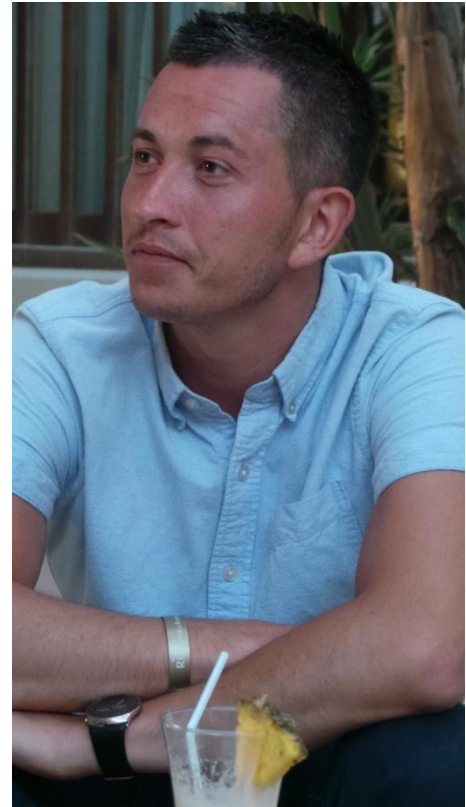


The Stroke

At 29, Chris was a fit and healthy young man, he had a physical job as a carpenter, played football 3 times a week and could run a half marathon with no training in less than 2 hours.

April 21st 2017; Chris got up and out of bed at 6:30am, and I remember these next moments of our lives like they were 2 minutes ago.

Chris was in the bathroom, and I could hear banging, I didn't know what it was, but I called out to him, there was no response, next thing I know, Chris is using the wall to hold himself up and as he enters the room, I can see something is not right. He tries to speak. Nothing comes out. I jumped up and pulled him to sit on the bed and looked at him straight in the face to ask him what happened. Nothing... I raised his right arm, and it dropped, no control. I just said: 'you're having a stroke'. I called 999. I remember feeling like they asked me so many questions and made me repeat my address twice, everything was in slow motion.



The ambulance took maybe 10minutes to arrive. It felt like a lifetime. I just wanted help...now.

Chris was rushed to hospital on blue lights and when I look back on it now, his treatment was quick. He had had an MRI and was on a stroke ward by 11am.

We were told that Chris had had a full Left MCA (Middle Cerebral artery) Stroke that had affected a third of his brain.

We didn't know for a while what long term deficits Chris had suffered. But from the beginning, it was clear that his communication was severely affected. We laugh about it now because I remember the consultant asking him if he knew who the Prime Minister was, and he replied 'Yep' with a coy smile. – I mean, of course he did, and he didn't ask him to name her!

(I also now know what that banging was coming from the bathroom, - he was trying to turn the shower on and his arm wouldn't work so he was leaning on the shower screen that was in turn banging the toilet cistern)

The Treatment

It was a Friday when Chris had his stroke so we were told that he wouldn't get to see a consultant, get any tests or see any type of therapist until Monday. 3 days. 3 days of not knowing what to do, what was wrong, how this had happened. **How can a '24/7' service be offering Monday to Friday care? (this is my biggest question of all, and I feel it applies to a lot of experiences)**

It was stressful, I had so many questions. There were leaflets in the family room. I had so much to learn, and I did. I researched. I learned. I started to learn about what sections of the brain did what. But what if I didn't have access to the internet? No one could give me any advice. Just 'be patient'.

It turned out Chris had both areas of his brain connected to communication affected by the stroke. He was - and still is - unable to read and write. He didn't have any language. It wasn't that it was in there and he couldn't say it. The pathway to the information was just gone, but it was about finding a new way back to the information. His physicality was not affected as these areas were on the other side of the brain. So, he had a disability that could not be seen. A lot of people on the ward would ask why he was there. (Especially because he was also the youngest by far). I think one day it took me 5 minutes to work out he was asking me to wait there until he came back from the loo! (We make an amazing charades and pictictionary team now!)

The Recovery



Chris was home within two weeks. He wasn't to be left alone as we still didn't know what had caused the stroke and he was still high risk of recurrent stroke.

