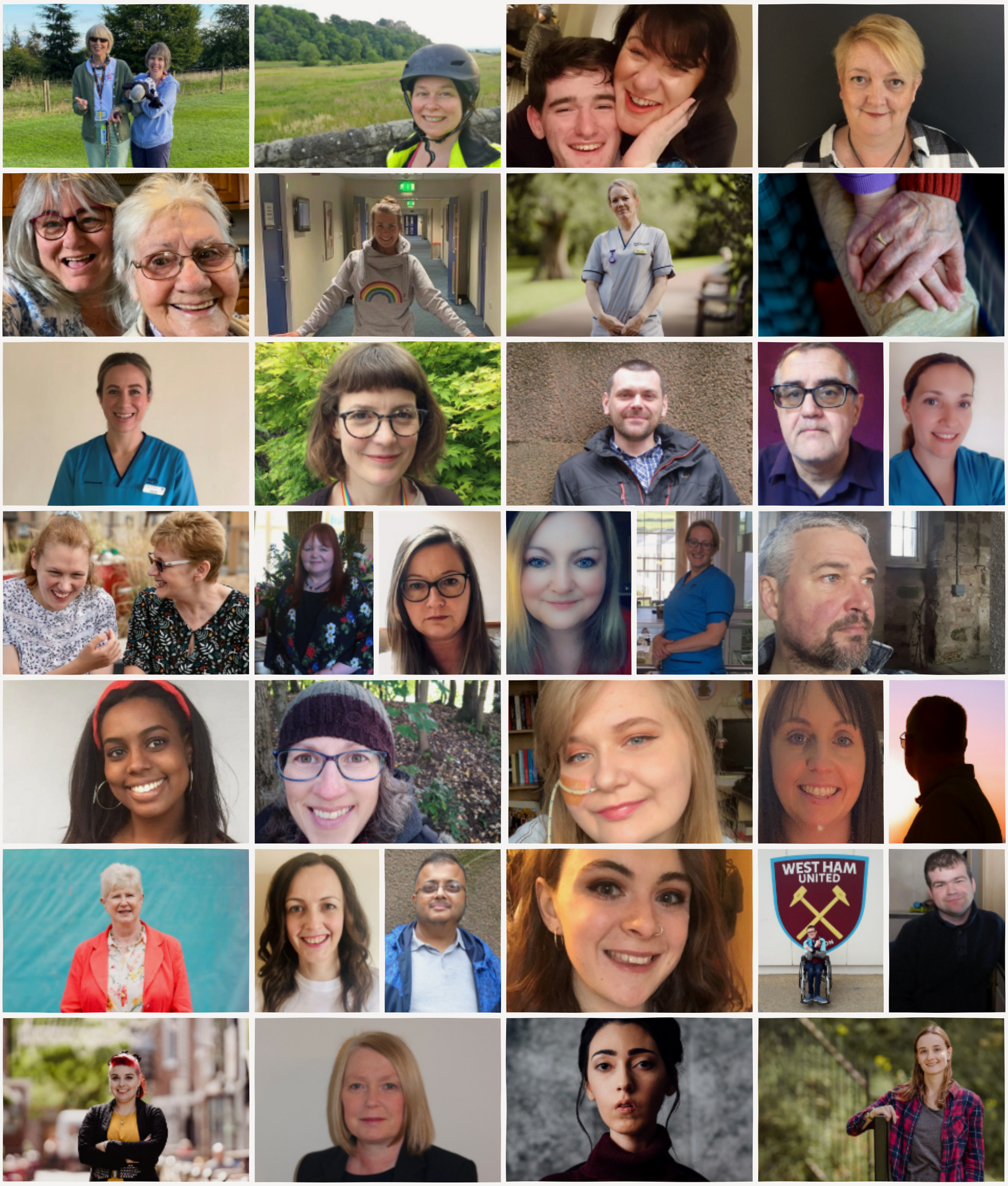
Humans of Scotland

Stories from people in Scotland
during COVID-19


WEST HAM
UNITED

Humans
of
Scotland

Sharing powerful and thought-provoking short stories from disabled people, people living with long term conditions, unpaid carers and health and social care staff

Foreword from Humza Yousaf MSP, Cabinet Secretary for Health and Social Care

Since the beginning of the pandemic we've all faced challenges and overcome difficulties none of us could have ever predicted.

But for some people it has been especially difficult.

In this, the second volume of Humans of Scotland, the ALLIANCE has brought together the lived experience of disabled people, people living with long term conditions, unpaid carers, our health and social care workforce and people living with Long Covid.

Theirs are stories that convey some of the anxiety, worry and frustration of the pandemic.

These stories speak to our common humanity. I was moved by the story of Carolynne, an unpaid carer who got some very rare time to herself at an art therapy class, and spent it painting a picture for her daughter Freya, whom she cares for. Nicola, who came home from working in a hospital COVID-19 unit and was so worried about keeping her own kids safe that she was frightened to touch them. Imran, who painted such a vivid picture of having to contend with challenges at the supermarket that I felt I was in the aisle with him. And Michala, Chris and Leanne's stories of how COVID-19 has continued to affect them for weeks and months afterwards.

You'll read in some of these stories about people frightened for their children, their families and themselves – where people are already living with serious conditions, and COVID-19 infection could be even more dangerous.

And you'll see some challenges for us as the government here too – is everyone able to get the help they need, and is it organised in a way that makes it as simple as possible to access? We're already consulting on the creation of a National Care Service, we're investing more in support for unpaid carers and a new £10 million fund to help people with Long Covid. But we know there's more to do and we will continue working with our partners, listening and improving.

There is also hope and solidarity inside these pages.

Humans of Scotland shows how our NHS and social care sectors have responded to the worst of circumstances, it shows how volunteers and the third sector have made life-changing differences, and it shows how being able to talk to someone has been critical for so many folk.

This book lays bare some of the most difficult situations people can face, and shows the best of us all in responding to those. I'm very grateful to the ALLIANCE for bringing these stories together, and very thankful especially to all those whose lives are so honestly laid out here.

Foreword from Professor Ian Welsh OBE, Chief Executive, the ALLIANCE

The ALLIANCE's Humans of Scotland project has now celebrated three years since its launch in December 2018. Since the outset, Humans of Scotland has sought to provide a platform for disabled people, people living with long term conditions and unpaid carers, sharing opinions, experiences and calls for change. The project embodies our guiding principle: 'People at the Centre' and it has become popular with the public, the people it seeks to represent, those providing support and services across Scotland and our elected officials.

When the first COVID-19 lockdown began in March 2020 we knew we had to keep sharing people's stories. The experiences of the people whose stories Humans of Scotland had always sought to spotlight were crucial to highlighting the reality of restrictions. For many it meant shielding. Higher levels of isolation were being experienced by disabled people, people living with long term conditions and unpaid carers than ever before. People were unable to access the care, treatment and support they relied on. We were not all in the same boat. The pandemic exacerbated the already existing inequalities experienced by too many.

This collection of stories is, then, an important record of the experiences of people who were disproportionately affected by COVID-19. It draws attention to the day-to-day lives of those whose caring responsibilities increased beyond what could ever be expected, to those who experienced difficulties with mental health as a result of being cut off from very necessary support networks and to those who already struggled to navigate systems that should be accessible. We also hear from people living with Long Covid, people who now find themselves navigating treatment and support and perhaps find themselves moving into the realm of being a 'patient'. We must remember that patients are people, each with unique needs and requirements for better supporting them to live well.

We also opened a space for NHS staff to share their stories. Some of them were redeployed to COVID-19 essential treatment and support services. Other staff retained their roles, much changed by social distancing, finding new ways to relate to and engage with those they supported every day. We bring you stories too from Scotland's health and social care third sector staff.

In publishing this, the second Humans of Scotland book that shares stories from people across the country, we draw attention to experiences that must inform how we plan an equitable future for Scotland. I strongly believe that disabled people, people living with long term conditions and unpaid carers should be the 'people at the centre' of our recovery.

Contents

Humans of Scotland

Stories from

unpaid carers

Lesley's story

> I am sure we will make it through but some days we do start to doubt ourselves and I am sure we are not alone...

"Our daughter, Kirsten, is 39 years old and has been a member of a Camphill Community since she was seven years old. Kirsten has thrived in the routines that are built into the Camphill ethos and we have seen her flourish over the past 32 years. Then Lockdown happened!

At the beginning of lockdown, we had five dogs, five adults and a new-born baby in the house. Life was very full on and time flew past. At the end of May Kirsten's sister returned home, so now we were four people and four dogs. And this is when things started to go wrong.

Our busy household was not quite so busy. Kirsten struggled to focus on activities and, in all honesty, we were struggling with them too. Kirsten's mental health deteriorated quite quickly and medical intervention was required. This helped and we all carried on as best we could. Unfortunately, a few weeks later her mental health took another turn for the worse and we needed help again.

