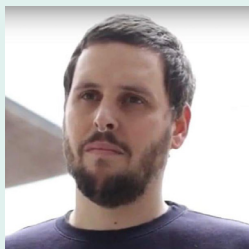


Appendix 2



Trigger warning: this is a personal account of Aaron's experience of stroke and contains information which may be upsetting. It also includes references to suicide.

"The most painful decision I ever made was to die. I had been out of a coma for about three days when it became clear how complex and difficult the journey ahead of me would be, not just for me but for my loved ones; for my wife, Emma, and our 2 children; Otis was 9 months old, Rue was 3 years old. I came to the conclusion that rather than burden them with the difficulties of my recovery and post-stroke life, it would be easier to close my eyes and let death embrace me. This, unfortunately, is the stark reality of confronting the world after a stroke for many people."

"I was remarkably healthy when I had my stroke. My implying ownership of the stroke. My implying the differences between strokes. My implying a personal trauma I was unable to share with others. I was thirty one years old, went to the gym 4 times a week, played basketball twice a week, and still maintained a similar level of fitness to my time serving in the military. This new world, one where the very core of my being had been shaken in a way I had never imagined, was terrifying. Little did I know, but being in hospital was the least terrifying part.

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I had been teaching a GCSE lesson on MacBeth when my life changed. The class were engaged in quiet work when I had a pain like somebody had boiled a kettle, waited for it to whistle, then poured the scalding water over the crevices of my brain. I got cover for the class, walked to reception, asked for paracetamol, and woke up a week later.

My wife was told that 85% of people who turn up at hospital in my condition are dead within a week, and of the remaining 15%, a very small portion are functionally independent. Emma was told to plan my funeral, and did so while coming to terms with the fact she may soon be a widow at 31 years old. While my brain shut my body down, and I lay on life support,

Emma was beginning to consider how to raise two young children without me, or, scarier still, how to raise two young children while also caring for me."

Up until that point, stroke had always been this THING, this fear that people spoke about in such extreme terms that I assumed it was either a death sentence, or a diagnosis from which a 'normal' life would no longer be feasible. As I lay on the Neuro ward in hospital, I hoped with every part of me that it hadn't been a stroke. So, when a nurse told the 'stroke Doctors' would come see me, my whole world fell in, and I felt the entirety of who I thought I was crumble before me.

Looking back, this is the first point at which my mental health began to erode, at the point of diagnosis. Telling somebody they've had a stroke is not like telling somebody they've broken a finger. No, this carries with it a history of stigma, a culture of fear, and a premonition of a lonely path ahead.

I left home at 17, I was a Caffe Nero Barista of the year at 19, I joined the military & served as a submariner at 20, I got my English degree at 26, my Master's degree at 27, my teaching degree at 28, was appointed as a boarding housemaster and teacher at a prestigious private school at 29, was awarded a medal at 30 and now here I was, at 31, being guided to walk again, unable to shower alone, being assessed on my safety while making a cup of tea in a hospital kitchen. All of these achievements, and now the most powerful thing I could do was not burn my hands making a brew.

I was transferred to a stroke rehab hospital where I saw the layers of a stroke for the first time. Other survivors filled with the anxiety of their future, or unable to present their thoughts in ways they were once able to. I met a man who could now repeat only one sentence, a young adult who no longer knew his own language, and a mum desperate to leave and return to her

children. All of us contradictions of each other, the multitudes of stroke presented as a palette of paint without a canvas to work on. That's the single thing we did have in common, none of us knew what was ahead of us, and none of us dared ask.

Finally, after a long stay in the hospital, at a time where lockdown meant I couldn't see my family, I was given the news that I was ready to return home and able to see my wife and children. This was the one thing I had wanted more than anything else, and the sole thing that had kept me going during days spent on a hospital ward. I was finally coming to the end of my journey with my stroke, and ready to turn the page and start a new chapter free from the burdens that had infected my life like a whirlwind.

Except, it wasn't over, I turned the page to find reams of fears, anxieties, and daily problems that were previously not there. What I assumed would be a blank slate turned out to be a slate covered in new neuroses and issues, with little understanding how to work my way through it all, or how to share my concerns.

