

How to live, not just survive

Brain surgery to remove a Grade 2 tumour the size of a small orange? A brain tumour? Three weeks since my diagnosis, but I still could not comprehend the enormity of my situation. How exactly do you take that on board?

Sally White

Ben was the first to speak. “Mum, you look crap.” Sally White did, indeed, look like she’d been through the wringer. A day after brain surgery and swelling, bruising and exhaustion had set in.

Sally writes of her experience, and that of her family – husband David and sons Ben and Josh – since being diagnosed with a brain tumour in 2007.

Three Quotes from a Plumber is an extremely personal and honest account of how the diagnosis changed her life and how, ultimately, she decided it was time to stop the tumour ruling that life.

“Given my experience, I want to encourage people to ask questions [of the medical profession],” she says. And that includes seeking a second opinion.

Sally credits her second opinion – from renowned neurosurgeon Dr Charlie Teo – with dramatically improving her quality of life. “And, potentially, he may have cured me.”

Sally is now 40. She was 38 when diagnosed – 10 years after her mother died from a brain tumour. After initial surgery by another neurosurgeon to remove 95 per cent of her tumour, she was told future treatment would involve regular MRI scans to monitor any changes to the tumour which “might stay the same for 10 or 15 years”.

Sally writes, “That night I said to David,

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‘We have to get it out. I have to have chemo to make it smaller.’”

An appointment with an oncologist followed, where she was told because the tumour was slow growing, it wouldn’t respond to chemotherapy until it became active.

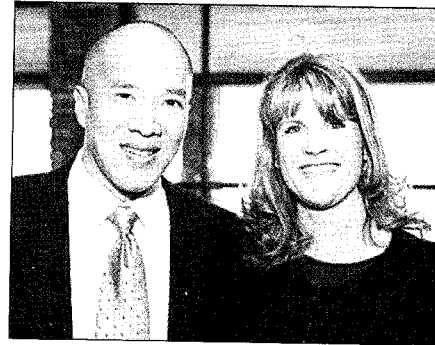
“We left his rooms and it had been decided. No more treatment. I would just have to sit and wait for something to happen. How could I do that? How could I have any chance of getting on with my life knowing there was still a tumour in my head that, at worst, would grow . . .”

By chance Sally met Teo at a conference where he encouraged her to get a second opinion. She did – his. “Dr Teo was more aggressive. He believed the more of the tumour that could be removed, the better the prognosis.”

Teo told Sally if the tumour was left alone it would eventually turn malignant and, when it did, she would die – there was no cure. He said there was no good waiting and, while there was an 85 per cent chance the tumour would grow back after surgery, there was a 15 per cent chance it wouldn’t.

Teo operated. Sally says the surgery has been extremely successful, with minimal deficits as a result. And if the tumour doesn’t grow back, she’s cured.

She says seeking a second, or third, opinion, is not easy, particularly if you are



Sally White with Dr Charlie Teo.

happy with your current specialist. “It can feel like you are being critical, like you are undermining them by searching elsewhere.

“I was not unhappy with my treatment, but I certainly had a feeling of unrest that I’d done all I could.”

She says it is important for “doctors to tell it like it is” so their patients can make informed decisions.

“If you have information it gives you control of your treatment plan.”

Sally writes openly about her experiences. After her first operation she says, “I felt as if I was at the mercy of the medical world. My body was no longer my own and had been invaded from every direction.”

She believes honesty has been crucial to her own, and her family’s, survival. “For us [David and her] it was important to be honest for each other and also with the children . . . to be able to tell them how I was feeling, to be able to cry with them in the hope I would be able to build their resilience.” In this way her children were able to understand that she would have good days and bad days.

She says one of the turning points in her journey was when one of her sons commented that they never had white bread any more because it was not on her list of foods she should eat.

“I was surviving, not living. I realised I had to stop revolving my life around my diagnosis and my family’s life around my diagnosis.”

In the book she writes, “I didn’t want cancer to define me or my life and I didn’t want to be constantly reminded that I have a brain tumour now or in the future. There is such a fine line between acceptance of illness and a healthy defiance. To have one foot on either side of that line is the challenge I face.”

The book also chronicles the development of a cancer research fund-raising organisation started by David and some of his mates, Blackwood 8.

Sally says it was a way for her husband to fight back against the cancer. “As a carer you feel so helpless. You have to sit back and watch the other person [cope with their illness], as I did with mum.”

So David challenged his mates to do something, anything, and they came up with a fund-raising auction. The first event raised \$35,000, the second \$47,800.

Sally still has four-monthly MRIs, but says her quality of life is so much better. “I am no longer on daily medication to prevent seizures and my clarity of thinking is better.”

She writes that while her future health is not guaranteed, she has learnt to accept that, while “still striving to honour my body and mind”.

■ *Three Quotes from a Plumber*. By Sally White. Michelle Anderson Publishing. 216pp. \$24.95.

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Sally White with her husband, David, and two sons.