with an annual discount on the energy bills. Householders receiving pension credit should automatically qualify, although the scheme can also help other customers in vulnerable groups. Contact your supplier to apply after the 1st April each year.

📞 0800 9541956

✉ advice@cep.org.uk

🌐 www.cep.org.uk



DISCOVER Directory

Advice and Support Organisations

ACAS (Employment Advice)	0300 1231100
Age UK Cornwall Community Helpline	01872 266383
Alcoholics Anonymous	0800 9177650
British Polio Fellowship	0800 0431935
CSW Group	0800 9755111
Charcot-Marie-Tooth UK	0300 3236316
Citizens Advice	0800 1448848
Cornwall Carers Service Helpline	01736 756655
Cornwall Complex Emotional Difficulties	01872 246884
Cornwall Eating Disorder Service	01872 246884
Cornwall Memory Café Network	01736 697459
Cornwall People First	07469 928565
Cornwall Rural Community Charity	01872 273952
Black Voices Cornwall	07891 001969
CRUSE Bereavement Care Cornwall	01726 76100
Direct Payments Scheme Advice Team	01872 324829
DIAL Cornwall	01736 759500
Dyslexia Cornwall	07716 639375
Epilepsy Action	0808 8005050
Headway (The Brain Injury Association)	0808 8002244
Hearing Loss Cornwall	01872 225868
Hearing Loss Cornwall text relay	18001 01872 225868
Huntington's Disease Specialist Adviser	07900 922535
iSightCornwall (Sight Centre)	01872 261110
Learning Disability Helpline	0808 8081111
Macmillan Cancer Support	0808 8080000
ME Connect	03445 765326
Merlin MS Centre	01726 885530
Mid-Cornwall Lifestyles	07967 822340
Motor Neurone Disease Association	0808 8026262
MS Helpline	0808 8008000
Royal Osteoporosis Society Helpline	0808 8000035
Parkinson's UK	0808 8000303
Relate (Relationship Counselling)	0300 0030396
Royal National Institute of Blind People	0303 1239999
Scope	0808 8003333
Sexual Health Cornwall & IoS	0300 3030714
Shelter Helpline (Housing Advice)	0808 8004444
Shine (Spina Bifida & Hydrocephalus)	01733 555988
SSAFA Forces Support	0800 2606767
St Petroc's	01872 264153
Stroke Association Helpline	0303 3033100
The Advocacy People	0330 4409000
Truro Young Women's Centre	01872 260847
Versus Arthritis Helpline	0800 5200520
We are with you (drug & alcohol)	0333 2000325
YMCA Cornwall Penzance	01736 365016

Cornwall Council

General Enquiries	0300 1234100
Housing	0300 1234161
Adult Social Care	0300 1234131
Council Tax	0300 1234171
Benefits	0300 1234121

Crisis Support

Cornwall Rape & Sexual Abuse Centre	01872 303038
Cornwall Refuge Trust (24 hrs)	01872 225629
National Domestic Violence Helpline	0808 2000247
Samaritans Cornwall	0330 0945717
Victim Support	0300 3030554
West Cornwall Women's Aid	01736 367539
Women's Centre Cornwall	01208 77099

Health

Cornwall P'ship NHS Foundation Trust	01208 834600
Derriford Hospital	01752 202082
Healthy Cornwall	01209 615600
Healthwatch Cornwall	0800 0381281
Humans Cornwall Hospital Discharge	01736 697914
Marie Therese House (MTH)	01736 758875
Millbrook Healthcare	0300 3030123
Neurology Care Advice Service	01209 318106
NHS Non-Emergency Service	111
NHS Complaints Advocacy	0300 3031660
NHS Kernow	01726 627800
Prosthetics Rehabilitation Service	01752 434200
Royal Cornwall Hospitals Trust (Treliske)	01872 250000

Mental Health

Cornwall Mind	01208 892855
Cornwall Children & Adolescent Mental Health Service (CAMHS)	01872 322277
MIND Information Line	0300 1233393
Pentreath Ltd	01726 862727

Mobility Equipment Suppliers

Cornwall Mobility	0333 3053398
EPC Wheelchairs	01872 218008
Unique Mobility	01566 774030
Pro Mobility	01326 569494
Tremorvah Industries	01872 324340

Parents, Young People & Children

Active8	07800 876421
Childline	0800 1111
Contact (for families with disabled Children)	0808 8083555
Educational Psychology Service	01579 341132
Family Information Service	0800 5878191
NSPCC Child Protection Helpline	0808 8005000
Parent Carers Cornwall	07973 763332
SENDIASS	01326 331633
SIBS (for siblings of disabled children and adults)	01535 645453
Young Minds (Parents helpline)	0808 8025544
Young People Cornwall	01872 222477

Patient Advice Liaison Services (PALS)

Cornwall P'ship NHS Foundation Trust	01208 834620
Derriford Hospital	01752 439884
Royal Cornwall Hospitals Trust	01872 252793

Police (Devon & Cornwall)

Emergency	999
Emergency text (Need to register)	18000
Crimestoppers	0800 555111
Non-Emergency	101
Non-Emergency text phone	18001 101

Taxis

A2B Truro	01872 272989
A2B Falmouth	01326 317898
Parnells Taxis Bodmin	01208 75000
Caradon Cabs	01579 340007
St Erth and Hayle Cars	01736 754000
Summercourt Travel (Minibus)	01726 861108
Travel 4000	01209 719961

Volunteers & Volunteer Transport

Age UK Community Transport (TAP)	01872 223388
Royal Voluntary Service	0330 5550310
Volunteer Cornwall	01872 265300

This information was correct at the time of going to press, but organisations' details are inevitably subject to change.

If you cannot find the number you need, please call DIAL Cornwall: 01736 759500.

Membership

From humble beginnings, delivering information and advice from a broom cupboard in St Michael's Hospital in Hayle, we have grown to become the pan disability Disabled People's Organisation for people living with a health condition or disability in Cornwall & Isles of Scilly, reaching thousands of people each year through our membership and services.

Through hearing the views and opinions of our members, we are able to use this intelligence to shape, influence and inform future policy and services across all sectors.

Can you get involved in our community of interest? Simply sign up! Membership is currently free and will ensure you are kept informed via a weekly e-newsletter, a copy of *DISCOVER* by post, in addition to being invited to our activities and events. You may also be eligible to join our Board of Directors.

To become a member please complete and return the form below.

Name: _____

Address: _____

Postcode: _____

Telephone (optional): _____

Email: _____

As a user-led, representative organisation, at least 51% of our members must reflect the people we are here to support (and 75% of our board).

Please tell us if you have a health condition / disability. Yes No

Please send us this form or let us know this information via phone or email.

🏠 disAbility Cornwall & IoS, Units 1G/H
Guildford Road Industrial Estate, Hayle TR27 4QZ

✉ hello@disabilitycornwall.org.uk

☎ 01736 759500

We hold members' contact details in a database but you can be assured this is never shared with others. Our privacy policy is available on our website.

