



been called the worst music video ever made. I'm playing Edwin the YouTube video "It's Friday, Friday, gotta get down on Friday" in the forlorn hope an earworm might trigger Edwin's memory of the date. Every half hour the nurses ask him the date. He looks blank each time. I try flash cards with Friday written on it but to no avail. Edwin is impervious to learning.

In the days after Edwin's stroke I obsess about Baz Luhrmann's *Sunscreen* song. The lyrics are uncannily prescient. "The real troubles in your life are apt to be the things that never crossed your worried mind. The kind that blindsides you at 4pm on some idle Tuesday..." Baz implores people to wear sunscreen. "If I could offer you only one tip for the future, sunscreen would be it," he draws.

And to that I would add: and check your blood pressure. Doctors believe Edwin's brain haemorrhage was caused by longstanding hypertension. He took medication for high blood pressure for several years. Two years ago, on a hot night after a couple of beers, Edwin fainted, fracturing his skull on the footpath. He was told his blood pressure had dropped too low and to stop taking the medication. He went cold turkey.

I am angry that no doctor thought to monitor his blood pressure over the next two years. Unbeknown to us it remained dangerously high. The pressure built in the blood vessels in his brain, until a catastrophic event, to use the medical term, caused them to explode one sunny Tuesday.

**Edwin's progress is remarkable. The speech therapist asks him to list every animal he can think of. She interrupts mid-stream: "That's enough". The first time they did this exercise all he could**

**Edwin, son Ted and partner Jewel must cope with an altered reality after Edwin's January stroke and life-saving surgery.**

Photos: Jason South



**'He requires life-saving but at the same time life-threatening surgery.'**

say was "lion". We look at the site of the haemorrhage on the MRI. There is a big black smudge where all the brain cells have been wiped out. This region of the brain plays an important role in motor control, co-ordination, balance and posture. No one can quite believe he is not only walking but can stand on one foot. A neurosurgeon sweeps past on his rounds; entourage in tow. "Lift your hands above your head," he barks. "Push against me. Squeeze my hand. Flex your toes. Show your teeth. Puff out your cheeks." He shakes his head. "Frankly, I'm amazed," he tells the entourage. "I mean this guy has lost half his cerebellum."

Nine days after the stroke Edwin is discharged. The doctors line up to congratulate him and shake his hand. We had been told he would be in hospital for six weeks. Secretly, my sister is worried it is too soon; that everyone has been carried away by the medical miracle. She is right. Less than 24 hours after he is discharged Edwin is back in the emergency department.

There is an episode of the ABC program *Q&A* that will always haunt me. Simon Sheikh, then director of *GetUp!* has collapsed on the set. Liberal MP Sophie Mirabella recoils from him, a look of horror etched on her face. Mirabella is pilloried for being so heartless but I can relate to shock. Edwin has collapsed on the kitchen floor. Waves of sweat are washing over him. The salad bowl is overflowing with vomit. His body is jerking like a marionette. I am timidly offering him a glass of water.

It takes the paramedics 40 minutes to stabilise Edwin before they can transport him to the ambulance. They say he is on enough medication to slay an elephant. The cocktail of drugs has sent his blood pressure crashingly low. He is readmitted to hospital for another four days to "tweak" the regimen. Edwin returns to hospital twice more before his blood pressure finally stabilises.

I am overwhelmed by the kindness of friends, family and our colleagues. Care packages arrive daily. My mother's group, 12 amazing women whom I hardly know, organise a food roster. One woman knocks on the door; bearing schnitzels and potato salad.

"I figure you probably have enough lasagnes," she says slyly. How does she know the freezer is groaning with every conceivable permutation of lasagne? I laugh, for the first time in days, and then feel guilty lest I seem ungrateful. "My brother had a stroke several years ago," she says. "My husband and I can never look at a lasagne in the same way again."

Acquaintances, some of whom I barely know, send extraordinary messages of hope. They tell of their own experiences of stroke, of brain acquired injury, of life-threatening illness. I am shocked by the suffering everywhere; how could I have been so oblivious?

Fatigue is one of the most common side-effects of stroke. It sounds like a such a benign problem to have. But fatigue is pernicious and debilitating. I have new sympathy for people who suffer glandular fever and chronic fatigue. Edwin spends most of his days in bed but is never rested.

