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CASE REPORT

Both Sides, Now: A Personal Stroke Recovery Journey

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Abstract
This is a personal narrative of my stroke and recovery experience, and the medical, psychological, and social circumstances surrounding it.

Key words: family; journey; recovery; stroke; support

Setting the stage: I am a neurosurgeon trained in New Zealand. After receiving a D.Phil. in philosophy at Oxford and a research fellowship at the University's Magdalen College, I returned to New Zealand as a neurosurgeon and Senior Lecturer in medical ethics at Otago University, where I am currently an Emeritus Professor.

Although the following personal narrative of my stroke and recovery experience is only possible because of the functional neuroanatomy of that particular stroke, the substance of the account carries wider promise for many stroke victims. This promise was expressed earlier in "Nick's story," which I coauthored with my patient Nick Chisholm, a rugby player in New Zealand who experienced a brain injury and progressed to the locked-in syndrome.[1] His story and mine are examples of how the human spirit and the support of others can transcend the physical limits imposed on us by brain injuries. I have had the privilege of interacting with many stroke victims in various rehabilitation programs run by Otago University Medical School since my stroke, and this narrative is inspired by their fellowship.

The Event

"The stroke," like so many was a "stuttering stroke," a protracted cerebrovascular event which unfolded while I was in the midst of an ethicolegal mini conference to launch a book. I was in Hamilton, New Zealand at the time and, on waking that morning, had decided to skip breakfast and walk to the venue, getting a snack there.

At the close of my presentation, after fielding the usual polite comments, coffee and a snack subjectively beckoned with some insistence. Hunger satisfied, I sat to attend the next presentation, but recall being a little shaky or "light in the head." That symptom just wouldn't clear, and another conference attendee called the hospital as I sat on the grass outside and felt wary of walking the short distance up the hill to the hospital. An ambulance duly arrived and, feeling stupid, I went to A&E (an emergency assessment area). A brain scan was speedily arranged but had inconclusive results.

Shirley, my wife was called. I was due to meet her in Auckland that evening where we had planned to stay before traveling to a hockey tournament in Rotorua. However, she drove to meet me, and we decided to stay in Hamilton (150 km from Rotorua) and travel on the following day.

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Because we could find no hotel available for the night, we resigned ourselves to sleeping in the car. The night dragged on, but I felt almost normal and agreed that yes, we should drive to Rotorua the next day. The drive saw me feeling less and less like doing anything and increasingly content to be a "feeble" companion.

That evening, after arriving in Rotorua, the next "stutter" occurred. I slept badly, feeling even less capable and more faint, when I awoke. The day dragged by. Welcome sleep brought little relief and (alarmingly) a more evident hemiparesis and hemi-incoordination, with a hint of dysarthria (speaking difficulty), not dysphasia (loss of speech/language comprehension). Things continued to deteriorate, and by the time we had driven back to Auckland to fly home 2 days later, I was in a bad way.

In Dunedin hospital, the thought of the immanence of death at certain points struck me, and I arranged to make my will. Scans intruded and clarified the lesion – large and left basal ganglia (an area of the brain associated with movement, cognition, and emotion), which was clearly related to the nearly blocked left carotid artery origin.

Despite my speedy transfer to Wakari Hospital (the Dunedin rehabilitation unit) and after I had had an inspiriting philosophical exchange with a woman X-ray orderly, which somewhat allayed my worst fears about my mental integrity, Shirley had alerted the family. Desolation no longer loomed, and the ties that bind made their presence felt literally dragging an almost shattered impetuous soul back into life.

The Glimmer of Light – A Little Help from My Friends

Shirley having swung into action, the family were immediately brought "up to speed" with my daughter, Rachel, and granddaughter, Anais, winging their way from Amsterdam. They arrived in Dunedin and were soon at Isis Rehabilitation unit. Family encouragement varied from total positiveness to urging further effort out of anxiety for my recovery. Memories of Anais come to mind tossing a ball for me to catch and patiently fetching it as I repeatedly failed and gradually improved.

