

My life: before and after surgery

Jack Packshaw

On the evening of April 14th 1999 Sydney experienced a huge hail storm. People still remember that night and the incredible electrical activity and the storm damage caused to properties throughout the city. My family and I remember that night for a different reason. I was eight and a half years old and I was watching a movie at home curled up on the sofa with my sister and auntie. The next thing I remember is everyone standing around me and panicking. I had experienced my first epileptic seizure. I felt exhausted and scared. I was having trouble speaking and felt very strange and my family were all in shock. The paramedics arrived, tested my blood sugar levels and told us that it was probably just a “one off” occurrence, perhaps to do with the extreme electrical storm. My parents put me to bed in their room, to keep an eye on me, and then at 4am, I had my second seizure. We then went straight to the hospital. The doctors commenced a range of tests and we were informed that I either had a brain tumour or epilepsy and we were all strangely relieved when I was diagnosed with generalised epilepsy.

Here began a huge journey for my family and me. Learning to live with this totally unpredictable, scary thing. Adjusting to taking twice daily medications, missing school because I was either exhausted after having a seizure, or because I felt terrible nausea from my medication, more blood tests, another MRI or EEG and a specialist or alternative therapist. During the past eleven years I have experienced a myriad of different types of seizures or episodes. Tonic clonic seizures, partial seizures, absences, recurring seizures every few minutes, flickering eyes and even a couple where I got stuck in a partial seizure for hours.

The impact of this on my life has been major. I have struggled against

the stigma of my condition. My family have encouraged me to share with my friends because there were issues around my safety. School camps were a negotiation with the teachers and my Dad used to come too. If I had a seizure while staying over at a friend's place, they needed to know not to freak out – although they usually did! As I became a teenager and enjoyed a little more freedom, I had to implement some basic safety strategies: wearing medic alert dog tags around my neck, carrying a card in my wallet and entering ICE (In Case of Emergency) into my mobile phone.

Just over two years ago, with my seizures still uncontrolled, something showed up on an MRI scan that had my neurologist excited. He wanted to explore it more and referred me to the Epilepsy Unit at Westmead Hospital. I spent a week in the unit undergoing telemetry and video monitoring with the amazing crew there. At the end of the week, the specialists there thought that they may be able to help me and that I might be a candidate for surgery. As I was only seventeen at the time and studying for my HSC, my parents agreed that it would be better to wait until I had completed school and was also an adult and therefore able to give my consent to the operation. Three weeks in hospital, two operations and the possibility of finally gaining control – bring it on!

March 2010

It is now four weeks since my surgery – which involved removing a portion of my left lobe the size of a redheads matchbox! I had a weakness in the right side of my body after the surgery and I have been doing physiotherapy exercises to regain my strength. I have had no seizures to date – not even an aura! It is early days to say whether it has been a success or not. However, I can report that I feel great – calmer, clearer and



Jack Packshaw is thankful that surgery to stop his seizures was an option for him

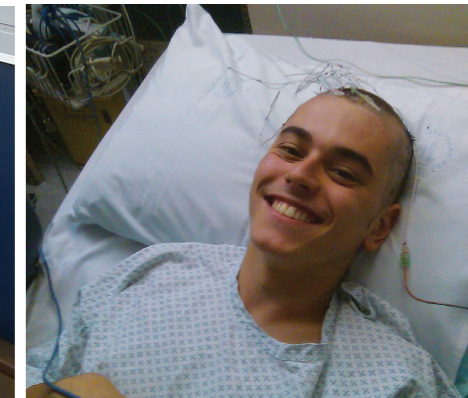
more focused. My thoughts and speech are more aligned and one of the things I love to do is write and perform hip hop. I have noticed that “my flow” has improved and it is now much easier for me to read straight off the page, rap and stay with the beat. I live near Byron Bay on the beautiful north coast of NSW and I am excited to think that I may one day soon be able to learn to drive and not rely on my mates and my family to chauffeur me around.

