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Reinventing Emma Gee: the inspirational story of a young stroke survivor

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Emma Gee

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After learning to talk again, Emma Gee is now an inspirational speaker. *Photo: Thom Rigney*

Emma is a bright, sporty occupational therapist when, in April 2005, after experiencing worsening left-side paralysis, she is diagnosed with an arteriovenous malformation (or AVM), a knot of blood vessels in her brainstem. Doctors relay the frightening news that this tangle of vessels is in danger of bursting – with potentially catastrophic results. After lengthy consultation with the best neurosurgeons in Melbourne and Sydney, Emma agrees to have the AVM removed surgically and on June 17, 2005, at Dalcross Private Hospital in Sydney's Killara, the risky, seven-hour procedure takes place. By the evening, though, her surgeon, Professor Michael Morgan, suspects that she is still bleeding internally and quickly schedules a second operation to remove the remaining AVM and disperse the blood that is pooling dangerously in her brain. Afterwards, Emma, whose condition is now critical, is placed in an induced coma.

DAY 7: I'M AWAKE INTERNALLY, but my body won't budge. I try to stir it again. Move! I command. I want to yawn and stretch out long and then turn onto my side in a warm foetal position. But I lie still. How do I instruct this body? It feels detached from my thoughts. It throbs, but I don't know where this awful sensation is coming from. In fact, I can't figure out where my body starts and ends. The pain seems to morph into the hard surface I'm lying on. I'm in a blur of agony.

Suddenly a bright light breaks through my impenetrable skin. The darkness turns into a glowing orange blur and my eyelids are probed open. "See if her pupils are dilated," a male voice commands, shining a pen torch in my direction. An unwanted beam of hot, stinging, yellow light enters my vulnerable body. I'm not ready to be found yet. The light beams from side to side, disco-like. My pupils are exposed like a deer in spotlights, vulnerable, immobilised and captured.



Emma Gee with her six-year-old cavoodle, Gilbert. *Photo: Thom Rigney*

A distinct flavour of stale blood coats the inside of my mouth. There's a disinfectant smell so strong I can taste it. "Good afternoon, Emma," a deeper voice joins in my wake-up call. Then the voices exchange medical notes about my status. I want to join in their conversation. This discussion is about me, after all. Shouldn't I be included? Has my operation gone okay? But their voices fade and again I'm alone. I opt to sleep, to rest to make sure I muster up enough energy to move or open my eyes for my next witness. The darkness has a heart beat.

When I muster the effort to keep my eyes open, the room is tilted, like a boat, and spinning like a fast ride I'd once been on at the Melbourne show. And there are two of everything. Cloned machines and two tubes sprout from my arm. Like a disjointed slide show, the blurry images gravitate around each other. The world is moving, but I am still. Tubes grow from my body like roots from a tree. I can feel the invasive cold fluid from the bags connected to these tubes travel around my blood stream. I taste blood. I smell fear. Everything to do with this body is now foreign.

Time stands still. My new routine involves being cleaned, rolled and fed by a stranger in darkness. Poked. Prodded. Pinched. Occasionally I see the familiar face of a family member, but their short visits only seem to highlight the distress I'm in. I try to speak to them behind the mask, but what comes out is just muffled and only seems to elicit frowns. How can they expect me to speak clearly with a plastic thing over my mouth? Take it off! I need to tell them what's going on so they can get me out – make them see that I need to escape this hell I'm trapped in.

Noise is torture. The constant humming of the fluorescent lights is soon joined by the collision of rubber soles with the lino floor. Each footstep causes a high-pitched scream inside my head. Why do I have no idea which direction these sounds are coming from? I can't anticipate their direction because my eyes won't budge sideways and my neck won't turn. The nurse has positioned my head in a downward direction and all I can see is lots of feet below the curtain at the end of my bed. The ripping sound of the curtain, as the thin, blue material is gathered along the silver track above my bed, penetrates my entire body and reverberates painfully in my head.

Every hour, the curtains are drawn, two staff enter and then, "on the count of three" I am turned. I feel like a tangled chain of kabana at the butcher. Although I'm just being rolled over in standard hospital style, to me it feels like I'm continually being spun round and round in a hammock. "Enough!" I inwardly shriek. As a kid on a swing I'd loved this kind of adrenalin rush, the grey metal chains twisting and spinning me. Now it is terrifying and I feel permanently out of control. After each turn, the dizzy blur doesn't ease; the double images spin around me in constant motion.

