

EDITORIAL

## Connection: stories not statistics

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When health professionals and systems reduce people who survive brain injury to their symptoms and “survivor narratives” they create *The Isolation Industry* - an industry that perpetuates a feeling of difference and deficit that caps the potential of those who they seek to help. So, how might stories disrupt this? I think the sharing of survival stories *should be sexy*. Not to be confused with sexual - I’m talking about making lived experiences of brain injury palatable, relatable and investible. Narratives that evoke empathy, understanding and excitement eliminate stigma and end isolation.

This paper holds familiar themes drawn from values consistent with research found in *Brain Impairment*; the importance of listening to the stories of people with lived experience of brain injury. Within the journal, I have read the work of many researchers on this topic; fancy-pants people with lots of degrees, who know a lot about brain injury. I am not a researcher; I am not an academic. I am a stroke survivor, a storyteller and a community mobiliser with first-hand experience of empowerment built through story-sharing.

Sharing (and listening to) stories is important, but the challenge for health professionals is to use these stories to improve their practice and the experiences for survivors. Through their research, Tevendale and Armstrong (2015) found that when survivors shared their stories with health professionals, it improved the health professionals’ understanding of issues affecting people with lived experience and helped to refocus their beliefs of what mattered most in assisting people living with brain injury. Stories invite an emotional response and offer a narrative that likely differs from the *patient history* engaged by some health professionals.

This work is an attempt to use my early stories to cast a spotlight on the disconnection that can occur in the rehabilitation process. By sharing these, I hope to start a conversation about the isolation that occurs for people with living experience of brain injury and how health professionals, policymakers and the system contribute to this. I want to create a dialogue loud enough to inspire you to pause and reflect on the part you could play in building a more connected rehab journey. Let us create a stronger connection; one built through stories, *not statistics*.

The rhetoric we use and the paternalistic approach we engage reduces survivors to their disability; disempowering engagement leads to more isolation and increases mental health problems. We can change these outcomes by creating safe spaces for peers to connect and build capacity, using supportive and empowering language, recognising the wisdom people with lived experience hold, and by making collaboration, not compliance, an industry standard. I know this because I live it and it has been my journey for the past 13 years.

Some of the most oppressive interactions that halted my recovery journey involved members of my healthcare team, particularly those looking after my voice. My voice was my primary vehicle for self-expression: *singing*. Singing was my source of escape and self-soothing. It was my financial and spiritual currency. It was *who* I was. However, my brain injury and lifesaving intubation resulted in unilateral vocal fold paralysis and my voice was cut off.

When my first Speech Pathologist removed my tracheostomy; their eyes were fixed on my mouth, hoping that I would spontaneously create sound by extracting the tube. I tried to speak, but only gurgling and spluttering was heard as saliva made its way into my windpipe. I was trapped in a black and white film, completely mute. My vocal cord and my identity were paralysed. I looked at my “Speechie” and tentatively mimed “I’m worried about my voice. I’m a professional singer”. Despondently, she interjected, “I’m not as concerned about your voice *as I am about your swallow*”. I felt unheard, abandoned and literally voiceless. I was surrounded by allied health professionals looking out for my best interests, but I was painfully alone. This event wasn’t the only time.

One afternoon at rehab, my day nurse, Melissa, was giving a hand-over to the night nurse, Chris. Melissa fondly looked at me before beginning her overture, “This is Caleb Rixon . . .”. I eagerly awaited her to bring my heroic story to life, but her eyes shifted and disengaged mine as she began reading a laundry list “Grade 5 subarachnoid haemorrhage, nil-by-mouth, non-verbal, diplopia, nystagmus, positive for single transfers, washing and toileting. *Wheelchair only*”. I was startled. The person she described was a helpless and hopeless old man. I thought, “Who is she talking about? It certainly isn’t me!”

Eventually, I was assessed by an E.N.T. surgeon – placed high on a pedestal as the sole saviour of my voice. By this stage of my recovery journey, my muted voice had strengthened into a hoarse whisper. Atop of my paralysed vocal cord, a paresis of my soft palate created a large nasal escape of air, so I was contending with the humility of sounding like the personification of Marge Simpson. All my hopes were pinned on the E.N.T.’s intervention plan based on his evaluation of my needs. While he poked and prodded inside my throat, I sheepishly looked at him and explained, “This is hard . . . for me . . . because . . . I’m a singer.” He replied, “You *were* a singer”. I was crushed. His disconnection from my humanity was unfathomable to me, also to my Mum and my new “Speechie” who witnessed it. His unintentional assault obliterated any sense of safety I had in working with him again. I desperately needed to engage with people who inherently understood me.

