

## Epilepsy Surgery: A Paediatric Perspective

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### Abstract

250,000 people in Australia live with Epilepsy and more than 40% of those are children. Medication is a first line, effective treatment. However, not all patients have the desired outcome of seizure reduction or cessation. In fact, 1 in 3 do not gain full seizure control with medication alone.

Epilepsy surgery, while not a new concept of treatment for seizure management, has gained significant traction in the past decade and has become a particular focus of the Neurology Department at The Children's Hospital, Westmead. This is evident by the expansion of the Neuroscience ward for the precise purpose of surgical intervention for the treatment of Epilepsy and other seizure conditions.

The paediatric patient journey to surgery is a complex and intricate one. It involves a collaborative approach of the multidisciplinary teams from diagnosis and beyond, whilst maintaining a high standard of holistic, family centred care. This paper aims to discuss this journey and the impact it has on the patients, families and the nurses involved.

### Key Words

Epilepsy, seizures, surgery, Stereotactic Electroencephalogram (EEG)

### Introduction:

Seizures are the most common neurological condition worldwide and the most common neurological emergency in children. While these medical emergencies are stressful, they are not all the same and can be divided into two categories based on chronicity (Stafstrom & Carmant, 2015; Chiou & Hsieh, 2008). A "seizure" is a transient, paroxysmal alteration of neurologic function which may be provoked by a non-epileptic or reversible insult such as trauma, hypoglycemia, or more commonly in children, febrile illness (Stafstrom & Carmant, 2015). Whereas, "epilepsy" (or epilepsy syndrome) is an enduring repetitive predisposition to unprovoked seizures due to complex genetic or structural causes, or damage to the delicate tissues and structures of the brain (Stafstrom & Carmant, 2015). Seizures have a lifetime incidence of almost 9% and epilepsy has a lifetime incidence of 3% worldwide (Epilepsy Action Australia, 2019).

Epilepsy affects 250 thousand people in Australia alone and half of these present before

20 years of age. (Epilepsy Action Australia, 2019; Sheng, et al. 2017; Kwan et al., 2010). The consequences of uncontrolled seizures in a child can differ greatly due to the group of symptoms that vary in frequency and intensity. The most obvious is recurrent seizure activity and the disruption this has to everyday life, cognitive impairment, poor school attendance and subsequent educational challenges. Even children with normal intelligence levels have a higher risk of learning difficulties. Additionally, uncontrolled seizures can lead to emotional and behavioural disturbances such as increased risk of anxiety, depression, irritability, hyperactivity, aggression and attention disorders. These challenges combined with social stigma, disability and death further impact on the overall quality of a child's life (Epilepsy Action Australia, 2019; Sheng, et al. 2017; Kwan et al., 2010).

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70% of children presenting to an emergency department in NSW with a non-febrile seizure event will respond to a single medication. The other 30% require poly-pharmaceutical management to control seizure activity. (Epilepsy Action Australia, 2019; Sheng, et al. 2017; Kwan et al., 2010). Of this 30%, half will have refractory or intractable Epilepsy; where seizure control is not achieved despite multiple interventions including trial of two or more anti-epileptic medications and dietary changes such as Ketogenic and Modified Atkins Diet (Epilepsy Action Australia, 2019; Sheng, et al. 2017; Kwan et al., 2010). It is this cohort of paediatric patients who may benefit from surgical treatment, as their brains are capable of reorganizing their neurologic function post-operatively (Sheng et al, 2017; Cross et al., 2006). Many types of epilepsy surgery exist including temporal resections, excision of seizure provoking lesions or developmental malformations, sectioning of the corpus callosum and hemispherectomies (Dwivedi, et al. 2017). Without such intervention, uncontrolled seizures may create significant disruptions to cognition, achievement of developmental milestones, and mental health; and impair the individual's quality of life particularly when the seizures are prolonged, frequent and associated with Status Epilepticus (Sugano & Arai, 2015; Harden, Black & Chin, 2016).