I always knew she needed consistent routines, but lockdown has shown just how dependent she is on them. Kirsten has floundered without them and become totally obsessive about her soft toys. The only routine we have for Kirsten are Zoom calls twice a week with a local charity. We also FaceTime the craft workshop every Thursday so that Kirsten can say hello to all her friends. She misses them all very much and it can be very cheering for her to see everyone and say hello.

Despite these activities we are still struggling to make a structure to the days for Kirsten. Her obsessions have increased and as I write this she has refused to get ready this morning. No bath, teeth brushing or hair washing. The need to deal with the soft toys now overrides personal care and meals.

Eventually, I know, everything will return to normal or as near to normal as possible! I am sure we will make it through but some days we do start to doubt ourselves and I am sure we are not alone..."

Carolynne's story

> "The biggest challenge for me is I've not got a lot of freedom in my own life.

"I'm Carolynne and I'm my daughter Freya's carer. She has severe cerebral palsy and severe respiratory problems. So me and a team of NHS complex care nurses and a couple of SDS staff look after her. It's been intense during lockdown. Imagine sharing your life with a lot of different strangers, not being able to leave the house.

I'm the project manager, I've got wages to do, rotas, stock to order and medicine to keep on top of. It's not the actual caring that's hard, it's everything that goes around it. The biggest challenge for me is I've not got a lot of freedom in my own life to go and do the things that I've dreamed about.

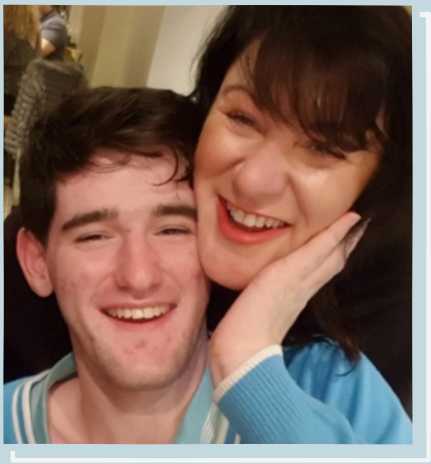
I did have a bit of a breakdown, everything was overload. At the beginning of this year I bought this bike. I thought this is something I need to do and I started going out on it. During lockdown I just loved it, every day to have that sense of freedom. I can get out in the fresh air and be in touch with the community. I think that's the big thing about cycling, as a carer you're isolated but if you're out on your bike you're saying hello to people when you're passing, that's important. People need that in life. Cycling is a positive for me. It's improving my mental health.

Art therapy has also helped me. My friend asked me if I wanted to go to an art class. I actually had the best day. I painted a picture for Freya of a wishing well and a sunflower. I went to more classes and spoke to people and what happened to me was I started to have confidence in myself again. My dream is to roll art classes out across carers centres. I've started college to learn more techniques and how to train people.

Between art and cycling I feel so much better about myself. It's all about having choices. Every carer should have a dream and it should be supported to be fulfilled."

Celia’s story

> “It’s time for real change! The new normal has to address unpaid carers vital role for now and the future!



“Issues of anxiety and stress have been exacerbated in lockdown. Paul, my son whom I care for, had a medical emergency early in the lockdown which was very scary. Initially, the doctor wanted Paul admitted to hospital in case the infection spread through his system. My eldest son was aghast. He said “Mum there is no way you and Paul can go into hospital, as you are both so medically vulnerable, there is a strong risk one or the two of you won’t come out!” It was a very worrying time. In addition to this, I have witnessed a regression in Paul’s behaviour which is heart breaking. His brain disease is neurodegenerative, and we do not know how long we will have him.

It’s all about round the clock care, increased exponentially with this lockdown. Services are closed and there is no respite. That means the burden of care I felt, which was already at the sharp end before, has become a knife edge. Loneliness is a huge factor. In some ways this lockdown gives people just a small insight as to what it’s like for Carers’ – a loss of freedom, job insecurity, financial worries, fear for the future, health both mentally and physically impacted and shock that our dreams for our future have disappeared.

I hope the Government will now look at the unequivocal evidence as to just how much unpaid Carers’ hold together the threads of society’s holes in social care. A change in world view has occurred, a ‘paradigm shift.’ It’s a time for real change! The new normal has to address unpaid Carers’ vital role for now and the future. We can no longer be invisible. We want action!

Our NHS has been invaluable throughout this pandemic, as well as so called ‘unskilled’ frontline workers who have kept society running. I call for an ‘NCS’, a National Care Service, equivalent to our wonderful NHS, where at a national, governmental level, unpaid Carers’ become visible and valued as well as our disabled loved ones. Carers’ and their cared for have to be seen and viewed holistically. Let Scotland lead the way!”

Karen’s story

> Being an unpaid carer can be hard at the best of times; add into that the uncertainty of an invisible virus.

“Being an unpaid carer can be hard at the best of times; add into that the uncertainty around an invisible virus whose name we did not even know until late 2019, and the caring role just became a whole lot more challenging. I know because I am an unpaid carer.

So how am I coping? Well I’m following the advice for a start. Hard as it is to be isolating it must be done. I’m trying to support my husband through this while his face-to-face support service moves to telephone support and reduced hours. I am keeping in touch with my elderly parents via telephone – digital age has passed them by. I take them essentials, a round trip of 130 miles, once a week and wave through window to them. These are difficult times indeed.

Finding yourself constantly checking social media or TV for updates? Try not to do this. I take a break from it all. I find watching some movies or comedy shows really takes me away from the situation, and it also helps my husband relax. Music is great as well, if it is lively music. Move around to the music, encourage the person you care for to do the same if possible, moving is a way of getting some exercise.

Talk to someone at a local carer service. I miss my one-to-one contact with fellow carers and support worker, so I keep in touch via email or phone. I write down how I am feeling and put it in a jar to be dealt with later. When I return to the jar sometimes the worry is not that great anymore. Other times I know it is something I will deal with when life gets back to normality. I am realistic, there is only so many things I can control and deal with. Accepting what you can control is essential. We can worry about reduced support, but we can’t do anything about that at this critical time because services are facing the same issues, we all are. I have to trust the people running services to be making the best decisions, not just for me, my husband and my parents, but for all of us.”

Gillian’s story

> “It has been a year where those of us who were capable simply had to put others first, embracing a human to human kindness.

“I never thought it was possible, the idea of having dementia and being contented. There’s a book by that title, it was one of the first I read when my mum was diagnosed with Alzheimer’s around 2009. Mum just celebrated her 90th birthday. Every additional year is a surprise and a blessing and I’m happy to report that now, she’s in a place of contentment.

With the arrival of COVID-19, we suspended mum’s care package last March and I moved into my brother’s home to help care for mum. Basically, we’ve shielded ourselves since.

The experience has transformed my brother and I into introverted, unsociable recluses. Yet a quiet life seems to have suited mum. Every day she is happy, laughing, smiling at something, be it playing with balloons, sorting cards, cosying into her fidget muff, or enthusiastically feeding herself any food that has been carefully dissected into wee squares. Tho’ she will let us know when her sippy cup of lukewarm tea is empty by gently banging it on the table.

When we smile cheerfully to interact with her, she gives the same right back with bells on. Being constantly enthusiastic does take its toll so my bro and I give each other time out, so that we can maintain our inner cheerleader. We also bought in help for her 90th birthday celebrations in the shape of Sir David Attenborough and Dame Judy Dench. Well, their life-size cardboard cut-outs. The esteemed celebs have taken on new roles as mum-sitters. When mum can see David or Judy close up, she will chat away to her new best friends.

The vaccine along with sunnier days have given us confidence to emerge from our hibernation. My heart goes out to all those who lost loved ones or who were kept apart from those they love in care homes.

So far, touch wood, we have come through this reasonably intact. It has been a year where those of us who were capable simply had to put others first, embracing a human to human kindness that can, in our case, keep even dementia contented.”

Humans of Scotland

Stories from the NHS and Scotland’s health and social care third sector workers

Alison’s story

> “My team have been in a unique and what I consider privileged position, supporting these patients when their loved ones can’t.

“Patient recruitment for studies was suspended as soon as COVID-19 came along and our focus for the last 10 weeks has been recruiting hospitalised COVID-19 patients for research that may help us understand more about the virus. This may involve taking samples from patients such as throat swabs, bloods or randomising patients to drug studies. Additionally, I have been supporting staff by providing nursing care in the COVID-19 wards. This has been busy and very challenging at times, both physically and mentally, but also exciting to be part of.

My team have been in a unique and what I consider privileged position, supporting these patients when their loved ones can’t. One thing that was very evident to me from the start was how few personal belongings these patients had. This could be anything from toiletries, reading glasses, phone chargers and nightwear. Most people were admitted under emergency conditions and with families isolating they had nobody to provide them with items we take for granted.

