EPILEPSY

Introduction

An epileptic seizure is the manifestation of abnormal or excessive discharge of neurons in the brain.[1] Epilepsy is defined as recurrent seizures, specifically two or more seizures separated by at least 24 hours but within 18 months of one another.[1] There are many different types of epileptic seizure. Seizures may involve abnormal movements such as jerking, twitching, repetitive movements or sudden loss of muscle tone, loss of consciousness, abnormal sensory perceptions such as strange tastes or smells or a feeling of déjà vu, or intense emotions such as joy or fear.[2] Prolonged or recurrent seizures (without a return to normal function between seizures) lasting 30 minutes or more constitute status epilepticus, a potentially fatal medical emergency requiring prompt treatment (usually in hospital) to prevent brain damage.[3]

Epilepsy is relatively common in children, affecting around four in every 1,000.[4,5] Epilepsy in children often occurs in association with mental health disorders or disabilities including developmental delay, attention deficit hyperactivity disorder, autism, anxiety and depression.[6,7] Epilepsy can result from genetic conditions (such as Angelman and Rett syndromes) and metabolic or structural conditions (such as head trauma and central nervous system malformations, infections or tumours) but in the majority of cases of epilepsy in children no cause can be identified.[2,5]

Children with epilepsy and their families need on-going specialist medical care.[8] While there are effective drugs for treating epilepsy, they are not effective for all children, and some children have difficulty adapting to drug treatment.[2,8] Living with epilepsy affects many aspects of quality of life. Studies have generally found that the emotional impacts are more significant than the physical ones.[9] Negative impacts of epilepsy include fatigue, medication side effects, anxiety and depression, social isolation due to being unwilling to disclose epilepsy to peers, restriction of leisure activities because of fear of having a seizure, and, for young people, being unable to get a driver licence, stay up late or drink alcohol.[9,10]

The majority of people with childhood-onset epilepsy do not need to take anti-epileptic drugs for life.[2] Patients followed long term have remission rates of around 65%.[11]

Data sources and methods

Indicators

Rates of epilepsy or status epilepticus among 0–24 year olds

Definition

Hospitalisations of 0–24 year olds with epilepsy or status epilepticus per 100,000 population

Data sources

Numerator:	National Minimum Dataset
Denominator:	Statistics New Zealand Estimated Resident Population (with linear extrapolation being used to calculate denominators between Census years)

Additional information

This section presents analyses where the condition was the primary diagnosis or was documented within any of the first 15 diagnoses (all cases). The rationale for presenting all cases is to highlight the full spectrum of health issues experienced by those with this condition, and their consequent requirement for acute health services. Analyses are per hospital discharge event therefore events are only included if the condition is documented within either the primary diagnosis or within any of the first 15 diagnoses. Error! Reference source not found. outlines the limitations of the data utilised from the National Minimum Dataset. The reader is advised to review this appendix before interpreting any trends.
Codes used for identifying cases are documented in Error! Reference source not found..

National trends and distribution

There was a total of 58 deaths of 0–24 year olds with epilepsy or status epilepticus as the underlying cause of death in New Zealand during 2009 to 2013, as documented within the National Mortality Collection.

The number of 0–24 year olds hospitalised between 2011 and 2015 with any diagnosis of epilepsy or status epilepticus is presented together with the total number of hospitalisations with epilepsy or status epilepticus as a

