



Lockdown Life Stories

Hello everyone! The last year has been such a challenging time for us all and I hope that by the time you are reading this, you have been able to meet family and friends and feel a bit more freedom. If you are keen to get on a bike, read an update from CYCALL based at Brooklands Park in Worthing on page 15, or if you're needing to travel further and need a new car or van, Southern Mobility Vehicles (page 16) will be happy to help find something suitable.



I have really enjoyed putting this newsletter together and have been inspired reading about all the different ways that everyone has adapted to the restrictions. Turn over to page 2 to find out how staff at the Lavinia Norfolk Centre at The Angmering School supported their students with additional needs in so many ways, and also read on page 3 about the successes of some of the students. PACSO have worked incredibly hard all year to support families both online and in person, go to page 14 to read more!

I am really pleased to have articles from three West Sussex families in this edition, find out about the past year in the Barnes' house starting on page 4, and how Karen coped with a big move to Selsey with triplets during lockdown on page 13. Inspired by Captain Sir Tom Moore, Harry Ragless took on his own walking challenge and raised £6695 for NHS charities, read more about this on page 12!! Congratulations Harry!!

Adam Gellibrand has been working with QM Studios based in Horsham running a variety of online music workshops (page 6) and on page 7 Chris North tells us about setting up his own Storytelling website and YouTube channel to connect with children.

Twin brothers Peter and Jimmy Langton have told me what the pandemic has been like for them as university as college students with Cerebral Palsy, start on page 10 with my interview with Peter and Jimmy's comments on page 12.

Finally, if you want to know what I have been busy doing all year, turn to page 8! The highlights have been my Swimming Challenge, receiving a Point of Light Award and running a special Wheely Wonders day in August! Living at Applefield has made lockdown life easier for me than for many and even though I have only been in

the car three times, I have really enjoyed getting to know our neighbours and watching the changing seasons!

As we come out of lockdown we will all feel differently about how quickly we want to go "back to normal", but it's important to remember we all still need to STAY SAFE!



Lizzie Bailey

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**WELLSPRING
WEST SUSSEX**
- A regular newsletter
for children and
young people with
disabilities, and their
parents and carers
across West Sussex

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A big **THANK YOU** to the **Thornton Trust** for their funding for this newsletter.
Thanks also to **Southern Mobility Vehicles** for donating to Wellspring and advertising with us (see page 16).

Lavinia Norfolk Centre

The LNC remained open during lockdown for vulnerable students to attend. Due to many of our students being extremely clinically vulnerable and therefore shielding at home, we had 12 of our 37 students attending key worker school. The LNC staff supported the students in a variety of different ways throughout this period.

The Angmering School ran a full timetable of 5 live interactive lessons a day for all students. This was carefully constructed by the headship team, who took into consideration everyone's wellbeing and need for rest breaks, off screen time and processing time from one lesson to the next. All students were required to attend their registration period from 8.45-9am every day to catch up with their tutor and tutor group for notifications and announcements.

Creating a model that worked logistically for the LNC was extremely challenging; to meet everyone's needs and ensure all students had the support that they required both in school and working at home. As usual the LNC team have been incredible, with everyone working cohesively to support the students and each other. We liaised with West Sussex County Council who provided transport for those students coming into key worker school, and we all adapted quickly to the new school day timings.

All lessons were delivered using Google Classroom as a platform. This is inclusive for all, easy to use and most importantly fully interactive and accessible. LNC students have IT allocated to them prior to transition in Year 7. Students with Physical Disabilities have laptops and Chromebooks issued via our IT department with adapted software installed such as Clicker, Dragon Dictate and Google Vox. We also source and adapt specialist equipment such as mini keyboards and trackpads for students that do not have the dexterity or

movement to use conventional ones. Visually Impaired students have a plethora of equipment including braille notes, Perkins brailers, or the Humanware Prodigy and Hearing Impaired students have laptops and Chromebooks. This made the transition to remote learning easier for the LNC as the students already had their own personal IT that was familiar to them to use at home during this period. Students that required coloured overlays changed screen background colours, captions on Google were used in lessons for Hearing Impaired students, and teachers and students used the chat box in Google Classroom for answers and discussion. Google Meet breakout rooms were used by LSAs and students during live lessons if further discussion or differentiation was needed on tasks set.



In order to ensure fairness for our staff the Learning Support Assistants were separated into two teams. Their time was divided between working in key worker school and 'virtually' from home. In key worker school staff were assigned 1-1 to every student. They assisted students accessing their online lessons whilst monitoring them pastorally. When working from home LSAs accessed their normal timetabled lessons. Their notes were shared with the students via Google Docs so that the support was interactive and supportive during lesson time.

Having LSAs in remote lessons enabled us to have an overview of all LNC students and how they were coping with remote learning, any issues could then be identified quickly liaising with teachers to overcome them. Our pastoral care involved weekly video calls or phone calls with each student. LSA mentors were required to make at least weekly contact via emails, and many did video calls to consolidate learning or to just catch up with their mentees. There was access to our school counsellor via video call if lead teachers felt any vulnerable students required this input. The school continued to use our reward



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and credits system for good work and effort via ClassCharts. This is always used at Angmering, and is an excellent platform for both students and parents to see the good work which is being produced. Many LNC staff sent personal postcards home for good work via post. Our headteacher Mr Liley actively encouraged parents to send him work that students were particularly proud of so that they could receive headteacher awards. It was important to us all that hard work and effort was recognised during this difficult time.