Epilepsy surgery has been shown to be a highly effective method of achieving seizure freedom in children with focal, drug resistance epilepsy (Jayakar, et al. 2014). Unfortunately, not all children with refractory epilepsy are candidates for surgical intervention due to the multi structure involvement. Hence, a detailed surgical work-up which involves a multitude of non-invasive tests such as Video Electroencephalogram monitoring (VEEG), magnetic resonance imaging (MRI) scans, functional MRI, Positron Emission Tomography (PET) scan, Single-Photon Emission Computerized Tomography (SPECT) scan, a neuropsychology assessment, and a baseline physiotherapy assessment, is necessary to determine whether the child would benefit from epilepsy surgery (Chassoux, Navarro, Catenoix, Valton & Vignal, 2017). Should these non-invasive assessments fail to correctly localize the epileptogenic zone, or if further information is required to clarify and support the data collected through previous testing, invasive Stereoelectroencephalography (SEEG) monitoring may be required (Alomar, Mullin, Smithason & Gonzalez-Martinez, 2018).

### **An Overview of Stereoelectroencephalography (SEEG) Monitoring:**

SEEG has been used in Europe since the 1960's (Batchelder, 2017). The Cleveland Clinic was the first centre to use this procedure in North America in 2009, and The Children's Hospital Westmead was the first to perform a paediatric case in Australia in 2011 (Alomar, Mullin, Smithason & Gonzalez-Martinez, 2018; Sala-Pedro et al., 2019). SEEG is an invasive surgical procedure used to localize the patient's epileptogenic zone (the area where a seizure starts), determine its relationship with the eloquent cortex, and determine whether the candidate is suitable for a tailored surgical resection (Minotti, Montavont, Scholly, Tyvaert & Taussig, 2018). It involves using three-dimensional imaging to place a stereotactic frame around the skull to plan intracerebral trajectories of depth electrodes (Batchelder, 2017; Ho et al., 2018). These electrodes have a precision of 3mm of the epileptogenic zone (Mullin et al., 2016). Consequently, if the area of cerebral dysfunction can be identified, the potential risks of surgery-related deficits are deemed to be acceptable, and it is safe to remove the associated brain tissues, then surgery will be undertaken with a view to eliminating the area of misfiring of neurons which in turn prevents the undesired electrical activity from commencing and spreading, and therefore eliminates seizure activity altogether (Ho et al., 2018; Ritaccio, Brunner & Schalk, 2018).

### **Advantages of SEEG:**

The advantages of SEEG include reduced morbidity, lower discomfort, better tolerability of electrodes, the capacity for deeper mapping of brain structures and accuracy while completing a surgical evaluation for epilepsy (Minotti, et al. 2018). Patients can be cared for in the ward and have a shorter length of stay (Iida & Otsubo, 2017).

Another advantage of SEEG monitoring is the capacity to perform cortical stimulation. The purpose of cortical stimulation (also known as electrical stimulation mapping), is to guide neurosurgical resective strategies by identifying areas of cortical dysfunction and mapping the electrophysiological pathways associated with the eloquent functions of the individual's brain so that post-operative sensorimotor and linguistic deficits are minimized or eliminated (Ritaccio, Brunner & Schalk, 2018). This is achieved via application of electrical stimuli via the depth electrodes inhibit or excite brain functions, usually while the patient is doing a language or behavioral test and observing the EEG and patient re-

sponse (So & Alwaki, 2018; Ritaccio, Brunner & Schalk, 2018). Hence, if a child is not actively having seizures, targeted parts of the brain can be stimulated to generate a seizure response (Ritaccio, Brunner & Schalk, 2018; So & Alwaki, 2018). This helps to identify the focal point if the child is not having spontaneous seizure activity. The procedure is carried out with the Neurology consultant and a team of doctors and Neurophysiologists at the bedside.

#### **Disadvantages of SEEG:**

Due to its invasive nature, SEEG Monitoring carries inherent risks including dislodgement of leads, electrode failure, intracranial hemorrhage and infection (Kamitaki, Billakota, Bateman & Pack, 2018; Mullin et al, 2016). In the paediatric population, the child's compliance is also a significant consideration for SEEG suitability as their movements are restricted to the bed or the immediate surrounding areas for a minimum of seven days due to the electrodes, and they need to be tethered to the monitoring unit so that data can be collected (Batchelder, 2017). A bedside sitter is therefore required at all times to ensure that the patient's intracranial electrodes are not displaced or dislodged as a result of normal childhood behaviours, or confusion as a part of the post-ictal period (Kamitaki, et al., 2018). The procedure is contraindicated in patients with a skull thickness of less than 2mm (usually children under three years of age), as their fragile cranium can fracture and prevent the intracranial electrode from being adequately secured (Minotti et al., 2018, Ho et al., 2018).

