

# My partner had a stroke at 46: how my family's life changed one sunny day

A stroke is the sort of thing that happens to old people, not people in the prime of their life, right? Not so, writes Jewel Topsfield.



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My partner of 17 years is puking into a Crumpler bag in the back of a cab. I am irritated with him; this stomach bug is jeopardising my dinner plans. I grimace out the window; repulsed by the thought of cleaning the canvas bag. I imagine scrubbing lumpy spew out of the red seams and idly wonder whether I have the temerity to drop it at the drycleaners.

Edwin had called from work. He had a severe headache and nausea. His boss was insisting I come and pick him up. This is overkill surely? It is obvious what is wrong: man gastro. A locum doctor confirms the gastro part of the diagnosis, and gives Edwin a Stemetil injection to treat the nausea, vomiting and dizziness. With the martyrdom of a freshly minted mother, I agree, between gritted teeth, to take our four-month-old son with me to the dinner party.

## ADVERTISING

Jewel Topsfield, Edwin and Ted at home this week. *Photo: Jason South*

Edwin vomits all night. As dawn breaks I suggest we go to the emergency department, not because I am particularly concerned, but because the relentless vomiting makes it impossible for him to keep down painkillers. Edwin is grey and unsteady on his feet. He can barely stand by the time we get to hospital but dutifully helps me lift the stroller out of the boot. This last act of chivalry will remain seared in my mind.

In the cubicle of the emergency department I repeat my glib diagnosis. Our son, Ted, is fractious. Edwin is in good hands, I figure, so Ted and I can have an adventure. It's a golden day. We wander along Lygon Street, I eat ricotta-flavoured gelato and try on a peasant-style top. Ted eats grass in Argyle Square. This was how I had imagined maternity leave during years of infertility and IVF. I don't realise it at the time but this glorious sunshine, the final spoonful of melted icecream, is my sliding door moment, the point at which life is interrupted.



Rebuilding: Jewel, son Ted and Edwin are living with their altered reality after Edwin suffered two strokes in January, aged 46.

*Photo: Jason South*

When I return to the hospital, a registrar offers to walk me to Edwin's bed. He is obviously distracted but is trying to be polite: "How old is your baby?" This should be a red flag; registrars are usually too busy for small talk. A group of people are huddled around Edwin's bed. The physician selects her words carefully. The gastro, she says, was a red herring. Edwin's blood pressure is extremely high. An MRI has revealed a bleed on the brain. "A bleed" is such an innocuous phrase. I think of a bruise; it looks worse than it is. I must look blasé. "This is very serious," she says gently.

The next eight hours are a blur. One moment I am on the phone to mum, who lives in Adelaide, the next moment she is with me in the brain tumour resource centre. A box of tissues is in the centre of the table. I don't let myself think about why the tissues are there. The neurosurgeon is bald, like Edwin. He is grave but sensitive; putting the lie to the stereotype that surgeons and good bedside manners are oxymoronic. Edwin has had a stroke. He requires life-saving, but at the same time, life-threatening surgery. The bleed, or haemorrhage, is blocking the supply of oxygen to the brain. A craniotomy will be performed in which a bone flap is temporarily removed from the skull to relieve the pressure. If the surgery goes badly, Edwin could be left severely brain damaged. He may spend the rest of his life in a nursing home. Or he could die. Edwin is 46.

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Stroke is Australia's second biggest killer after coronary heart disease and a leading cause of disability. And while we inevitably associate it with old people, stroke doesn't just affect the elderly. Thirty per cent of strokes happen in people under the age of 65. And they can be particularly devastating at younger ages given the potential impact on young families and careers and the shock loss of self and identity.

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Life-saving: Edwin underwent surgery in January after the 46-year-old suffered a stroke out of the blue. *Photo: Jason South*

Edwin is flirting with the nurses. This is slightly disconcerting; he is normally so phlegmatic. "Hell? The Grand Canyon?" he quips when nurses ask him if he knows where we are. Nurses aren't paid enough to put up with all the dad jokes they must encounter. We are in the theatre recovery room in the bowels of the hospital. The neurosurgeon rang at 3am to say the six-hour surgery had been a success. However Edwin's blood pressure is still so high he can't be returned to the ward. He has a gruesome L-shaped wound in the back of his head. It is closed with a row of gigantic bloodied staples; he resembles an evil character from a Bond film. A tube emerges disturbingly from a hole in his head draining fluid from his brain.