Key LNC staff had weekly contact with sixth formers who were transitioning onto university, and we had a weekly 'social' evening where we played fun games for social interaction! The school ran a mock exam period for the Year 11s and sixth form in February. It was arranged for some of the LNC students who require a scribe to come into school to do these 1-1 with an



LSA. This was gratefully received by families as it alleviated the pressure on them at home.

The LNC have continued to run annual reviews remotely for all year groups, and are still continuing with video calls and preparation for all Year 6 students coming to us in September. When students have required new work books, staff have delivered those personally to their doorsteps, and our amazing VI team have delivered embossed diagrammatic work to students for Geography, Maths and

Science. This has continued our holistic approach and support for all students and families. This has definitely been a challenging and difficult time for all and we all look forward to having all students back face to face on the 8th March.

*Natalie Searle
LNC - The Angmering School*

Student Achievements at LNC

- Despite the challenging times, **Lucy King** in Year 13 completed virtual work experience.

She has accepted an offer at Essex University to study Speech and Language Therapy with a year's work experience placement.



- **Louis Saunders** in Year 13 has continued on his path for sporting and academic excellence thus far achieving two A*'s in A level Biology and History. He awaits his A level Geography result and will be going to Sussex University. Louis is still training hard as part of the Boccia UK BC4 squad for the Tokyo Paralympic Games - roll on the Summer!



- **Zoe Ferrigno** in Year 13 has been using an app on her iPad to demonstrate her amazing skills and drawn her favourite F1 drivers - Lando Norris Pierre Gasly and George Russell.



- **Emma Kerney-Hayes** in Year 8 was set a junk challenge over half term by her Mum. Together with her sister Isla they were set the task of using recycling and rubbish to create their very own version of Steyning where they live. The finished photos went to Steyning Museum, The LNC and Blue Peter. Blue Peter replied and asked for more details so that Emma could be nominated for a badge.



WELL DONE to all the students!

Thoughts on a Very Strange Year

Life in our household is never entirely normal at the best of times. I'm the very lucky mum of 3 beautiful children, my eldest is 13 and as yet undiagnosed with inattentive ADHD and ASD traits and then I have my 10 year old twins, Tom, who has Quadriplegic Cerebral Palsy, complex Epilepsy and Cerebral Visual Impairment and Iris, who is neurotypical. I'm used to trying to be supermum. But this year has been something else!

In February last year we were on the holiday of a lifetime – Tom's Make A Wish trip to Florida to see The Muppets at Disney World. We'd not flown since the twins were babes in arms. Make A Wish were absolutely fantastic and hired all the equipment we needed – profiling bed, toilet frame and hoist for our villa at Give Kids The World in Kissimmee, the most incredible wish village just outside Disney World. They also helped me make arrangements for seating support and hoisting for the plane. I spend a happy few weeks planning which parks and which rides we could access with Tom and then on the morning after Storm Dennis we were off to start our trip of a lifetime! The storm had been responsible for thousands of cancelled flights and we weren't even sure we were going to get to leave the UK but we were amazingly fortunate that the wind had dropped by the time our flight was due and we were off! Virgin Atlantic were fantastic and made us feel really welcome and special and although the Eagle hoist didn't show up and a manual lift had to be carried out it was all fine and we settled in for our first ever long flight together.

Florida was absolutely incredible – the most magical week we have ever had

together. We visited Epcot on our first day and rode all sorts of amazing rides giving Tom an absolute thrill. Our experience of theme parks in the UK hasn't been great – pretty much a big fat no to everything for Tom because he can't walk off a ride in an emergency. However, in the USA Disney have an entirely different approach and gave Tom the chance to ride pretty much everything and to allow us to lift him on and off the rides. For a thrill-seeking kid it was just a magical experience and so wonderful for us all to be able to have fun together! We met so many of Tom's favourite characters at Epcot – a highlight being meeting Wreck It Ralph and Vanelope!



Day 2 was the big day for Tom – a chance to see his beloved Muppets at Hollywood Studios! When we turned the corner into the Muppet Courtyard, Tom became so excited that I thought he might fall out of his wheelchair! We watched the 3D Muppet Show many times that day and even got to meet Sweetums as a special surprise.

It was a magical moment for me to see my boy in absolute bliss. To top all that off we got to ride the 2 new Star Wars rides which were mind-blowingly brilliant and Tom is still bragging now that he flew the Millennium Falcon!

The rest of the week was packed with fun and laughter – trips to Walmart to load up on American candy, a chance to try out Taco Bell and Wendy's, trips to Disney's Animal Kingdom, Magic Kingdom, Universal Studios and Universal Islands of Adventure – we just didn't stop all week! Our last day was spent in Sesame Street at Seaworld which was the other part of Tom's wish and he got to party with Elmo



and Cookie Monster and have a spend-up with his holiday money in the Sesame Street shop and get a Super Elmo cape and toy.

While we were in America the news of the new virus that had come out of Wuhan was getting more and more alarming. It had seemed so far away at first but towards the end of our week away, as we stood in the heaving Disney Magic Kingdom we really started to worry about quite how many people we were in contact with. It was even more apparent that things had changed when we got back to the airport and saw everyone wearing masks and temperature scanning units being erected. Within 2 weeks of our return the whole of the UK was in lockdown and the unthinkable had happened – we were in the midst of a global pandemic that you would only previously have seen in sci-fi movies. Talk about emotional whiplash – an absolute pinnacle of joy to crashing fear about keeping my babies safe.