Months later, I was excited and hopeful about meeting up with other young survivors at my first “support group” meeting. I thought “Hopefully my peers will understand”. Sitting around a table, we begin introducing ourselves. I am petrified to speak up and share my experience. Hearing the sound of my husky voice is confronting and humiliating – even amongst a group of peers, it is just so embarrassing. *Who am I now?* The first person tentatively begins, “Hi, I’m Adam. Basal Ganglia haemorrhagic stroke, left-sided hemiplegia.” The group hesitantly replies “Hi, Adam”. We move to the next person in the lineup. “I’m Sarah. Carotid Artery Dissection, ischemic stroke, right-sided weakness, dysarthria.” The group responds in monotone, “Hi Sarah”. Surprised to hear everyone identify by their symptoms, it’s suddenly my turn. “I’m . . . I’m . . . Cal. I’m a musical theatre performer . . . and I’ve had a stroke”. Throughout the event no one enquires much beyond another’s ailments. I was startled. I wondered why we identified so strongly with only our afflictions. *Why are we more confident to connect via our symptoms than our stories?* I wanted to hang out with new friends who I could relate with; to connect and rebuild my life alongside my peers. But this felt more like a collection of symptoms rather than a posse of peers.

When I turned to society for support through our government agencies, even more disempowerment occurred. Finding support through insurance schemes like the N.D.I.S. or the Disability Support Pension is a lonely trek. I’ve never felt more disempowered, demoralised, scrutinised or isolated than when evaluated for this process. To see my worth be based upon my “worst day” - **but be provided with no strategy or capacity to aspire beyond my current physical or psychological constraints** - depleted my self worth. How can these systems expect people with disabilities to aspire for more when their value is based on their worst day and they are seldom supplied with the tools needed to actively engage in community life? The system detached me from my story and reduced me to a statistic.

Fast forward to the present day and I have a number of experiences that highlight how nurses, doctors, support groups, universities and the government utilise rhetoric that further entrenches a

reductive self-belief for survivors. The following stories expose how this occurs in unconscious but insidious ways.

Over the past few years, I have been grateful to speak at conferences and events for health professionals, research and fancy-pants allies alike. Conversations at these events espouse exciting dialogue around building a world where survivors of brain injury are empowered, celebrated and partners in their recovery. However, a significant issue I see is the blind agreement to use terminology such as “consumer” to identify brain injury survivors. At best, this term reduces someone with a living experience to a mere “recipient”, perpetuating their stance as a passive entity, rather than an active member of the team. I pushed back about the reductive label when I was asked to present at another brain injury conference. I mean, brain injury has undoubtedly consumed a lot of my life, but I’ve never perceived my most prized attribute to be my consumption of the injury, or its impact on my lifestyle. The term “consumer” doesn’t encapsulate my experience, my knowledge, nor any of my inherent value. It is *unintentionally othering* and doesn’t position a survivor as a partner in their rehab journey.

When a person’s individual living experience isn’t acknowledged as a primary expertise which they own, it reduces their agency and identity into the role of a receiver, ultimately stifling their potential for growth. It is disappointing to see the systemic reduction of survivors to the total of their disability and symptoms.

At another stroke conference, I was shocked to learn that some presenters with living experience were asked to eat lunch in a separate room amongst only other “Consumers”. After kicking up a stink, my peer presenters and I were permitted to eat in the same room as all conference delegates. But it was too late. The divisive act had done its damage and broadened the chasms already existing. I felt separated, siloed and degraded.

More recently, I was selected by a jury at a consumer health conference to present genyus network’s peer-led research engagement platform *genyus roundtable*. A fellow survivor and I were allocated a restricted amount of time to present our peer-led research solution which uses mixed methods to create defined cohorts, gather unbiased evidence and provide peer analysis. I was disappointed when the event host focused their questions solely onto our “*stroke survivor hardship narratives*” instead of placing any attention on the value of our innovation.

Another time, I was part of a critical task force for a feasibility study about building an accessible and inclusive city. I was one of two people with living experience of disability participating in a workshop focused on “community infrastructure” and our group was posed the question “What makes a strong community infrastructure?” I raise my hand “safe spaces.” The facilitator wrote it on the board and opened the floor to invite contribution from industry experts in attendance. They chimed in eagerly “Yes! We need more lighting”, “More rails!”, “More ramps!”, “Sensory-quiet areas!”. These are all great, necessary answers. *But they didn’t get what I was saying.* A safe space isn’t just the built environment; it’s also the emotional and psychological infrastructure. It’s relational.

All of this disempowers survivors and causes withdrawal and isolation, because there is no place to feel physically, psychologically and emotionally safe! We must create safe spaces for all survivors (and their supporters) involving meaningful engagement, true collaboration and empowering rhetoric. Meaningful engagement is the effort, intention and interaction that takes place within a safe space.

During in-patient rehab, after an exhilarating “day leave” with my family and friends, I explained to Amy (my O.T.) that I had played Jenga with friends and family. Using my “weak” hand to strengthen my dexterity, I almost removed the final block to win before a friend deliberately toppled the tower. I exclaimed “You just ruined the first game of Jenga for a stroke victim!” Amy retorted “Really Cal? I don’t see you as a stroke victim, *I see you as a stroke survivor!*” And with those few empowering words, my paradigm shifted from one of victimhood to perceiving my life with a renewed sense of positivity and possibility. I never considered I had a choice in how I framed myself.

