"I had brain cancer, but I'm one of the lucky ones"

Brain cancer destroys the lives of thousands of Australians, so why is it "the forgotten cancer"? Brendan Spain, 56, reveals to Beverley Hadgraft why his survival is so rare

Brendan with his wife, Bronwyn, and two sons, Chris, 27, (left) and Jake, 22

PHOTOGRAPHY: JANINE EASTGATE

"My work life was hugely stressful. I was a financial risk investigator, dealing with billion-dollar companies, I worked very long hours and had an awful diet.

My wife, Bronwyn, was terrified I was heading for a heart attack, but I kept going, until one day, in August 2004, I fell over as I was getting ready for work. Putting it down to exhaustion, I walked into the office, but the next thing I knew I was being wheeled into Royal Melbourne Hospital.

In my groggy state, I registered I didn't feel too well but presumed I'd be back at my desk in a few days. It soon became obvious that wouldn't happen. I'd collapsed due to an epileptic seizure and I continued to have multiple seizures each day. Scans revealed a white mass on my brain; it was a brain tumour, and a decision was made to operate. As I went under, I heard the anaesthetist say, "I don't think this guy is well enough for surgery." The surgeon replied, "It's now or never."

Post-op, I was unable to move my right side, my head hurt like buggery and I was barely able to talk. To gain access to the tumour, a large section of my skull was removed. It was fixed back in place with titanium plates. My brain was still swelling and the pressure was immense.

The tumour, which was on the left frontal lobe, was a grade 3 anaplastic astrocytoma – a malignant brain tumour. I was given a three-year window of survival. My wife and I were 46, our sons, Chris and Jake, were just 16 and 12. As Bronwyn drove me back to our Melbourne home, I felt as I had when we'd brought Chris home as a baby, thinking, what happens next?

Brendan had a bad diet and a high-stress career, which he believes contributed to his brain cancer

EVERY DAY IS A NEW BEGINNING

Ongoing treatment included radiotherapy, in which a mask was fitted over my head and I was secured to a table so there was no risk of me moving and it affecting the good part of my brain. I felt strangely serene during radiotherapy, I think because other cancer patients were there and it was like we'd all moved into this different world.

My family was my rehab team. Bronwyn was fantastic; she was everything from my health advocate to my carer. I slept 18 hours a day but they gradually got me up, eating and walking, although the first 30m to the end of our street nearly crippled me. I tried returning to work but even 30 minutes once a week was too much.

It's now more than 10 years since I collapsed. Each time I go for an MRI, I see the operator confer with a colleague and worry about what they've seen. But each visit to my neurosurgeon, so far, concludes with "the scan is good". Today I consider myself cured of the cancer at least.

My overall health is another matter. I'll need epilepsy medication for the rest of my life, I suffer severe tiredness, headaches, a loss of hand-eye coordination and weakness down my right side. However, I know I'm one of the lucky ones and I feel as if every day is a new beginning.

I've all but closed my mind to my working life and I have no regrets. I'm learning to play golf again, using my left hand to putt, I eat well, I no longer drink alcohol, I walk as much as I can and Bronwyn and I have resumed making plans for our future. We travelled to China last year and plan to visit New Zealand, Europe and the US.

PUTTING BRAIN CANCER ON THE RADAR

I wanted to tell my story because brain cancer is low on the priority list for research funding, even though the mortality rate is high. We still don't know what causes it, although in my case I'm pretty sure stress and mobile phone overuse were contributory factors.

The other problem is those with malignant brain cancer have little opportunity to publicise the issues as our survival rate is so low after five years. Thankfully, there are now good support groups for patients and their families – especially the Olivia Newton-John Cancer & Wellness Centre (oliviaappeal.com), Grey Matters (greymatters.org.au) and Brain Tumour Alliance Australia (btaa.org.au). They were set up too late for me but I hope they can help others."

BRAIN CANCER: FACTS AND FIGURES

WHO DOES IT AFFECT?

Brain cancer accounts for just 3 per cent of Australia's cancer deaths, but it's the leading cause for people under 39. In its malignant form it's almost 100 per cent fatal. About 1600 Aussies are diagnosed with it each year, and about 1200 will pass away. Professor Andrew Kaye, a world expert on brain tumours (and Brendan's neurosurgeon), says it "disproportionately affects young people and cuts them off in their prime".

WHY ISN'T MORE KNOWN ABOUT IT?

"We need more money for research but it's very difficult to get that money without a big lobby group," Kaye says. "Our patients are too ill to fundraise and afterwards the families are so traumatised they just want to move on."

WHAT ADVANCES HAVE BEEN MADE?

There's been considerable progress in understanding tumours but advances in treatment have been modest. There's no routine screening test and it's far harder to treat than other cancers as it can't simply be cut out. However, trials of new treatments have seen the number of patients who live for two years rise to more than 20 per cent. Funding could greatly increase this figure.

CAN IT BE PREVENTED?

Little can be done to prevent brain cancer, but maintaining a healthy lifestyle is recommended – don't smoke or take drugs, do eat well and exercise. Anyone with ongoing, severe headaches, especially if accompanied by drowsiness and nausea, should see a doctor.

Cancer Council NSW is raising awareness with Brain Cancer Action Week from May 3-9. Visit braincanceraction.com.au for details.