

Carly Sygrove

Take Sudden Hearing Loss Seriously!

Hi, my name is Carly. I'm 38 and I live in Madrid, Spain. I am originally from a small seaside town in Yorkshire called Bridlington and have also lived in China and Thailand where I taught as an Early Years teacher. I love spending time with my sister, walking in the countryside, getting lost in Madrid with my boyfriend, going out for breakfast, listening to music, yoga, storytelling podcasts, drinking wine, and eating spicy food!

■ Four and a half years ago, a guest speaker was giving a presentation in a school auditorium where I was working as a teacher. As I lifted my head up from my notetaking, out of nowhere came a loud screeching sound that filled my head with pressure. The sound grew quieter into a dull ringing, but the pressure continued, and I was soon feeling lightheaded and disorientated. I turned to talk to my colleague sat to the left of me. I could see she was talking; her mouth was moving, and she was looking at me and was gesturing. But I couldn't hear anything she was saying.

During the break, I made my way to the toilet with a small group of colleagues. I was dizzy and things were spinning like when you've had too much to drink and can't focus. In the toilet cubicle, I desperately tried to pop my

ears, holding my nose and trying to exhale through my nose. This momentarily seemed to ease some of the pressure, but my head was still spinning, and I was aware there was something wrong with my left ear. Though I was extremely uncomfortable, I wasn't too worried. I was tired and thought that maybe after a good sleep, I would feel normal again.

Not Getting Better

It wasn't until a few days later, while on the Metro train to work when I realised the extent of my hearing loss. I removed my right earbud to listen to a public service announcement and realized there was no music playing in the left ear. Naturally, I thought it was an issue with the earbud and tried the left earbud in my right ear. It was working perfectly. I tried again in my left ear. Nothing.



I struggled through the next few days, determined to keep going to work. But when my classroom was busy, and alive with chatting little voices, I couldn't hear individual children when they came to speak to me. After work, I'd lie on the living room floor exhausted from the day and watch as the room tirelessly spun.

Seeking Medical Attention

On day 9, following the day in the auditorium, I went to see my GP. She looked in my ear, said that it looked normal and that maybe there was some inflammation. She gave me a prescription for some Ibuprofen tablets and nasal sprays. A week later, after no improvement, I was referred to a specialist.

I began day 19 by going to see an ENT specialist. I was hoping that this would be the end of my hearing loss journey and that someone would find the problem, give me some medicine, and I would be better.

I was asked to carry out a hearing test—this was to be the first of many. After the test, the audiologist took me by my arm and spoke quickly and in Spanish. She told me to go to the A&E department of a nearby hospital immediately.

Testing and Treatment

After she had listened to my story, and looked inside my ears, the ENT specialist told me that I would have to stay in the hospital over the weekend. They were going to try giving me various medications, and on Monday they would do some tests.

The tests that followed included a tuning fork hearing test, tympanometry, and further pure tone audiometry to monitor whether the treatment was having any effect. Blood tests were taken and later an MRI ruled out a serious underlying cause of my hearing loss.

I spent a week in hospital and received treatment of antibiotics, antiviral medication, and intravenous corticosteroids. At the end of the week, I left the hospital with a tapering dose of steroids to continue treatment at home.

After finishing the treatment and having no recovery of hearing, I was told that there wasn't anything else that could be done, and that it was very unlikely I would regain any hearing.

Understanding and Acceptance

I couldn't understand how the hearing in my left ear could shut down so suddenly. I had so many questions. I was young and healthy; How could this kind of thing happen? How was there no cure? I felt lost. I worried about my 'good' ear. Every morning when I woke up, the first thing I would do was to click my fingers near my right ear to make sure I could still hear.

Not only was I struggling to deal with the practical challenges of living with a reduced sense of hearing, but I was also overwhelmed by the emotional aspects of hearing loss such as feelings of isolation and the need to grieve the sound I had lost.

Four months following my hearing loss, my boyfriend and I travelled to a hearing specialist in London to seek a second opinion. After a day of intense testing, the same conclusion was drawn; the hearing loss in my left ear was profound, and there was no other active treatment that could help the left hearing threshold. I was told bluntly that I wasn't going to get any hearing back. I hugged my boyfriend tightly and cried. This news was devastating yet I was also relieved; it was time to move on with my life without full sound.

