

All
about
my

Actress Carol Willesee was a sassy 58-year-old when her body and mind started to mysteriously fall apart. And few in the medical system seemed to care. Here, **Amy Willesee** recounts what happened next.

mother



IT IS JUST OVER A YEAR SINCE TWO AMBULANCE officers wheeled my mother, Carol, into the clatter and dash of a hospital emergency department at 9 o'clock on a Saturday night. She was sleepy and confused, dehydrated and having trouble speaking, but she was happy, she mumbled, because she was about to have a baby. "Make sure Dad [media legend Mike Willesee] knows he has to look after you while I'm having the baby," Mum instructed. "Okay," agreed Lucy, my 29-year-old sister, as she slipped Mum's thin arms into a hospital gown.

Incoherent, delusional, no longer able to walk unassisted and in need of constant supervision, Mum was now unrecognisable as the strong, sassy 58-year-old of just five months earlier. And the scariest thing was, nobody could tell us why.

WHEN MY TWO SISTERS AND I WERE LITTLE GIRLS, we thought Mum was a princess. We'd watch her at her dressing table, laid out with its antique silver hairbrush and pretty perfume bottles, brushing her long golden hair. She was beautiful.

As it turned out, she wasn't a princess at all. She had too much spunk for that. She danced on tabletops, laughed with an almighty snort and was happiest either in her King Gees driving a tractor or having dinner with her girls. The best meals at Mum's were always running late because they were so full of dancing and silliness. The night I introduced her to my future husband, she interrupted dinner to lead us in a handstand contest.

She took great juicy bites of life and chewed like crazy. In her late 30s, having seen my youngest sister off to preschool, she embarked on an acting career, bagging a Sydney Theatre Critics' Circle Award for best newcomer before going on to fulfil her dream of playing Blanche in *A Streetcar Named Desire* at the Opera House in 2000. Later, with no farming experience, she took on a vineyard in the Hunter Valley.

By 2006, she was living on a gorgeous old dairy farm in Berry, two hours' drive south of Sydney, running a small herd of Murray Grey cattle. Then, one crisp June morning, she woke to find her legs tingling – a feeling like champagne running through her veins. For eight days the bizarre sensation persisted, along with an aching in her legs and back. She made an appointment with her GP, who prescribed something to relax her muscles. But her symptoms started to multiply.

The Panadeine Forte stopped working. Her feet felt inexplicably cold. She couldn't sleep, couldn't stand bright light, couldn't remember things. She began a round of doctors' appointments, but nobody could figure out what was wrong.

By her 59th birthday in early August – just two months later – she couldn't walk in a straight line and had difficulty sitting due to the pain. Her eyesight was deteriorating and, when she swallowed, it felt as though she had golf balls in her oesophagus. Pretty much all she wanted to do was lie down and close her eyes. Of greater concern than the physical symptoms to us at the time was that she seemed like a different person. We couldn't say quite what it was, but something in Mum had changed. She was submissive and fearful, disconnected. She didn't seem interested in us. Didn't want to hold my new baby.

She had brain scans, spine scans, blood tests galore and everything was normal. Only she *wasn't*

normal. Acquaintances who saw her in the street were stunned by her appearance: one thought she'd had a stroke, another a car accident. A tremor that enveloped her whole body would come and go. But it was in October, four months after her legs started tingling, that I began to get really scared.

Her rapidly deteriorating condition had forced her to move up to her apartment in Sydney, where Lucy and I could visit her every day. (Our other sister Jo, 27, was working in Ethiopia.) She had a live-in nurse. She had a wheelchair. A *wheelchair*. Holy crap. How had it come to this? Then I phoned her one day and asked how she was. "Good," she replied, not sounding at all good. "Jo was just here." By now, she had become difficult to understand, her thoughts jumbled, her words slurred. I thought I must have misheard.

"Jo was just there?" I checked.

"Yes, Jo was here. She's just left."

I felt sick. Jo was still in Africa.

MUM HAD HAD AN EPISODE OF DEPRESSION 10 years earlier, so there was enough of a history for the specialists to concur: in the absence of a physical disease, her symptoms were psychosomatic. They called it conversion disorder. It seemed bizarre that such severe symptoms could be triggered by an emotional event, but we were assured it happens. People can develop paralysis, lose their sight, their motor functions, even suffer seizures, and it's attributed to psychological factors.

So we asked Mum if anything was upsetting her, was there any trauma that could have triggered this. She kept insisting she was fine. She'd been happy before it started. She was distraught now, of course: no one would believe how sick she was. She talked about checking her will. Asked me if I wanted the farm.

"You're not dying, Mum."

She was quiet in the car as we drove her to a private psychiatric hospital, fidgeting pointlessly through her handbag, staring out the window. We hoped we were getting her the right help.

The place felt cold, her room all empty surfaces and bare walls. "We don't normally accept people in wheelchairs," one staff member said, annoyed. "Don't leave me here," Mum begged, struggling to form the words. It was horrendous. But we were acting on the only medical advice we had and we desperately wanted her to get better.

