



# At the stroke of midnight...

Stewart Jackel

In order to help us better understand our patients' experiences, *Australian Family Physician* is pleased to introduce the fourth in a series of articles written by people who are willing to share their stories. Stewart Jackel is a Melbourne writer and editor. He suffered a right side ischemic stroke in January 2002 that resulted in severe left side deficit. He is now walking, driving and working. His cognitive faculties, sense of humour and drive were unaffected: one of the fortunate ones.

The hours between 3 and 5 am were the witching hours. The demons swooped down from the corners of the ceiling into my brain: the terror for the first few nights was paralysing.

Initially, in casualty, it was not so bad. People everywhere: medical staff doing tests, wife nearby, bits of banter. Then up to the neurology ward. Lots of activity: more tests, people with clipboards, experts of all types. But eventually everyone went home and suddenly I was alone. Even the staff in the nurse's station fell silent about 3 am.

It was never dark in the ward, but darkness was not the problem. It was the total psychological isolation. All I needed, simply, was another human. And there was no-one.

I didn't want to wake up dead; I didn't want my wife to spend the next 30 years alone. I didn't want to see my kids distraught and weeping over their carefully prepared funeral speeches. The terror was real – so solid I could touch it; so real that panic built on panic. It didn't help that I knew enough biology to understand what had happened inside my head: that some neurons were dead and the functions they controlled were gone, that 5 cm distant and I'd be dead. I knew that if I could stay awake I'd be okay. If someone could have talked to me I'd still be there in the morning.

The terror persisted until the dawn arrived

and the demons retreated into the corners of the ceiling. They returned, of course, the next night.

After a few days I realised that the longer I was alive, the less likely it was that I would have another stroke. The probability would decrease, but I knew of course, it would never reach zero. A week or so later there was a round table – or more exactly a round bed that morphed into a round huddle – about my next move. This was a matter of high anxiety. It was critical that my preference be heard while the 'argy-bargy' was going on. I was heard, up to a point, but I got the impression nobody was really listening. But eventually I got the rehabilitation I wanted.

Rehabilitation was built on common sense – and lies. The common sense bit was that I was not sick. The nurses had to help me do the most trivial things and that was humiliating. The big lie was that I would walk out in 6 weeks. I handled that because I didn't know it was a lie. Six weeks became seven, then one more, and one more... to 12.

The explorations of the extent of the loss: skin sensations? taste? the ability to laugh? the ability to wink? (no, sorry), does 'it' still work? (yes!) continued. But these were minor worries. Even the speech pathologist and her bloody thick liquids could be borne.

With time the cold fear of another stroke subsided and a survival trick developed in my

head: it's temporary, I'm getting better, soon I'll be back to normal – walking around, using my left hand, touch typing again, playing the piano. But every now and again, wandering cheerfully along life's path, an unforeseen black hole appeared and I fell in. There was only one bottomless black pit, so big that I saw it coming about 30 seconds prior, just in time to push the bell. Thank God David came. I fell apart spectacularly on his shoulder while the hysterical grief at what I had lost and would never get back poured out all over his silent, understanding shoulder.

There was a neuropsychologist in rehabilitation who was good to talk to if I could get an appointment in her part-time schedule. And there were a couple of mature age nurses – one with a severely disabled son – who liked to chat in the small hours. But where was the compassionate, understanding, available human on the end of the bell? There was no-one. Not for me, not for my wife.

And interestingly, when I tried to volunteer into several major hospitals nobody wanted the resource. It was too hard to work out how to handle me even though I knew where the demons were at 3 am.

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