September 2010

It has now been almost 7 months since my operation and I'm powering on! There have been a couple of “bumps in the road” – I have had 2 fitting episodes, both times after very late nights and very busy weeks. I have found that I need to be very focused on my health and wellbeing and to also make sure that I get plenty of sleep – no late night partying, alcohol or recreational drugs (which is hard as all my friends go out and enjoy themselves and I am an outgoing 20 year old). I have just recently finished an Electronic Music Production course at SAE Institute, Byron Bay and am currently studying Media at the Byron Region Community College (similar to TAFE and other tertiary education facilities).

Since recovering from the operation my memory is much better and I am more confident and less nervous when performing my hip hop songs on stage. I can now think and process quicker, you could say I've got a new quick wit (ha ha!). I'm very excited about going to get my drivers' licence next July and then hopefully soon after moving down to Sydney and getting a job or an internship in a recording studio. Overall, I am so much happier and everyday I wake up with a big smile on my face, knowing how fortunate I have been to have this surgery option. If I continue to take care and look after myself I hope to be fit-free forever!!

So that's where I am at today and I wanted to share my story. To give some hope to other teenagers out there battling to control their epilepsy. To encourage discussion and openness, to increase public awareness of this condition and the strategies on how to support someone during and after a seizure.



clockwise top left: tracking Jack's recovery

How the team at Westmead prepared for Jack's surgery

At the Epilepsy Unit at Westmead, staff specialist Andrew Bleasel and his specialised team conduct the highly technical scans and tests that when planning for all epilepsy surgery.

In reviewing Jack's case, Dr Bleasel describes how these investigations provided the information necessary to determine if surgery was possible.

“There were a number of neuroimaging studies that did show a very definite abnormality in the region that was eventually removed.

“The first very helpful scan was the PET scan in 2007 that showed a clear defect in the mesial aspect of the left frontal lobe.

“Jack came into hospital for video EEG monitoring on two occasions, one in 2007 and one in 2009. The video EEG studies confirmed that he was experiencing frontal lobe seizures.

“One of the most valuable tests during Jack's assessment was the ictal SPECT scan. This involves injecting the patient with a radioisotope as soon as the seizure begins which then maps the area of increased blood flow.”

SPECT scans require careful planning to ensure that the isotope is ready for injecting as soon as a seizure occurs. For

Jack this meant having a nurse sitting at his bedside with the ready-mixed isotope ready to inject at the onset of a seizure. Sleep deprivation is a well known provocation for seizures and Jack was kept up at night so that he would sleep once the isotope was available in the morning. He had a seizure shortly after falling asleep and the nurse was able to immediately inject the radioisotope. The resulting scan again showed an abnormality in the left frontal lobe.

The next step was for the EEG technician to co-register the PET scan and the SPECT scans (functional neuroimaging studies) with the MRI scan (a structural neuroimaging study). With these studies and the EEG studies, which included an intracranial EEG evaluation (where electrodes are placed on the surface of the brain) the team was able to plan Jack's surgery.

Yet surgery is not without risks and when asked about the risks associated with Jack's surgery, Dr Bleasel said, “Perhaps the most likely problem would be that we would fail to cure his epilepsy. There is always about a 30 – 40% chance of this happening with the non-lesional extra temporal epilepsy cases. Other possible bad outcomes are

much less common, but it is possible to get an infection, a stroke, a hemorrhage or even to die with intracranial EEG evaluations. We would usually quote these complications as being less than 2 – 3%,” he said.

Understandably, Jack and his parents asked a lot of very important questions and Jack spent a lot of time considering whether to go ahead with the surgery. However once the decision was made, the relationship that Jack had developed with the team during his stays at the Epilepsy Unit in 2007 and 2009, gave him and his family the confidence to go ahead with the surgery in February 2010.

For Jack the cause of his seizures was indeed a malformation of cortical development as had been predicted by his referring neurologist.

Dr Bleasel explains, “The pathology showed a focal cortical dysplasia where neurones had not matured normally and were in abnormal spots within the microscopic architecture of the brain.”

Through the skills of the Dr Bleasel's Westmead team and the neurosurgeon, Dr Mark Dexter, Jack's surgery was successful and he is now looking forward to a future without seizures.