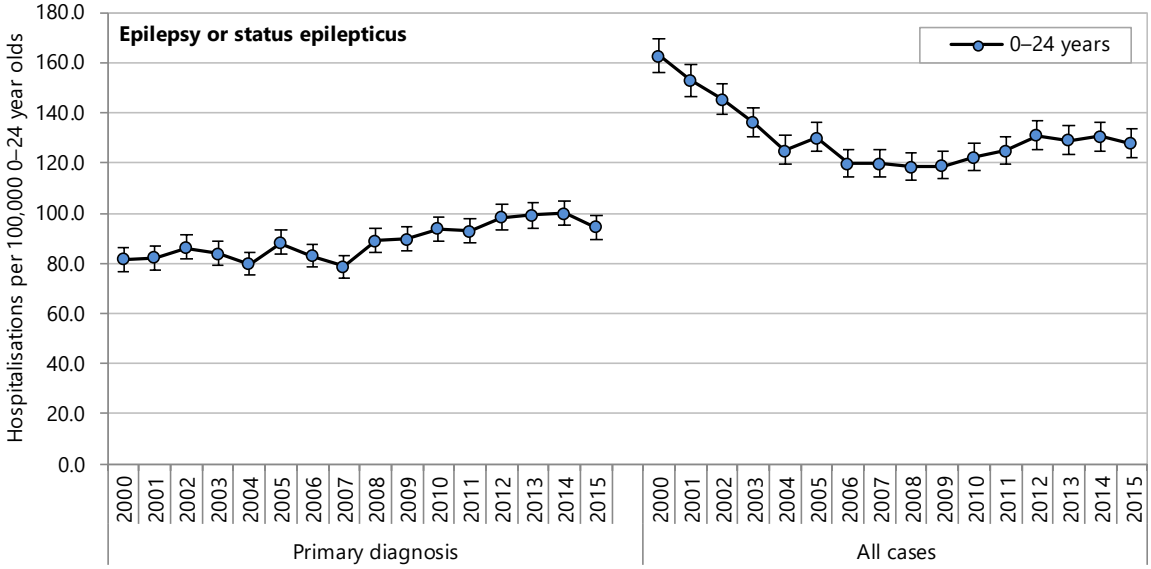
primary or any diagnosis. Most hospitalisations of 0–24 year olds with epilepsy or status epilepticus had this condition as a primary diagnosis (**Table 1**).There has been a small increase in hospitalisation rates for epilepsy or status epilepticus since 2000 with a drop in 2015 (**Figure 1**). Hospitalisation rates were highest for 0–4 year olds (**Figure 2**). Similar patterns over time were seen in Māori and Pacific ethnic groups while rates for European/Other are trending down, and Asian ethnicities are trending up (**Figure 3**).

Table 1. Individuals aged 0–24 years hospitalised with epilepsy or status epilepticus using primary diagnosis compared to all cases, New Zealand 2011–2015

Age group	Unique individuals *(n)*	Hospitalisations *(n)*		Ratio All:Primary
		Primary diagnosis	All cases	
Epilepsy or status epilepticus				
Hospitalisation				
0–24 years	4,336	7,440	9,876	1.33
0–14 years	2,542	4,809	6,237	1.30
15–24 years	1,884	2,631	3,639	1.38

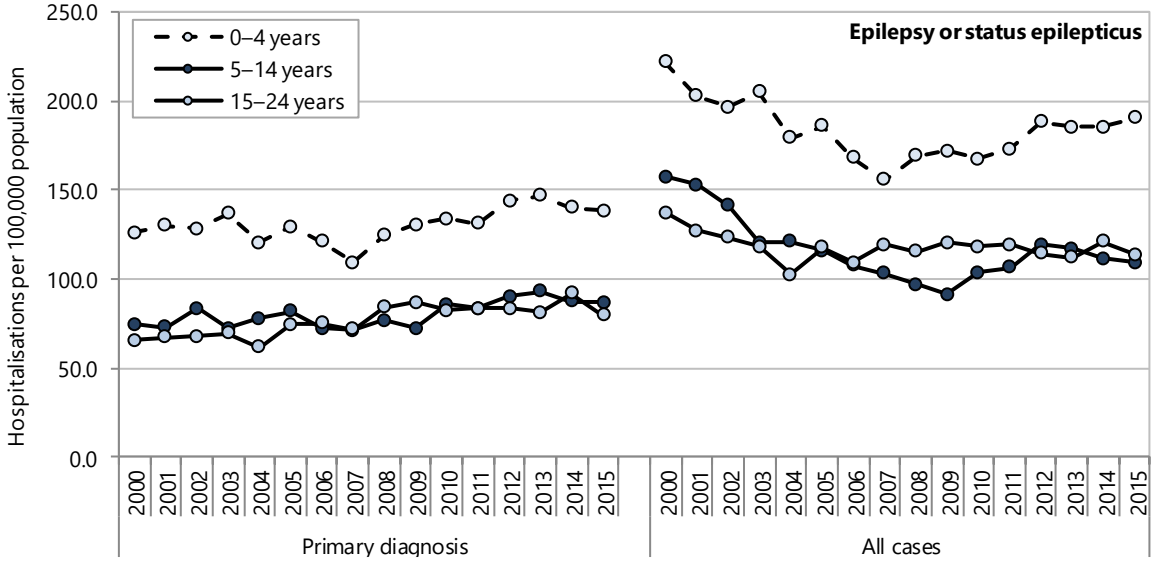
Source: National Minimum Dataset. 'Primary' corresponds to hospitalisations where epilepsy or status epilepticus was primary diagnosis; 'All cases' = inclusion in any of the first 15 diagnoses; The sum of the age groups may total to more than the 0–24 year old total

