

How predicting seizures has changed Jason's life



In June last year at Melbourne's St Vincent's Hospital, 26 year old Tasmanian Jason Dent became the first person in the world to receive an innovative seizure advisory device designed to predict a seizure before it happens – a device that offered the potential to change his life. Denise Chapman catches up with Jason to see whether this device has fulfilled its promise.

The concept of predicting seizures has tantalized neurologists since the 1970s, because some, but not all, patients can feel a seizure coming on and prepare accordingly. But a systematic warning system has never come close to becoming a reality, until now.

The Seizure Advisory System™ developed by American company, NeuroVista, is a system that involves permanently implanting electrodes on the surface of the brain that continuously monitor the brain's electrical activity. This data is delivered to a small device implanted in the chest that is programmed to calculate the risk of a seizure which is transmitted to a small paging device worn by the patient using a colour coded system: red light (high risk) white light (moderate risk) and blue light (low risk).

Now at the clinical stage of testing, NeuroVista in collaboration with three leading medical centres in Melbourne – St Vincent's Hospital, The Royal Melbourne Hospital and the Austin Hospital, implanted ten patients with the device. Leading the team at St Vincent's that implanted the first device, Professor Mark Cook said "This will really be revolutionary. Predicting seizures is sort of the holy grail of epilepsy therapy.

"With advance notice of an epileptic seizure, a person could ensure that they are in a safe place before they have a seizure. If this device works as we hope, it will reduce the worry and uncertainty

of not knowing when they might have their next seizure. If their risk rating is low, it can also give them the confidence to take part in daily activities most of us take for granted."

For patients with uncontrolled epilepsy, like Jason Dent the first recipient of this device, a warning system that can seizures would be life-changing.

Living with severe epilepsy for most of his life has meant that Jason has had to forgo many things. He even had to give up playing cricket, a game he loves, after having a seizure while batting. He can't drive, cook or live alone. His seizures occur suddenly and without warning. He loses awareness, becomes confused, is unable to respond and often collapses into a convulsion. Even walking down the street can be hazardous; he was almost hit by a car after staggering onto a busy road during a seizure.

Jason has been to St Vincent's a few times since he was 16 to see if he could have surgery to eliminate his seizures. The last time was in 2010 when he was told that as the seizures were coming from both sides of the brain, surgery was not possible. This was a disappointing outcome for Jason as he had been hoping that surgery would provide some lasting respite from seizures.

So when he was asked whether he would like to participate in the trial for this new device, Jason didn't think twice, he grabbed the chance to

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hopefully have some control over his seizures. And on being the first? Jason just said, "It didn't matter – the seizures couldn't have got any worse."

Prior to the surgery, Jason's mum, Helen, talked about how the family managed over the years. "It's always a fear, you're always worrying. We monitor him very closely so it's always where is he? What's he doing? Is he safe? she said. And her hopes for this device? "Just knowing he's safe I think I'd be able to relax a little bit more. And him having some control over something that's been out of control for nearly all his life and unpredictable for all of his life, would be pretty amazing."

With the utmost faith in Professor Cook and neurosurgeon A/Prof Michael Murphy, Jason underwent the three hour surgery that had the potential to change his life forever.

Jason returned home a week after the surgery and over the following weeks the device collected data building a picture of what a seizure looked like in his brain, identifying those periods associated with pre and post seizure activity. This information was sent regularly to Melbourne.

“After approximately six weeks after the surgery, we travelled back to St Vincent’s and the device was programmed. When it was turned on the device immediately showed red, which indicated the possibility of a seizure occurring,” recalled Helen

“As Jason and I were staying over night to catch up with family, we decided to dine close to the hotel room, rather than travel too far away. As we sat down to dinner, Jason had a seizure – I believe the first predicted seizure in the world – some 5 hours after the device gave a warning! Some close family members, and myself were amazed at how precise the device was.

“We felt confident returning to Hobart the next day, believing that the device would let us know when Jason was going to have a seizure. There is always a concern when flying, as Jason sometimes requires medical intervention when seizures become clustered. That day - no red light! I just knew Jason’s life was about to change!”

Adjusting to the technical aspects of the device has not been a problem for Jason. The implant in his chest requires charging each night (although there is enough charge for approx 3 days) and he is also required to place the personal advisory device (PAD) next to his bed on a charger, to monitor him during the night. There are times when he faces away from the PAD during sleep, covering his chest and blocking the signal. Provided the PAD is carried on Jason, it is monitoring his brain activity for 24 hours.

Well it’s now been some ten months since Jason’s surgery and the outcome couldn’t be brighter.

“As time has gone by the results have been better than expected. In the last two months or more I have been taking a fast-acting medication when the device goes red and it has completely stopped my seizures,” said Jason.

Jason then explained how the system has allowed him to become more confident in himself. “I carry the medication with me and do a voice recording on the PAD to indicate I have taken the extra medication. I don’t walk to or from work, because that involves crossing a busy four-lane highway, until the PAD changes or until a family member can take me.”

Jason is also back playing his beloved cricket. While there has been times when the red warning light has come on, Jason has chosen not to play for safety reasons. The cricket club has worked around this and called on other players to fill his spot. Prior to this he would often have a seizure whilst batting which made Jason feel like he was letting the team down and often the team would have to play the remainder of the game short.

When asked how the warning system has changed his life, Jason replied

“I feel more confident in the things that I do from day to day and I enjoy the fact that I am not having seizures every fortnight. I feel like I have more control over my life, as before the seizures would come with no warning and stop me from doing the things that I love doing, like my cricket and time keeping at the local footy games.”

According to Helen, Jason’s quality of life has improved markedly. He now has control over the things he loves to do:

playing cricket, volunteering at the local Football Club, and work.

“He now has confidence catching buses and travelling to the local shopping centre and visiting friends,” said Helen. “As a parent, I do not worry as much as I know that Jason will call me if his device is red. Previously I would contact Jason on many occasions every day and I now limit that contact, as I am confident that he is doing OK.

“This technology has been truly life-changing.”

Jason was the first of ten patients to participate in the clinical study to evaluate the safety and effectiveness of the system. In May a further five patients underwent implantation bringing the total to fifteen taking part in the two year trial of the Seizure Advisory System.™

When asked how the trial was going, Professor Mark Cook replied that the data was encouraging.

“While it is still early days with some patients still in the data collection stage so their device has not been programmed yet, the results we have to date indicate the device appears to be working much better than we had hoped and the future looks positive,” he said.

“This technology provides us with a new way of looking and thinking about seizures. For the patients, the warning system allows them time to implement risk management strategies, which they didn’t have before. For the first time, they now have some control over previously unpredictable seizures thereby improving their quality of life.”

NEUROVISTA: Seizure Advisory System™

Developed over five years by American company, NeuroVista, the Seizure Advisory System™ involves permanently implanting electrodes on the surface of the brain to monitor electrical activity 24 hours a day, seven days a week.

A pacemaker-like device implanted in the chest takes this information and calculates the risk of a seizure, sending a risk rating to a wireless personal advisory device (PAD) the patient carries, much like a pager. The

PAD shows whether the risk of a seizure is high (red light), moderate (white light) or low (blue light). The PAD can also be set to vibrate or make a warning sound to alert the patient when the risk level changes.

Armed with this information the patient can make lifestyle decisions based on the level of susceptibility and adjust their circumstances during the course of the day – make sure they are safe, notify others, or the possibility of taking a fast-acting drug to prevent it.