The first day back, I was reminded that I couldn't pick up my children, the doctors' fears that the increased pressure of heavy lifting would damage me further or cause another stroke. I was reminded that I could no longer see 25% of my field of vision in both eyes, the stroke having been on my visual nerve, and an ophthalmologist appointment still a few months away. Mostly, though, I was reminded that I was, and always will be, the sum total of my experience with stroke, and as such had to learn to navigate this new world in a new body with a new mindset.

A week after my return, I began to experience a deep, irritating, pressure headache and was beginning to believe that I was having another stroke. This was the first instance of a mental health battle I would continue to wage for the next three years, and still fight to this very day. It was also the day I arranged a doctor's appointment to investigate the possibility of counselling.

After being put on a waiting list, and being left at a dead end with regards to the solution for these headaches, I joined a Facebook group and a Discord group, both for stroke survivors, and reached out to people across the world for help. It turned out a lot of stroke survivors had similar headaches, and they were just that, headaches. This loosened my fears slightly, but it would take years before I was finally able to convince myself that these weren't signs I was dying, but signs I had survived.

My children had their father home, my wife had her husband back, but I was never fully present, far too concerned with fighting a daily battle just to exist. I was able to walk, able to talk, able to make a hot cup of tea, but I wasn't able to make it through a day without a wave of fear and anxiety that gripped me by the core and reminded me of how close I was to death.

This is the unfortunate reality facing stroke survivors, the constant reminders of what could have been, of who you used to be, and of the murkiness of the path ahead. There is no end to the journey stroke takes you on, there are minor detours, or small moments where you learn to take a breath, but the path is long and unceasing.

The counselling never materialised, I sat on a waiting list for years, but got no luck. I reached out to a counselling service for military veterans, hoping I could utilise that as an ex-military serviceman, but the brief was consistent in that the sessions were specifically designed to discuss issues based upon time in the military. I tried hypnotherapy, but found it no help, then I went for acupuncture and got nothing out of it. I searched for local stroke support groups and discovered the nearest one met in a Tesco café a forty five minute drive away. Lack of funds meant they had to use a public spaces to share stories of the most difficult time of their lives, and I wasn't ready to speak so openly, with so many people around.

Every avenue I had tried was met with failure, failure on behalf of a duty of mental health care, and a systemic failure of post-stroke guidance. My wife had done everything she could possibly do to try to calm my fears, and to guide me towards seeing the future as something positive and malleable that I could shape, but she was alone in this endeavour, and it was unfair of me to place this burden on her.

A year to the day of my stroke, my grandfather passed away. A Hungarian war refugee who came to this country fleeing the Communist Revolution in Budapest in 1956, he was my first experience of a stroke when he suffered one while watching a Laurel and Hardy movie with me, when I was sixteen years old. He passed away, sixteen years later, in a hospital bed, having spent 16 years unable to climb his stairs to the bedroom, ashamed of the effects the stroke had on him. This man, this war refugee who started a new life for himself at 17, now stricken by the poverty of his stroke, because he was never taught that there is life after survival.

Two and a half years after the stroke, after I had managed to engage with life again as I had known it, I was in a good position. I had caved and finally paid for private counselling, which I still have weekly to this day, and I had begun to work my way through the mental fatigue recovery takes on a person. My business had improved and was enough to support my family meaning I was no longer burdened with the idea of going back to the career where I suffered a stroke, my physical health, besides the vision loss, was back to previous levels, and I was able to exercise and do both cardio and strength training again without risk of causing another brain haemorrhage. I thought I had achieved that rare feat of surviving the survival process, when I was reminded that this breather was a mere minor detour.

I was putting my son to bed in August of 2023, when I suddenly felt the walls close in around me, and an undefinable impending sense of doom. I couldn't confirm the feelings that had enveloped me, but I was rapt by the idea that I was dying, that my brain was bleeding again and I was about to die. I held my three year old son, and wondered if I would ever see him again, if he was about to watch his father writhe and coil in the throes of death on his bedroom floor, if I were about to burden him with a memory no child deserves. Then it passed. The next day, as I prepared lunch, it happened again. This continued two to three times a day for the next week before my GP prescribed me beta blockers, and told me I was having panic attacks due to PTSD from my stroke, Three years down the line and here it was again, rearing its head and controlling my life.

This is my story, but also the story of so many stroke survivors across the nation. Not the core facts, because every stroke, and every recovery, is different, but the need for support where

there currently isn't enough. The impetus is on stroke survivors' physical recovery, upon their ability to achieve physical goals afterwards, but we need to celebrate mental accomplishment, and care for the mental health of stroke survivors too.