Figure 1. Hospitalisations for epilepsy or status epilepticus in 0–24 year olds, New Zealand 2000–2015

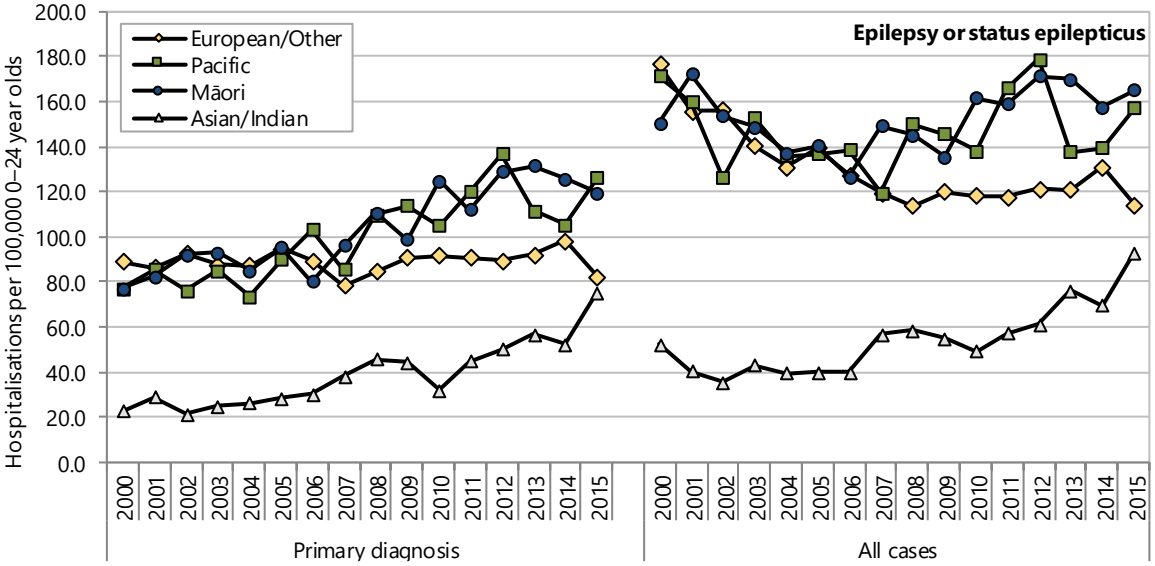


Numerator: National Minimum Dataset, Denominator: Statistics NZ Estimated Resident Population. 'All cases' = inclusion in any of the first 15 diagnoses; Hospitalisations per 100,000 0–24 year olds

Figure 2. Hospitalisations for epilepsy or status epilepticus in 0–24 year olds, by age group, New Zealand, 2000- 2015