She took it badly, her body shutting down ever more rapidly over the next couple of days. At times, she became almost catatonic, just sitting, staring. When we weren't with her, she'd call, asking us to take her home. Sometimes you could hear her down the line trying to work out how to use the phone or how to talk. She was terrified, hallucinating. People were coming to get her. There were rats and snakes in her bed.

The doctor told us this wasn't usual for patients with conversion disorder. Typically, once treatment was started, they got better very quickly. But Mum was getting worse. His opinion now, he said, was that Mum's symptoms were not consistent with a psychiatric illness. We needed to keep searching. With no referrals, no guidance, the hospital gave us the weekend to make alternative arrangements for her care.

By the Saturday night, though, she was in such a bad way the nurses called an ambulance and that's how she ended up in a hospital in outer

"Meals at Mum's were always running late because of dancing and silliness. The night I introduced her to my future husband, she interrupted dinner to lead us in a handstand contest."

"She took great juicy bites of life and chewed like crazy": (opposite) Carol Willesee with fellow actor Henri Szeps at Sydney's Ensemble Theatre, 1989.

Sydney. Maybe this would be for the best, we reasoned. She was in a public hospital now; someone would have to investigate her condition properly.

PART OF ME FELT RIDICULOUS TYPING MUM'S growing list of symptoms into Google each night after the kids were in bed. But no one else was offering us any explanations. No one else seemed to feel there was any urgency.

One night, I came across a case study from *The American Journal of Psychiatry*. It told the story of a 49-year-old woman, Ms A, who suddenly began experiencing severe lower-back pain that didn't respond to treatment. Soon she developed a body tremor and difficulty walking. All the tests came back normal and she was assured her symptoms would, in time, take care of themselves.

They didn't and, five months later, Ms A was diagnosed with major depression and conversion disorder and sent to a psych facility. Her deterioration was rapid: soon, she was confined to a wheelchair and had double vision, speech problems and difficulty swallowing. At which point she was hospitalised. It sounded exactly like Mum.

It got worse: she began squinting or closing one eye to compensate for her double vision. While standing, assisted, she was unable to place her left heel on the floor. Her legs grew rigid. Ongoing neurological testing revealed nothing; her aggressive treatment for conversion disorder was unsuccessful. Then, one night after dinner, Ms A was found in cardiopulmonary arrest, apparently having choked. Thirty-six hours later, an EEG declared her brain-dead. It was only at autopsy that the mystery of her condition was revealed: her brain tissue was riddled with tiny holes. It gave pathologists their answer: she had been suffering from Creutzfeldt-Jakob disease.

I Googled it. Creutzfeldt-Jakob disease (CJD) is a rare degenerative brain disease, marked by rapidly progressing dementia, co-ordination difficulties and personality changes. It is a "prion" disease, and occurs when usually harmless prion protein in the brain changes shape, setting off a chain reaction by converting other healthy prion proteins into the abnormal shape. This process essentially turns the brain into a sponge. Unlike the more famous variant CJD (mad cow disease), which is a separate disease not yet seen in Australia but thought to be caused by eating contaminated beef products, classic CJD – the one I was looking at – is thought to occur spontaneously and at random. In other words, no one really knows why classic CJD occurs, but if this is what Mum had, it wouldn't be related to her beloved cows.

CJD affects about one person in a million. Symptoms most commonly appear around the age of 65 to 70 – Mum was 59 – and it can be difficult to diagnose. Electroencephalograms (EEGs), MRI scans and lumbar punctures are the best diagnostic tools doctors have, although they're not always conclusive, particularly early in the disease. CJD can only be confirmed with a brain biopsy or at autopsy. There is no known treatment.

THE DAY AFTER THE AMBULANCE DASH TO EMERGENCY, I arrived at the hospital with my sister Jo, back from Africa, to find Mum lying motionless in a dull, soulless medical ward. A nurse told us Mum was under the care of a neurologist, Dr X, and a member of his team told me by phone that

she'd have an EEG and lumbar puncture the next day. I hoped to meet Dr X and discover what was going on. I was worried they would just run their tests and discharge Mum, like everyone else had done. I wanted to make sure, since she could no longer properly communicate for herself, that I could give him a thorough history. I wanted to ask him what he was looking for, what he could do. What if we were all missing something and irreversible damage was being done? Mostly, I wanted to know that Mum was a priority to him, that he was going to see this through to the end.

The nurses said he did his rounds in the morning. So I turned up early. I didn't see Dr X, but I saw his intern, either that day or the next. He turned up to check on Mum, young and neat, breezy and perfunctory, jotting down notes.

"What are you looking for?" I asked.

"We just want to exclude some things," he said.

"What things?"

"Prion disease," he said.

"Like CJD?" I prompted.

"Yeah. But it's unlikely." He finished writing up his notes and left.