With the help of a Speech and Language Therapist (SALT) from our local Community Stroke Rehab Team (CSRT) it was concluded that he had Global Aphasia – speech, language and communication difficulties.

He had had physio and Occupational Therapy (OT) assessments at the hospital. I recall crying – a lot - when the OT rang me to tell me he was coming home. She said he was safe, having done a few tests in the hospital to determine his ability to carry out 'day to day' tasks. I was scared. I didn't know how I was going to support him. I

was scared it was going to happen again. How could I? I was only 28 myself. I felt like he would have been safer in the hospital. There were so many unknowns. Luckily, I was given 3 months off my full-time job, so that was one less worry to add our situation.

We were contacted by the Stroke Association, who came and visited us, and told us how they might be able to support us. We had a visit a week for the first few weeks, and gradually that wore off and we were finding less and less support, when actually that was when we needed it most. Chris' Speech and Language Therapist Hilary and the SALT team though

were another level, we couldn't have done any of this without them. They visited almost every day at the beginning and carried on supporting us for over a year after Chris had the stroke. They would come, do their thing for around an hour and then Chris would need a rest. I couldn't believe how lucky we were to have Hilary and the team supporting us through the NHS. They helped us find the fun in all of this and we had some laughs too, it wasn't all serious.

As time went on, each day was a new experience, a new word a new way of communicating, and a newfound patience for me. It is important for someone with aphasia to have someone who waits for them to find their words before even trying to help them. That is what the team helped me to understand as well. He was literally unable to say what he was thinking and couldn't write it down either!

Chris slept, a lot. Brain injury causes a lot of fatigue, and it was really important for his recovery and therapy. He had so many new feelings, and sensations and I had so many questions. Chris had trouble controlling his emotions, and as a 'lads' lad' he was really struggling because he kept crying. He said he wasn't sad, but he couldn't stop. It was very overwhelming for us both, but Chris was really starting to realise he was a different person, he had more barriers now, he had new anxiety, and we felt like there wasn't anyone out there to ask our questions to and to talk to. If we could have had better mental health support, I think our journey would have been less bumpy. Chris was scared - naturally. So was I! I would be lying if I said I hadn't thought about walking away at some points. He even kept telling me it was OK to leave because he felt like he was a different person to the person I married. (All I could think was that I was lucky to have such a caring and considerate husband, one that knew it was still so important for me to have time to relax and be me)

The Cause

We had many appointments to attend and tests to figure out why this happened. There was a suspicion Chris had PFO (Patent Foramen Ovale – a hole between the chambers of the heart). He had a 'Bubble Echo'. I waited anxiously in the waiting room, not sure what I was actually hoping for from this test! When the cardiologist came out to get me, he said straight away they concluded Chris DID have PFO. Chris was indifferent at the time, but I knew that it would give him relief in the future knowing that there was a reason this awful thing could have happened to him. I was relieved. We had an answer. This helped us to recognise that a small clot had passed through the PFO and had got into the wrong side of his heart and passed straight to his brain instead of being processed by the lungs.



PFO is something that you can be born with and live with -without knowing - and it could be fixed. Little did we know, because then we were hit with:

“the NHS doesn’t do this routine operation any more as they can’t prove it is related to anything significant health wise”.

So that was it, it was time for me to fight. And I did. I wrote to Huw Merriman (our local MP) to get some support. They were helpful, but East Sussex Healthcare Trust were still not prepared to offer Chris the operation to fix it. So, his consultant referred him to a specialist at Guy’s and St Thomas’. We had to meet him, and he was to put Chris’ case to the panel to decide whether it was worth it. We found out in November that the panel had approved the operation, and he was being booked

in. He got the operation in January 2018. All was well...

More to come

In 2019, Chris had some new symptoms after visiting the gym. He was having a TIA (transient ischaemic attack) He waited to get medical attention because everything he had been experiencing over the last two years, all these new sensations he was having, he was told that they were normal for stroke survivors. He called me at work and said he was waiting in A & E (his communication was still difficult to explain to doctors what was going on). I got there a few hours later. (Something I still cannot get out of my head). I communicated to the doctor that he was having NEW weakness in his arm and leg, and it was more profound than that of the weakness he experienced in his first stroke. The words the doctor said to me resonate in my head regularly:

“YOU should have got here sooner, then we would have got him examined quicker and got him straight to the stroke unit!”