I yearn for a future in which stroke survivors are walked out of hospital doors with a solution, and a pathway to recovery. A future where stroke survivors don't say goodbye to their hospital bed and their mental health at the same time. And a future where a stroke isn't the great unknown for survivors and family members alike, but a clear, concise, careful journey defined by the success of this mental health provision.

For mental health support and information from Mind:

- Call the Infoline on **0300 123 3393**
 - Visit **Mind.org.uk**
 - Find your local Mind **Mind.org.uk/localmind**
-

About the author

Aaron Kent is a working-class writer, stroke survivor, and insomniac from Cornwall, now living in Wales. His second collection, *The Working Classic*, is available from the87press. He has read his poetry for The BBC and The Shakespeare Birthplace Trust among other places, and has had work published in various journals. Aaron is a tutor at Arvon and Tŷ Newydd, and is an advocate for low socioeconomic artists. His poetry has been translated into languages including Cymraeg, French, Hungarian, German and Kernewek, and has been set to music.

"I'd go to a dark place every night when I tried to go to sleep, specifically wondering if it would happen again. I got to the place where I couldn't sleep at all at night. I was exhausted."

G, Stroke survivor,
interviewed July 2023

Each stage of the service design process - research, generating ideas, testing and prioritising - was led by people with experience of stroke. This means that the ideas generated were not created in a vacuum, but were guided, designed, and encouraged by those with lived experience of stroke and its impact.

Wales currently has over 70,000 stroke survivors with little statutory, stroke-specific emotional and psychological support. This is not just a hole in the health service, but a crater which has already seen countless people fall into its depths. As such, the Stroke Association and Mind Cymru, working with Shift, worked to create sustainable solutions to respond to this gap, and to ensure we aren't left with generations of people on the crater's edge, looking at those who have fallen in.

'It feel my family are prisoners in this life with me"

M, Stroke survivor,
interviewed July 2023

"It was when I got home that I got thinking and it was the little things that got me like not being able to butter my bread - I was comparing myself to a toddler"

M, Stroke survivor,
interviewed July 2023

Through the interviews, workshops, and surveys, survivors made regular reference to struggling to make sense of what was happening and what they were feeling. Others mentioned that following the days, months, and years after their stroke they began to lose contact with friends and were unable to do the activities they loved, as a result of feelings of exhaustion, teariness, and loss of independence. those who have fallen in.

The effects of stroke on physical, cognitive, and mental health are compounding, and as such it can be hard to separate mental health from all the other impacts of stroke; social, financial, and emotional. Symptoms of anxiety and depression, such as fatigue, can be easily misconstrued as an effect of the stroke, and go untreated, meaning stroke survivors run the risk of missing the markers that signify changes in their mental health.

"I thought "Why me. I'm 48. I've looked after myself." My mental health hit rock bottom. I was struggling everyday."

F, Stroke survivor,
interviewed July 2023

"Things were so bad [at hospital]. I wished I hadn't survived. Things in the beginning were really bad. I couldn't call. Couldn't nothing. It was so bad. Is this what it's going to be now?"

C, Stroke Survivor,
interviewed July 2023

"A lot of people I have met who are Stroke Survivors have said you have to think of your Stroke as a new part of your life. The old you is dead, as soon as you can accept that, the sooner you can get on with the rest of your life. I'm still waiting for that acceptance"

G, Stroke Survivor

We worked with stroke survivors and those working with stroke survivors to come up with, test, and refine ideas for improving mental health after stroke. We started with a workshop to generate as many ideas as possible, another to refine those ideas down to eight, and a final workshop to prioritise which to bring forward.

Every stroke is different, meaning there is never going to be a one solution approach - Stroke is a whole mind, body and life trauma, and this is something that impacts someone's identity meaning they have to learn to grieve for who they were. This meant we needed a holistic response to what is a complex problem, and a variety of ideas meaning we could help stroke survivors on their own terms.

“My sister said I was dumped. They didn’t prepare us for the mental health side of it.”

S, Stroke survivor,
interviewed July 2023

“I hated the hospital. My husband and I spoke and I discharged myself. This meant I couldn't access the NHS specialist support for stroke because you have to be an in-patient. But we decided it was worth it for my mental health.”

