



How VNS changed Allison's life

"Sometimes I even have to remind myself that I have epilepsy!"

Plagued by seizures for fifteen years, medication alone could no longer control Allison Johnston's seizures, and her hope of brain surgery to eliminate the seizures was dashed when investigations found such surgery would be too risky for her. There was one option left – the implantation of a vagus nerve stimulator (VNS). This was not a promise of a cure, but a treatment option that had the potential to greatly reduce the frequency of her seizures.

Believing 'anything's worth a try', Allison agreed to give it a 'go'. In September 2002 she had the device implanted and, in her words, 'got my life back'.

For years Allison struggled to find a medication or combination of medications to control her seizures and allow her to get on with life, without debilitating side effects.

'I experienced skin rashes and welts, weight gain, and hair loss. I had really thick hair and to my neurologist at the time a bit of hair loss didn't seem an

issue until, at one appointment, I arrived with a plastic bag full of hair to show him just how much was falling out on a daily basis' Allison recalls.

Her mother, Jean, recalls the first time she became aware that Allison, then fifteen, was having seizures in her sleep. 'We were travelling by car from the South Coast to Fraser Island for a holiday, and whenever Allison fell asleep she would have a turn. On our return we saw a doctor, investigations were carried out, and Allison was diagnosed with epilepsy.

'At first Allison was only having seizures in her sleep, but as time went on she began to have them when she was awake as well.'

Determined to embark on a nursing career, Allison completed the Assistant in Nursing Certificate at TAFE.

'But getting a job was a struggle. As soon as I said I had epilepsy, they would find a reason as to why I was not suitable. I had so many knock-backs – I was shattered for years. However the places where I have worked have been understanding and willing to give me a go' said Allison.

After a move to Sydney and living on her own, Allison began to experience frequent daytime seizures.

'I was working at a nursing home and I began to have seizures at work. They would ring an ambulance and I'd be taken to hospital. I would wake up and think 'oh no, not another one'. Because I lived alone, I was not allowed to go home so mum would come up from the South Coast and stay with me.

'After this happened a few times, the Matron decided that I could be taken to a back room where I would sleep it off.

'But my seizures changed and became more frequent. I was 32 when my neurologist advised me to stop working and I moved back to the South Coast to be closer to family. Having to apply for the disability pension was probably the

worst time of my life.

'Life was so restricting. I couldn't even go shopping on my own in case I had a seizure; I always went with Mum who kept an eye out for me and even then I would 'go down' and wake up with people staring at me.

'It was a very stressful time for me, my partner Ian, and my mum'.

'When I was told that I couldn't have the brain surgery, after all the investigations, I was shattered.

'Then when the VNS option was put to me, the decision was easy. I had nothing to lose. And I am so glad that I did – it worked! I began to experience less seizures and with the gradual adjustment to the settings on the device, my seizure frequency decreased to 2-3 absence seizures a week while awake and I still had seizures in my sleep. By the end of 2003, my overall seizure frequency had decreased markedly and my neurologist gave me the OK to go back to work.'

Since receiving the implant, Allison has been working at the Blue Haven Nursing Home in Kiama, on the NSW South Coast, enabling her to relinquish the disability pension.

In March 2004, Allison and Ian, her partner of four years, married and travelled to the US for their honeymoon.

'Life is so good now. I can hold down a job, run a home, work in the garden, go shopping on my own, travel, and go out with the girls from work and not be frightened'.

Until recently, when Allison experienced a brief seizure, she had been seizure-free for two years. But, not to be deterred, Allison has taken this in her stride.

'I was hoping for improved seizure control, so to experience seizure-freedom has exceeded all my expectations. I feel blessed and can say without doubt, this has really turned my life around.'