We were devastated. Chris had weakness in his arm and was limping. My heart was breaking for him. We were just getting past the initial shock of the first. We did feel broken after that. We both had given everything, this was a blow to him, to us and to his recovery.

A few days, and more tests, he was coming home. They couldn’t explain what had happened, but we had to take a breath and recoup. The CSRT revisited us and suggested a place that we had never heard of before – AVANTI (Acquired Brain Injury). Honestly at this point we would take anything we could get support wise.

Chris got the referral and was able to and have his initial meeting. He went for a whole day, and I will never forget his attitude change after his first day there. They made him feel 'normal'. He had access to a SALT, Physio, Personal Trainer and Therapy. On top of that they were offering him activities with other people who had ABI (acquired brain injury). He felt supported, listened to and like he was able to do things he wouldn't have tried before. They have continued their support throughout 2020 to present and I couldn't be more thankful to them for their amazing efforts and opportunities they offer to people with ABI. I honestly think this should have been offered in the first instance from day one and should be available to more people. I know we could have done with more support overall.

During lockdown and throughout 2020 Chris was still supported by AVANTI but just online. I just remember him saying to me when we had been a few weeks into the first lockdown:

"This is like my stroke life, people are all interested at first and then that wears off after a while and you're left on your own and everyone else's lives carry on and you have to just watch while you struggle in the background, and you feel like your life is standing still. Except for I had no choice, and I don't know when I will get my life back, everyone else does"

That really rang true to me, he was right. He had had so many things just snatched away from him, but he didn't know if his was coming back. It certainly put it in perspective.

Our Support Network & Me



Chris has been taking part in new studies at UCL for 'Fatigue After Stroke' (he will hate me for sharing this picture!) and aphasia-based studies for neuroscience students as well, helping people find ways of coping with daily life if you're unable to read – like Chris. He uses technology such as speech to text – that's easier now his language is better – and text to speech accessibility tech on his phone. We are lucky to have access to these amazing apps right in the palms of our hands.

As his wife - I wouldn't say Carer - I still do things for him, but with each new bit of technology and time, Chris becomes more independent and is becoming more confident in his ability to do things himself. 5 years on he is only just starting to accept who he is now, and not compare himself to who he was – before stroke. There are so much more accessible things now and I do believe that we can all play a part in helping people and being patient with them, because like Chris, they might look 'normal' but ABI can be totally invisible. If I think back now, I am glad I didn't know any timescales really. You do just have to be patient and take it at your own pace. Everybody is different and no two brain injuries are the same.

I know SAMEYOU has only been around for 3 years, but had they been there when we were first going through our experiences, perhaps I would have felt like there was more information than I felt there was at the time. That's not to say that they would have solved all our

problems but, already I can see that they are creating many new pathways and bringing ideas to light. Their Neurorecovery Directory has lists of where you can get help and support near you. I believe they are going to help make a change for the better, for people in the future to feel less alone, to have access and to feel like they can get the help and support they need.

They are also listening to survivors and making changes already, we have plans to start a 'Buddy System' which would have been so beneficial in the beginning and throughout for both Chris and I. The SameYou Centre will also bring another level of support for survivors and their families.

Finally



I just have to say that without the unwavering support of our family and friends, both of us would not be where we are today. The calls, the texts, the flowers, the love, support and surprises (watch this video >> <https://youtu.be/onI3EM7QmKQ>) visits and chats. (Some strong language in the video)

We always have some laughs when Chris asks for the opposite thing to what he actually wants in a restaurant as he still has some communication difficulties, but he can also use it to his advantage when he wants to!

In 2022 Chris and I Took the decision to separate. We still love each other, its just that our relationship had changed and we realised the best thing for both of us was to call time on our marriage. Regardless, I am forever proud of this man and I am glad to say we are making it work with sharing our beautiful dog Harry!