Every family has to make their own decisions about what's right for them and we decided to pull the kids from school the week before formal lockdown happened in March. We also decided to shut the doors to our 2 beloved carers. Whether it be some level of unresolved trauma from their early days in the Trevor Mann Intensive Care Baby Unit or Tom's subsequent diagnosis of severe CP and then later Epilepsy, a fear hit me like a tidal wave that this virus might actually take my boy from us and I couldn't contemplate having him going to school with all the close contacts that would entail with his level of personal care needs. I also had fears that Terry and I might get sick and then who on earth would take on the commitment of caring for Tom? We just didn't want to take any

chances so we shielded him and I took on the significant challenges of homeschooling all 3.

Whilst Tom is bright and eager to learn, he can't yet read so it was down to me to deliver all the work set for Tom and to find innovative ways of recording his work. Thanks to Blatchington Court Trust we managed to get the most amazing computer for the Visually Impaired funded super quickly for Tom which enabled him to use voice to text software to record his work and then scan the work into his computer and have it read back to him

so he could check that it said what he wanted. The days were frantic and each blurred into the next – 3 worried kids to homeschool, one sleep deprived mum with not enough hands to help all 3 kids, worries about getting Tesco delivery slots and enough breadflour and yeast to keep the breadmaker going and ever-increasingly frightening news reports of the devastation the virus was wrecking on the vulnerable.

We pulled together to support our eldest through severe anxiety over the challenges of self-guided learning when ADHD hasn't given the skill set required to handle that challenge, and with the spiralling mental health fall out of feeling overwhelmed, out of their depth and robbed of all confidence.

Eventually summer came and thanks to the Mid Sussex Round Table we managed to get a second hand gantry and portable hoist funded for the garden so we could use our large inflatable hot tub for much needed hydrotherapy to keep Tom moving while away from school physio and for all 3 kids to be able to play together in the sunny garden.

I am incredibly proud of myself and of my hubby Terry for keeping our little family unit safe and sound and for managing



what this year has thrown at us. Little did we know when the kids returned to school in September, that this return was to be short-lived and that we would once again be homeschooling all 3 through another lengthy lockdown but this time round I had more confidence, a system in place to try to keep everyone organised and a bit more structured input from the schools.

I sit here on the sofa on my 3rd school day without the kids and my ears are almost ringing with the silence that this house hasn't heard in a year. I was desperate for a break but now I miss them! By my side is a small but beautiful buddy who has joined us thanks to lockdown – our rescue dog Winnie! I'd always said no to a dog for fear of the additional work for me but seeing the kids struggle with isolation in lockdown made me reconsider and in September Winnie came to join our family! I haven't regretted it for a single moment – she's got my eldest through some tough emotions and continues to provide a feeling of safety by being a night time companion.



She has got Iris through by providing kisses and cuddles and always being up for playtime and Tom just adores her and she adores him. For a dog that spend 14 hard months on the streets of Romania and who came to us having been badly beaten and having a repaired broken leg to show for it, Winnie has taken to family life like a duck to water. She is patient and accepting of Tom's more uncoordinated strokes and pets and she rides on the front of his powerchair like a wooden mermaid on the stern of a ship! She is quite amazing and we all love her dearly.

Now it's just me and her during the day, waiting for them all to get back home for cuddles! This week I'm going to have coffee in the park for the first time with my mummy since before Christmas and I can't wait. It's not 'business as usual' yet and probably won't be for a long time yet but I'm relishing the return of some aspects of normal life hugely.

Maria Barnes

QM Studios

QM Studios in Horsham run an extremely popular Outreach Program and deliver a wide range of music based workshops for those with disabilities, additional needs and other vulnerable groups in our local community.

For the past year, the studio's outreach team have had to adapt their sessions to make them accessible remotely, throughout lockdown. The team have successfully delivered a wide range of sessions including: electronic music making workshops, singalong sessions, interactive drum workshops, vocal therapy workshops, jam sessions and many more. These weekly sessions have been incredibly well received, especially as many of these individuals have been shielding and are missing regular contact with others. Not only have they provided a welcome distraction to the lonely reality of lockdown, they have ensured a

regular video call from a friendly, familiar face accompanied by a fun and interactive workshop.



The workshops encourage learning new skills, getting involved and having a go, promoting self-confidence and combatting loneliness, all in a relaxed, friendly, sociable and fun environment.

If you, or anyone you know would benefit from one of our sessions, then please do not hesitate to email us:

info@qmstudios.co.uk

We currently offer group and one to one sessions through Zoom.

You can keep up to date with studio's outreach work on their Facebook Page -

www.facebook.com/qmstudioshorsham

Adam Gellibrand

Tales Upon an Extraordinary Time

In many different ways for all of us, this has been a very strange time. Plans we'd made and our life's routines went 'out of the window'. For some of you, life's been additionally and particularly difficult.

By comparison I've been quite fortunate. The main effect on me has been losing the various workshops I'd set up throughout the year including of course 'Lizzie's Craft Club' and 'Wheely Wonders'!

Some of you will know my Storytelling and 'Lifting Poetry off the Page' as part of my 'Freedom Through Fun' workshops. Memorable moments as groups of children and young people use words, signing, musical instruments, fabrics and wonderful imaginations to create their tales. Painting pictures of alien worlds, outer space, fantasies of castles and jungles, journeys through time, Antarctica, pirates, oceans, seas or deep dark underground caves. Magical, mysterious moments!