I decided to put out an appeal on for toiletries and £500 to buy an iPad that I thought would be useful to connect families. The appeal gathered momentum quickly and within a week we had reached around £20,000!

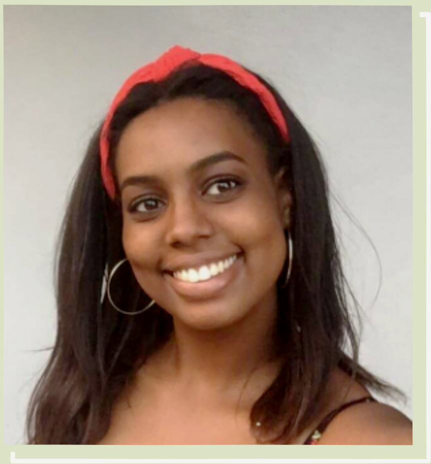
We came up with the idea of Rainbow Boxes – coloured, organised drawers of single use essential items that would be easily accessible in wards. We decided that a nightwear Rainbow Box would partner each ‘essential items’ Rainbow Box as nightwear has been something desperately needed by patients.

We also provided all COVID-19 wards at Edinburgh Royal Infirmary with iPads enabling families to connect with loved ones in hospital. These moments for me as a nurse were so special and memories that will never leave me. I connected a wife with her husband just days before he sadly passed away.

I’m so proud of what we have achieved. We are now a registered charity and have provided over 60 wards across 10 hospital sites in and around Edinburgh with Rainbow boxes.”

Wendy’s story

“I feel confident that I have developed a whole new set of skills revolving around learning how to be a support for someone in a COVID-19 world.



“Looking back at when the pandemic hit, it marks a time of uncertainty and confusion. I was a third-year student with no idea how my studies would continue. More so, it was very uncertain how I would be able to pursue my volunteering roles. During those difficult circumstances it became very clear that I would have to adapt to continue pursuing the things I love.

My volunteering at both the Royal Edinburgh hospital and with Rowan Alba gave me a sense of purpose and fulfilment when I needed it most. I was a newly inducted volunteer at the Royal Edinburgh hospital when the pandemic hit. This meant I started my journey doing remote volunteering. This involved creating tasks that could be used in the wards to provide meaningful activities and some normality for patients. I was aware that this would not replace face-to-face interaction. However, this became the new normal and I was happy to know that I could contribute in some way and potentially brighten a patient’s day.

My work with Rowan Alba as a Community Alcohol Related Damage Service (CARDS) Volunteer did a full 360. I went from visiting my client in her care home to not being able to see her at all. This was a big adjustment period and I had to learn how to convey empathy and active listening through the phone. This was really daunting at first as I often relied on my facial expressions and body language during our sessions. As this was no longer possible, I had to learn how to communicate using just with my voice. It was important for me to stay motivated and passionate about my volunteering roles this fuelled me to stay positive through tough times during several lockdowns.

Currently, face-to-face interaction has made a return and I am a recent graduate. Although I hope we never go into lockdown again, I feel confident that I have developed a whole new set of skills revolving around learning how to be a support for someone in a COVID-19 world.”

Leonna’s story

> “The first week the clap for carers happened it was quite emotional. I felt that wee bit more valued.

“Everything changed overnight with COVID-19. We look after hospital discharges, going from house to house organising medication and helping people with daily tasks like washing, dressing and meal prep.

I notice how lonely people are. There’s a lot of lonely people without many people in their life. Because of COVID-19 people went from having maybe one person coming in with their shopping, like a family member, to having no one. It’s hard to see people change, withdrawing into themselves a wee bit because they’re missing people. Sometimes people just want to chat and sometimes I think ‘I wish I could talk to you for hours’. It can be hard to leave them.

I think people need to see their family members but people are still frightened to go near their elderly relatives in case they pass anything on. People need their social clubs and social interaction back.

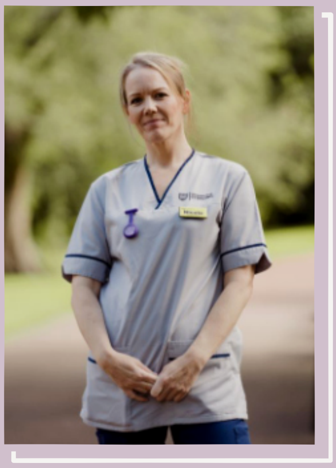
Everyone I work with is really dedicated, a lot of us do that bit extra to make a client’s life that bit easier. Just wee things we do to make people feel better. I get the feeling sometimes we’re looked on as being ‘just a carer’. But it’s a respect thing. The job that all carers do is important. We’re going into clients’ houses and mostly we’re keeping people out of hospital and care homes. The work we do is really important.

The first week the clap for carers happened it was quite emotional. I felt that wee bit more valued, more recognised. Then I got embarrassed because I’d come out of a client’s house and all the neighbours would be clapping as I walked to the car. My face was scarlet! It was a brilliant idea and it lifted our spirits a bit. I went out and clapped as well when it was my week off work to show my support.

It seems a bit calmer now, we’re not as nervous as we were when it all started. Hopefully things will keep getting better and we can get back to normal.”

Nicola’s story

> “The unit I work in is an admissions unit so it is a COVID-19 zone (a red zone) you cannot enter the doors without your masks on.



“I feel I am practically running to the hospital entrance, I am genuinely happy to be here, I had forgotten at that moment why I was there. I didn’t forget for long. The unit I work in is an admissions unit so it is a COVID-19 zone (a red zone) you cannot enter the doors without your masks on.

We have quite a few patients come in, for various different reasons and for today I am doing a bit of everything while getting to know my new mentor. I always make sure I go round and see who each patient is, find out what is going on and try to find time to introduce myself and tell them my name. I find that even more important right now, as no one can see my mouth so they can’t see me smile, even if I still do it instinctively, I find it a bigger need to speak and make my body language say ‘you are welcome here and I want to help you!’

It has been a long day and I am sore all over, it is a day of mixed emotions, some people went home, some had bad news and some unfortunately were dealing with the true nightmare of COVID-19. But it is home time now and I need to think about my plan into the house so I can keep my family safe. I have packed my dirty uniform into my pillow case. Once I actually get in my house I can shower and make myself feel safe so I can see my kids before they go to bed. But I still don’t want to touch them, the fear of passing on COVID-19 when I am in such close contact with it all day is terrifying. All in all it’s been a good day and I feel I made the right decision to go on placement, I am absolutely in the right place. It’s bed time now and then I can wake up at 5am again tomorrow to do it all again.”

Emma's story

> I now feel proud and full hearted that the job I do, that I love, can make such a difference in these challenging times.

"At the start of the pandemic I was filled with such guilt. I am a physiotherapist, a job I am passionate about but as a high risk/shielding individual I couldn't be redeployed to support acute services like many of my colleagues. I work in a pain management service working with individuals with complex long term pain conditions as well as having a national clinical lead role. With out-patient services paused I was keen to look at how I could continue to work with individuals. Coaching people is an art form which aims to empower individuals to live as well as they can whilst managing a long-term pain condition. How was I going to do this when I wasn't seeing them face-to-face?

I've realised meaningful conversations can arise in many ways and telephone and video consultation have allowed those connections to still happen, even during lockdown. Yes, we've had to think out the box about how people keep active and participate in meaningful activity in different ways, but above all individuals have known we are still here to support them with the challenges they experience every day, including isolation, fear, change to their function, emotional impact and not always being able to see their loved ones due to the persistent pain they live with daily.

Fast implementation of digital platforms has allowed me to support the sharing of online resources and the development of online toolkits to support people now and in the future. Connecting virtually with colleagues across Scotland has strengthened collaborative working, leading to improved options for the management of persistent pain and it has been a real opportunity to support each other, share practice and engage in positive change for the future of pain management services.

Days and weeks have vanished in busyness, nothing like the contributions many have made on the front line. I now recognise that I'm making a different but important contribution to supporting people during COVID-19 and rather than guilt, I now feel proud and full hearted that the job I do, that I love, can make such a difference in these challenging times."

Jackie’s story

> “I am extremely proud of our team; we have adjusted every aspect of our personal lives and professional lives to ensure our patients were cared for.

“March 2020 is a time where none of us will forget. The fear, the anxiety and the isolation will be feelings that most of us would recognise from that time. In the inpatient unit of the hospice patients with life limiting conditions still needed and deserved the highest standard of care.

Most of our extended work family consisting of office staff, artists and counsellors were all sent home to work. At the time we likened it to the titanic and we were hoping we were not going down. Normally the hospice would be a buzz of activity, it very quickly went silent.