#### **Development of a Specialized Paediatric Epilepsy Monitoring Unit at The Children's Hospital at Westmead (CHW) :**

The International League Against Epilepsy (ILAE) *Paediatric Epilepsy Surgery Recommendations*, determined that dedicated paediatric epilepsy surgery centers were necessary as the neurobiological aspects of childhood epilepsy are unique to children and thus require specialized care (Cross et al., 2006). The Children's Hospital at Westmead (CHW), located in New South Wales, Australia, contains one such example of this; a 22-bed specialized paediatric Neuroscience unit that treats and cares for patients between the ages of 0-17 with a range of Neurological and Neurosurgical concerns (SCHN, 2019). Within the ward sits a four-bed Epilepsy Monitoring unit and laboratory that was upgraded in 2011 to include innovative technologies that enable the Neurologists, Neurosurgeons and

Neurophysiologists to pinpoint the epileptogenic zone of the brain responsible for seizure events (The Children's Hospital at Westmead, 2012). Between 2011 and October 2019, the team at The Children's Hospital at Westmead performed 116 epilepsy surgery operations and completed 23 SEEG evaluations. A multitude of resources are required to ensure that the best service possible is provided and expedite surgery.

In 2011, the largest room on the Neuroscience unit was converted into an Epilepsy Monitoring Unit with the capacity for Video Electroencephalogram (VEEG) monitoring for up to four concurrent patients. Stafstrom, & Carmant (2015) explain VEEG is a video recording of the brain's electrical activity. It can detect abnormal electrical activity, such as focal spikes or waves (consistent with focal epilepsy), or diffuse bilateral spike waves (consistent with generalized epilepsy). Stafstrom & Carmant further state that VEEG allows recording of longer periods of time including wakefulness, drowsiness, and sleep because the prevalence of epileptiform abnormalities varies in these different states of consciousness includes infrared cameras for better viewing of nocturnal events, continuous back to base cardiac, respiratory and saturation monitoring and remote access monitoring so the scientific officers and doctors on call can view events when not on hospital grounds. The establishment of the EMU also required the implantation of an after-hours troubleshooting service so valuable recording time is not lost should a disruption occur out of hours. The neuroscience department also offers a portable VEEG monitoring outreach service, which enables patients in other areas of the hospital such as the emergency department or Paediatric Intensive Care Unit to be monitored. (SCHN, 2019). In addition to the four-bed EMU, a single monitoring room was upgraded to accommodate VEEG monitoring and newly available Stereotactic Electroencephalogram (SEEG).

Furthermore, the proximity and layout of Westmead Hospital and The Children's Hospital Westmead creates a unique position of having a paediatric and adult epilepsy unit in the one campus. This allows for a network of experts to meet regularly and discuss cases. Families are often comforted by this knowledge that their child is getting excellent care in a state-of-the-art location with multiple experts covering the full patient journey. The complexity of presenting cases is equal to that of leading surgical centres world-wide and the surgical outcomes are on par with those centres at around 70% to 80% for spe-

cific types of Epilepsy such as Temporal Lobe Epilepsy (Lee & Lee, 2013).

#### **The CHW Stereotactic Electroencephalogram (SEEG\_ Protocol):**

The adoption of SEEG has required widespread changes in the nursing care of patients on the ward including the development of new policies and procedures to ensure that best practice is maintained. Post operatively, the patient is admitted to the EMU from recovery into the specialised single room and nursed at a 1:1 ratio for the first 48 hours. After this time, the patient is reassessed to determine if the 1:1 ratio is still required. If it is deemed safe without a nurse in the room, then a sitter must always be present, and this is usually a parent or guardian. Kamitaki, Billakota, Bateman, L., Pack, (2018) explain the increase in safety for the patient with these measures in place. The patient is placed on a strict regime of neurological observations including continuous cardio respiratory and oxygen saturation monitoring. They also receive prophylactic antibiotics and aperients and are on bed rest with toilet privileges. The patient remains on their regular anti-epileptic medications at the discretion of the Epileptologist and diet as tolerated. If medication withdrawal is deemed necessary the patient has intravenous cannula for immediate access should an adverse event occur. Furthermore, nurses carry out hourly documentation of functioning equipment, maintain a seizure safe environment and receive widespread education on VEEG monitoring and how to safeguard equipment and proper functioning. (SCHN, 2019)

The Neurosurgical Registrar and Epilepsy Fellow are on call and must be notified of any seizure activity. These practices have been developed in consultation with the entire Neuroscience team and are regularly reviewed to ensure they are the most appropriate and safest course of action. This is demonstrated during monthly Neurosurgical safety meetings. (SCHN, 2019).