When the pandemic arrived and I was just at home, I thought about how I could use my imagination and still continue to be 'with' others but in a different way. This is now a digital age when life as we once knew it continues but online including YouTube, so I decided to create my own storytelling channel. YouTube is of the time and popular with all ages. Initially creating it was a challenge. Making a video for the first time, uploading onto a video editing suite then onto 'YouTube' but when I saw [chrisnorththestoryteller](http://www.chrisnorththestoryteller.com) for the first time as a live channel I thought "I've done it"!

Stories and tales cover a whole range of genres and themes. Myths and legends; fairy tales; stories based on historical fact; tailor made tales; fables. So what's on my channel? My first videos were of fables by Aesop who told them 2000 years ago. 'The Peacock's Complaint'; 'The Lion and the Mouse'; then Oscar Wilde's 'The Selfish Giant'. These fables were written with a moral message. Next I used my story telling boxes using cards which I pulled out to improvise a story – Who? Where?

What? When? Also included is the Folk Tale of 'The Bosham Bell' which can still be heard ringing out on a stormy night below the waters! In conjunction with an exhibition at The Novium Museum in Chichester about North Bersted's 'Mystery Warrior', I wrote two stories about him. I wrote stories requested by children. Travels to the Moon for Sam and Fairy Doors for Freya. Another story is about times when we feel strange or different. For this I wrote about two young aliens from a Jupiter moon who visited a school and how it felt to them and also to their class. Two Christmas stories are based on 'Twas the Night Before Christmas' as well as two magic shows with Charlie the Chimp. Finally some Romany traveller tales including one about a traveller family's horse called Amber and seen through her eyes.



NOW I'm really keen to hear from you (families, children, classes in schools) for your ideas for a story. Would you like me to use costumes? Puppets? Some poems? Music and songs? If you have any ideas or requests, please go to www.chrisnorththestoryteller.com and under the heading 'Contact' leave your story request where it says 'Comment.'

My aim is to create stories which are fun and engaging. Let me know what you'd like and in advance to all of you a huge THANK YOU!!! We have very many things now to look forward to, not only stories on YouTube. TOGETHER we can all create our own different stories at Applefield!

*Together we can be in the story,
Be anyone we want to be.
Knights in a castle,
Pirates by the sea.
Aliens from outer space,
Or performing in the 'Greatest Show'.
So very soon to Applefield
We'll all go,go,go,go.....GO!!!!*

I can't wait to see you all again!!

Chris North

Lizzie in Lockdown

At the beginning of 2020, I published a Wellspring Information Booklet and a leaflet about Wheely Wonders to share the work that we do with more families. We were really looking forward to seeing everyone in the spring. In February and March I met students at the University of Chichester, talking about My Educational Journey and encouraging them to be inclusive in their teaching. Some of them were very keen to volunteer at Wheely Wonders.



As the news about Covid got more worrying, I reluctantly decided to stop going in to work as a teaching assistant two weeks ahead of the official lockdown. I was also really sad that I had to shut down my Spring Craft Club which had started so well with some lovely new children. Our Wheely Wonders dates also had to be cancelled.

At first it just felt as if I was on an extended Easter holiday and the weather was incredible! We felt so lucky to live at Applefield with so much space and fresh air so having to stay at home was not bad at all! I recorded a video message for the Wellspring website sharing news about updates to the website and over the course of the spring and summer I added photos and films, featuring our lambs being born and chicks hatching. I really missed working with children at school and here, but I packed up Easter crafts for the children who missed the rest of the Craft Club, and also posted packs to friends around the country! I also made Halloween and Christmas craft packs which I sold locally in aid of Wellspring.



I stopped having my weekly physio last March, but I continued to do my daily respiratory exercises with several tools for keeping my airways open. A lockdown activity I really enjoyed was singing with Gareth Malone's Great British Home Chorus on YouTube; the warm up exercises were another great way to give my lungs a good work out. I kept a daily record of my oxygen saturation and heart rate using my Oximeter which reassured me that I was keeping my levels stable.



In May, I watched a Channel 4 news report about the work of some of the incredible staff who were working to treat very unwell patients with Covid-19 in ICU at the Royal Brompton Hospital in London who help me to keep strong and healthy with my BREAS ventilator I use overnight. The team also looked after Alexandra (my sister who also had

CMD and died in 2015) and some of my friends are patients too.

I had started swimming in our small outdoor pool at the end of April so I decided that I would take on my **Swimming Challenge** to raise money to help the hospital get the vital equipment they need to help patients with Coronavirus. I have always loved being in warm water and hydrotherapy is a great help for people with Muscular Dystrophy, so it was a perfect way to get my daily exercise while I could only see my physios on Zoom! Our pool has moved house with us 3 times and is now part of our smallholding; we love swimming with all our animals looking at us!

Every day (weather permitting), I did my hydrotherapy exercises which I made up myself during my half hour in our pool. These really helped me keep my body healthy, especially my respiratory system! I was inspired by a little girl called Carmela who, like me has Congenital Muscular Dystrophy (www.carmelasstanduptomusculardystrophy.co.uk)

- she shows such strength and determination in her daily physio! I decided to do 100 swims and started off with an initial target of £150 – this was smashed in 48 hours so I was able to raise the bar quickly and with so many friends and family supporting me, it was incredible watching the money coming in!

The summer weather really helped so I was able to swim practically every day (even in a rain storm and a gale!) and I reached Swim 100 on 31st August. We had family visiting for the bank holiday weekend so it was extremely motivating to have "cheering crowds" as I crossed the finishing line with an incredible total of £3320!

This would buy one of 20 IntelliSpace Critical Care and Anaesthesia (ICCA) systems needed to centralise the clinical data of a critically ill patient through connected technology. These help to better manage patient deterioration and aid faster and more accurate treatment.

