Living and Playing with a Cochlear **Implant**

Russell Tyler

Russell was rehearsing the soundtrack of Harry Potter when he suddenly began to 'see stars' and feel dizzy. These symptoms signalled the start of a journey every musician dreads: learning to cope with hearing loss.



Russell Tyler with members of the Vienna Philharmonic Orchestra

I am the Principal Oboe with Orquestra do Norte in Portugal, a position I have held since March 2001, fresh from finishing my Master's degree at the then Royal Scottish Academy of Music and Drama. Healthwise, thankfully I've led a largely uneventful life so I initially thought nothing of my symptoms: I even put them down to the quite 'heavy' reeds I use. However, these symptoms continued, even when not playing.

I went to my GP where she did the routine tests, but couldn't pinpoint anything. She proceeded to write a letter to the Ear Nose and Throat specialists for me to take to the Santo Antônio Hospital in Porto, going directly through to the emergency

department. There they also did an array of tests but also couldn't find anything either, so I ended up just getting on with it. No diagnosis, no more tests.

The symptoms continued during the following months though milder. When, however, they returned to the extent that made me go to my GP the first time, I went back again. She repeated exactly the same process; tests, letter to ENT specialist, and off I went again to Santo Antônio Hospital.

At the hospital, it seemed that I had suddenly turned into a performing monkey. None of the ENT specialists could fathom what was going on. So every time another specialist walked by the room

where I was being prodded, poked and made to walk blindfolded etc, they would be called in to give their opinion. Then in came one of the older generation of specialists who proceeded to so some seemingly incredibly outdated tests.

After completing his tests, he said: 'Off the record, for me, this is a rare condition you have. Only one in half-a-million people have it. I can't confirm it until we do a CAT scan. It's called Semi-circular Canal Dehiscence Syndrome (SCDS).' He explained the symptoms to me to pre-empt my personal consultation with Google. It seems that people who have been suffering with this condition have either been mis-diagnosed or labelled hypochondriacs.

After the CAT scan it was confirmed. What a relief it was to have a diagnosis and know that I wasn't going crazy! Immediately the ENT surgeon and a Neurosurgeon got in touch by phone to organise some consultations. This procedure had never been done at this hospital so they decided on a joint venture to make sure every possibility was covered and nothing left to chance. I didn't give having the surgery a second thought.

Both surgeons are younger than me, but everything they said was incredibly carefully considered to put me at my ease. They also have a great sense of humour which helped a lot! To my surprise, after being 'diagnosed' in September, I was going to have my operation on the day after Boxing Day. I was informed of the

risks but everything pointed to a positive outcome. They were also incredibly careful about my operation knowing I am a professional musician. To me there was no other option.

In the meantime I gained some more symptoms: incredible dizziness, muffled hearing and autophony. Autophony is where one can hear one's bodily functions amplified in the head. So I could hear my heart beating, my muscles in my neck contracting whilst doing yoga, the thud of my feet when walking. At the quietest times I could hear my eyes moving from side to side, like someone scratching their nails on sandpaper! It didn't seem to affect my playing, apart from my hearing being slightly muffled on the left side. However I stopped going to the gym and I stopped canoe training (canoe sprint) which I used to do every day. I stopped everything except work, and when I got home I would lay down on the sofa until bedtime.

Then I had my surgery (technically brain surgery). After 5 days in hospital in total I was discharged on the Friday, but would return on Monday for a check-up. During that weekend, although I found I had lost my hearing on my left side, I thought this was par for the course, so I didn't concern myself. When I went for my check-up on the Monday, Dr. João asked me how my hearing was. I replied that I couldn't hear in my left ear. Although he tried to hide it, I could see the panic in his face. He did everything that was humanly possible to rectify whatever had gone wrong, even to the point of using the biggest needle I have ever seen to inject my ear with Cortisone. Nothing! Though he tried everything I already knew it was a lost cause. I could sense his feeling of guilt: he knew there was no solution and was already thinking that I might have to retire from music.

I was bumped to the front of the queue for a month of daily hyperbaric treatment thanks to Dr. João using his connections. I had no expectations but went through the motions to show that I was keeping up my end of the bargain. After that month nothing changed. I was put on sick leave until they could decide what to do. They didn't want me to make it worse. Dr. João. and also now a vertigo/dizziness expert, Dr. Ângela, supported me throughout making sure that I had every test possible.

I twice had a re-occurrence of my initial symptoms which resulted in undergoing brain surgery two more times. I can't stress enough how amazing the ENT, Neurosurgeon and vertigo staff were. They moved heaven and earth to make sure I was alright. They also organised a psychologist and psychiatrist for support, something I am still attending.