Numerator: National Minimum Dataset, Denominator: Statistics NZ Estimated Resident Population. 'All cases' = inclusion in any of the first 15 diagnoses; Hospitalisations per 100,000 population**Error! Reference source not found.**Figure 3. Hospitalisations involving epilepsy or status epilepticus in 0–24 year olds, by ethnicity, New Zealand 2000–2015



Numerator: National Minimum Dataset, Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 age-specific population; 'All cases' corresponds to hospitalisations with epilepsy or status epilepticus listed in any of the first 15 diagnoses

Demographic distribution

Table 2 presents the demographic distribution of individuals hospitalised with epilepsy or status epilepticus in New Zealand between 2011 and 2015. The prevalence of epilepsy or status epilepticus was significantly higher among individuals residing in areas with high deprivation scores (NZDep2013 deciles 9–10). Compared to 15–24 year olds, the prevalence was significantly higher among 0–4 year olds and significantly lower among 5–14 year olds. The prevalence in Māori and Pacific 0–24 year olds was significantly higher than in European/Other 0–24 year olds. The majority of 0–24 year olds with epilepsy or status epilepticus were of European/Other or Māori ethnicities.

Table 2. Individuals aged 0–24 years hospitalised with epilepsy or status epilepticus, by demographic factor, New Zealand 2011–2015

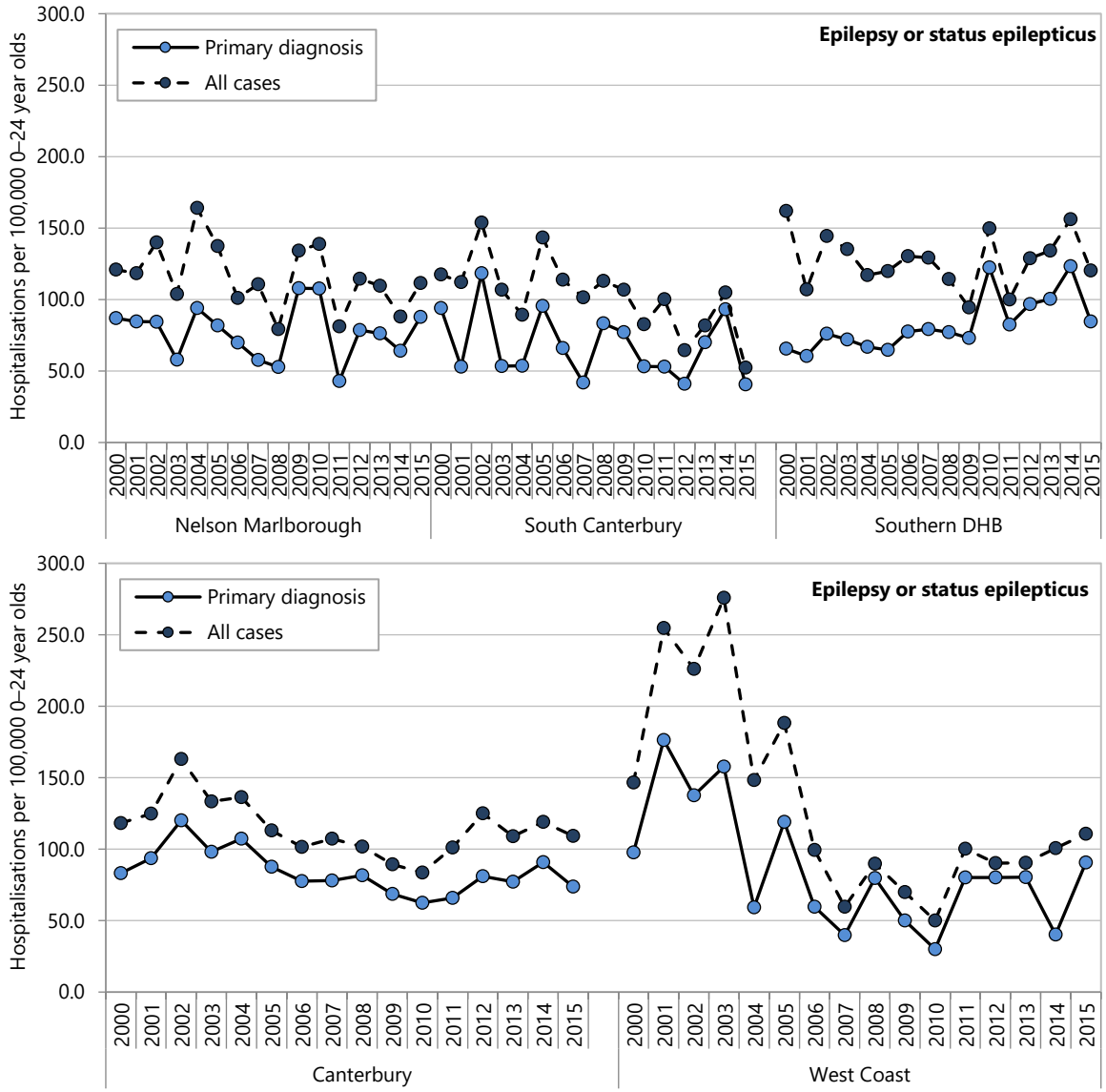
Variable	Unique individuals 2011–2015 *(n)*	Rate per 100,000 population	Rate ratio	95% CI
Epilepsy or status epilepticus* in 0–24 year olds				
New Zealand				
NZ Deprivation Index quintile				
Deciles 1–2	578	40.73	1.00	
Deciles 3–4	711	53.17	1.31	1.17–1.46
Deciles 5–6	757	52.51	1.29	1.16–1.44
Deciles 7–8	1,062	65.37	1.61	1.45–1.78
Deciles 9–10	1,621	87.24	2.14	1.95–2.36
Prioritised ethnicity				
Māori	1,230	68.19	1.23	1.14–1.31
Pacific	491	69.29	1.25	1.13–1.37
Asian/Indian	289	30.15	0.54	0.48–0.61
MELAA	70	69.41	1.25	0.98–1.58
European/Other	2,286	55.64	1.00	
Gender				
Female	2,060	54.87	1.00	
Male	2,276	57.97	1.06	1.00–1.12
Age group (years)				
0–4	1,195	76.62	1.28	1.19–1.37
5–14	1,466	49.13	0.82	0.76–0.88
15–24	1,884	60.06	1.00	