"Now Emma, the doc says that to get out of [intensive care] we have to get you drinking, get your fluids up." A nurse sits next to me balancing a tray on her lap with a spoon, a plastic jug and a cup. She drops two spoonfuls of a thick, white substance from a large jug into a plastic mauve cup. I choke unless all fluids are thickened. With a teaspoon, she brings it to my mouth. I'm confused. I'm meant to drink to get out of this prison, but this isn't fluid.

"Open your mouth, sweetie," she instructs and opens her own mouth wide hoping that I'll copy her. The teaspoon is pressed against my lips, waiting for permission. I tell my brain to widen my mouth but it refuses to co-operate.

"Open wide," she repeats impatiently. I feel like a toddler refusing to eat. She forces the teaspoon between my lips and scrapes the tasteless metallic clag-like contents against my teeth. It pools in my mouth and then seeps out, the clear muck oozing. The nurse wipes me, saying, "Let's clean you up, Sweetie, it's all over your chinny chin chin." Great, I'm drooling and I can't even tell.

Each visit from my close family brought warmth and familiarity into the stark environment, but their complexions were greyish, the worry zapping any colour. They seemed upset. If only I could move to comfort them, I thought. My sisters paint my toenails bright pink. The colour is a welcome contrast to the cold whites and greys of my surroundings. I know, though, that I'm going to need something way brighter than nail polish to fully wake up this body and help me on my road to recovery.

AS THE MEDICATION WAS REDUCED and I became more alert, I started to get an inkling of what had happened to me. All the time in ICU I'd convinced myself it was the drugs that had been stopping me from getting back to being my old self. How could I recover with all the hospital paraphernalia, the mask and tubes smothering me? Now it slowly dawned on me that even my close family couldn't understand me. I longed to communicate and escape the terror I was trapped in. But I couldn't, the words inside me seemed set in concrete.

They call on Bec, hoping that as my identical twin she might be able to comprehend my gibberish. But she just shakes her head at my attempts to communicate. Her lips begin to tremble and her eyes well up with tears. She has no idea.

Determined, she arrives a few days later with a red magnetic letter board under her arm and a big grin as if to say, "I don't know why I didn't think of this earlier." I inwardly smile back – finally a way to communicate! She holds the board near my right hand and puts the loose letters in my

flaccid fist, wrapping her fingers around my useless digits to guide them. But she must have lathered the colourful letters in soap as they are too slippery to grip. This is no time to play tricks, Bec, I silently huff. My blood pressure rises with my frustration and soon the nurse is with us and sternly saying to her, "You'll have to stop that and go."

I opted to have this procedure. I chose to have my head cut open to remove the teeny weeny thing in my brain. Although I'd heard the associated risks and signed my will, deep down I thought the chance of anything bad occurring was unlikely. In my mind I had thought I would get this over and done with and return to my life as a normal 24-year-old, living independently, running and working full-time again. Becoming disabled was not part of the plan.

The truth was dawning. I'd had a stroke. I'm too young to have had a stroke. I'm an active healthy girl. Aside from the odd cold, I've never been to many doctors. Plus, I'm an occupational therapist. This shouldn't happen to me. My patients have strokes, not me! But there was no doubt. I'd had a bleed in my brain and acquired all these deficits. My medical file now had a long recent history. Dysphagia, dysarthria, nystagmus, diplopia, sensory, balance and mobility deficits. All big medical terms that I understood in theory but was now experiencing first hand. Terms that I used daily as a health professional that seemed to stress the importance of my role and add to my credibility. Now I was beginning to see that, to a patient, they were just gobbledygook, adding unnecessary confusion and complexity to their situation. How differently I viewed the medical jargon now that it applied to my own body.

In plain English, I had trouble swallowing and needed tubes shoved inside my throat to help me (dysphagia); people couldn't understand me (dysarthria); I wobbled like jelly (ataxia); I couldn't point directly at anything and approached any object in a zigzag fashion (dystonia); my world was angled (vertigo); I couldn't control my bowels and needed a catheter to wee (double incontinence); I now saw two of every image – and trust me, seeing one bed pan was enough! – (diplopia); my world now spun (nystagmus). My left hand clawed in like a scared turtle hiding in its shell (left-side paralysis); my mouth permanently drooped to the right, my eye wouldn't close and I drooled (right-side facial paralysis.) But wait, there was more. They were predicting that my balance and mobility would also be an issue when I got out of bed as the bleed was in my cerebellum, the control centre for balance.

