

FINDING HIS VOICE AGAIN

IT'S BEEN 10 YEARS SINCE CALEB RIXON'S LIFE CHANGED AFTER SUFFERING A STROKE. HE TELLS GRETA LANNEN OF HIS JOURNEY AND WHY HE'S WORKING TO ENSURE THE VOICES OF OTHER STROKE VICTIMS ARE HEARD



IN THE 13 years since a stroke left Caleb Rixon without a voice, he has been on a journey to find it again – physically and metaphorically – and he's sharing his story along the way, ensuring that the voices of other stroke survivors are heard.

The former Geelong man, 37, has used humour and vulnerability to share his transformative story with thousands of people, reframing his own perspective of what it means to have a voice, and discovering a new one.

Caleb grew up in Newtown as a musical theatre-loving student at Belmont High School.

With a passion for singing, dancing and acting, he studied at Ballarat Arts Academy and the Western Australia Academy of Performing Arts, before moving to Sydney where he signed to an agent, won his first professional gig in *Altar Boys*, and was cast in the national tour of *Chicago*.

The young performer was breaking into the theatre scene and had his sights firmly set on Broadway.

Caleb expected to spend his 24th year making his first big steps towards the bright lights of Broadway, but instead, his 24th year was spent learning how to walk and talk again.

It was three days after his birthday during a gym class, when Caleb suffered a massive stroke.

"I felt the most excruciating smash behind my left eye, and I thought that my eye had fallen out, and so I sat up to catch it," he says.

One of two haemorrhages Caleb would endure had burst at the lower back of his head, referring pain behind his left eye, bleeding into his brain stem and cerebellum.

"Over a matter of minutes I started to lose the ability to balance, swallow, stand, sit up, speak, then remain conscious," Caleb says.

The young man was placed into a medically induced coma, a state in which he stayed for several weeks in an intensive care unit.

Caleb had suffered a grade five subarachnoid haemorrhage – "the most severe grading of the rarest form of stroke", caused by a rare congenital brain abnormality that was undetected until Caleb was in a coma.

"All the ventricles in my brain were full of blood, so they had to drill in very quickly just to relieve the pressure before they could find

"WHEN I REALISED THAT THE RECOVERY JOURNEY WAS A JOURNEY OF HOLISTIC HEALTH AND WELLBEING, EVERYTHING CHANGED."

what was going on," he says.

Days later, Caleb had a craniotomy, in what was a harrowing time for his family.

Already gravely ill, Caleb suffered more blows, contracting pneumonia, golden staph, septicemia and meningitis.

He awoke from his coma without the ability to swallow, breathe, eat, see, walk and talk; starting the long journey of relearning the actions.

A unilateral vocal fold paralysis and

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paralysed soft palate caused Caleb to become mute for 10 months.

Caleb describes the loss of his voice – and the ability to sing – as like having his identity completely obliterated.

“I had an ENT surgeon assessing my throat for the very first time surgically,” he says.

Through a cracked voice, Caleb told the surgeon “this is very hard for me because I’m a singer”.

“(The surgeon) turned his back to me and said ‘you were a singer’. I was absolutely devastated.

“At that moment where I was at in my life is that I didn’t want to live if I didn’t have a voice.

“My identity, purpose, mission and vision for my life were all wrapped up in my capacity to perform in music theatre, so letting go of that aspiration was quietly agonising,” Caleb says.

He spent the next two-and-a-half years in inpatient and outpatient rehabilitation, enduring countless hours of varying kinds of therapy.

During his recovery, Caleb decided he wanted to connect with and help others who were on a similar path.

He founded Genyus Network in Geelong in 2015, a peer-led online community for young survivors of stroke and trauma, “about stories, not symptoms”.

“I needed to connect with people who inherently understood me. That meant people touched by trauma. Everywhere I looked for it, it was based on a clinical model, a medical model of recovery, it wasn’t about the journey of life after trauma,” Caleb says.

What started as a Facebook chat thread has evolved into a social enterprise and



More than a decade after suffering a stroke, Geelong’s Caleb Rixon, 37, has been on a journey to find his voice again and is ensuring that the voices of other stroke survivors are heard as well. Photos: Supplied

foundation, with more than 1600 members across more than 56 countries.

Genyus Network has a vision of a world where people touched by life-changing trauma are empowered, emotionally resilient and connected. Where they can build resilience and capacity, find their sense of identity and improve their mental health.

Caleb’s advocacy won him the Improving Life After Stroke Award at the 2022 Stroke Foundation Stroke Awards earlier this month, national recognition he says he was humbled

to receive. More than a decade on from that life-altering day, and with amazing strides in progress, Caleb acknowledges that he still lives with lasting impacts, visible and invisible, that will always be with him.

He says there are always bad days but that he has never felt like the victim, with his occupational therapist instilling in him from the start that he is a survivor.

The Theodore Roosevelt quote “comparison is the thief of joy” has helped Caleb reframe his experience, ensuring he

continues to look forward, and not yearn for his pre-stroke life.

“I used to think that things were finite. I used to think there was a recovery, that you recovered,” he says.

“I no longer put this idea that I had to return to some previous identity and that the benchmark of life when we face adversity is the pre-life.

“When I realised that the recovery journey was a journey of holistic health and wellbeing, everything changed.”

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