Numerator: National Minimum Dataset, Denominator: Statistics NZ Estimated Resident Population* Epilepsy or status epilepticus in any of the first 15 diagnoses; Rate per 100,000 age-specific population; Rate ratios are unadjusted; Ethnicity is Level 1 prioritised; Decile is NZDep2013

Regional trends and distribution

Hospitalisation rates for epilepsy or status epilepticus showed year-to-year variability in the South Island DHBs between 2000 and 2015. The incidence of epilepsy or status epilepticus being the primary cause of hospitalisation was lower than all cases (**Figure 4**). Numbers of unique individuals and hospitalisations between 2011 and 2015 are shown in **Table 3**. Nelson Marlborough, Canterbury and South Canterbury DHBs have a higher ratio of All:Primary hospitalisations than the national while West Coast and Southern are lower.

Figure 4. Hospitalisations for epilepsy or status epilepticus in 0–24 year olds, Southern DHBs vs New Zealand 2000–2015



Numerator: National Minimum Dataset, Denominator: Statistics New Zealand Estimated Resident Population. "All cases" corresponds to hospitalisations with epilepsy or status epilepticus listed in any of the first 15 diagnoses; Hospitalisations per 100,000 0–24 year olds

Table 3. Hospitalisations for epilepsy or status epilepticus in 0–24 year olds, Southern DHBs vs New Zealand 2011–2015