I was so surprised and delighted to find out on 23rd June that the Prime Minister had chosen me for a **Point of Light Award** for my Swimming Challenge, and work for Wellspring West Sussex which I have been involved with since 1999. I felt very honoured to receive this Award for doing things that I love so much! It was very exciting to be interviewed for Spirit FM and talk live on BBC Sussex about the award.

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It was wonderful to be reunited with my brother and family in June as well as being able to see other people again. In August, I met up with Jen and Sam for a socially distanced lunch in our field and we decided it was a safe time to have a **Wheely Wonders Wellbeing Day** funded by The Headley Foundation. A couple of weeks later it was wonderful to see familiar smiling faces arriving; many not having been away from home since March. It was a fantastic day and despite the pouring rain everybody was so cheerful and made beautiful, bright pipe cleaner flowers as well as other Forest School crafts and toasting marshmallows on the campfire.



In September, I had to cut my swimming season short as my father was unwell and underwent emergency surgery for a bowel tumour. We were relieved to receive a phone call from the surgeon to tell us he had removed it successfully, then later in the afternoon a text from Daddy announcing "I'm alive"! We were well supported at home by family and friends and some agency carers, for me and for Daddy. It was quite a long recovery through to mid-November as Daddy's scar erupted twice, resulting in two more stays in hospital.

Since July, I have been working with Social Services to have a working hoist and tracking from my bedroom to the bathroom. This has been a long process, getting a profiling bed and a sling that is the right size for me and was extra complicated as I am a child size but under Adult Services so everything has to go through extra "hoops" and "red tape"! In January the new tracking was installed and I finally got my access sling. Having never been hoisted before, this was a huge learning curve for me and my parents and we have had many frustrating and funny moments with Velcro belts getting stuck to woolly jumpers, straps getting twisted and the hoist trying to pick up my whole



Permobil when we had failed to get my chest belt out of the way! It is now a normal part of my day and I know that once I can start having more PAs it will make everything much easier.

When school started in September, I was very pleased that my Head arranged for me to continue teaching from home via Microsoft Teams. My work PA continued supporting me with Year 5 and 6 children in school who I worked with on reading comprehension. I have worked with Year 5 key worker children through the winter lockdown and one of the other

TAs in school has been helping me as it wasn't safe for my PA to be there. I really enjoy online teaching and the children have adapted well to a different style of working. I am hoping I can return to school after I have had my second vaccination; I think I will find it quite strange but I am also looking forward to being away from my computer screen!

As I write this, there is hope on the horizon as we watch spring bursting out everywhere and our daily walks feel a bit warmer! We have got to know so many of our neighbours through the year which has been a real bonus. We also have Wheely Wonders dates on the calendar for the end of April! I have kept up my work with the University of Chichester and have found more students who are eager to come and join in the fun. Jen and I are so excited about welcoming families once again; I have been keeping in touch with some of them via Facebook all year. It has been fabulous to see how, despite the difficulties children have been able to achieve great things! I am also looking forward to getting back in the pool again

and my current project is researching pool hoists! My dream is to have a telescopic roof over the pool so I can continue my hydrotherapy for longer!

Lizzie Baily

lizzie@wellspringwestsussex.org.uk

As well as running Wheely Wonders with me, Jen runs Little Wonders Farm Adventures, a parent and toddler group here at Applefield on term time Wednesday mornings 9.30 – 11.30am.

During school holidays and half terms, Woodland Wonders run themed Forest School mornings and afternoons. Birthday parties are also available.



Lizzie's Craft Club normally runs during term time on Saturday afternoons from 2.30 4pm in my accessible art studio at Applefield. I welcome children of primary school age of all abilities. Each course follows a theme and children take home all crafts at the end of term. All materials and refreshments are provided.

We are always looking for new sources of funding so we can continue to provide Wheely Wonders days and places at Lizzie's Craft Club free of charge. If you have fundraising ideas let us know!

Please get in touch with us if you would like any more information or would like to book a special day for your family and friends or group! Contact Jen - Tel: **07786 368800**

Email: woodlandwondersforestschool@gmail.com
www.woodlandwondersforestschool.co.uk
www.facebook.com/woodlandwondersforestschool

www.lizziebaily.com/craftclubintro.htm
www.facebook.com/LizziesCraftClub

Student Life

In 2019 Peter Langton told Wellspring about his first year at university. I've been in touch with Peter and his twin brother Jimmy to find out how the past year has been for them.

Lizzie Bailey

How was the start of your second year at university?

The beginning of my first year on the degree (second year at Solent), I was ready to face hard modules and to pass all to go on to my second year on the degree. I lived in the Uni accommodation and when my wonderful PA at the time could not do any particular day, I would go home the night before and receive PA help at home the next morning and go by train to Uni. I really struggled to get more than one PA at that time, so had to compromise between home and Uni together, but it all worked out in the best way possible.

How were you affected at the start of the pandemic?

I didn't pay much attention to it until late February, when it was heard to be quite serious and life-threatening, and at that point, it started to come into the UK.

I was hoping the pandemic would stop us from studying, but how wrong I was! It took the university 2 weeks to put everything online, however as we had already started our assignments, I just got on with it, and had some video calls alongside it with lecturers and sport staff to catch up and check on the work.

I did a bit of uni work each day, and by the end of the day before the deadline, it all came together and it got passed! So that helped me and others to not panic and calmly go through a bit each day.

What was the first lockdown like for you and your family/carers?