The words we use are so influential in shaping our narrative and our self-perception of what it means to have experienced a significant medical event. Meaningful engagement is meeting someone where they are at; actively listening and shining your expert light on things that matter, before partnering with a person as they navigate their way towards your agreed goals. For a vulnerable person entering a safe space with you, they should feel more whole at the end of the engagement than they did at the start! Feeling connected, truly valued and involved. As much as it's your job to *give* information and advice based on intellectual expertise, you also have to be open to *receive* the idiosyncratic information that the survivor in front of you presents through their subjective lens. It's only through this interaction that creative, sustainable solutions can be built. Like any art form, Meaningful Engagement requires many different techniques and modalities to create impactful collaboration.

Two stories that highlight how Meaningful Engagement benefits the pathway to self-empowerment come from my lived experience. The first was with Amy (my O.T.). She engaged and probed to understand what was most important to me. This critical thing turned out to be my relationship with my then partner. Amy steered me to do "relationship rehab" by guiding me to create a "Valentine's Day Expedition". Struggling to speak, I had to make a phone call to book a hotel and set up a romantic adventure. Next, I had to go to J.B. Hi-Fi and buy a special CD that meant something to my partner and I. Through Amy's encouragement, I achieved my mission, got a leave pass from rehab and set off on an hilarious romantic-rehab-rendezvous!

The second engagement was with my Deb, my fav "Speechie". She probed and found out why my voice was so important to me. Innovatively, Deb got me using a CPAP machine for soft palette work (unconventional at the time) and had my Geelong speechie refer me to CPAP Victoria. Further, Deb got her physio colleague to use an electrical stimulation machine on my throat/cord (not typically recommended) and worked tirelessly with a surgeon to figure out options to help me progress further.

Meaningful Engagement with these two professional allies had an immeasurable impact on my ongoing success. They built trust with me and were guided by their curiosity and creativity. They each created a safe space where I could share my vulnerabilities; try, fail and try again, as many times as needed. This gave me confidence in taking on their advice and empowered me to take charge of my role in my recovery journey. Their pursuit to connect with my story deeply humanised our connection and we became equal partners in the recovery journey.

Dictionary definitions of the term collaboration highlight the personal relationship that must be present for collaboration and the common goal. Cambridge dictionary defines it as "two or more people working together to create or achieve the same thing" (Procter, 1995). Working on the same thing, building a future together should be the ideals of rehabilitation after brain injury. I encourage you to truly collaborate with a person with lived experience and consider what you are trying to achieve. Ask yourself, whose common goal are you seeking to achieve? Afterall, everyone wants to feel safe to share their stories and to connect with people like them.

When you read over these conversations, I trust you've had a sense of the isolation I felt. But just as the language you use as a health professional has the power to wound, remember it can also empower. Beyond that, I believe that stories offer a pathway to building what I term as a S.A.F.E. space. A space where our conversations and our work together is

Specific to me

Affirming of me

Fun for me, and

Engaging with me.

S.A.F.E. spaces within a relationship are built by empowering all parties to vividly and candidly share their stories and ensure receivers are actively listening with empathy. Our S.A.F.E space, which is the *genyus network*, provides people touched by trauma with tools to share their stories

and most importantly, connect with their peeps - with all aspects being peer-led and delivered through a social lens. I first brought people together through videos with community members and utilised the familiar social network Facebook. Over time, our community has organically grown to develop an online platform, including thousands of *genyus* members from over 50 countries, who come together to share stories with the purpose of paying it forward.

The question I get often is “Can you join a peer-led community as a researcher, health professional, or ally?” Can you join *genyus*? Absolutely!! *genyus network* is a community for survivors, supporters, health professionals and researchers. But that’s not going to be the case for every community. Every community has different needs. Some might have privacy needs that, if disrupted, would disrupt the flow of their community. Honouring the S.A.F.E. space and the specific needs of that community is something we must always keep in mind. So, after you knock on that door and are invited in, find out who’s in charge, be polite and act in accordance with the values and beliefs of the collective. Most importantly, find ways to add value to that community. Work together to achieve a common goal. Disrupt the status quo.

We must work together to solve our world’s crises and believe me, rehabilitation needs a little help right now if we are ever going to deliver on value-based healthcare. Recognise the value of people with living experience as a core component of the rehabilitation infrastructure. Question the traditional power hierarchies – they simply do not align with person-centred and value-based healthcare. Addressing these power imbalances will require a concerted effort from healthcare providers and people with living experience. Using key communication strategies to build a S.A.F.E. space within the rehabilitation environment will help patients become an equal part of their care team.

By listening to my story, I hope it’s made you think of the stories of the people with whom you engage. My challenge for you now, is to dissect your dialogues and remove the reductive rhetoric. Create S.A.F.E spaces and make *meaningful engagement* and *story-sharing* the new currency. By disrupting the status quo, you can help disrupt the isolation industry. Then take pride in knowing you are helping to create stories, *not statistics*.

## References

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