I dreaded how many more deficits I had yet to discover. At just 24 I had been in full flight.

Now, my wings had been clipped. I might never fly again.

As I became more awake and aware of my surroundings I found my life depended on and was dominated by hospital staff. In my former life nurses and other health professionals were just part of the team, but now as a patient my relationship with them was quite different. I was helpless, a child, so reliant on their good grace to get through each day.

"Okay let's get these staples out," says the nurse, after parting my remaining hair as if looking for nits. Is she sure? These metal clips have clamped my head together and, although I hate them, I can wait. Besides I've already endured 10 days of not washing what's left of my hair. But she is ready even if I'm not. She slips on a pair of rubber gloves, grabs a green kidney dish full of instruments and fiercely grips a pair of giant tweezers.

"Now just sit still and let me get these buggers out," she instructs through clenched teeth. Sit still? Even if I wanted to squirm free, I couldn't! I try to close my eyes.

"Gawd I've had an awful morning today. I woke with a horrendous headache and haven't felt right all morning – think I need another coffee," she says, plucking the metal clips from my skull. Am I hearing right? She's complaining of a coffee-deprived headache while plucking these things one by one from my head. Plus she is carrying out this procedure when she's tired. Great!

Being young, mute and mentally alert made me the perfect sounding board for nurses' concerns. I'd lie there unable to sleep while their caffeine-loaded bodies dumped their personal sagas into my vulnerable ears. One nurse interpreted my night "buzzing" for a drink as boredom. She danced my toy lion around my bed, putting on a deep voice. "My name's Simba the lion, I will protect you." She seemed to think she was entertaining a kid. I lay there thirsty and humiliated, longing for a means to convey my needs.

After the stitches were taken out came another milestone – the day they removed the catheter. What a relief! But then my continence was tested. If I sensed I needed to do a wee I'd call the nurses and they would assist me to the toilet. Often I'd try so hard but there'd be no action, even when they tried the running water technique. One nurse saw my inability to go as a huge time waster and, with a long, loud huff and a look at her watch, stood about one metre from me, expecting me to go. How could I when she was hovering over me? I was toilet training again.

The first time I walked I needed a physio and two nurses to support me. Each strongly gripped a limb or section of my unco-operative puppet-like body. I was so bendy that they all struggled to co-ordinate my limbs. Apparently, in that initial attempt I only walked three metres. A few months before, three kilometres had been a tiny distance. Unable to walk me, they returned me to a huge bear-like chair that was so soft it almost swallowed me. Exhausted, I slept.

When I wake I see a young girl staring directly at me. "Look at her," I gasp inwardly. "Poor thing." Her weak, pale body occupies a similar chair to mine. Her body seems flaccid, her limbs strapped in. Her torso is tilted to one side, angled like she's about to fall asleep. A white folded pillow acts as a bumper, positioned on her right shoulder, and forces her neck to sit upright. Her facial features look wrong, asymmetrical, almost like a mosaic we'd studied in art at school. She only has one eye – the other is hidden behind a white eye pad, and her mouth is askew. She's obviously had surgery on her head. The right side is shaven and staples bridge a 20-centimetre bloody incision. Greasy tufts of hair sprout from the other side of her skull ... Then the blue knitted poncho around her neck catches my eye. That's the garment my grandma gave me! Why is she wearing it, too? With a shock I realise it's mine and this is my reflection. This is ... me. This is me. What has happened to me? This girl is me. Terror surrounds and engulfs me.

In July 2005, Emma was transferred from Dalcross Private Hospital to Royal Talbot Rehabilitation Centre in Melbourne's Kew for six months of intensive therapy, during which time she began to learn again how to walk and talk. Afterwards, she moved back in with her parents, Lyn and David, for a year before buying her own unit close by. She lives there today with her six-year-old cavoodle, Gilbert. She has since launched her own inspirational speaking business, regularly offering her thoughts and solutions on resilience and person-centred care through her keynote

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