F, Stroke Survivor,
interviewed July 2023

“It's around the time services withdraw that the reality hits (it can be 6-12 weeks or 6-12 months). People might have been holding onto hope and goals up to this point, then an adjustment needs to happen.”

Clinical Psychologist,
interviewed July 2023

Stroke survivors told us that they felt ‘dumped’ once they came home from the hospital, especially when at-home care and services were withdrawn. This meant we had to design services that bridged the gap between the hospital and the home, that encouraged survivors to return to the life they once knew, while not pulling the support of professionals out from under their feet at the same time.

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There is a sense of uncertainty when it comes to recovery. Some stroke survivors felt they were not progressing as quickly as they thought they would, and some felt they had taken steps back rather than forward. With no guidance or understanding of the steps ahead, stroke survivors generally had to be their own advocates.

“People would tell me I’m lucky but I didn’t feel lucky. They’d tell me I looked fine. It was like I was imagining it. I wanted to be me again.”

F Stroke survivor,
interviewed July 2023

In the days and weeks following their stroke, people mentioned the very necessary focus on the physical and communication side of their recovery; the speech and language therapists, the physiotherapists and nurses and support staff. However, those we spoke to said they did not feel at all prepared for the struggles they experienced with their mental health soon after having had their stroke. Many said they, and their loved ones, had not been told that their mental health could be impacted by having had a stroke.

One of the ideas that came up throughout the process was the concept of an information pack to be given to survivors in hospital. This would outline what to expect not just physically, but also mentally, ensuring survivors were not left facing a barrage of unexpected outcomes. The information being presented to a stroke survivor will help to prepare them for what is to come, ensuring they are ahead of any potential anxiety and not caught out.

“Stroke recovery is a very isolating experience. No one else in my family or friends has experienced it so they can’t fully understand how it feels.”

T, Stroke survivor,
interviewed July 2023

“Your personality changes and your family have to cope with that. It could really help your family to talk to other families who’ve been through it.”

R, Stroke survivor,
Co-design workshop

“It’s like a bomb going off in your life. That’s how people describe it.”

T, Mind NPT

Stroke survivors we spoke to said what they wanted was to talk to someone who ‘gets stroke’, who could listen, understand and tell them it’s going to be ok. They felt that they needed somebody who had been through what they had been through, and could relate, and not somebody guided by a manual.

An idea that gained traction was an online course & peer group for loved ones to be active partners in recovery. By being online it meant survivors could take part from the comfort of their home, while still feeling connected as part of a stroke survivors’ community. This would have the benefit of ensuring loved ones understand and empathise with stroke survivors’ experiences. However, it would be for stroke survivors who have a partner, adult child or close friend, meaning some could feel excluded, meaning it isn’t for everybody and is just one of many solutions that are needed.

Stroke survivors told us that they were sometimes left with arranging their own mental health care, at their own costs. This meant that a lot of survivors turned to avenues that weren’t stroke-specific or designed for help with a stroke. Stroke survivors were left engaging with their mental health without confronting the core of their difficulties.

For stroke survivors who want to talk about wellbeing one-to-one, the ability to speak to a mental health professional who “gets stroke” is a powerful incentive, and a fundamental route to learning to cope and move forward.

"I do 'Here for You' at the Stroke Association. Nearly everyone I speak to has mental issues and are desperate for someone to talk to. I'm not a counsellor and can't give them that help"

Stroke survivor

"Going from being a busy, independent person to absolutely nothing. That's been the biggest thing. Depending on other people to take me places, it's been an absolute nightmare."

S, Stroke survivor,
interviewed July 2023

A refrain we regularly heard from research and in design was how important it felt to speak to people who get stroke who can relate to what stroke survivors were going through. The shared connection and identity meant those accessing the service did so in the knowledge they didn't have to explain what it was like to have a stroke, because that information would already be known.

A wellbeing recovery group for stroke survivors experiencing poor mental health and actively seeking support would allow space for survivors to share and process their experience of stroke - in a group setting with other stroke survivors. After survivors overcome initial physical and cognitive recovery, they'd have a place, facilitated by a stroke-experienced mental health practitioner, to talk about the impacts of stroke on their mental health.

For 10 weeks, survivors would be able to share and process with people who get stroke so they don't feel alone, meaning they could build new relationships, get professional and peer support, and be given the opportunity to join a wider stroke network afterwards.

Rebuilding lives after stroke



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