

Trapped in a body that has failed its owner

CHRIS BARRON

HIS eyes are alive with humour and intelligence but the rest of him is, for all intents and purposes, dead.

Except for his hand, which he can barely move — just enough to point at letters of the alphabet printed on a piece of cardboard on his lap. Communicating this way is agonisingly slow.

His mouth hangs open. Every now and then he tries to speak, but the most he can manage is a tortured moan. His frustration is palpable. He gives up and resorts to the alphabet, using a chopstick held weakly between two fingers as a pointer.

After three or four words the effort of keeping his hand aloft becomes too much and it falls onto the cardboard. What he has left four years after being diagnosed with motor neuron disease is pathetically little, but even this is slipping away almost as one watches.

Justin Varian, 55, lived for sport. He played seriously competitive tennis until the age of 18 against the likes of future Wimbledon finalist Kevin Curren.

He didn't have the discipline or focus to turn professional, although his exploits on the court continued for some time at Sun City, where he coached tennis and swimming in the '80s and early '90s. He and his doubles partner were known as Blitz Vinnig and Smokey Robinson, he says. His nicotine-stained fingers leave no doubt about who Smokey was.

He was born in Johannesburg and attended Bishops in Cape Town for several years. It was an uneasy fit and he matriculated at Woodbridge College outside Port Elizabeth, where he learnt rock climbing, swam for the provincial schools team and worked as a lifesaver.

After leaving school, he became a trainee electrician and submariner in the South African Navy for two years.

Afterwards he worked as a buyer in the footwear business, a sports and social manager at Sun City and a general handyman. His choices of work, and indeed love (he had many girlfriends but resisted marriage), were informed by a fear of commitment and a refusal to com-



VITAL SIGNS: Justin Varian led a life of vigour before he was struck by a nerve disease

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promise his independence.

The only reason he worked, he says, was to make enough to indulge his passion for travelling and mountain climbing.

He spent five years exploring Asia, India and Nepal. For a while he lived in Hong Kong, where his girlfriend was a professional dancer. He climbed in the Himalayas and the Atlas Mountains in Morocco, and bungee jumped from the 216m-high Bloukrans bridge, the highest bungee jump in the world.

Although he never drank, he loved parties and being with friends, he says. He was gregarious almost to a fault. Never could stop talking. The soul of

every party, say his friends.

Like Tennyson's Ulysses, he was determined to drink life to the lees.

Four years ago he had what appeared to be a stroke but was soon diagnosed as motor neuron disease. His condition quickly deteriorated, his descent into helplessness accelerated by a lack of modern medication.

His hospital plan doesn't cover him for motor neuron disease. He relies on his brother Robin, who sends money from Ireland where he lives with their mother. She has Alzheimer's.

For three years his world has been a small flat above the Atlantic in Presnaye, Cape Town.

He is carried every day from his bed to an armchair in the lounge, where he watches sport on TV before being carried back again. There is no view of the sea from where he sits or lies, which for the past two years is all he has been capable of. He does have a close-up view of Lion's Head, which he used to run and cycle up. He has to be turned to face the picture.

He's not in physical pain, says Varian, but he sleeps in fits and starts, never for more than four or five hours out of 24. It's becoming increasingly difficult to swallow. He can't manage more than 20ml of liquid at a time and that takes forever. Getting food down is an ordeal, even when thoroughly liquidised. Breathing is getting harder.

The thought of not being able to breathe brings on panic attacks which paralyse him so that he really can't breathe. He has to focus his entire being on controlling the panic enough to take a breath, and then another, until composure returns.

The worst thing about waking up is realising he is still alive.

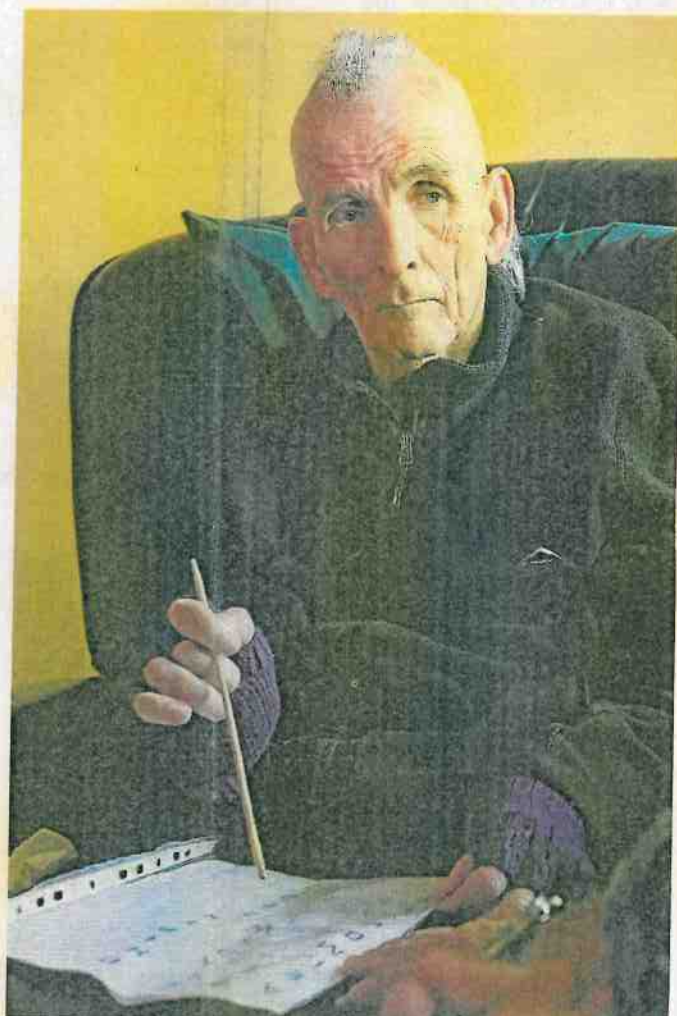
"I stress out when I wake up and know I am still alive," he says, his chopstick moving feebly from letter to letter. "I've had enough."

What is the hardest thing for him I ask.

Under the letters of the alphabet is the word "toilet". This saves him having to spell it out to his carer when he needs to go. He points to it.

"Loss of dignity the hardest for me," he elaborates.

"No secrets. No privacy." At



HEAVY WORDS: Justin Varian uses a list of letters to communicate

Picture: RUVAN BOSHOFF

ter a pause the stick moves again. "Lonely. Isolation."

Friends come around, but because of the communication barrier their visits only enhance his sense of isolation.

He has had enough, he says. He wants to die.

"My body is of no use to me. Useless. I am tired of being miserable."

Varian nursed his neighbour who also had motor neuron disease, so he has no illusions about the road ahead. He has decided to pre-empt the inevitable and leave the life he has lived so fully, on his own terms while he can still communicate. He has asked Sean Davison,

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New Zealand-born professor of biotechnology and founder of Dignity SA, to assist him.

Assisted suicide is illegal in South Africa. A court judgment in May this year which allowed a doctor to assist a terminally ill man to die is being appealed by the government.

Varian's eyes flash angrily. "They allow abortion. But don't allow people like me to

decide when I want to die."

He has no time for arguments against assisted dying.

"Religious nuts can f--- off and get a life," he says.

He doesn't believe in God or an afterlife. "There could be. I don't know."

What if Davison ends up facing a murder rap like he did in New Zealand for helping his terminally ill mother to die?

"Sean must think about it," says Varian. "I don't want anything to happen to him. He has a young family."

We say goodbye. His eyes smile. "I hope you understand my feelings," he says.

Five days later he is dead.