DHB	Unique individuals *(n)*	Hospitalisations *(n)*		Ratio All : Primary
		Primary diagnosis	All cases	
Epilepsy or status epilepticus in 0–24 year olds				
Nelson Marlborough	94	147	212	1.44
South Canterbury	43	51	69	1.35
Canterbury	427	645	935	1.45
West Coast	29	37	49	1.32
Southern	275	505	662	1.31
New Zealand	4,336	7,440	9,876	1.33

Source: National Minimum Dataset. 'All cases' corresponds to hospitalisations with epilepsy or status epilepticus listed in any of the first 15 diagnoses

Evidence for good practice

Possibilities for prevention

Epilepsy in children is generally not preventable. Interventions to prevent traumatic brain injuries could reduce the number of children with epilepsy due to brain injury but this would have only a very small impact on the total number of children with epilepsy.

Evidence-based health care for children and young people with epilepsy

All children suspected of having epilepsy should be seen by a specialist paediatrician with expertise in epilepsy and children diagnosed with epilepsy need on-going regular specialist care.[12] Drug therapy is generally recommended after a person has had a second epileptic seizure and around two thirds of people with epilepsy achieve satisfactory control of their epilepsy with anti-epileptic drugs.[12] The use of sodium valproate is contraindicated in young women of childbearing age because it poses risks to unborn children (fetuses).[13] These include increased risks of congenital anomalies, developmental delay and autism.[13]

When seizures are not controlled by anti-epileptic drugs other treatments that may be effective include the ketogenic diet, vagus nerve stimulation and brain surgery to remove the area of the brain causing the seizures.[12]

Most childhood seizures last for less than five minutes. Prolonged or recurrent seizures (without a return to normal function between seizures) lasting 30 minutes or more constitute status epilepticus, a potentially fatal medical emergency requiring prompt treatment (usually in hospital) to prevent brain damage.[3]

Children and families affected by epilepsy need to be given, and have access to, high quality information about epilepsy and its management and they should be able to contact a named member of the healthcare team when they require information.[12] There is insufficient evidence to determine how best to facilitate self-management of epilepsy.[14]

These national and international guidelines, systematic reviews, other publications and websites relevant to the management of epilepsy are provided for further reading.

International guidelines

- Sauro KM, Wiebe S, Dunkley C, et al. 2016. The current state of epilepsy guidelines: A systematic review. *Epilepsia*, 57(1), 13-23. http://dx.doi.org/10.1111/epi.13273
- The International League Against Epilepsy. 2015. Guidelines and reports http://www.ilae.org/visitors/centre/guidelines.cfm accessed, July 2016
- Scottish Intercollegiate Guidelines Network (SIGN). 2015. Diagnosis and management of epilepsy in adults. Edinburgh: SIGN. http://www.sign.ac.uk/pdf/SIGN143.pdf
- Huff JS, Melnick ER, Tomaszewski CA, et al. 2014. Clinical Policy: Critical issues in the evaluation and management of adult patients presenting to the emergency department with seizures. *Annals of Emergency Medicine*, 63(4), 437-47.e15. http://www.annemergmed.com/article/S0196-0644(14)00080-8/pdf
- National Institute for Health and Clinical Excellence. 2012. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care (Clinical guideline no. 137). London: National Institute for Health and Clinical Excellence. https://www.nice.org.uk/guidance/cg137

- National Clinical Guideline Centre. 2012. The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care. London: National Clinical Guideline Centre. https://www.nice.org.uk/guidance/cg137/evidence/full-guideline-6664855034 (This is the full guideline with details of the evidence.) The appendices to the guideline, including a 2014 evidence update, can be found here: https://www.nice.org.uk/guidance/cg137/evidence accessed, July 2016
- American Epilepsy Society. Guidelines https://www.aesnet.org/clinical_resources/guidelines accessed, July 2016
- American Academy of Neurology. Practice guidelines Epilepsy. https://www.aan.com/Guidelines/home/ByTopic?topicId=23 accessed, July 2016