PPE was a huge adjustment. The thought of masks for a 12-hour shift was scary, gowns, face shields it all felt alien for us…then we saw fellow nurses in ITU in the newspapers, in the PPE that they had to wear then I felt guilty.

Everyday tasks became a frightening experience. I am the main carer for my parents. We are all very close. To keep them safe I did their shopping and errands. The saddest I felt was my mum coming to the window to wave. I saw dad the days I was working only to drop my dog Rosie off, socially distanced. Then the news of single people could become a bubble with family members. I will never take my family for granted again.

I am extremely proud of our team; we have adjusted every aspect of our lives to ensure our patients were cared for. Those who lived alone, like me, took comfort in coming to work and having people to talk and laugh with. I had to keep myself safe to ensure my patients and my parents were safe.

I am proud of myself. I completed a leadership course and passed a postgraduate module through the pandemic alongside working full time.

It remains scary and feels never ending. I am passionate about mental health and at times I have struggled myself. My hope going forward is for us to be able to have team building days and reward ourselves for sticking together and getting through a very challenging time.”

Mai’s story

> “My role is to connect with patients by making art together, and help them relax, feel listened to, safe.

“I am an art therapist at a psychiatric hospital in Edinburgh. I work with adults on acute inpatient wards who have been admitted because they are in crisis; usually in huge emotional distress. The patients I encounter often say they are confused or overwhelmed by their thoughts and emotions, and feel they cannot cope with them. My role is to connect with patients by making art together, and help them relax, feel listened to, safe, and better able to think about whatever is going on for them.

COVID-19 restrictions have brought barriers to the ways I normally build relationships. Wearing a face mask means patients have to try to get a sense of who I am and my responses from just my eyes, eyebrows and forehead. Also, my time on the wards is kept to a minimum giving me fewer opportunities to get to know patients or discuss art therapy before offering a session. A good chunk of this time is spent cleaning the surfaces and materials in the room I use.

However, I am starting to see how some of these barriers might help me make better connections. For instance, several patients have noticed and laughed with me about my glasses steaming up. This has opened up conversations about how difficult it can be to feel safe when something stops us from understanding other people – and that these barriers can take many forms, including delusions, anxiety, or a face mask.

Another example is how my time spent cleaning helped me empathise with one very angry, frustrated patient who was trying to work out the source of her feelings. When I suggested trying to draw these feelings, she took a large sheet of paper and pushed an oil pastel repeatedly across it, sighing heavily as she did so. Stopping, the patient said this pushing movement reminded her of cleaning, and of how much she missed looking after her young children and her home; her hospital admission meant she had lost this role. Now when I clean, I remember this is time set aside to think about and care for my patients.”

Dan's story

> I've seen a community spirit that I hope remains long after COVID-19 dies out.

"With the temporary cessation of face-to-face support, we are working from home for the time being. We're using technology wherever possible to make video calls to the people we support to maintain some visual contact. When this isn't possible we provide structured phone calls to try and continue the facilitation of the positive outcomes we usually do.

Coronavirus has impacted upon every area of our lives and I'm no exception. It's disheartening when I see all the cancellations and postponements in my diary and the impact it has had on the routines of the people we support.

Recovering from alcohol related brain damage (ARBD) requires a degree of structure which we've helped people put in place over the years. We try to get people to engage in community activities to widen their social circles and build their self management skills. So with everyone being asked to stay at home, this is all on hold at the moment.

The staff team at Penumbra have pulled together and adapted to these ever-changing times remarkably well, we're helping each other out making the best of technology to stay connected with one another. Barring the unnecessary stockpiling that created shortages for others, I've seen a community spirit that I hope remains long after COVID-19 dies out.

We've all seen the horror stories about various employers treating their workforce with apparent disdain, so I'm feeling fortunate that mine has been supportive and attentive to our wellbeing and mental health. It means a lot during these uncertain and anxiety inducing times.

Personally, I've been able to spend more time at home with the kids and indulge in spare time interests such as art and poetry. Sometimes, all you can do is keep yourself safe and ride out the storm. Once normality resumes, first thing I'll do is have a haircut."

Jennifer's story

> The reward of seeing some of our most unwell patients being discharged home has made it all worthwhile.

"Normally I work in a small Women's Health team as a physio treating continence and maternity patients. In March, just before lockdown I was redeployed to the acute services at Ayr hospital, after nearly four years off the wards. It was nerve wracking coming back to my old base. I was excited about working with old friends but unsure about having to make new relationships with staff I'd never met before.

If it hadn't been daunting enough returning to acute wards the idea of COVID-19 wards and PPE was a lot to get my head round! Thankfully our department has done regular updates and training on PPE, infection control, hand hygiene so it soon felt normal and my skills were back up to scratch.

I felt a real anxiety about working with patients with COVID-19. The main reason was returning home every night to my young family and the risk of spreading infection to my home. I quickly got into a routine of putting my uniform in its pillow case, shoes in to a plastic bag then showering before leaving work. When I walk into the house my husband makes sure the washing machine is empty for me coming through the door to throw my bag in the wash. Then I feel safe for cuddles with my kids.

I have also had to get used to a change of shift pattern, working four long days including a Saturday. While it's been nice to have three days off to help with home schooling, it has impacted on family life as we only have one work free day off as a family. However, we are finding new ways to spend time together with evening walks and now out on our paddle boards.

I have been amazed at the support I've received from my new colleagues, as some days have been physically hard and emotionally upsetting. However the reward of seeing some of our most unwell patients being discharged home has made it all worthwhile."

Jenny’s story

> “Some good will come of our new ways of working, but we must never lose sight of what matters most to people.

“Six weeks before coronavirus struck I sadly lost my father. He had been living with dementia and Parkinson’s. My family knows first-hand how important it is to have the support of health and social care professionals to manage even the simplest things in life and how much of a difference that makes to coping with difficult circumstances. In my professional role as an occupational therapist I have had to change the way that I engage with people living with long term neurological conditions during the coronavirus.

Some people tell me that their life has not changed greatly due to the difficulties they always experienced getting out and about and engaging in everyday tasks and things that are important to them. Others tell me on the phone that they are “fine”. But I can’t see their eyes, or their faces on the telephone so I need to work harder, to understand if they really are fine or if it is just easier to say that, a trick I learned with my mother as my dad’s main carer. Just in the same way that the person can’t see my face, my eyes, or my smile on the telephone, nor behind the mask that I have to wear when I visit them.

Engaging with people in a genuine and meaningful way is a key part of what I do within my role. I engage with lots of people throughout the day including people living with neurological conditions, colleagues, family and friends and the way that we do this changed. I understand that some people are liking the new ways of working and using technology instead of lengthy, inconvenient and time consuming trips to the hospital, but for others that more personal touch, that reassuring stroke on the arm, that gentle smile or that sly wink that is so common in everyday practice is just not quite the same through the phone or on a video screen. Some good will come of our new ways of working, but we must never lose sight of what matters most to people.”

Helen’s story

> “Whatever people face, we are there to support them and that’s what makes my job so worthwhile.

“Hello, I am Helen and I am a Speech and Language Therapist (SLT) in Dumfries and Galloway. A lot of people presume that speech therapists only work with children, but SLTs support people throughout their lives. We see people in the hospital, in the community, in care homes and day centres.

During the COVID-19 pandemic we’ve been busy working in the hospital with all kinds of patients, in the critical care unit, in palliative care, on the respiratory and rehabilitation wards, supporting people at end of life or helping people to get on the road to regaining their speech or swallowing. It can be a long road to recovery and so we’ve also been supporting people at home and in care homes using digital technology, the new NHS Near Me service, where people can sit in their own homes and talk to one of our therapists or support workers over a video link.

We’ve had to be very flexible and adaptable and do lots of things differently but being able to communicate is a fundamental right and I’ve seen some really touching personal practice – staff on the wards holding up an iPad for a patient to speak to their daughter or using specialist picture pointing charts for someone unable to speak due to a breathing tube, to help them express an opinion.

I’ve also been supporting people with dementia by writing blogs for Alzheimer Scotland providing information to carers through the charity Dementia Carers Count.

If I’m being honest, at times it’s been scary, overwhelming and exhausting, but I am part of a team and I can absolutely say that every member of the team has played their part in continuing to find new ways to support our patients and each other. Being able to speak, eat and drink is something we take for granted, but it’s complex. I guess you could say SLTs help people keep blethering, supping and nibbling! It really is the stuff of life. Whatever people face, we are there to support them and that’s what makes my job so worthwhile.”

Ross's story

> “One of the great things about art is its inclusivity, we can all call ourselves Artists.

“I work for Health in Mind, a Scottish charity which strives for people to live in a supportive and resilient community where mental health is understood and people can lead fulfilling lives. I work in Midlothian, dividing my time between being a support worker and a project worker.