Edwin confides he is as high as a kite. He is trying to get me to shoot a video of him breathing into an oxygen mask in a menacing fashion in a parody of Frank Booth in *Blue Velvet*. My sister, Rom, a doctor in Adelaide, has driven through the night to get to the hospital. "My personal physician has arrived!" Edwin trumpets. This ebullience is plain weird. "Has Edwin had a personality transplant?" I ask Rom. She hesitates. "I think he may be disinhibited as a result of the pressure on his brain," she says carefully. I figure I can live with this new effervescent Edwin. And then everything goes to hell.



Edwin and son Ted.

Edwin is reciting a list of what he wants me to bring to the hospital. Deodorant, fresh underwear, my laptop. I have half tuned out. And then his words jam. I jerk to attention. I don't have a clue what he is trying to say. And then his hands are shaking; he manages to convey he is freezing. I scream for the nurse.

An MRI reveals Edwin has had a second stroke. This time it is a different type of stroke, caused by a clot on the brain instead of a haemorrhage. His right side is weak, he has lost periphery vision and most devastatingly, he has lost words. At his worst; he speaks gibberish; the anguished string of nonsensical syllables produced by mentally-ill men on trains. At best, he is hopelessly confused. The date is 1967. He is 28. He is in Adelaide. There is something about dead dogs. When the speech therapist asks what it feels like when he tries to speak he says that if he can't see things they disappear. I have no idea if this is supposed to be a metaphor. I can cope with anything but this. A wheelchair, incontinence, but not this. I can't do it. I go home.

We are on the high -dependency neurosurgery ward. The patients all have dead eyes and plaster tape on their head. The visitors all wear the same frozen expression.

My sister stays with Edwin throughout the long, terrible night. He has deteriorated further. She arrives at the doorstep at dawn, ashen-faced. She knows it is painful for me but I have to come back to the hospital. The consultant has told her Edwin could have a third stroke and die within the next 48 hours. We need to assemble everyone who wants to say goodbye.

We are on the high dependency neurosurgery ward. The patients all have dead eyes and plaster tape on their head. The visitors all wear the same frozen expression. Tragedy lives here. There is a girl who looks lobotomised. She had an accident and an MRI searching for concussion found a brain tumour instead. At night another girl screams: "Stop bothering me, leave me alone." She has hurt her spine; the nurse warns if she doesn't keep still she will not walk out of this hospital. Fear has a soundtrack; it's the beep, beep, beep of machines that suddenly become shrill - b, b,b,b,b,b,b,b,b. High dependency wards are like purgatory. Get better and you go to another ward; get worse and it's intensive care. We don't see anyone come back from intensive care.

We are all here. My 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 patients who have a stroke will die. Sixty five percent of those living with stroke 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 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: "Is it after my birthday?" 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 drawls.

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 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. Edwin's sister is screaming at me to call an ambulance. "How do I do that?" I want to ask her.

It takes the paramedics 40 minutes to stabilise Edwin before they can transport him to the ambulance. They say Edwin 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. Once because his GP is alarmed by the high reading. Another time Edwin collapses on the toilet. I am pounding on our next door neighbour's door at 2am; asking them to take Ted as Edwin is carted off in the ambulance yet again. I dream Dad has a stroke. I try to call the ambulance but my sausage fingers fumble and I keep hitting ;) instead of 000. After half an hour I get through and the operator tells me I have the wrong number.

I am overwhelmed by the kindness of friends, family and our colleagues. Care packages arrive daily on the doorstep. 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 least 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.

A 2014 study of young stroke survivors found the shock of diagnosis, the initial symptoms and the impact on day-to-day functioning, which was once second nature, were met with much frustration. "Frustrations at losing certain abilities, such as multi-tasking, which is critical to juggling work, child-rearing and other social activities were common," according to the medical journal report [Life interrupted and life regained? Coping with stroke at a young age](#). "The impact that the stroke had on family, marriages and social relationships was noted."

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 and changed 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 a good patient, 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 neurointerventionist. 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 states. "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, which runs from September 8 to 14, is an annual event that aims to raise awareness of stroke and encourage Australians to take action to prevent it. [strokefoundation.com.au](http://strokefoundation.com.au)

Recommended

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