My Nan Irene passed away aged 92 in hospital (not COVID related) 1 week before the first lockdown was put in place. I like to believe it was a blessing in disguise as if she were still alive at the time of lockdown starting, we wouldn't have been able to see her, so at least that was of comfort but it was heart breaking that we could not give her the send-off she wanted and that we couldn't get everyone to come to her burial but at least we have a memorial service to look forward to for everyone else once the virus has been fully kept under control.



With regards to carers, we had a discussion and decided that as dad were to be working from home, and mum needing family support following Nan's death, we kept the PA's safe and of course us safe as I was, and still am, of high risk. As dad and mum were home, they did our personal care and everything else that the carers would've done. We brought the PAs back in July, after the restrictions were lifted, and unfortunately due to the pandemic opening their eyes and seeing what could be their future, most of them sadly resigned. We then used the rest of July and August before the academic year started to get new staff in.

How were your studies affected?

My studies were only affected in my second year (this academic year - 2020-21) as it was harder to learn online... if only the wifi behaved itself! It was easier in the first lockdown, mainly because we knew what to do and we could just get on with it, but this time, we started from scratch and had to learn, look and listen, which to a deaf student is already difficult when trying to hear the lecturer with

background noises from different cameras... thank god for that mute button and pre-recorded videos!

I also had a scribe from Randstad but she left at Christmas and it was a big struggle getting in contact with them for another scribe... but it worked out in the end, after 2 months!! I have to mention and thank the Access Solent staff for sorting that out their end for me so I could concentrate on my studies. TIP: If you are having problems, don't try and sort it out, give it to the relevant people, as your studies are more important and the studies will set you up for life.

The studies now are going well and it's the next best thing. I personally feel for the staff who have had to be put under pressure to deal with the unknown and when staff left (due to saving money as a result of COVID) it was a struggle to see what the quality of teaching would be like, but the staff coped with it and are thriving! I just can't wait now to be able to get out and start getting back to normality again.

Were you able to get out more after the first lockdown ended or did you carry on shielding?

As advised by the government, I shielded until 1st August. After that date, I went out four times within my local area; three of them I met up with the same person (in this case, my best mate) to limit the number of people I interacted with to prevent either of us getting COVID 19, and the other time to have lunch in my local park on my own.

What have you found difficult over the past year?

Not being able to live our normal day-to-day lives, as it was an out of body experience to stay in for what has been almost a year since the pandemic started in the UK. It is been very difficult not knowing when the virus was going to strike among your family and friends, but at least we have had technology to keep in contact with one another during those difficult times.

How have you managed to keep active during lockdown?

During the first lockdown, I did get some resistant bands free of charge from WheelPower and stayed fit upper body wise. I also switched from electric chair to manual to use around the house to keep the muscles going too. I did a few videos for BluePrint 22 to help others keep fit and keep their mental health at bay (on their Facebook page).

What have been your best moments from the last year?

Definitely staying at home and spending time with my immediate family which we never really got the chance to before, especially for five months. I love my family, but as much as you love them, it gets to a point when they annoy you! Especially when people say that we need to get out more.... (but of course we couldn't!). I have loved telling people to back off (at least that's what I think I said!) and to follow government guidelines to the letter and to criticise anyone who had not followed the rules as that was my pet hate, so you can imagine how I felt when I saw the photos of beaches being full and other people in the media or in the famous bracket breaking the rules.

Have you achieved any goals/personal projects during the lockdowns?

I've achieved passing a mental health awareness course for sport and physical activity from UK Coaching, and of course most of my assignments from uni. I also found time to make, edit and publish a few videos for Solent Boccia on my Instagram account (@p_langton1997) doing singalongs for charity. At the end of 2020 I did "A reflection of 2020 – a Saturday Night Live-inspired sketch" which is on YouTube here:

www.youtube.com/watch?v=xM9fTXg7rLc

What are you most looking forward to doing when you are able?

Getting back to physical contact with people and to be able to see people in the flesh, rather than through a screen. I have been longing

for that to happen and at the moment that seems to be within touching distance. I might have jinxed it now but we will see!

I did do a bit of Boccia on the side as uni was the main priority. I cannot wait to get

back on court playing again as an individual and also as a team; of whom I am captain of and is called Solent Boccia'.

Anything else you would like to say?!

I'd like to give a huge thank you to all front-line staff and key workers that have done everything for us over the last year and my generation will most definitely not forget what you have done for us. I really found the 'clap for carers' events very emotional and fitting, as we couldn't support them in the normal way that we would do, and it was such a lovely thing to be able to do with your neighbours. It really helped in my area (there's more elderly and vulnerable people here) and it boosted their morale to keep going and to have those bits of time to talk to people on your road.

I would like to thank those who have not allowed this virus to spread and followed government guidelines. We have had to stop ourselves from living our normal day-to-day lives, hugging people that we care about deeply and all of our plans that we were going to do got cancelled to keep this virus at bay.



*Peter Langton
(Turn over for Jimmy's reply!)*

It's been a year since the start of the COVID-19 pandemic and in that time I've only spent about 2 months in college.

In the last lockdown, I wasn't able to go to college.

Since October, I've gone back to face-to-face learning. I'm enjoying being back as it means I get out of the house! Over this time, I've also had multiple carers leave, including the ones who supported me with college. This has meant mum and dad are having to support me a lot more, and while I love them, I'm a young man in my early 20's and want my space from them too!

Lockdown learning became difficult for me, I'd moved onto a new unit at college but we weren't sure how it was going to work with the technology I use and the support I need. I've been back 2 weeks now and feel like I'm making progress.