Evidence-Based Medicine Reviews

- The Cochrane Library has many reviews relating to epilepsy management, mostly concerned with drug treatment: http://www.cochranelibrary.com/topic/Neurology/Epilepsy/?per-page=100&stage=review
- Lewis SA, Noyes J, Hastings RP. 2015. Systematic review of epilepsy self-management interventions integrated with a synthesis of children and young people's views and experiences. *Journal of Advanced Nursing*, 71(3), 478-97. http://dx.doi.org/10.1111/jan.12511
- Fleeman N, Bradley Peter M, Lindsay B. 2015. Care delivery and self management strategies for children with epilepsy. *Cochrane Database of Systematic Reviews*, http://dx.doi.org/10.1002/14651858.CD006245.pub3
- Geerlings RPJ, Aldenkamp AP, de With PHN, et al. 2015. Transition to adult medical care for adolescents with epilepsy. *Epilepsy & Behavior*, 44, 127-35.

Other relevant publications

- Keenan N, Sadlier LG. 2015. Paediatric EEG provision in New Zealand: a survey of practice. *New Zealand Medical Journal*, 128(1411), 43-50. http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2015/vol-128-no-1411–27-mar-2015/6479
- Special Issue: Transition of Epilepsy Care from Children to Adults. *Epilepsia*, 55 (s3), 54–55, August 2014. http://onlinelibrary.wiley.com/doi/10.1111/epi.2014.55.issue-s3/issuetoc
- Ridsdale L, McCrone P, Morgan M, et al. 2013. Can an epilepsy nurse specialist-led self-management intervention reduce attendance at emergency departments and promote well-being for people with severe epilepsy? A non-randomised trial with a nested qualitative phase. *Health Services and Delivery Research*, 1(9). http://www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0011/87086/FullReport-hsdr01090.pdf

Websites

- Epilepsy NZ. http://epilepsy.org.nz/
- Epilepsy Australia. http://www.epilepsyaustralia.net/
- Epilepsy Society. https://www.epilepsysociety.org.uk/
- American Epilepsy Society. https://www.aesnet.org/
- Epilepsy Foundation. http://www.epilepsy.com/

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5. Camfield P, Camfield C. 2015. Incidence, prevalence and aetiology of seizures and epilepsy in children. *Epileptic disorders*, 17(2) 117-23. http://dx.doi.org/10.1684/epd.2015.0736
6. Plioplys S, Dunn DW, Caplan R. 2007. 10-year research update review: psychiatric problems in children with epilepsy. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46(11) 1389-402. http://dx.doi.org/10.1097/chi.0b013e31815597fc

7. Dunn DW, Besag F, Caplan R, et al. 2016. Psychiatric and behavioural disorders in children with epilepsy (ILAE Task Force report): Anxiety, depression and childhood epilepsy. *Epileptic Disorders*, http://dx.org/10.1684/epd.2016.0813
8. Wilmshurst JM, Berg AT, Lagae L, et al. 2014. The challenges and innovations for therapy in children with epilepsy. *Nature Reviews. Neurology*, 10(5) 249-60. http://dx.doi.org/10.1038/nrneurol.2014.58
9. Harden J, Black R, Chin RFM. 2016. Families' experiences of living with pediatric epilepsy: A qualitative systematic review. *Epilepsy & Behavior*, 60 225-37. http://dx.doi.org/10.1016/j.yebeh.2016.04.034
10. Thomson L, Fayed N, Sedarous F, et al. 2014. Life quality and health in adolescents and emerging adults with epilepsy during the years of transition: a scoping review. *Developmental Medicine and Child Neurology*, 56(5) 421-33. http://dx.doi.org/10.1111/dmcn.12335
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13. Medsafe. 2015. Use of sodium valproate (Epilim) in pregnancy. http://www.medsafe.govt.nz/safety/EWS/2015/sodiumvalproate.asps
14. Fleeman N, Bradley Peter M, Lindsay B. 2015. Care delivery and self management strategies for children with epilepsy. *Cochrane Database of Systematic Reviews*, (12) http://dx.doi.org/10.1002/14651858.CD006245.pub3