Like many others, because of the COVID-19 pandemic, I have been working from home since 16th March.

I'm proud at how quickly we were able to shift our ways of working as an organisation. We have been able to develop and put in place creative ways to support people and I now provide more phone support and host support groups online where people can connect with each other and feel like a community. We have seen a large increase in the number of people contacting us looking for information and support with their mental health and wellbeing.

It's important now more than ever that we all look after our mental health and practice self-care. One of the ways I take care of my mental health and wellbeing is by being creative.

For most of my life I have used art as a way of understanding and contemplating the world and it has provided an escape from the stresses that modern society often places on people. I remember loving Art classes at school, getting away from academic learning, the dualistic right or wrong of other subjects, a place where I could relax and have time to express myself.

One of the great things about art is its inclusivity, we can all call ourselves Artists. Anyone can have a go and once the initial concerns of ‘being good at it' are addressed, people can realize that the process alone is valuable, the sensual joy of simply working with our hands, slowing down, carefully observing and becoming involved with the medium….

And so I encourage the people I work with to allow time for contemplation through artwork, taking the time to just sit down and draw is a mindful and meditative experience, bringing your awareness and senses to the present.”

Ashley's story

> Once the patients were well enough to leave ICU, this milestone moment was celebrated by staff.

"As a physiotherapist working in the intensive care unit (ICU), I had to provide training and upskill a large number of staff to deliver safe and effective care in order to double our ICU capacity. It was great to have extra staff to help us through this challenging time. We supported our nursing colleagues by helping with washing patients, changing their position and generally being an extra pair of hands where we could.

One method for helping the oxygen levels of COVID-19 patients is to lie them on their front, in the prone position. The physiotherapy team became the 'proning team' where we would assist our nursing and medical colleagues to turn a patient prone or on to their back again. This is a labour intensive job as it takes up to six people to safely perform this task. This can be of great benefit to the patient, slowly reducing the amount of help given to them by the ventilator.

The greatest part of my job was getting patients, who were on a ventilator, to start their rehabilitation journey and achieve sitting at the edge of the bed for the very first time. Often, these patients had been in ICU for up to three weeks critically unwell before they were well enough to start moving. As visiting had been suspended we were able to capture these moments on video to share with the patient's family which also turned into a video diary for the patient. Once the patients were well enough to leave ICU this milestone moment was celebrated by staff lining the ward and clapping them out of the unit, almost like a guard of honour! A huge amount of care and hard work as a whole ICU team allowed us to share and participate in these special moments.

Personally I live alone so have been able to keep myself isolated from friends and family which has helped my anxieties about spreading the virus to those I care about most. I'm looking forwards to becoming an auntie in the summer and hope I can visit my wee niece or nephew, maybe even getting a cuddle!"

Humans of Scotland

Stories from

disabled people and people living with long term conditions

Kiana’s story

> “The pandemic has been a shared experience and affected everyone on the planet.

Photo credit: Kevin J Thomson

“The pandemic has pushed us into the ‘New Normal’.

But I feel it’s not necessarily going to be a better normal for me, or many other disabled people. At least not without a fight.

We’ve learned over the past 18 months to sanitise surfaces, respect people’s personal space and think very carefully about whether we should hoard toilet paper.

Some things have changed for the better – I’m hoping the prospect of flexible working will continue to shine brightly. Not because I have spinal muscular atrophy Type 2 and offices are woefully ill equipped for my needs, but because working from home means I can get a banana cake mix ready in 10 minutes and it can rise in the oven as I type emails over the next hour.

But the pandemic has been a shared experience and affected everyone on the planet. And the adaptations and accommodations made as a result are because the majority of the populations needs something.

But what about when the minority needs something? What about all the things I’ve needed pre-pandemic and continue to need?

Funding for a new stairclimbing wheelchair so I can finally access all terrain. Access to specialist medical procedures and innovative expensive medicine for my health condition. Or just being able to go outside without having to dehydrate myself or hold it in [yes, in the 21st century we still don’t have real accessible toilets in most places].

These are the things that cause an unequal playing field. These are the things others can’t fully relate to. There’s no shared empathy. COVID-19 has overtaken everything, every time, attention and fund. And it is important that everyone who’s been affected by the pandemic receives the outstanding support they need and deserve.

But I wonder for once, why can’t society accept and support the needs of people like me? If the pandemic has proved anything it’s that diversity is what gets us through the storm – we need diverse leaders who look at problems from all directions. So exclude me, and people like me, at your own cost.

When will we learn?”

Kirsty’s story

> “People with invisible illnesses like myself said welcome to our world.

“When I was in my mid-20s my health went haywire. Doctors continually dismissed my concerns. It was a huge relief at age 36 to be diagnosed with Lymphatic TB. I thought I’d finally got some answers. However after the treatment it became obvious something else was still going on. Frustrated with repeated “normal” test results I resorted to private testing, which thankfully I could afford. I was diagnosed with Hashimotos, an autoimmune condition. This explained my symptoms and provided a starting point for healing.

Throughout this my energy and health became such that all I could do was make it to work. Time with loved ones and my social life vanished. I was in survival mode. Sadly I became so ill I also had to stop working which was difficult.

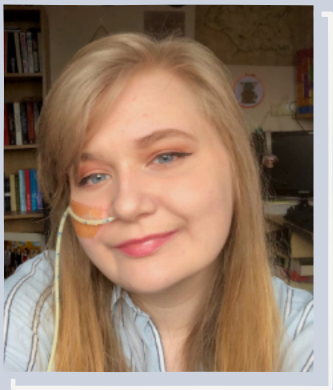
Fortunately I have savings and not working provided time to focus on my health. I’ve tried numerous treatments involving a great deal of emotional and economic investment. However I dread to think where I’d be now if I ‘d been unable to do this. I am so grateful at age 47 to be healthier. I’ve started reconnecting with people and doing more.

This progress was halted by the COVID-19 lockdown which having experienced my own lockdowns felt very familiar. People with invisible illnesses like myself said welcome to our world. We’d already learned not to take our health for granted and about the need for testing. Having gone from struggling to walk down my street to completing a 10k walk I appreciate my daily walks and nature.

I really hope lockdown lessons are remembered. Everyone with any kind of illness should have access to accurate and comprehensive testing and diagnoses. Your health should not be dictated by the amount of money you have. The recognition that the same illness impacts individuals differently is long overdue. It is and has always been vital that patients’ voices are heard and that they are treated holistically. The way I am managing my health shows what can be done when people are able to take this kind of approach to their health.”

Leanne-Sydonie's story

> “ COVID-19 has been a huge barrier to my medical treatment.



“I have known I was disabled since I was very young, but only with the diagnosis of additional conditions in my early twenties did I realise how important disability advocacy was to me. Throughout school I was embarrassed by my extra accommodations and tried my hardest to fit in with my peers who did not experience the same challenges as me. I did really well despite my low attendance, and went to university to study law. In my second year I really struggled with new and uncomfortable symptoms that lead to a diagnosis of Crohn's Disease, then in my third year I was diagnosed with Gastroparesis so now I rely on a feeding tube. I had been taking the rest of this year as medical leave, and that's when COVID-19 hit.

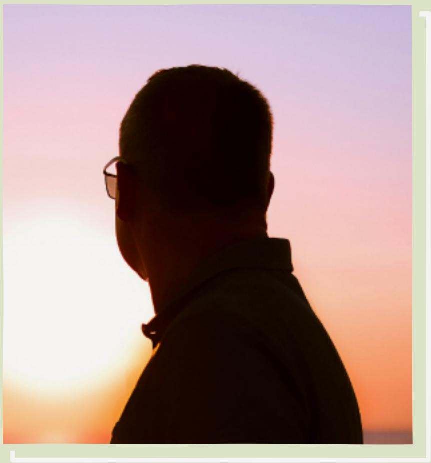
COVID-19 has been a huge barrier to my medical treatment, and I've had to grapple with the struggle of my medical leave, my symptoms, the struggle of shielding at home where I haven't lived full-time for three years, and my own mental health as I come to terms with my new way of life. On coming home I had hoped to volunteer in my community, return to a part-time job and develop some new sense of normal, but this just hasn't been possible with my vulnerabilities to the coronavirus.

When I was approached to volunteer with the Mental Health Foundation's #morethanacondition Youth Panel sometime in lockdown, I agreed immediately. It gave me something to do after months of focusing on my symptoms and not being distracted by my studies or work, and it also allowed me the chance to reach out and help others with Long Term health conditions. I have always wanted to help others – be that through the law or just chatting, and creating content that ensures we're seen and heard in such a strange time demanding attention in so many different areas of life, has been really important to me.

I am due to return to university in September, and despite the uncertainty with COVID-19, lockdowns, and treatment, I am really looking forward to being back.”