Early psychometric testing revealed deficits and conveyed the approved functional localization message with a suitable clinical gravitas. Yet my experience over time told a slightly different story. Yes, I had cognitive and memory "gaps." But these proved to be dynamic symptoms within a broader associative neural network that was designed to re-adapt itself to an ethological niche of linked activities constituting my idiosyncratic personal history. Science, medicine and healthcare were important, of course. Nonetheless, for professionals, they were often limited to investigating variables that could be codified and quantified with statistical recovery trajectories that my own research had questioned.[2]

The way that my "support crew" and I melded the lessons into my life was a matter of creativity and commitment. This could not be made to fit the "procrustean bed" of scientific study except in crude, almost inhuman terms. The scientific neuropathology needed human skill, relatedness, and virtue to forge a recovery out of the neural disability and preserved function.

The Redeeming Move – Companions

The journey "there and back again" thus requires companions whose qualities differ but, if one is lucky, complement each other (like "the fellowship of the ring"). Working with all of them was Shirley, the loving and demanding orchestrater, a person who had, as part of the mix, to maintain her own "being in the world" – a difficult juggling act in the shadow of disability.

The family were a great support crew, but New Zealand to Europe is a daunting gap to bridge, although the internet is a great epigenetic enabler. Messages home from abroad carried value that any recovering person becomes addicted to, and that lift the spirits, inducing a desire to go on improving "until we meet again." And in COVID-19 times, the words "don't know where, don't know when" really apply. But the offstage relationships affectively nurtured the hope "but I know we'll meet again some sunny day." These echoes from a childhood world bridging to the past become salient at times of reflection, of which there are many in hospital.

But family can only do so much. Other mental and lived scaffolding must enter the story to move it on. My friend and coauthor, Walter Glannon, took the stage, and a book project became "a thing" not just

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"a pipe dream." The book was *The Neurodynamic Soul*[3] and, as it began to take shape, Walter observed "This is a summary of your last 40 years of work." Indeed, it was probing into the relationship between contemporary neurodynamics and the philosophy of mind and language and, in doing so, involved learning a great deal of neuro-philosophically informed metaphysics, existentialism, philosophy of science, and esthetics. In that work, we arrived anew at a place we had explored separately many times before, and "knew it for the first time." It was a satisfying synthesis of science and phenomenology.

The cerebrovascular event had provoked a unique life journey in an unstable realm full of danger and pain. It did not result in personal destruction, though, but renewal. The return to harness was a burden assumed with relish as it constituted a reawakening of the mind. My recovery had reached the stage of being conceivably useful in fulfilling my pre-stroke calling with the immense gains in perceived self-worth.

A feeling of fulfillment in taking up the challenge of creative scholarship anew is an important lodestone for a university academic. I have been fortunate to have that guide and motivation restored and have seen it at work in many others whose "happy place" was also a place of participation as the person what each of us was – the same but different.

In my training as a medical student, I had many formative experiences, including a salient meeting in the wards with a patient in "locked in syndrome." In my days at Oxford, I was encouraged to write about the persistent vegetative state, and in my career as a medical ethicist to develop the idea that recovery involved a problem-solving partnership between the healthcare team and the patient. In my stroke, I "walked the talk." The "help from my friends" was a major part of that journey, though a "fate," as Nick Chisholm calls it "I would not wish on my worst enemy." The journey from the last of my cascade of strokes has left me changed, with a constant awareness of the proximal (near the beginning of the vessel) carotid artery (one of the main arteries to the brain) aneurysm (an expansion of the artery likely to cause a brain hemorrhage). But my recovery shows that I, and other stroke survivors, will have their day.

Notes

1. Gillett G., Chisholm N. The patient's journey: Living with locked-in syndrome. *BMJ* 2005;**331**:94–7.
2. Gillett G., Butler M. "When the music's over," then "dancing with a partner will help you find the beat." *Cambridge Quarterly of Healthcare Ethics* 2021;**30**:631–6.
3. Gillett G., Glannon, W. *The Neurodynamic Soul*. New York: Palgrave Macmillan; 2023.

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