I'm currently doing Level 3 Media at Chichester College and I'm hoping to return next year to study for my Higher National Diploma (HND) in Journalism, as long as the needed support can be put in place. In the long run I want to be a sports writer and have even had some of my interviews with footballers published online already.



If I could change one thing around my education to make it better for me, I would be able to get support on my days off, as even though I'm not in college I'm still completing work. It's important to me that support is available and put in place when I need it, rather than when they can do it.

Having support when I'm not in college will improve the standard of my work, and that is something that's key for my career prospects as it is evidence for future employers.

Jimmy Langton

Harry's Walking Challenge

Harry Ragless aged 7 has Spina Bifida. He has been coming to Wheely Wonders days since the start in 2017. I caught up with Harry's mum Selina to find out about how the past year has been for Harry and his family.

Lizzie Bailly

We found the first lockdown very difficult being shut off from our loved ones and home schooling with a 2 year old was very difficult too as I couldn't give Harry the attention he needed.

When Harry saw Captain Tom with his frame, Harry said I have a frame like that...why don't we walk to raise money too! By walking as far and as much as his legs could manage daily with his KayeWalker around our estate for 2 months, Harry raised £6695 for NHS charities.

The main challenges were that Harry tires easily and often wants to give up. He has recently been also diagnosed with Tethered Cord Syndrome and has been experiencing pain so this was great physio and exercise! We have received letters and donations in the post from as far away as Scotland which has resulted in Harry writing to an 84 year old lady regularly.

Last year we also wanted to raise money for a power add on for Harry's wheelchair. When we raised money for his Trike I organised a

fun day where lots of local businesses offered their services and goods for free at our fun day as well as donating prizes to raffle off. This wasn't possible for me to do this time, so I managed to contact many local businesses who kindly offered vouchers for meals, tattoos, items again to auction off on a page I had set up. The person with the highest bid at the end time would win. We managed to raise £7000 in around 8 weeks or less! We then managed to get Harry a new wheelchair as well as the power add on! This has been life changing for us, giving us and Harry so much more freedom to explore. Harry always wanted us to push him in his chair but now he can be independent!



Harry returned to school at the end of January as home schooling was quite tough...he needed more support with learning but he absolutely loves being back!

We love attending Wheely Wonders and cannot wait to be back!

Selina Ragless

Moving House in Lockdown

Hi, I'm Karen, a single mum to 7.5 year old triplets – Loxie, Logan and Jaxon.

Logan was diagnosed with Duchenne Muscular Dystrophy in February 2020. I was living in Cambridgeshire with no support and, following the diagnosis, I knew I would need emotional, mental and practical help. My best friend lives in Selsey hence the decision to move here. When Covid started last year, thankfully my wonderful best friend Ali packed a suitcase, waved goodbye to her husband and came to Cambridgeshire to lockdown with us. Ali was with us for 8 weeks and we all left to come to Selsey – I rented a house whilst our property purchase was completing.

As the weather was so lovely, the children spent hours in the garden (in the newly purchased hot tub) and we took a daily 1 hour walk together.

The biggest challenge in moving house has been the legal aspect. The first house I was planning on purchasing fell through in September so the whole process had to commence again. It's only now in March 2021 that we can finally move to our new home.

The support in West Sussex has been amazing. I always say we have an army of professionals supporting us. As a family we have a community nurse, a specialist nurse, a disability social worker, a counsellor, support from The Snowdrop Trust, support from Chestnut Tree House Children's Hospice, 2 occupational therapists and a physio. The Social Worker has been amazing and has arranged some Personal Assistant hours to support the family. She has also contacted 2 charities who have provided Logan with an Apple iPad and stylus for use in school.

Along with my best friend Ali and her husband Bob, my sister has recently sold her house and relocated her life from Watford to Selsey to support us as a family.

I'm so grateful to Seal Primary Academy for supporting me through the lockdowns. At the beginning of the year, I was struggling mentally to deal with 3 children at home (alone) AND homeschooling. Thankfully, the school offered all 3 children a full time place at school.

The best things about our new life are that I've got my sister and best friend within

minutes now. I'm building a small village to help me raise my children and I'm coping so much better now.

When restrictions are eased I'm looking forward to hugging my older son Toby (26). He lives near Watford and it will be amazing to be able to see him again. I bought a caravan last year and we managed a few weekends away which we

all loved. I could drink a hot cup of coffee without being interrupted by the trio every few minutes. They ran off and found new friends. I'd like to do more trips away this year. I'd also like to be able to meet friends obviously.

Life has certainly thrown me a curve ball. Logan's diagnosis rocked my world and I grieved for the life that was no longer what I had planned. However, I'm now far more positive and keep telling myself that no one's life is guaranteed. This is Logan's life and, whilst it's going to get really tough for him, it can also be a good life. I don't look too far into the future and I try to live with today.



Karen Lightly

PACSO Covid Response

PACSO is a local charity that supports children with disabilities aged 0-25 and their families in the Chichester and Arun districts of West Sussex. We offer a range of respite activities and fun events for the whole family to enjoy!

2020 was a tough year for everyone and not least for small charities like ours. I am so proud to be able to share with you the rollercoaster journey that our little charity has been on over the last 12 months, as I am sure that many of you can relate to the highs, lows and constant changes in direction that have required us all to dig deep, stay strong and adapt. After all, what choice did we have?