Derek's story

> “The whole experience was challenging mentally and physically.



“Due to my visual impairment and being a chronic asthmatic, at the time of writing this personal account I have just completed my eightieth day of self-isolation. However, for the first seven weeks of this lockdown, I was completely unable to identify a wholly accessible support service to help me sustain my daily living routine following the loss of my two Personal Assistants due to their own personal concerns of contracting COVID-19 through their daily working schedule.

The support I initially found via an online search of my local authority website led me to a community centre who were providing people in my circumstances with essential provisions but this generous community resource created additional difficulties as I couldn't identify many of the food products provided never mind cook them due to my visual impairment.

When I accessed the Scottish Government 0800 service on the 1st of April I was told that I did not qualify for support and that I should contact other organisations within my area who may be able to aid me in getting shopping in but this too proved fruitless for a variety of reasons i.e. much of the literature I received from these community sources was in a graphic format that my assistive technology couldn't read, I was ineligible for support from many groups as I didn't meet their criteria say for geographical reasons and those groups within the community who were identified by the local authority never responded to my emails requesting help with shopping irrespective of how often I contacted them.

Finally, having contacted my MSP and MP for the third time seeking their intervention, I was eventually called by the council emergency social work department who put me in touch with a community group who could take my personalised shopping list and drop my shopping off at my door. The group themselves dismissed eligibility criteria in order to assist me to meet my basic shopping needs.

The whole experience was challenging mentally and physically, but made me ask the question on how my peers were faring at these difficult times.”

Imran’s story

> “ I try to walk at the side of aisles and be aware of people around me, but some people just walk right next to you.

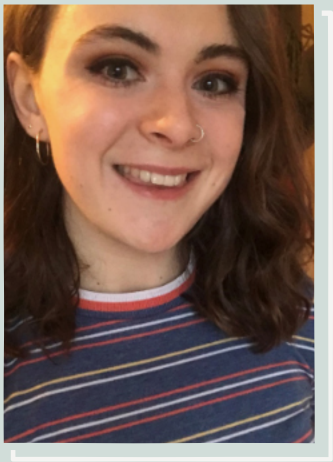
“The lockdown has been fairly tense for me and my family. We are thankful that nobody we know has been affected but everybody is still remaining vigilant. I am handling it OK, but I feel more sorry for the kids. They are finding it more difficult not socialising outdoors or going to school. I have to admit, it’s the kids that are keeping me sane. Helping them with their homework and spending time with them helps to break up the day.

I haven’t been able to work since the middle of March, which has been the hardest thing, but the financial help from the government has been extremely useful. I suppose the only silver lining is that, as my vision is deteriorating further, I have time to learn JAWS (computer speech software) before I go back to work. A cyst is growing in my good eye which will require surgery in the very near future, which I am not overly optimistic about given I have had so many procedures already.

I pretty much stay in the house all the time, and only really go out in the back garden or to the supermarket. AAARRHHH, the supermarket is sooooo annoying. I can’t believe how many people are still ignorant to social distancing. I try to walk at the side of aisles and be aware of people around me, but some people just walk right next to you, chat with friends in the middle of the aisle and pick up items next to me. Even with my symbol cane, I am now having to look down to make sure I don’t bump into anything, look up to see if there is anyone near me and then look around for people near me while I am trying to find what I need. Needless to say, it is exhausting. That’s my rant over for today!

I hope everyone is keeping safe and well and I am sure we will come out of this crisis stronger than ever. If we just hang in there a little bit longer, I know we can make it through.”

Adrienne's story



> “I don't know what it's like to not be in a state of panic. This fight-or-flight mode is a new normal for many of us.

“I have lived with anxiety for more than a decade of my life. Probably closer to nearly two decades. As a GP once said to me: you have lived with anxiety for so long that you don't know what normal is. It's true. I don't know what it's like to not be in a state of panic. This fight-or-flight mode is a new normal for many of us, regardless of the presence of a mental illness or injury. According to the Institute of Disaster Mental Health, a pandemic such as COVID-19 causes a struggle due to the uncertain end in sight. This leaves us trapped in a constant state of fight-or-flight. Initially, I was doing well because I have distraction techniques, medication and an ability to unashamedly talk about my general mental health. My anxiety also plans for the worst-case scenario so my worried state came in somewhat handy.

However, as I write this, the UK is in its ninth week of lockdown. Now, my fight-or-flight response has stepped into the secret third option. Freeze. With the vagueness of what the next steps are in moving forward after such a pandemic when it is still going on in a devastating way, I am falling into my older coping mechanism: learned helplessness. With intense and severe anxiety, usually paired with depression, you believe everything will never right itself. You've lived with anxiety for so long that you lack the general insight in how to cope with anxiety. You've never known a life without anxiety there. So, you think you might as well resign to these debilitating feelings. Yes, I am running out of steam, and this was to be expected, because this whole thing is so incredibly exhausting. I do think we have to be careful with the concept of continuous distraction, and talk about the way to deal effectively with learned helplessness. I still struggle with this, and I think I will always have to fight it off, but each day I plan gets better. This lockdown, and this pandemic, won't last forever. I have to remember that.”

Sandy's story

> I did have worries about COVID-19 because I was listening to the news 24/7 and things were happening really quickly.

"I'm Sandy and I'm a big Aberdeen fan. I've been a season ticket holder for about eight or nine years now and I'm a West Ham fan as well and I've just recently become a season ticket holder for them too. I'm a volunteer DJ for the local pubs and I volunteer for my local community radio station. It's given me the opportunity to meet new people.

Having additional support needs and having a disability means absolutely nothing and anything is possible. I think people with additional support needs sometimes do need help and I think people are wary of speaking up. I was part of that as well. I used to let somebody else do all the talking but I sat back and thought 'well if I want to do something I've got to do the talking'. It was a comfort barrier to overcome and I've certainly done that. Never look back always look forwards.

I did have worries about COVID-19 because I was listening to the news 24/7 and things were happening really quickly so I had to stop listening. But I was very lucky before I went into lockdown that I was able to get myself a PS4. A lot of my friends that I used to go to school with have the PS4 so we play FIFA most nights. Because I've been part of radio for a good number of years I'm in touch with one presenter who does a football show on a Saturday. So he's set up a COVID-19 isolation football tournament on PS4. It's all about taking part and it's brought us more together as friends. We're keeping in touch more so that's really helped me.

I don't know what I'll do when life gets back to normal. I don't know what's going to happen with my community radio station. I don't know if I'll still have my role because of social distancing. We'll never have that life back again. We'll just have to come together and grin and bear it. I think COVID-19 has shocked everybody. I would say stick with your family and friends and we'll all get through this together."

Pat and Lauren’s story

> “When we went into lockdown it was no longer possible for us to visit Lauren nor for her to come to us.

Photo credit: Paul Wenham-Clarke

“I am the parent of a 31 year old daughter with a profound and multiple learning disability (PMLD). This means that Lauren is non-verbal, has limited understanding of many things, has complex epilepsy and needs support with all aspects of her life. That sounds like a bit of a challenge but she is also full of life and fun and very much enjoys her life. Her favourite activities are music, swimming, picture books, using her swing and being outdoors.

She lives in supported accommodation with three others and has a wonderful team of carers who not only care for her but care about her. She comes to visit us several times a week and we love spending time with her. When we went into lockdown it was no longer possible for us to visit Lauren nor for her to come to us. Of course, it’s sad for us because we miss her and understand why that has to happen but Lauren won’t understand why her life has changed in so many ways. She’ll miss her family, her day service, her activities and being out and about. I’m in frequent contact with her staff and they report that she has adapted surprisingly well and we speak to her most days on FaceTime.

My way of coping with my anxieties about Lauren is to keep very busy but the lockdown has left me with lots of time on my hands. The first week I spent creating resources on Lauren’s tablet for her staff to use with her including updating her digital passport should she have to be admitted to hospital. I added family photos and films of us singing Lauren’s favourite songs and games and photographed her favourite picture books with us reading the stories.

I’ve also been helping PAMIS, a charity supporting people with PMLD and their families and carers. I’m enormously proud to be the Chair of their Board and have seen at first hand how much they continue to contribute to the Scottish Government’s understanding of this vulnerable and often invisible group of people.

I haven’t managed to clean out any wardrobes yet, but there may still be time...”

May’s story

> “I'm not the only one who feels left out and anxious due to unforeseen communication difficulties.

Photo credit: Marc Millar

“It currently seems to me rather ironic that the advice for us all during this pandemic is to ‘stay at home’, to ‘social distance’, even to ‘self-isolate’. I totally agree, and comply with the advice however this is the type of behaviour that so many of us with hearing loss are usually struggling day in day out to overcome! Now everyone is experiencing the distancing from family and friends, the shrinking of social lives and challenges to daily interactions with colleagues and others. For me, the isolation I feel is increased due to my inability to just lift the phone to speak to people, to have a spontaneous, easy conversation.