#### **Benefits of the Family Centred Care Philosophy of CHW:**

The goal of all patient interventions is to improve overall quality of life and lessen the seizure burden. Comprehensive patient care involves developing a relationship with both the child and family, understanding the child and the dynamics of their particular family, working within these challenges and maintaining clear communication. This builds trust and a mutually respectful relationship and enhances the outcomes for the child. Keeping lines of communication open helps to fo-

cus on the surgical rationale and to manage patient and family expectations. Patient and family-centred care is an approach to health care that empowers patients and their families and fosters independence. It supports family care-giving and decision-making. (Harden, Black, & Chin, 2016), It respects patient and families' choices, their values, beliefs and cultural backgrounds. It builds on individual and family strengths and involves patients and their families in the planning, delivery and evaluation of health care services. (Harden, Black, & Chin, 2016),

#### **Case Study:**

Patient X is a 9-year-old girl who has had epilepsy since the age of 5. She has had no prior Status epilepticus, febrile event and no family history of seizures. She had failed four medication trials and in March 2012 had epilepsy surgery for resection of right temporal cortical dysplasia. She remained seizure free for 6 months on Carbamazepine.

In September 2012 she began to have recurrent weekly events which were difficult to characterise. She had changes to her vision where "things became very blurry and appeared close up". She sometimes saw "rainbow colours" at the start of a seizure and felt "like clouds were all around her". She also had non-sustained head turning to the right. These ongoing events required further investigating.

After significant testing in 2013 it was hypothesised that there was an area of dysplasia around the previous surgical site but that more extensive exploration of other areas would need to be considered. It was then decided that she would proceed to Stereotactic EEG monitoring in 2014. Patient X had SEEG implantation in April 2014 and had seven days of monitoring. This included stimulation to elicit seizure response and to cement all previous findings of a residual epileptogenic area. The electrodes were removed at the conclusion of monitoring and she was discharged home the following day. Her sutures were removed by her GP and she continued on Carbamazepine. Five weeks later she underwent a craniotomy and resection of epileptogenic right posterior temporal lobe. She had an uneventful recovery and was discharged home 5 days later on Carbamazepine. To date the patient remains seizure free.

Patient X's parents conveyed that decision making was the hardest part. It was "a gut-wrenching decision" but expressed a sense of relief once the decision was made. They

stated that they “placed enormous faith in both the neurologist and neurosurgeon”. They stated feeling safe in the familiarity of the hospital environment they had become used to and the clinicians that they already knew. They felt comforted by the reassurance and support they were given throughout the process.

### Conclusion:

Due to the extensive influence of refractory Epilepsy on the life and future of a child, after other treatment options have been exhausted, surgical intervention is considered. The diagnosis, dynamic management plan and possibility of surgery can be a daunting and complex construct for any one with epilepsy. The disease pathway of a child can be even more complex and has its unique challenges. With the assistance of advanced imaging techniques, a multidisciplinary as well as a family centred approach, clinicians can offer progressive and radically life changing options that shift this disease from a purely management perspective to a disease with a possible cure in the form of surgical intervention.

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The poster features a blue and yellow color scheme. At the top, it includes the logos for 'The World Federation of WFNNS Neuroscience Nurses' and 'ANNA Neurosciences Australia'. The main title 'Sydney Neuroscience Symposium' is in large yellow font on a blue background. A blue banner with white text says 'NEW DATE!'. Below that, a yellow banner with black text states 'Friday 12<sup>th</sup> February, 2021' and '8:30am - 5pm'. A yellow box lists 'Keynote Speakers: Christi DeLemos (USA) • Dawn Tymianski (Canada) • Cindy Bautista (USA)'. A yellow box with black text says 'Registration - www.anna.asn.au'. The background of the lower half is a photograph of the Sydney Harbour Bridge at sunset. At the bottom, a blue box with yellow text lists the venue: 'Royal North Shore Hospital, Kolling Auditorium, Sydney ♦ Australia'.