Friends pop by, Edwin looks so well, they say, so normal. I can tell they are nervous about what to expect and leave hugely relieved. It will take Edwin eight hours to recuperate from their

10-minute visit. One day he insists we go to Aldi to buy nappies because they are vastly superior to those at our local supermarket. We get to Central West Plaza and he is too exhausted to get out of the car. We go home without the nappies. I am shaking with rage. I know it is irrational but I never wanted the f--king Aldi nappies in the first place.

We argue about gratitude. It annoys Edwin when people tell him how lucky he is. He prefers the word "arsey". He says he is unlucky to have had a stroke. I worry we are not grateful enough. The gift of perspective is supposed to be the one trade-off of a near-death experience. And yet we are not gentler with each other and the sunsets are not brighter. I still sweat the small stuff. I am annoyed with a friend when she cancels dinner. It infuriates me when drivers don't acknowledge with a wave when I let them in. I catastrophise daily; I have allowed Dr Google to persuade me Ted has autism, is cross-eyed and developmentally delayed. Where is my warm fuzzy glow? A friend, who is in remission, tries to reassure me. He is crankier now than he ever was before he had cancer. This is tough on his family. Recovery is not easy.

Edwin has started rehab. It is a disaster. I drop him off; he is the only one not inching towards the door in a Zimmer frame. Crocheted coat-hangers are on sale at the front desk. The TV is blaring infomercials. Edwin comes home ranting. Appointments have been made without notifying him. The physio has refused to touch his neck. The speech therapist has recommended a big book of crosswords as therapy. He fulminates with frustration and then collapses into bed exhausted. It is odd how we feel the need to be compliant when sick. We want to be patted on the head.

Weeks go past. Edwin seems almost institutionalised. He insists on going to rehab even when I am convinced it is making him worse. I snap when the neuropsychologist rings Edwin to tell him she has asked VicRoads to suspend his driver's licence. Edwin had been cleared to drive months ago by the most senior member of his stroke team, a neuro-interventionist. Psychologically and practically, this loss of independence is a massive blow. It is also the last straw. Edwin tells the rehab team he will not be back.

Different Strokes, a charity for younger stroke survivors in the UK, says recovery and rehabilitation from stroke present particular challenges for younger people. "One day fit and well, the next moment on sick leave, often with a young family to support and relying on employment for income rather than a pension," its website says. "The specific and complex needs of the younger and more active stroke survivor have not received the full attention that they deserve."

Life slowly returns to normal. Edwin's GP now co-ordinates his rehab. He is happy with his new physio, who gives him exercises for his neck. Six months after the stroke Edwin returns to work part-time. I wake one night. It is 3am, the witching hour.

Ted has been unsettled and Edwin has brought him into our bed. He is asleep in the crook of Edwin's arm, his long black eyelashes studded with tears. The two of them snore softly. Suddenly I get it, the long-awaited gift of perspective. I am lucky beyond belief. I watch my partner and my son and know I am not alone.

National Stroke Week, September 8 to 14, is an annual event to raise awareness of stroke. [stroke.foundation.com.au](http://stroke.foundation.com.au)

family from Adelaide, Edwin's aunt from Townsville, his brother from Canberra, his sister from New Zealand, a best friend from Adelaide. Edwin's father, whom he has not seen for 25 years, has been in touch. He wants to visit.

**When a brain has undergone trauma it doesn't lay down new memories. Every day I tell Edwin he has had a stroke. Everyday he looks astonished - no one has told him that. He later says it is only when he sees he is wearing compression stockings to prevent clots - the uniform du jour on the ward - that he realises he is in deep shit. The neurosurgical team and the stroke team are in furious discussion over whether to give Edwin blood-thinning drugs. These could save his life by busting the clot that caused the second stroke thereby preventing another stroke. Or they could cost him his life if they reignite bleeding at the site of the initial haemorrhage. The decision is made not to administer them. Ted is grizzling, I push him around the ward. A chart on the wall says one in three stroke patients will die.**

Sixty five per cent of stroke survivors also suffer a disability that impedes their ability to carry out daily activities unassisted.

There is a ghastly teen-pop song called *Friday* by Rebecca Black. It's