As with everyone I am relying more and more on text based communication and/or video connectivity. The necessity of wanting to see the faces and hear the voices of my family is pushing me explore all the digital ways available to keep in touch. To just phone isn’t an option for me because my speech recognition is so poor I cannot understand what is being said to me unless I can lip read. Speech to Text software for Apps and video-conferencing helps. I am finding keeping in touch a constant struggle.

I have always enjoyed peer support from others who are deaf. During this lockdown I am relying on social media a lot. Other people with hearing loss posting on Facebook or tweeting are a huge source of advice and support; I know I’m not the only one who feels left out and anxious due to unforeseen communication difficulties.

I am lucky to live in a small village where folk always greet each other when we meet. I currently miss even these casual exchanges. Due to distancing I find it hard to lip read, and when masks are worn it is impossible! I am still trying to find solutions to these problem, especially with service/health providers who need to keep safe too. I anticipate us deaf people are going to continue to experience more unexpected communication problems as we all seek to stay safe during this pandemic.

However a walk away out deep into the countryside when it is sunny and the birds singing (yes, my hearing aids let me hear them now!) and wild flowers blooming will always lift my spirits.”

Janice’s story

> “ I have been pleasantly surprised by the kindness and compassion that not just I have been shown.

“For me the #StayAtHome message, I was fully in favour of as a way to reduce the curve affording our NHS some crucial time. But it also filled me with dread of being put into further uncertainty and isolation, even though having a chronic respiratory illness limits my day to day living outwith the current pandemic, I was able to have friends and family visit or sometimes they would offer to take me out for lunch, cuppa catch up. Simple pleasures that we all take for granted.

I must admit I have been pleasantly surprised by the kindness and compassion that not just I have been shown. It has restored my faith in humanity, communities rallying together making and delivering soups to the elderly and vulnerable.

Seems we are truly in this together rather than what my fears were telling me when I heard on the news people saying ‘oh it is only the vulnerable people that will be at risk’! What I would like to say to these people is your ‘only’ is someone else’s everything.

I am fortunate I have received a lot of telephone calls texts, emails offering support or assistance if I ever need it that is reassuring for me as I live quite rural, with no extended family members living nearby.

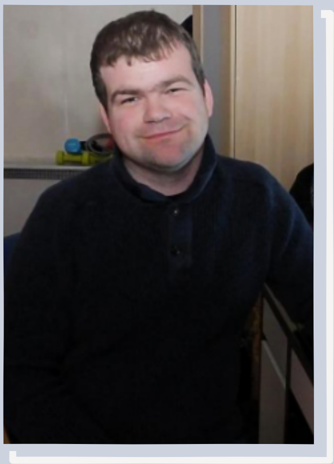
My nearest Carers Centre in South Ayrshire has closed its doors to general public in compliance to guidelines but they firstly called to let me know they would still be only a phone call away if need be. I also received a further message when the social distancing, vulnerable groups guidelines were issued. They phoned to ask permission for a designated member of staff to be allocated to me if I need some assistance and not to hesitate in letting them know.

I used to be a frequent member of a singing for lung health group Dayr to Sing. Even though I have not attended for quite some time due to my illness I have received telephone calls from my lovely friends asking if they can assist me in any way. Our facilitator has been sending some happy positive upbeat songs too. The British Lung Foundation keep me updated with information during this pandemic.

Keep safe everyone during these unprecedented times”

Michael’s story

> “We should all come together and help each other as one and also think about people in your community with disabilities.



“This is a distressing time for everyone, though take a minute to think about people the needs of those who need additional support, like people with disabilities and long term health conditions, also their support workers.

The messages that are being put out there need to be considered for how they would be perceived by people with a disability. I would imagine people are feeling very confused, overwhelmed and panicking. We need to work together to take a steps to control the outbreak and prepare best ways to get though at this critical point.

When news that COVID-19 had reached Scotland, a number of different disability organisations published information in easy read and designed them to be accessible to all. It should be that public and statutory bodies are mindful of clarity when producing information about the impact of coronavirus.

Talk about self-isolation can be difficult to put into practice for people with disability and long term conditions, as they would often need support from another person to do everyday tasks.

I have been talking to some carers and they are also as worried as when they go shopping to get everyday items they are sold out, and they need to safeguard from those around them in the street or the supermarket.

It is difficult to get accurate figures about adult carers as there is a high level of under reporting, people often don’t think themselves as a carer, and many of those often will not ask for help.

I know it is a stressful time for everyone. I would just like to say to all carers and the people who work with the NHS, well done, keep well and safe. We should all come together and help each other as one and also think about people in your community with disabilities and long term conditions, to check up on them. Maybe just a phone call, to ask “How are you and do you need anything?”. We should think about the support we can give to family, friends or a neighbour.

We need all to work together to take steps to control the outbreak and prepare to get through this critical time as one.”

Fiona’s story

> “Living with anxiety can be challenging at the best of times without a major virus outbreak.

Photo credit: Marc Millar

“This is a scary time for all of us. We’ve found ourselves in the midst of a global pandemic filled with uncertainty, fear and change. Uncertainty because COVID-19 is new and no-one seems to know exactly how to deal with it. Fear because people are literally dying and at the moment there is no real cure. Finally change because so much of our daily life has been altered and we’re all now living in some weird dream-like state where all of the things we used to do are now no longer possible. Living with anxiety can be challenging at the best of times without a major virus outbreak. Going out with friends, sitting in coffee shops, even going to work are all things which usually help relieve so much of my daily anxiety. Being connected and having things to do gave me a purpose and a sense of normality. Sitting at home faced with hours of ‘nothingness’ does not sit well with me. I need structure to my day and to be active in order to stop my mind overthinking.

Don’t get me wrong, I’m incredibly grateful to be safe and healthy and have a roof over my head during lockdown while many others have it worse than me, but it doesn’t mean that it’s not an incredibly stressful time for people living with mental health conditions. Multiple ‘what if’ questions enter my mind daily; what if my parents get ill, what if the shops run out of food, what if I can’t get my medication, what if the hospitals are full and there’s not enough ventilators, what if this lockdown goes on for months? Many of the symptoms of coronavirus are the same as anxiety. I’ve found myself asking multiple times a day “is this tightness in my chest due to coronavirus or anxiety”? Obsessions and compulsions creep in. Thinking to yourself “wash your hands or your family will die” would usually be thought of as irrational and a sign of obsessive compulsive disorder but in today’s world it quite literally could be considered a realistic thought.

What do I suggest to help ease anxiety at this turbulent time? Talk to your friends, stay connected. We live in a time where technology gifts us the ability to be interconnected at the touch of a button. Keep going, one day or even one hour at a time. We WILL get through this.”

Raven’s story

> “Each day it’s getting harder and harder to manage my pain and fatigue levels.

Photo credit: Marc Millar

“Living day to day with a disability that is unpredictable at the best of times is stressful but with the outbreak at the moment I find I am having a flare up due to stress and worrying.

There is an upside in that I have not needed to panic buy hand sanitiser as I already have a collection in my home because I have a compromised immune system.

But other things such as food have been very hard to come by as the local shop is empty. I did get a dirty look the other day for taking the last milk because I look healthy enough to travel further away. I am in the high risk category too.

Having an autoimmune disorder I had a difficult decision to make; stay on my immuno suppression and be at a bigger risk of catching the virus or come off my meds and lower the risk but increase my pain levels and flare up. Ultimately I picked to come off my meds. Each day it’s getting harder and harder to manage my pain and fatigue levels.”

Humans
of
Scotland

Stories from

people living with Long Covid

Michala’s story

> “Long Covid has not only impacted on my life but also that of my family.

“I was a fit, healthy 33-year-old mum of two girls who enjoyed life and spending time with my family prior to COVID-19. I worked full time.

March 2020, just before lockdown I fell ill with what turned out to be COVID-19. It started with what I assumed was a sickness bug, however as the week went on the “typical COVID-19 symptoms” started (continuous cough and fever). As I fell ill so early on in the pandemic a test was not available. I thought I was beginning to feel better and then around day 7-10 I became very unwell and was barely able to get out of bed. With advice from the COVID-19 assessment centre and continued care from my GP I started to feel more like my “old self”.

By June I felt I was in a position to return to work on a phased return. I was slowly building up the number of hours I was working a week when I felt the symptoms flare up again and the overwhelming feeling of fatigue and shortness of breath began to dominate my life. I was extremely fortunate and saw a Respiratory Consultant who performed numerous tests/ examinations and diagnosed me with Long Covid.