On 17th March 2020, we made the difficult decision to temporarily stop all front-line respite services with immediate effect. This decision was not made lightly, and it left our team with heavy hearts, knowing that for so many families PACSO is a real lifeline and makes family life more enjoyable and more manageable.

With this in mind, the team worked quickly to mobilise a whole new set of services to support children, young people and their families. Setting up a brand-new offer was a real learning curve and required a huge amount of creativity and resilience from the whole team. I don't think we had even heard of Zoom back then, which is hard to believe now! I am proud to say that Team PACSO developed a range of services to keep our families in touch with our playworkers and their friends.

Services included:

- 1:1 weekly video calls with our playworkers
- Group weekly video calls with our playworkers and PACSO friends
- Sensory and activity packs delivered to children's doorsteps
- Handwritten letters from playworkers to children to let them know that we missed them
- Personalised videos of children's favourite songs/stories/games etc

- A PACSO YouTube channel so that children could listen to stories, join in with quizzes etc from the safety of their homes

Whilst we weren't able to come together face to face, we were able to maintain a sense of community and belonging. The children looked forward to seeing our playworkers and their friends each week and some groups got really creative with weekly themes and dressing up!



As summer approached, we hit a new phase and were able to deliver a 'blended offer' of our 4 week virtual summer playscheme, alongside some socially distanced park meets with individual families. Our playscheme included dance and drama workshops, arts and crafts, sensory play, singing and so

much more. Meanwhile, our playworkers were busy meeting families for water fights, outdoor games and messy play in outdoor spaces across Chichester and Bognor.

Autumn soon arrived and so came phase 3 of the PACSO offer. We were delighted to be able to deliver small group respite activities that felt a bit more like 'normal.' The children and young people enjoyed a range of outdoor activities including forest school, horse riding and active club. We braved the cold right up until December and I have never been so grateful for fleece lined leggings! We even managed to squeeze in some wonderful trips to Paulton's Park, Marwell Zoo and Fisher's Farm before lockdown hit for a



second time. Whilst we could continue to offer respite services under government guidelines, it became ever more challenging to find venues to run our services from. We are exceptionally grateful to Lavant House for allowing us to convert office space into a wonderful play room to run PACSO sessions from.

When lockdown 3 hit, PACSO phase 4 began. The mood at this point was sombre, and although we could legally run group sessions,

it felt unsafe and irresponsible to do so. At this stage we decided to provide 1:1 sessions only. Our playworkers met children and young people 1:1 in parks, at their doorsteps and in our playroom to provide respite for families. In an average week during this time would deliver:

- 9 family sessions in our playroom
- 7 1:1 respite sessions in the playroom
- 7 park meets, 3 Little PACSO meets
- 2 Zoom youth

sessions

- 1 parent support group via Zoom
- 1 woodland walk
- 1 beach walk
- 1 trip to feed the ducks



What a journey it has been! Amongst all of this there was the added concerns of PPE, vaccinations, lateral flow tests and so much more. The core team at PACSO were very lucky and incredibly grateful to be in the first wave of frontline professionals to be vaccinated against Covid-19, under the 'Health and Social Care' tier.

Sadly, this came too late for a much-loved member of our team who contracted the virus and, despite excellent care at Guys and St Thomas' Hospital, London, lost their battle on 26th February 2021.



The whole PACSO

community are deeply saddened by our loss. Vinit will always be remembered as a kind and gentle soul who loved his work with the children.

As we look ahead to the future, we see a glimmer of hope amongst the rain clouds. We are busy making preparations to welcome back small groups of children over the Easter Holidays and have released our Playscheme 2021 dates. We hope to welcome the PACSO children across 4 weeks of summer fun in 'a land far far away, of fantasy and fairy tale!'

If any families would like to become members of PACSO then please do contact us on the details set out below.

Emma Kennedy

PACSO CEO with Play Lead

Tel: 01243 533353

Email: admin@pacso.org.uk

www.pacso.org.uk



CYCALL

Lizzie has very kindly invited me to share an update on CYCALL - an inclusive cycling project based at Brooklands Park, Worthing. We have 20 adapted trikes for adults and children which include a wheelchair transporter, a hand propelled trike and a 4 seater side by side trike. Our sessions run on a Friday and a Saturday from May until mid-September (weather permitting). We also take weekday bookings from groups, organisations and schools. Brooklands Park has a purpose laid safety cycle track, a Changing Places Toilet and Disabled Parking. CYCALL is run by a team of enthusiastic volunteers.

2020 was a challenging year for all and our sessions were very 'stop-start'. We implemented COVID 19 safety procedures which allowed us to have a glorious August welcoming many families to our sessions. As we move forward, we continue to ensure that we

are taking precautions which will allow us to resume our sessions on Friday April 2nd. We are also delighted that we will be a Ping! Community Table Tennis champion. The wheelchair accessible table will be available for all users of the park during CYCALL sessions. We aim to make our sessions about 'more than just pedalling'. They are a valuable opportunity for social interaction and we also provide outdoor games such as Jenga, Connect 4 and sensory toys.



If you would like to book a session please call Martine on **07784 918122** or Email: cycallworthing@gmail.com Specification of our bikes and photos which can be used for a social story are available on our new website

www.cycall.info

Thank you to Lizzie and Wellspring for your continued support!

Martine Walters

Southern Mobility Vehicles

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The next edition will be
Celebrating Diversity

If you would like to contribute any articles or letters to this edition, please send or e-mail to us by 31st August 2021

Printed by Instant Print www.instantprint.co.uk
Typeset and designed by Lizzie Baily:
lizzie@wellspringwestsussex.org.uk

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