I was given the go-ahead to work but, at this time, everyone's nightmare happened...COVID19. The irony just made me laugh. I had spent two years cooped up at home, and as soon as I was given the green light to restart work I had this new confinement! You couldn't invent this. As I'm quite autonomous (and antisocial) it didn't bother me having to spend more time at home. However, I just wanted to get back to playing.

Anyway, I did get back to playing at home. I wasn't expecting the loss of technique and stamina to be so apparent. It was like starting from the beginning. It was very difficult making softer reeds and trying to play without using any pressure in my head. Not an easy task. But I was a man on a mission (despite realistically no outlet for the foreseeable future).

In the meantime, unbeknown to me, things were happening on the ENT front. Dr. João had always spoken of a Cochlear Implant, to which my immediate answer was a straight-out 'No!' I have no hair and those devices were so conspicuous and ugly. This was the first time I had cried about my situation. I would be a freak, everybody would stare at me. Just, NO! As Dr. João has an amazing sense of humour and also knows how to diffuse a tense situation, he quickly replied that I'm already ugly, and have no hair! It was probably the best way to diffuse the situation and it really did make me laugh; more importantly, it actually made sense.



So I agreed to look at the devices on offer. They were all ugly. Then he showed me a device without an earpiece but with wireless charging (Med-El Rondo 2). Now that I could live with. Dr. João checked to see if it was viable and, although technically/officially it wasn't, he pulled out all the stops to make sure that I would get the implant, both to improve my quality of life and hopefully to continue my career as Principal Oboe. He knew the likelihood of my SCDS becoming bi-lateral.

He was given the go-ahead and in the September (2020), when Covid was still around, I had my implant. The device is not given immediately after surgery. One then has to wait four weeks minimum for the scarring to heal and to recuperate. At your first appointment you have the speech therapist, then the specialist informs the Cochlear Implant company to connect the device, do a hearing test and then start calibrating frequencies.

As soon as I had the device magnetically stuck to my head and connected, I could hear white noise in my left ear. I marvelled and shed tears of happiness even though it sounded like a very badly tuned radio station, with only the very occasional word filtering through. Then came the frequencies. I had to raise my hand when each frequency was comfortable to my ear, without being too muffled or too strong. I think being a musician helped me with this process as we all have a good idea about pitch, frequency, volume, etc. Next came the speech therapy, and with face masks to boot! During my two years on sick leave I had become more adept at lip reading, but with face masks everything was ten times more difficult.

I had speech therapy sessions once a week with the most amazing speech therapist, Cátia: incredibly friendly, but very demanding. She made me work hard because she knew I was capable. It was a very difficult time as I wanted to prove that I was worthy of my implant and I didn't want to let anyone down. In six weeks I was already at the level of hearing as a non-musician would be at six months. Every three months I get my device re-calibrated to have the best hearing experience possible.

I started back to work. It was a huge cacophony of sound that my brain couldn't interpret straight away. I had to get myself re-acquainted with the position of the 2nd oboe (which I had already become used to

hearing on my right side), and also with the bassoons as the closest instruments to my device. I had to train myself to make sense of these sounds. Trumpets were very painful, but nothing so much as the percussion section. Indeed this is still an ongoing process.

Sometimes the sound is just too much during a rehearsal so I will quickly take the device off (as its only held on by a magnet). However, I have a remote control with different settings to compensate for those times. The oboe is obviously a difficult instrument to hear and decipher, due to the lower and higher harmonics produced by the reed. In the beginning, I would hear a full whole tone between the note I was playing and what I was hearing. Having pretty good pitch I seemed to be able to trick my brain into believing what I knew I was playing. This, over time, reduced to half a tone and is now pretty normal. I have to say at this point that I haven't actually regained my hearing; I have had to learn a new way of hearing.

For some reason, the note that will always stick out is an E natural, in both the low and middle octave. It must be the frequencies. I have become used to it. I would never now play in orchestra without my device and, to be honest, I am incredibly proud to have it and be able to continue playing.



Russell duets with a VPO cellist

It has been an interesting journey, and is still ongoing, not only for me but also for my friends and colleagues. My initial condition (SCDS) is now becoming bi-lateral, meaning that I am just the same as I was before. I have lost my balance: I still do canoeing but it's extremely difficult and uncomfortable. I have also regained my autophony. The only option will be to operate again on my right side.

I am always in contact with Dr. João, Dr. Ângela, Dr. Sérgio and Speech

Therapist Cátia. Another surgery has recently been offered with a different approach: more complicated technically, but with less risk. I feel I have been incredibly lucky to have had so much support both from Santo Antônio Hospital in Porto and the whole Med-El team, both here and in Austria. They have both been so extremely helpful and supportive and instrumental in my recovery and progress.

Photos by courtesy of Med-El.