Living with Single-Sided Deafness

I was fitted with a CROS hearing aid, which I trialled for three

months. Unfortunately, it didn't provide the support I'd hoped for. I returned the device and was told that I was out of treatment options.

With only one hearing ear, I couldn't identify where sound was coming from. I might hear some music or a noise, but I didn't know which way to look to see what had produced the sound.

My boyfriend automatically started walking on my right side, where he knew I could hear him. When I was on my own in everyday situations, I often felt vulnerable. I worried about crossing the road, and not hearing traffic approaching on my deaf side. I worried about strangers talking to me, and not being able to hear them, or even worse failing to acknowledge them.

In noisy environments, it was difficult to focus on a single person's voice. Socialising was demanding amongst background noise. In restaurants and bars, I learnt to sit in a corner, or with my deaf ear against a wall and my hearing ear facing the person I was speaking to, to have some chance at hearing them in conversation.

There were, however, a few positives in having single-sided deafness. I could block out sound when sleeping, by putting my 'good' ear to the pillow. I only needed to use one earphone when listening to music, and if there was someone I didn't want to listen to, I could make sure they were sitting on my deaf side!

Raising Awareness and Making Connections

I had put my work before my health. I should have seen a doctor sooner. I've thought about if I'd done things differently—If only I'd received treatment within 48 hours of onset, would I have gained any hearing back? This is something I will never know the answer to and so something I cannot dwell on. For now, I feel thankful for the hearing

I do have, and I now appreciate this wonderful sense, so much more than I did before my hearing loss. I've made peace with my hearing loss and I feel I am a more compassionate person because of it.

I now know I should have seen a doctor immediately following my sudden hearing loss, yet I didn't have this knowledge at the time. But neither did my GP; she later told me that she had only ever seen sudden hearing loss in stroke victims.

My Blog

Raising awareness became my passion. In December 2016, I started my blog, My Hearing Loss Story, as a way of sharing my story with others. Through my blog, I started connecting with people from over the world who had been affected by sudden hearing loss.

Emails began landing in my inbox, from people who wanted to talk about their experiences of sudden hearing loss. They were looking for support and advice about living with hearing loss,

different treatments options, and how to deal with associated issues such as tinnitus and the emotional impact of losing hearing so suddenly.

I took comfort in being able to help people through their difficulties. I listened to every story with sympathy and offered personal advice and as much support as I knew how to.

Online Support Group

Reading so many similar stories of sudden hearing loss, and of struggles with tinnitus, grief, anxiety, and isolation, I decided to provide a space where people with similar experiences could connect with each other.

In November 2019, I created the My Hearing Loss Story group on Facebook, a support group where people with hearing loss can share their stories, ask questions, and offer support and advice to each other. I began to realise how much value there was in communicating with others living similar experiences—through sharing our stories we were learning from each

other and no longer alone in the experience.

My New Project

There is still relatively little known about sudden hearing loss, which makes it difficult to know where to find information and support. Although, various articles can be found online, I couldn't find anything which encompassed the whole sudden hearing loss experience, all in one place.

I am now working on a new project, developing a website dedicated to supporting people with sudden hearing loss: suddenhearingloss.support. This website will offer information, support, and advice for anyone who has been affected by sudden hearing loss.

Through crowdfunding, I have raised enough money to pay for the first year of a website plan and the initial start-up and running costs. I am now working on writing content and collecting resources from hearing loss charities and organisations.

How YOU Can Help!

Now, here's where all you audiologist readers come in!

If you would like to get involved in the creation of this incredibly valuable resource, by donating content with a sudden hearing loss theme (plain English articles, videos, images), or in any other way, please get in touch with me through the following email: carllysgrove@suddenhearingloss.support

I can send you a list of the content I am hoping to include, and I am also happy to hear your thoughts and advice.

Thank you for reading my hearing loss story. I hope you will all join me in helping to bring awareness to sudden hearing loss and the importance of receiving treatment quickly, helping to reduce the number of people who have lasting effects from this devastating condition.



Sudden Hearing Loss Support