Lucy, Jo and I took it in turns to be with Mum. Dr X remained elusive. I gave Jo a copy of Ms A's story to read. She rang me from the hospital one day soon after. "Mum's starting to squint. She's been closing one eye." Another time she reported that, during a physio session, Mum had started walking (assisted) on her toes. Her muscles were spasming so badly that she could no longer place her feet flat on the ground. "Everything that happened in that case study is happening to Mum," she said.

And still no doctor. Nor had the promised tests been carried out. "Tomorrow," they kept saying. It turned out to be five days before the lumbar puncture was performed; 11 before she was given the EEG. A week and a half in which Mum withered, in pain and afraid, waiting for tests to rule out a catastrophic brain disease. The lumbar puncture results would take at least two weeks, we were told. The EEG, however, revealed apparent changes in brain function. That might mean something – or it mightn't. If only someone could explain it to us.

In the absence of a human, I took to rifling through Mum's chart. There I saw an entry from the neuro intern: "Patient comfortable." *Comfortable?* Was he serious? Nothing about Mum looked comfortable. She was "stiff" and "frightened", as noted by the nurses. "Anxious", "withdrawn", "easily startled". Her muscles were seizing ever tighter. When she held my hand she would squeeze so tightly, involuntarily, that she'd cut off my circulation. Her cheeks were hollow, her eyes haunted. One day I arrived to find her sitting with her right arm held above her head, motionless, like one of the patients from Oliver Sacks's book *Awakenings*. Her muscle contractions were too strong to pull down her arm. Even as her eyes closed for more and more of the time, and she slept more and more, her muscle spasms made her look perpetually tense.

None of this was written in her chart by anyone from the neuro team. And since Dr X was not seeing Mum's condition for himself – according to the chart he saw her just twice in the first three weeks – I don't know how he was keeping abreast of it. Where was he? We couldn't fathom it. We were in a foreign environment, frightened and in shock, watching as, for all we knew, our mum lay dying. It was happening right under the noses of doctors and nurses in a public hospital and, as far as we could see, no one was doing anything. It was left to us to discover her pressure sores, the size of gold balls. Her mouth ulcers and bleeding gums. Most days it didn't even look to us as if Mum's face had been cleaned.

Word trickled down that Dr X wasn't expecting it to be CJD. As far as he was concerned, we were told, she had depression. From what we heard, he wanted to hand her care over to a psychiatric team. We wanted to hear it from him.

Jo asked the registrar to set up a meeting with him. A television producer, she approached it like a job. She researched, looked up words that we didn't understand, wrote a list of questions. She asked our dad [he and Carol's marriage had ended 18 years earlier, but they remained on good terms] to join us. And, come Wednesday, she suited up. But Dr X didn't show up. His young registrar did his best to fill in. Maybe, Jo felt, contrary to his boss, he was leaning towards CJD, but it seemed he couldn't find the words. When Jo pressed him, asking whether we should tell Mum's family overseas that she was dying, he didn't explain that he'd seen others die from CJD and that it wasn't something you forgot. He only whispered, "I can't answer that."

AN ATTEMPT TO GET MUM MOVED TO ANOTHER HOSPITAL AND ANOTHER NEUROLOGIST failed, and by then the test results were due. It was the afternoon of November 27, 2006, when Jo called me at home from the hospital. She was crying so hard I couldn't understand what she was saying.

"Has she got it?" I asked.

"Yep."

"She's got CJD?"

"Yes."

The lumbar puncture results had come back positive. Only the day before, the psych team had been ready to take over from the neurologists. Instead, Mum was handed over to the palliative care team. We never met Dr X.

CJD is universally fatal. Nothing anyone did could have protected Mum from that. But she had been robbed of her choices and her dignity. The chance to say goodbye. For months she had desperately wanted someone to acknowledge how sick she was but, by now, we didn't even know if she could understand her diagnosis.



"CJD is fatal. Nothing anyone did could have protected Mum from that. But she had been robbed of her dignity, of her chance to say goodbye."

Little women: (above) Carol Willesee with her three daughters – from left, Amy, Lucy and Jo – circa 1989.

WITH HIS SANTA CLAUS BEARD AND honest voice, our palliative care specialist was our soft landing. He had a gentle touch when he acknowledged that Mum appeared to be in pain and distress. Why had no one else noticed? He started her on sedatives and morphine, the first time in 25 days she had been given any pain relief stronger than paracetamol. The tension in her body, the distress on her face, finally, mercifully, melted away. Her beauty returned.

Mum was transferred to Sacred Heart Hospice in the inner city, where Lucy, Jo and I sat with her for her last four days, among the gardenias, hydrangeas and lavender that filled her room. Dancing and silliness interspersed with the tears. Until it was time to say goodbye.

In many ways it was like a birth. The births of her children were the happiest moments in Mum's life, especially her youngest, Jo. That was an easy birth, at dawn. Afterwards, her baby at her breast, she ate marmalade on toast and watched the sun come up. **GW**