I have now been suffering with Long Covid for 12 months. My main symptoms include breathlessness and chronic fatigue. The breathlessness is starting to subside with the help of regular physiotherapy. Like many long term illnesses, Long Covid does not only affect me physically, it has also impacted on my mental health.

Long Covid has not only impacted on my life but also that of my family. Family time involves ensuring a “nap for mummy” is planned into our activities. Never in a million years did I expect COVID-19 to affect me, as a young, healthy fit mum the way it has. 12 months on and still living with the real long term effects of COVID-19. Unable to return to work and live the life I was leading prior to COVID-19. I cannot thank those who have been involved in my care enough.”

Chris's story

> "I am learning to pace myself, but it is hard, and frustrating not being the person I want to be.

"In my fifties, out of shape, slightly overweight, homeworking, coronavirus worried me. People like me seemed more at risk. While I was well, I wanted to stay well, so I made some changes, a low carb diet, a three mile walk morning walk before starting work.

By September, when I tested positive, I was in good shape. I was a little unwell for a couple of weeks, but no but nothing serious. Returning to work I was understandably a little tired, but confident I would recover.

But, instead of recovering I started to feel run down, family and work colleagues were starting to be concerned about me. I was concerned, I was getting tired, fatigued, breathlessness, forgetting things and getting confused. My body ached and my heart raced.

My GP wanted me assessed at hospital. There were some chest and heart issues, and I was clearly run down. Not so sick I needed to be in hospital but told I needed to take time off work and rest.

Two weeks before Christmas I started a slow phased return to work, a couple of mornings. In January, I worked mornings and slept afternoons.

It was not working, but I tried to push through, until one Friday the chest pains would not go away. NHS 24 arranged an ambulance. There was an irregular heartbeat, and my energy levels were rock bottom. Again, told I need to rest, need to give it time.

It is now six months. I am working two hours a day, mostly for the social connection. I had been walking 15,000 steps a day, now I hardly leave the house. If I do manage a short walk, I sleep in the afternoon.

I think I should be capable of more, sometimes I think I can, but then if I over stretch myself, fatigue affects me for days. I cannot naturally just rest, my body and mind want to be doing something. I am learning to pace myself, but it is hard, and frustrating not being the person I want to be."

Leanne's story

> “One year on, and not yet recovered, I have had a mountain of tests with no answers.

“Just over one year ago I started to feel poorly and discovered my temperature had shot up. We sent the kids away, my husband and I moved into different rooms and tried not to panic. On the advice of NHS24 I was assessed at the COVID-19 Assessment Hub. The conclusion was my chest didn’t sound great, but it wasn’t bad enough to go to hospital, phew! I still remember waking up struggling to breathe and worrying I might not wake up in the morning. Anyway, I expected it to pass.

One year on, and not yet recovered, I have had a mountain of tests with no answers. I am now waiting for them to check my heart. I have respiratory physios coming to my house, an Occupational Therapist, a respiratory consultant, an amazing GP and a mountain of pills and gadgets to help me through the day. Fatigue, headaches, brain fog, sore joints and muscles, high heart rate, breathlessness, new allergies and stomach problems are only a handful of the weird symptoms which come and go. And I have had a temperature every single day for a whole year!

This is Long Covid. No one knows if or when I will get better. I battle to work from home, do the shopping and all the other things we do in normal life. I might even, when we’re allowed again and I feel up to it, meet friends or go for lunch. It’s good for mental health and if I end up back under the blanket on the sofa then hopefully it will have been worth it.

I don’t speak about this normally because of a strange feeling of embarrassment that I couldn’t just shake this off, but also, I wasn’t in hospital on a ventilator. However, this is not binary. There are thousands of us stuck here somewhere in between. I have now joined a Long Covid PPI group, have trialled a Long Covid app for a University research project and I have trialled a book about brain fog. Anything to help the thousands of others following me down this path.”

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE)'s vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

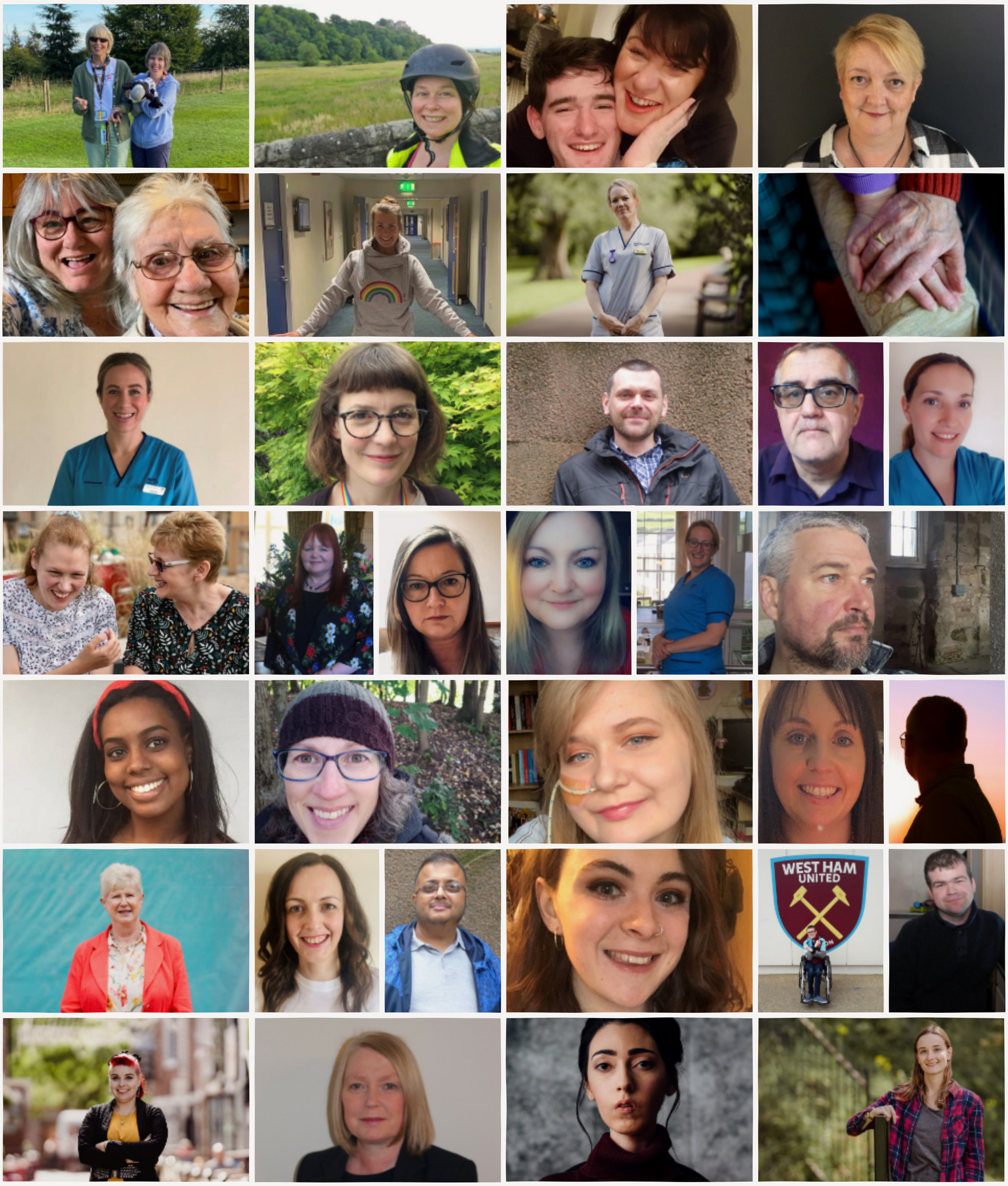
ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

www.**alliance-scotland**.org.uk   **@ALLIANCEScot**   **alliance.scot**

Acknowledgements

The ALLIANCE would like to express gratitude to everyone who generously shared their story with us during the pandemic. Everyone who has taken part in the project has given of their time to capture the lived experience of disabled people, people living with long term conditions and unpaid carers throughout national lockdowns. This selection of stories also captures the working lives of those we are so grateful to in the NHS and third sector health and social care services whose commitment and dedication must be recognised.

The ALLIANCE is a company registered by guarantee. Registered in Scotland No. 307731
Charity number SC037475 Registered office, Venlaw Building, 349 Bath Street, Glasgow, G2 4AA


WEST HAM
UNITED

Humans of Scotland is a unique collection of stories about people's lives

Sharing the experiences of disabled people, people living with long term conditions, unpaid carers and staff working in health and social care during the pandemic, Humans of Scotland captures the realities of life for people during COVID-19 whose voices must be heard.

The book tells the stories of people who experienced isolation, increased caring responsibilities, challenges in accessing crucial support as well as stories of those working in vital health and social care support and services. This collection is an important one, and one that we hope will be revisited by readers for years into the future.

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre