Question ID	Uncertainties	Original Submissions	Response Distribution							Evidence
			People with Seizures	Caregivers	Friend or Family Member	Health Care Provider	Community Agency Representative	Other	Unknown	
1	Can genetic markers be used to diagnose and treat epilepsy and seizure disorders?	Is it possible that epilepsy could be genetic in some cases? What is the genetic pathways affected, and how does this differ between types of epilepsy and whether it is treatment refractory. Are there specific genes that identify someone will have epilepsy? Why do some people grow out of seizures and others do not? Is there a genetic component to epilepsy? Are there ways to decrease the transmission? What gene(s) are responsible for the lowered seizure threshold in epileptics, is there any correlation to migraines and tumors? What is the likelihood of epilepsy being inherited? I believe more information still needs to be provided about Catamenial Epilepsy. Why exactly do some women have this type of Epilepsy? Is it hereditary? What are ALL the different types of seizures, not just the most common ones? How is Juvenile Myoclonic Epilepsy passed on? If someone in your family has epilepsy, are you at a greater risk of getting it? Will I pass my epilepsy onto my children?	47	14	21	11	1	2		Offringa, M., Newton, R., Cozijnsen, M. A., & Nevitt, S. J. (2017). Prophylactic drug management for febrile seizures in children. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD003031.pub3 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
3	What are the impacts of long-term use of anti-seizure drugs, the causes of side effects of these treatments and how can we prevent the side effects?	What is the long term impact on a developing brain of being on anti-seizure medication? What are the long term effects of some seizure medications? Are there any natural or diets that may help in reducing Juvenile Myoclonic seizures? What are the long term effects of meds like Lamotrigine, Keppra? What is known about the long term effects of taking a cocktail of epilepsy drugs over a lifetime? What is the impact in longevity? When do scientists predict there will be a cure? What happens to the brain/body after prolonged drug treatment for epilepsy (10 yrs. +)? Do anti-seizure medications cause long term cognitive deficits? How does consumption of large volumes of medications over 35 years affect your medical health (e.g. Tegretol, Keppra and Clobazam)? How do you minimize the side effects of medications? What is the long term effectiveness of medication-based treatments? Are there risks to being on the medications long term? How are we going to better assist patients that have uncontrollable Epilepsy after 10, 20+ years of having the disorder who have also already had at least one brain surgery. What number of surgeries and medication changes are too damaging to the body?	39	8	15	1	2	3		Evidence Not Identified
21	What are the long-term impacts of seizures on a person's brain, and overall health and development?	What is the longterm impact of absence seizures on my son? Do our children have a chance or inheriting the disease? Or any diseases after their born? What are the long term prognosis of those types of epileptics? To what extent does neurodegeneration play a role in long term effects. How much research is there re the long term effects of repeated brain trauma for ongoing seizure activity (my son has been having seizures for 15 years) We are noticing he is taking a longer time to process information etc. We know it's organic in diagnosis because it's because of tumors, but she's a baby and I am wondering what's next or of there is a cure? Do recurrent seizures that are not prolonged cause brain damage? Epileptogenesis in children and how it affects their development. I think we have studied a lot epileptic encephalopthies however focal onset structural epilepsies in children have not been well studied by our group Can epilepsy create limitations or deterioration to certain levels of my health?	6	3	3	3	1	1		Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
48	How can the risk of SUDEP (Sudden Unexpected Death in Epilepsy) be reduced in people with epilepsy?	How do I decrease the risk of sudden death? Many of my seizures are nocturnal with violent full body convulsions is there a way of decreasing my risk factor? Why don't we talk about SUDEP? Is it more prevalent than we are led to believe? Any safety measures? managing expectations related to sudden death Preventing SUDEP	1	1		1	1			Maguire, M. J., Jackson, C. F., Marson, A. G., & Nevitt, S. J. (2020). Treatments for the prevention of Sudden Unexpected Death in Epilepsy (SUDEP). Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD011792.pub3
7	What is the most effective testing protocol for determining causes of seizures and/or a diagnosis of epilepsy or other seizure disorders and to reduce time to diagnosis?	I understand there are Epileptic Seizures and Non-Epileptic Seizures, how can a correct diagnoses be made to differentiate between the two? If a prolonged EEG is not possible are there any specific ways to distinguish between the two? Are there new tools to understand the root cause of idiopathic epilepsy? Why does it take a long time to diagnosis epilepsy if the problem is so common? What protocols are being developed to better determine underlying causes of seizures? Can the medical community find out if an unborn fetus has epilepsy before it's born? Do the biological parents health or chromosomes have to do with the epileptic getting epilepsy? Are there cost-effective tests that can be done as children to detect/diagnose epilepsy before the first seizure? I feel it takes too long to diagnose epilepsy. Are there any research initiatives that could be done so confirmation of the condition would be done more quickly? It seems many places still do not consistently follow an algorithm for diagnosing-why is this? Are we diagnosing to early? not early enough? When is the best time to be diagnosed? When do we know a child/ adult has epilepsy and do the child/ adult refer to themselves as a person living with epilepsy? How/ when do patients learn of their diagnosis (1st appointment, after medication, seizure freedom)? How is epilepsy diagnosed if EEG, MRI tests are normal?	23	7	9	2	2	2		Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Guidelines on Neonatal Seizures. Geneva: World Health Organization; 2011.
4	What are the brain changes, on a cellular level, that lead to seizure development?	Why can I develop epilepsy at any time without a known cause (head injury, etc)? Why do so many people have idiopathic epilepsy? What causes epileptic seizures to happen every four to eight weeks? 1) What medical problems may be causing my seizures - i.e., Are the seizures being caused by something. 2) What combinations of seizures can happen for a person and how can they be treated in combination. Why is it that some people don't present symptoms until the age of 11 or 12? What changed in the brain to have resulted in show of symptoms? What causes epilepsy in middle aged persons who have not suffered head trauma? What changes occur that cause epilepsy to present itself later in life (20+ years old)? What causes adult onset epilepsy, if no obvious reason can be found (I.e brain injury or tumour)? Once an mri comes back with results showing normal is there ever a way to know what has caused someone to have epilepsy.	27	5	18	2			1	Tatum, W. O., Rubboli, G., Kaplan, P. W., Mirsatari, S. M., Radhakrishnan, K., Gloss, D., . . . Beniczky, S. (2018). Clinical utility of EEG in diagnosing and monitoring epilepsy in adults. Clinical Neurophysiology, 129, 1056-1082. doi:10.1016/j.clinph.2018.01.019

		My daughter has lived with epilepsy for about 14 years. We still have no known cause for it -- after extensive genetic testing, brain scans, etc. Do we simply live with the fact that we cannot know?								
17	How effective is surgical treatment for adult and children who experience seizures/epilepsy?	How likely is sz occurrence after brain surgery in childhood and sz free for 9 years? (temporal lobe epilepsy) If surgery is an option what are the advantages if drugs still need to be taken? Why do some people have successful brain surgery and others not despite similar seizure types/surgery? Once patients have been offered surgical treatments, are they able to fully rehabilitate back into society? Can they drive again? Is surgery the best course of action for children with epilepsy due to brain lesions? statistically, who benefits most from so-called 'grid surgery'? how often is epilepsy refractory to surgical and medical treatment? How early epilepsy surgery affects the long term outcomes in children with focal onset drug resistant epilepsy Do some of the new neurological procedures 'cure' or eradicate epilepsy ? How successful is surgery to remove the scar tissue in MTS? How to determine if your type of epilepsy is drug-resistant? Why do some people start having seizures again even after the surgery?	9	5	3	3				West, S., Nevitt, S. J., Cotton, J., Gandhi, S., Weston, J., Sudan, A., . . . Newton, R. (2019). Surgery for epilepsy. Cochrane Database of Systematic Reviews(6). doi:10.1002/14651858.CD010541.pub3
2	What causes memory problems associated with seizures? Can these memory problems improve over time and what are the best treatment options for memory loss in people who experience seizures?	Is there a biological relationship between memory and epilepsy (is it directly related to seizure activity or a medication related side effect)? What can be done to limit memory issues in people with epilepsy? Are mood issues related to epilepsy, inter-ictal/ictal activity or AEDs? Do we have strategies to prevent loss of memory or learning as a result of seizures? How to manage memory problems and anxiety Do I lose memories when I have a seizure? Is it the drugs, seizures or surgery that causes depression and memory problems in those with seizures due to cortical dysplasia? Does epilepsy cause brain damage that reduces memory? Does status epilepticus cause brain damage? Could brain damage be proved via MRI? Are memory problems correlated to all with epilepsy? What causes the memory loss? What are the best methods to counteract the memory problems to strengthen your memory? Does having epilepsy cause memory problems forever, does it get worse ? Will memory improve as years pass or will there alway be memory problems. Is depression more a symptom of epilepsy or a side effect of the medications.	56	7	11	4	3	2	1	West, S., Nevitt, S. J., Cotton, J., Gandhi, S., Weston, J., Sudan, A., . . . Newton, R. (2019). Surgery for epilepsy. Cochrane Database of Systematic Reviews(6). doi:10.1002/14651858.CD010541.pub3 Gloss, D., & Vickrey, B. (2014). Cannabinoids for epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD009270.pub3 Jackson, C. F., Makin, S. M., & Baker, G. A. (2015). Neuropsychological and psychological interventions for people with newly diagnosed epilepsy. Cochrane Database of Systematic Reviews(7). doi:10.1002/14651858.CD011311.pub2 Blümcke, I., Thom, M., Aronica, E., Armstrong, D. D., Bartolomei, F., Bernasconi, A., . . . Spreafico, R. (2013). International consensus classification of hippocampal sclerosis in temporal lobe epilepsy: A Task Force report from the ILAE Commission on Diagnostic Methods. Epilepsia, 54, 1315-1329. doi:10.1111/epi.12220 Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Liu, J., Wang, L. N., Wu, L. Y., & Wang, Y. P. (2018). Treatment of epilepsy for people with Alzheimer's disease. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD011922.pub3 Shi, L. L., Bresnahan, R., Martin-McGill, K. J., Dong, J., Ni, H., & Geng, J. (2019). Felbamate add-on therapy for drug-resistant focal epilepsy. Cochrane Database of Systematic Reviews(8). doi:10.1002/14651858.CD008295.pub5 Strozzi, I., Nolan, S. J., Sperling, M. R., Wingerchuk, D. M., & Sirven, J. (2015). Early versus late antiepileptic drug withdrawal for people with epilepsy in remission. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD001902.pub2 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Kerr, M. P., Mensah, S., Besag, F., De Toffol, B., Ettinger, A., Kanemoto, K., . . . Wilson, S. J. (2011). International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. Epilepsia, 52, 2133-2138. doi:10.1111/j.1528-1167.2011.03276.x
18	Aside from anti-seizure drugs and some brain lesions, what causes behavioural changes in people who experience seizures? What is the best way to treat behavioural issues?	Behavioural issues: Why is there such a high rate in epilepsy? Differentiate between behaviour and seizures? -Are my child's behavioural issues part of a larger syndrome that relates to the epilepsy? -Will my child ever develop enough to 'catch up' to peers in terms of abilities? With seizures come behaviour issues. Does taking more drugs on top of a whole regime of anti epileptic drugs possibly bring about more behaviour issues? That is does it make things worse? Are behaviour changes because of the seizures or the medication? Why do some people with epilepsy develop post-ictal psychosis? Is there a way of identifying these patients and preventing psychosis before it manifests? Can epilepsy cause behavioural changes, depression, or increased anxiety? Can epilepsy affect learning capabilities? Could we initiate research to better understand the correlation between epilepsy, learning disabilities and mental illnesses? Maybe we could develop treatment for all of these if we better understood why they seem to co-exist? What is the latest evidence about the treatment strategies of depression, anxiety, and behavioural problems for people with epilepsy? How best to treat behavioural issues eg. medications can make seizures worse How can my daughter's aggressive and impulsive behaviours be related either to epilepsy or to the side effects of her medication?	6	1	10	2	1			Ayuga Loro, F., Gisbert Tijeras, E., & Brigo, F. (2020). Rapid versus slow withdrawal of antiepileptic drugs. Cochrane Database of Systematic Reviews(1). doi:10.1002/14651858.CD005003.pub3 Nevitt, S. J., Tudur Smith, C., & Marson, A. G. (2019). Phenobarbitone versus phenytoin monotherapy for epilepsy: an individual participant data review. Cochrane Database of Systematic Reviews(7). doi:10.1002/14651858.CD002217.pub3 Geng, J., Dong, J., Li, Y., Ni, H., Jiang, K., Shi, L. L., & Wang, G. (2019). Intravenous immunoglobulins for epilepsy. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD008557.pub4 Brigo, F., Igwe, S. C., & Lattanzi, S. (2019). Ethosuximide, sodium valproate or lamotrigine for absence seizures in children and adolescents. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD003032.pub4 Brigo, F., Igwe, S. C., Bragazzi, N. L., & Lattanzi, S. (2019). Clonazepam monotherapy for treating people with newly diagnosed epilepsy. Cochrane Database of Systematic Reviews(11). doi:10.1002/14651858.CD013028.pub2 Tatum, W. O., Rubboli, G., Kaplan, P. W., Mirsatari, S. M., Radhakrishnan, K., Gloss, D., . . . Beniczky, S. (2018). Clinical utility of EEG in diagnosing and monitoring epilepsy in adults. Clinical Neurophysiology, 129, 1056-1082. doi:10.1016/j.clinph.2018.01.019 Nevitt, S. J., Marson, A. G., & Tudur Smith, C. (2018). Carbamazepine versus phenobarbitone monotherapy for epilepsy: an individual participant data review. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD001904.pub4 Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Nevitt, S. J., Sudell, M., Weston, J., Tudur Smith, C., & Marson, A. G. (2017). Antiepileptic drug monotherapy for epilepsy: a network meta-analysis of individual participant data. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD011412.pub3 Brigo, F., Igwe, S. C., & Del Felice, A. (2016). Melatonin as add-on treatment for epilepsy. Cochrane Database of Systematic Reviews(8). doi:10.1002/14651858.CD006967.pub4 Strozzi, I., Nolan, S. J., Sperling, M. R., Wingerchuk, D. M., & Sirven, J. (2015). Early versus late antiepileptic drug withdrawal for people with epilepsy in remission. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD001902.pub2 Jackson, C. F., Makin, S. M., Marson, A. G., & Kerr, M. (2015). Pharmacological interventions for epilepsy in people with intellectual disabilities. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD005399.pub3 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Cheuk, D. K. L., & Wong, V. (2014). Acupuncture for epilepsy. Cochrane Database of Systematic Reviews(5). doi:10.1002/14651858.CD005062.pub4 Scheltens-De Boer, M. (2009). Guidelines for EEG in encephalopathy related to ESES/CSWS in children. Epilepsia, 50, 13-17. doi:10.1111/j.1528-1167.2009.02211.x Ranganathan, L. N., & Ramaratnam, S. (2005). Vitamins for epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD004304.pub2

39	What is the efficacy (i.e. the effectiveness of reducing seizures) of adding a second anti-seizure medication compared to changing to a different anti-seizure medication? How can we determine which combinations of anti-seizure drugs are effective?	If I tell my dr that I feel slow, depressed and tired now when I'm taking 2 meds, why can't we lower the dose (or drop one completely) to see what happens? I just want to start from scratch - no medication and a healthy life. How will life change? Why do I have to take 2 meds now? If one stopped working, shouldn't I stop taking it when I started the new one? If I had to change drugs why don't I stop taking the last one instead of taking two drugs at a time? Is there any treatment other than medication? Why do neurologists put patients on multiple anti seizure medication as opposed to changing the medication to one that works keeping them on only one? why do i have to take 2 seizure med? Do they cause me to have depressed moods? There should be just 1 medicine to take once a day because I also have memory problems with topiramate and I can't stop the fact that it has been going on for 4 years I have had a hard time but medications 2 times per day is too hard for me	7		1					Panebianco, M., Bresnahan, R., Ramaratnam, S., & Marson, A. G. (2020). Lamotrigine add-on therapy for drug-resistant focal epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD001909.pub3
19	How do seizures impact the mood of people who experience them and what are the best methods to manage mood swings?	What can be done about mood fluctuations after seizures? What can be done to limit memory issues in people with epilepsy? Are mood issues related to epilepsy, inter-ictal/ictal activity or AEDs? How can one manage severe mood swings and drastic changes in attitude. How can we improve the mood in patients with epilepsy? How much that problem impact in the seizure control? Recent studies have identified loneliness (feelings of isolation) as having detrimental effects on mental and physical health. Are specialists able to identify the feeling of isolation before it becomes a more persistent problem? Has there been enough research on isolation and loneliness in regard to epilepsy and co-existing conditions? 1) How can I improve my physical and emotional energy to interact with others 2) How do I step yelling and breaking down prior to seizure What can I do to deal with suicidal thoughts? How can I reduce mood swings? What should I do to reduce my memory problems Is it possible to help treat post Mania after my seizures. Is their possible treatment for weird and uncontrolled behaviour / freak outs after seizures Sometimes anger or unknown reactions get in the way of relationships. Is medicine to blame for change in mood? If so, how do we control it? Why aren't mood issues treated proactively instead of waiting for patients to bring it up?	9	1	6	2				Jackson, C. F., Makin, S. M., & Baker, G. A. (2015). Neuropsychological and psychological interventions for people with newly diagnosed epilepsy. Cochrane Database of Systematic Reviews(7). doi:10.1002/14651858.CD011311.pub2 Maguire, M. J., Weston, J., Singh, J., & Marson, A. G. (2014). Antidepressants for people with epilepsy and depression. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD010682.pub2 Blümcke, I., Thom, M., Aronica, E., Armstrong, D. D., Bartolomei, F., Bernasconi, A., . . . Spreafico, R. (2013). International consensus classification of hippocampal sclerosis in temporal lobe epilepsy: A Task Force report from the ILAE Commission on Diagnostic Methods. Epilepsia, 54, 1315-1329. doi:10.1111/epi.12220 Kerr, M. P., Mensah, S., Besag, F., De Toffol, B., Ettinger, A., Kanemoto, K., . . . Wilson, S. J. (2011). International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. Epilepsia, 52, 2133-2138. doi:10.1111/j.1528-1167.2011.03276.x Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
6	Are cannabis products (e.g. Marijuana, CBD oil) a safe and effective treatment for seizures alone or in combination with standard treatments (e.g. anti-seizure drugs)?	What is the hypothesis on being able to eradicate the use of anti-seizure medication and treat solely with CBD oil? Is CBD oil becoming a more commonplace treatment for epilepsy with legalization of marijuana in Canada? Should a wider variety of treatment options be considered by MD's? Have alternative therapies ie.cannabis been researched and are they being considered as adjunct treatment options? I would like some more info on CBD for Drug resistant absence epilepsy. If CBD oil is used as a treatment, should it be used in conjunction with anti-seizure medications? How effective is cannabis and what research and white papers have been written to show the efficacy? What is the efficacy of cbd with idiopathic seizure conditions. Is it more broad spectrum than specific antiepileptic medications? How successful is the use of cannabidiol in treating Dravet syndrome and Lennox gas taut syndrome. Is medical marijuana being investigated as a possible treatment for epilepsy and seizures? Is there treatments that have less of an impact on motor planning such as for patients with Rett syndrome? Anecdotal evidence suggests that CBD oils may help. I would like to know if there are good studies about possible interactions with meds. Also, how meds affect driving. Also, if medication side effects can be better studied.	24	8	9	3	3	2		Gloss, D., & Vickrey, B. (2014). Cannabinoids for epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD009270.pub3 National Institute for Health and Care Excellence. (2019). Cannabidiol with clobazam for treating seizures associated with Dravet syndrome. Technology Appraisal Guidance, TA614. Available from: www.nice.org.uk/guidance/ta614 National Institute for Health and Care Excellence (2019). Cannabidiol with clobazam for treating seizures associated with Lennox–Gastaut syndrome. Technology Appraisal Guidance, TA615. Available from: https://www.nice.org.uk/guidance/ta615
24	Is there a relationship between hormonal changes (e.g. puberty, menopause, pregnancy) and seizure onset and/or frequency, and what are the effects of seizures during pregnancy?	What is the role hormones play in adolescent seizures for youth who have no history of seizures? I wonder when people hit puberty why it changes the amount of seizures a girl may have Does menopause have any effect on having seizures? Effects on pregnancy, labour, birth & parenting. Are hormones related to seizures? (Seizures at the age of 6-8, then at age of 13 onwards). After sexual activities? I'd like to know more about menopause and seizures. Actually hormones and seizures in general because I know my seizures can be worse that time of the month. Are my seizures related to my menstral cycle? Where did my sex drive go? And my memory? Why are my seizures worse and more frequent during ovulation and my menstrual cycle? Why isn't there more research and development in the areas of Sleep & Seizures (direct relationships) and then Hormones & Seizures (primarily puberty and menopause)? How do fluctuations in seizure frequency relate to hormones (e.g., adolescence, peri-menstrual)	9	2	1	3				Maguire, M. J., & Nevitt, S. J. (2019). Treatments for seizures in catamenial (menstrual-related) epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD013225.pub2 Harden, C. L., Hopp, J., Ting, T. Y., Pennell, P. B., French, J. A., Allen Hauser, W., . . . Le Guen, C. (2009). Management issues for women with epilepsy - Focus on pregnancy (an evidence-based review): I. Obstetrical complications and change in seizure frequency: Report of the Quality Standards Subcommittee and Therapeutics and Technology Assessment Subcommittee o. Epilepsia, 50, 1229-1236. doi:10.1111/j.1528-1167.2009.02128.x Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Haruna, M., Matsuzaki, M., Ota, E., Shiraishi, M., Hanada, N., & Mori, R. (2019). Guided imagery for treating hypertension in pregnancy. Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD011337.pub2 Weston, J., Bromley, R., Jackson, C. F., Adab, N., Clayton-Smith, J., Greenhalgh, J., . . . Marson, A. G. (2016). Monotherapy treatment of epilepsy in pregnancy: congenital malformation outcomes in the child. Cochrane Database of Systematic Reviews(11). doi:10.1002/14651858.CD010224.pub2
13	Is it safe to wean a person who has experienced seizures off of anti-seizure drugs and if so, when is the right time to wean off anti-seizure drugs?	Why do specialists make their patients stay on medication when they were initially told they can come off of it once brain surgery is complete and the patient has been seizure free for over 1 year? After an absence of seizures how long before you should try decreasing medications If a person has not had a seizure in over 6 years, is it safe to stop medications? Will there ever be a time when medications won't be needed? How is the future looking for a permanent cure? Is a lifetime of medication necessary after just one seizure? When and how to re-evaluate anti-epileptic drug use after a period of no seizures? When multiple medications are not stopping the seizures what is the concerns a caregiver should be aware of. Should weaning medications be considered and how to go about that. The use of anti epileptic medications are difficult especially when the patients are on 4 of them. How do we decide on which one to reduce and stop/ How long after surgery should a person be on medication? How many years seizure free until there is no more risk of seizures? How long does someone need to be on anti-convulsants and seizure free until they can come off them? Or is this for life?	12	4	8	2				Strozzi, I., Nolan, S. J., Sperling, M. R., Wingerchuk, D. M., & Sirven, J. (2015). Early versus late antiepileptic drug withdrawal for people with epilepsy in remission. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD001902.pub2

		2. Is there a general rule for how long one has to be seizure-free before a reduction in medication would be considered or does it vary from healthcare provider to provider? Is the treatment “for life”? Can all drugs be taken during pregnancy? What impact would drugs have on a baby if taken during pregnancy?								
5	What are the best ways to support people who experience seizures secure and perform in employment (e.g., through accommodations) and what interventions can reduce workplace discrimination?	What are the most common occupations people with medication resistant epilepsy, or have work restrictions like no heights, or dangerous objects? Do what extent do refractory seizures impact memory, educability and career options? How does my son continue working if he has epilepsy? Is my epilepsy a discriminating factor for a job? If I hide my epilepsy at work will people treat me differently? Without my epilepsy will I be better at work? It's difficult to keep and maintain a career, how do I approach my epilepsy with a potential employer? Can my employer fire me if I have too many seizures and I miss too much work? How are people expected to hold down a job if their epilepsy isn't controlled? If someone is unable to hold down a job shouldn't they have some sort of government support? Can epilepsy prevent you from getting certain jobs, even after receiving the surgery? What support is available for people with epilepsy that are looking to work? Epilepsy and the job market, this relationship is difficult. You study to find a job and keep it. When will support and accommodation for epileptics be more accessible?	43	6	3					Epilepsy Ontario. (2018). Epilepsy and employment. Available from: https://epilepsyontario.org/epilepsy-and-employment/ Schachter S., Osbourne Shafer R., Sirven J. (2013). Safety at Work. Available From: https://www.epilepsy.com/learn/seizure-first-aid-and-safety/staying-safe/safety-work Clinic to Community. (2016). Epilepsy and Employment. Available from: https://www.clinictocommunity.ca/strategies/38-epilepsy-and-employment Job Accomodation Network. (No Date) Epilepsy/Seizure Disorder. Available from: https://askjan.org/disabilities/Epilepsy-Seizure-Disorder.cfm Wo, M.C.M., Lim, K.S., Choo, W.Y., Tan, C.T. Employability in people with epilepsy: A systematic review (2015) Epilepsy Research, 116, pp. 67-78 Beran RG, Devereaux JA & Buchanan D. (2020). Some legal aspects of epilepsy. Epilepsy & Behavior, 111, 107244. https://doi.org/10.1016/j.yebeh.2020.107244, 10.1016/j.yebeh.2020.107244 Krumholz A., Hopp J.L. & Sanchez A.M. (2016). Counseling Epilepsy Patients on Driving and Employment. Neurologic Clinics, 34, 427-442. https://doi.org/10.1016/j.ncl.2015.11.005
8	What non-drug lifestyle treatments (e.g., cardiovascular exercise, yoga) are effective for controlling seizure frequency with or without standard treatments (e.g., anti-seizure drugs)?	Why isn't there more research into alternative methods to treat epilepsy, not just medication? Have we found more proven lifestyle (diet, sleep, activity) choices that can help treat epilepsy? What lifestyle changes and regular activities (e.g. meditation, exercise, etc.) would help in reducing the chances of a seizure being triggered? Can you reduce the number of seizures through yoga, mindfulness meditation or other non-pharmacological relaxation techniques? Can exercise and other lifestyle management techniques like eating/sleeping/mindfulness reduce seizure frequency and/or improve quality of life? What treatment alternatives exist instead of drugs? Is there anything else besides drugs and ketogenic diet or vasal surgery that can be done to control seizures? Are there any naturopathic options to increase the likelihood of seizure management? In my view, low impact cardiovascular exercise (biking, fast walking) contributes to the success of avoiding future seizures. Is this correct? What new non-invasive treatments can stop seizures, without having to resort to surgical intervention?	26	3	6	3	2	3		Jackson, C. F., Makin, S. M., Marson, A. G., & Kerr, M. (2015). Non-pharmacological interventions for people with epilepsy and intellectual disabilities. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD005502.pub3 Panebianco, M., Sridharan, K., & Ramaratnam, S. (2017). Yoga for epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD001524.pub3
9	Do dietary changes alone or in combination with standard treatments (e.g. anti-seizure drugs) provide increased seizure control?	Are there nutrition choices that will help make sure I don't have another seizure? How can your diet affect seizures? Rescue meds and when to administer it at school. What supplements is needed depending on what seizure meds are being used. Besides the ketogenic diet what foods can benefit an individual with seizures? Are there any natural or diets that may help in reducing Juvenile Myoclonic seizures? What are the long term effects of meds like Lamotrigine, Keppra? Why are diet therapies ignored for adults? Have we found more proven lifestyle (diet, sleep, activity) choices that can help treat epilepsy? How effective is the ketogenic diet? Is the ketogenic diet or is vagus nerve stimulation more effective in reducing seizures in people with drug-resistant epilepsy? is a ketogenic diet proven effective or any type of diet for decreasing seizures Will there ever be a new natural way to help with seizuring instead of a pill?	22	2	13		1		3	Martin-McGill, K. J., Jackson, C. F., Bresnahan, R., Levy, R. G., & Cooper, P. N. (2018). Ketogenic diets for drug-resistant epilepsy. Cochrane Database of Systematic Reviews(11). doi:10.1002/14651858.CD001903.pub4 Kossoff, E. H., Zupec-Kania, B. A., Auvin, S., Ballaban-Gil, K. R., Christina Bergqvist, A. G., Blackford, R., . . . Wirrell, E. C. (2018). Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. Epilepsia Open, 3, 175-192. doi:10.1002/epi4.12225
10	Apart from monotherapy (e.g., being prescribed a single drug, using the keto diet without drugs), how can we personalize treatment options to combat a specific type of seizure or syndrome (i.e. specific drugs, combination of pharmacological and non-pharmacological treatment)?	Is the cause of epilepsy important to the treatment pathway? Can medication be more targeted to specific epilepsy? With the information available about the effects of diet on the brain and epilepsy in general, why are doctors not suggesting proven dietary habits with medication? How can we best tailor epilepsy treatments to the underlying cause or etiology of epilepsy? Why do we use the same treatment approach for such a heterogenous condition? What is the best treatment for cortical dysplasia? What treatments are there for my son's SPECIFIC form of seizures/epilepsy? (Jeavons Syndrome) What combinations of meds work best for people with JME who are women and also mental illness (also what types will lessen the risk of sleepiness) Why does it seem so arbitrary to find the right combination of meds to control epilepsy in refractory cases? How do I treat people with 2-5 seizures in their youth, who are seizure free without anti epileptic drugs? What are the best treatment options for seizures from traumatic brain injury? Is there a specific screening test and treatment for catamenial epilepsy?	10	8	9	11	1			Nevitt, S. J., Sudell, M., Weston, J., Tudur Smith, C., & Marson, A. G. (2017). Antiepileptic drug monotherapy for epilepsy: a network meta-analysis of individual participant data. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD011412.pub3
11	How can healthcare professionals communicate diagnostic information and collaborate with each other and people who experience seizures to ensure quality care?	How do I manage multiple diagnoses and medications? How do I know what is working and what isn't? I have a brain injury because of seizures and that causes me to not be accepted as 'normal' in society. I have anxiety and depression and seizures. When will all the Dr's work together to improve these issues as a team? We know based on the guidelines, that individuals should be seen at an EMU upon the failure of two anti-seizure medications. How often is this happening and how is this messaging being communicated to GPs, Emergency Room doctors, Neurologists, etc. How do anesthetists take into consideration my drug (Lamotrigine) if I need general surgery? Would a comprehensive approach to co-morbidities such as (social worker, clinical psychologies, and psychiatrist) should be part of the comprehensive epilepsy clinic models to tackle those issues? 1. Is it best to see a neuropsychiatrist or a psychiatrist with whom I have a strong relationship? 2. Does it really matter if I die? It would make it a lot easier for everyone	8	8	7	4	3			Fitzsimons, M., Power, K., White, M., Cavalleri, G., Dunleavey, B., Delanty, N., Doherty, C., McCormack, M., & Corbridge, R. (2017). Information When and Where Needed for Safe and Effective Integrated Care. International Journal of Integrated Care (IJIC), 17, 1–2. https://doi-org.myaccess.library.utoronto.ca/10.5334/ijic.3796 Altalib HH, Elzamzamy K, Pugh MJ, Gonzalez JB, Cheung KH, Fenton BT, et al. (2016). Communicating diagnostic certainty of psychogenic nonepileptic seizures - a national study of provider documentation. Epilepsy & Behavior, 64, 4-8. https://doi.org/10.1016/j.yebeh.2016.08.032, 10.1016/j.yebeh.2016.08.032 O'Toole S, Lambert V, Gallagher P, Shahwan A & Austin JK. (2016). "I don't like talking about it because that's not who I am": Challenges children face during epilepsy-related family communication. Chronic Illness, 12, 216-26. https://doi.org/10.1177/1742395316644307, 10.1177/1742395316644307 Pakpour, A. H., Gholami, M., Esmaeili, R., Naghibi, S. A., Updegraff, J. A., Molloy, G. J., & Dombrowski, S. U. (2015). A randomized controlled multimodal behavioral intervention trial for improving antiepileptic drug adherence. Epilepsy & behavior : E&B, 52(Pt A), 133–142. https://doi-org.myaccess.library.utoronto.ca/10.1016/j.yebeh.2015.08.036

		Treatment plans should involve more then just the epilepsy team why don't they? We have questions on the use of harsh medications were told it's epilepsy with no reason why no cause and told no cure but you gotta take these pills forever Also how do we handle meds during a surgical procedure? he will be sedated and having shoulder surgery to repair a dislocated shoulder from a seizure last year. How to connect patients with community supports in timely fashion I am wondering about team visits (whole team approach including psychs, SW, etc) rather than visits with the neuro. How best to deliver care to children and young people with epilepsy, teenage issues and transition.								133–142. https://doi-org.myaccess.library.utoronto.ca/10.1016/j.yebeh.2015.08.036 Mayor, R., Brown, R. J., Cock, H., House, A., Howlett, S., Smith, P., & Reuber, M. (2013). A feasibility study of a brief psycho-educational intervention for psychogenic nonepileptic seizures. Seizure, 22(9), 760–765. https://doi.org/10.1016/j.seizure.2013.06.008 Buelow J.M., Shafer P., Shinnar R., Austin J., Dewar S., Long L., et al (2016). Perspectives on seizure clusters: Gaps in lexicon, awareness, and treatment. Epilepsy and Behavior, 57, 16-22. https://doi.org/10.1016/j.yebeh.2016.01.028 Mayor R., Smith P.E. & Reuber M. (2011). Management of patients with nonepileptic attack disorder in the United Kingdom: A survey of health care professionals. Epilepsy and Behavior, 21, 402-406. https://doi.org/10.1016/j.yebeh.2011.05.019
12	What are the impacts of common non-drug treatments (e.g., surgery, diet changes etc.) on a person's overall health and development?	What is the long term impact on a developing brain of being on anti-seizure medication? What is the longterm impact of zarontin on a small child's developing brain? Our son has been through quite a drug treatment trial and error session for most of his life. What toll is this taking on his body and health? Are there any natural or diets that may help in reducing Juvenile Myoclonic seizures? What are the long term effects of meds like Lamotrigine, Keppra? can your medication effect your organs after taking them for such a prolonged time? Does the medication harm the liver overtime? Do we grow a tolerance to medication Do anti-seizure medications cause long term cognitive deficits? How does consumption of large volumes of medications over 35 years affect your medical health (e.g. Tegretol, Keppra and Clobazam)? She's been on keto diet for 5 years now. What are the long-term impacts of the keto diet and when is it appropriate to wean her from it. How are we going to better assist patients that have uncontrollable Epilepsy after 10, 20+ years of having the disorder who have also already had at least one brain surgery. What number of surgeries and medication changes are too damaging to the body?	17	4	6		1			Evidence Not Identified
14	What is the relationship between age and seizure onset?	How common is seizure onset in adolescents for youth with no history of previous seizures? Does the age of onset of seizures impact one's resilience to having epilepsy? Why youth onset? How would epilepsy suddenly appear in a spirited, academically strong young girl? What triggers it? Trauma? Brain growth? Genetic? (with no reported cases on either side of family) Why do some people develop epilepsy in their early twenties with no prior history? Why don't doctors know what triggers my seizures? Why do they appear at 25 years? I am particularly interested in the causes of 'Adult Onset Epilepsy'...what prompts epilepsy in a young adult who has been healthy with no brain trauma events...I am learning that this has been more prevalent of late Why is it that some people don't present symptoms until the age of 11 or 12? What changed in the brain to have resulted in show of symptoms? What causes epilepsy in middle aged persons who have not suffered head trauma? What causes adult onset epilepsy, if no obvious reason can be found (I.e brain injury or tumour)? What is the origin of my condition? Symptoms started at 39, diagnosed at 43. Did I always have this inactive condition, or did it appear?	10	4	11					Evidence Not Identified
15	What barriers prevent the general population from understanding the challenges facing people who have seizures?	Why aren't more first responders trained in recognizing seizures and post-ictal behaviour? Why are people only aware of convulsive seizures? I have suffered with PTSD, a hemorrhagic stroke, brain surgery and it is so hard to describe my emotions and depression to medical staff. How do you make front line people take you seriously in your confusion of what's going on!!! You are left to believe that it is not an emergency to them, however it sure is to you 2). Do the emergency Room triage nurses, doctors and admissions personnel know the risks of status epilepticus and how to recognize it? Is there a notice at the top of the file that I have both convulsive and non convulsive status? How is the risk decreased? Why were so little medical providers aware of the auditory and visual hallucinations aspect of seizures? Could the people around me be better informed on the subject? How can I better accept my diagnosis? How aware are people administrating medical and other support services about the effects of epilepsy and the impact on income and daily function. There are some general opinions we have encountered re epilepsy and access to support that is available to people with other medical conditions. The consensus seems to be that the person with epilepsy has 'some seizures sometimes' and that it does effect them outside the actual seizure event. No one takes into account the pre and post seizure effects (exhaustion, loss of bladder, bowel, mangled tongue, risk of injury from falling), nor do they consider the embarrassment, side effects of medication, and effect on overall brain function and processing speed. What is being done to train paramedics, doctors, nurses, teachers, etc., about epilepsy so there is not so much of a stigma and fear surrounding it. So many inaccuracies/wives tales still exist!! Why do neurologists refuse additional treatment when an Epilepsy patient's body does not comply with the expected results of treatment? When seizures do not respond to drug treatment, or medications cause seizures the why are Epilepsy patients not assisted by the broad medical community or social services? Why are they are left to the margins of society? Epilepsy is a family condition, family support is necessary for the survival of anyone with refractory epilepsy. if there are no family supports people with epilepsy live a lonely and deadly life. Why is this allowed to happen in 2019? What are GPs and emergency doctors taught about epilepsy? What are educators/teachings being taught about epilepsy and treatment? How much training are they receiving about the condition and treatments?	11	4	5		1			Perzynski, A. T., Ramsey, R. K., Colón-Zimmermann, K., Cage, J., Welter, E., & Sajatovic, M. (2017). Barriers and facilitators to epilepsy self-management for patients with physical and psychological co-morbidity. Chronic illness, 13(3), 188–203. https://doi.org/10.1177/1742395316674540 Lewinski, A.A., Shapiro, A., Gierisch, J.M., Goldstein, K.M., Blalock, D.V., Luedke, M.W., Gordon, A.M., Bosworth, H.B., Drake, C., Lewis, J.D., Sinha, S.R., Husain, A.M., Tran, T.T., Van Noord, M.G., Williams, J.W., Jr. Barriers and facilitators to implementation of epilepsy self-management programs: A systematic review using qualitative evidence synthesis methods (2020) Systematic Reviews, 9 (1), art. no. 92,
		Why does no one care about epilepsy issues?								

16	What barriers prevent healthcare providers from understanding the lived experience of their patients who have seizures?	Why are people only aware of convulsive seizures? 2). Do the emergency Room triage nurses, doctors and admissions personnel know the risks of status epilepticus and how to recognize it? Is there a notice at the top of the file that I have both convulsive and non convulsive status? How is the risk decreased? Why were so little medical providers aware of the auditory and visual hallucinations aspect of seizures? Could the people around me be better informed on the subject? How can I better accept my diagnosis? What is being done to train paramedics, doctors, nurses, teachers, etc., about epilepsy so there is not so much of a stigma and fear surrounding it. So many inaccuracies/wives tales still exist!! What are GPs and emergency doctors taught about epilepsy? What are educators/teachings being taught about epilepsy and treatment? How much training are they receiving about the condition and treatments? memory problems, confusion are intermittent and my GP isn't quite understanding or educated in this problem, being ongoing. It is triggered by lack of rest. Are GPS kept in the loop or is it because the changes are so fast and frequent that they don't go through the chain of practitioners? Why aren't more first responders trained in recognizing seizures and post-ictal behaviour?	11	4	5		1			Pretorius, C. (2016). Barriers and facilitators to reaching a diagnosis of PNES from the patients' perspective: Preliminary findings. Seizure, 38, 1–6. https://doi-org.myaccess.library.utoronto.ca/10.1016/j.seizure.2016.03.007 Owens S., Sirven J.I., Shafer P.O., Fishman J., Wild I., Findley M., et al (2019). Innovative approaches reaching underserved and rural communities to improve epilepsy care: A review of the methodology of the Connectors Project. Epilepsy and Behavior, 90, 273-283. https://doi.org/10.1016/j.yebeh.2018.09.029 Swarztrauber K. (2004). Barriers to the Management of Patients with Surgically Remediable Intractable Epilepsy. CNS Spectrums, 9, 146-152. https://doi.org/10.1017/S1092852900008506
20	What primary and secondary prevention measures can be used for epilepsy/seizure disorders?	Why did my child get absence seizures? Where does it come from? What could I have done differently to prevent this? And what do I, as the patient, need to do, in terms of prioritizing prevention strategies? What causes cortical dysplasia and what preventative measures can be taken? It took over a year and many hospital trips and tests to identify the cause of my child's seizures...a cortical dysplasia. However her seizures only began at 6 years of age and initially occurred only at night. After a functional MRI revealed her seizure activity traveling along thalamic pathways, a new medication was introduced (ethuxomide/zarontin) and immediately had a positive effect where other medications had failed. Many years and medications later, her EEG shows seizure activity only during light sleep. Are there ways to prevent epilepsy? Can it be prevented? It is not clear why I developed epilepsy in my mid 50's. Is there anything I could have done to prevent developing epilepsy? It took 4 years for me to get a diagnosis and start treatment. Could an earlier diagnosis and start of treatment reduce possible future related problems? With refractory epilepsy, I am wondering about why seizures occur when they do (patterned) and what else can be done to prevent them. If yes, do they inform the parents and are there possible means of prevention ??? How to prevent seizures during the day	4	4	8		2			Thurman, D. J., Begley, C. E., Carpio, A., Helmers, S., Hesdorffer, D. C., Mu, J., . . . Newton, C. R. (2018). The primary prevention of epilepsy: A report of the Prevention Task Force of the International League Against Epilepsy. Epilepsia, 59, 905-914. doi:10.1111/epi.14068 Epilepsy: a public health imperative. Geneva: World Health Organization; 2019
22	Is vagus nerve stimulation (VNS) an effective treatment for reducing seizure frequency, and how effective is it in people where anti-seizure drug therapy has failed?	Effectiveness of VNS treatment for children with focal to bilateral tonic clinic seizures. Does effectiveness change with ongoing brain growth and development in children. Is VNS the last option for a patient if medication doesn't work, and they are not a candidate for more surgery? Can VNS help absence seizures? I sometimes have 100+ in one day. I also have tonic clonic? What devices are available to help with decrying seizures? Is laser surgery safer than having your skull and brain actually cut open? Can VNS MACHINES help or work against us in thunder and lightning storms? Why do things like VNS implants work for some types of epilepsy but not all? Is there a study to show what meds the VNS is effective at displacing? How does VNS work Is the ketogenic diet or is vagus nerve stimulation more effective in reducing seizures in people with drug-resistant epilepsy? What is the electric device that can be used to counteract the abnormal brain waves and prevent seizures?	10	1	3	1			1	Panebianco, M., Rigby, A., Weston, J., & Marson, A. G. (2015). Vagus nerve stimulation for partial seizures. Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD002896.pub2
23	How can people who experience seizures and their caregivers or care partners manage fear associated with seizures?	How as a parent can I get more sleep? I dont sleep good anymore cause I'm scared of the seizures during sleep time, so I check my son all night. How do I best help her with her fears? How can we best support patients and their families in a disorder of anticipation; anxiety over not knowing if or when they or their child will have another seizure? the fear we as his parents feel is constant....i feel like im holding my breath all the time....filled with worry for the 'next one' so im sure our son is feeling that way too,,,,,he has full time job and lives independently, but we think about him ALL the time. how do we manage or better still how do we stop worrying about the next seizure? My daughter being very young, 2 fears haunt me. I am very afraid that she will have a crisis at night and that she will die from it. She stops breathing during her seizures ... so, I can't sleep anymore! Do others fear another seizure at school that could have life threatening results if the seizure occurs? We were afraid that she would take public transport and get robbed. Now she cannot be alone with her baby, it is difficult to manage on a daily basis. We are not aware of all the resources available with the CLSC, for example Will there ever be support for people with PTSD from having seizure?The daily fear of seizures recurring, inability to participate in certain activities again because of the fear of what could happen...these fears can be rational and irrational but, all relating back to the actual fear of a seizure, the recovery, the affect on quality of life etc.	6	3	6	1				Wu, Y. P., Follansbee-Junger, K., Rausch, J., & Modi, A. (2014). Parent and family stress factors predict health-related quality in pediatric patients with new-onset epilepsy. Epilepsia, 55(6), 866–877. https://doi.org/10.1111/epi.12586 Walker, E. R., Barmon, C., McGee, R. E., Engelhard, G., Sterk, C. E., DiIorio, C., & Thompson, N. J. (2014). Perspectives of adults with epilepsy and their support persons on self-management support. Qualitative health research, 24(11), 1553–1566. https://doi.org/10.1177/1049732314548880 Miller W.R., Von Gaudecker J., Tanner A. & Buelow J.M. (2020). Epilepsy self-management during a pandemic: Experiences of people with epilepsy. Epilepsy and Behavior, 111, no pagination. https://doi.org/10.1016/j.yebeh.2020.107238 Mitter N., Ali A. & Scior K. (2018). Stigma experienced by family members of people with intellectual and developmental disabilities: Multidimensional construct. BJPsych Open, 4, 332-338. https://doi.org/10.1192/bjo.2018.39 Miller WR. (2016). Parental Perceptions of Family Social Supports in Families With Children With Epilepsy. Journal of Neuroscience

		I've learned that even when seizures are fairly frequent - say several a day - the time in between them is still the vast majority of the life of the person living with them. And having a seizure disorder really invades and colours the entire life in ways we rarely recognize. How can we better support people living with epilepsy to live from courage and heart (and not fear)? Seems to me we need a whole person strategy - nutrition, mindset, exercise, emotional intelligence, spiritual development. I don't see any resources for this? Are there any?								Nursing, 48, 342. https://doi.org/10.1097/JNN.0000000000000262
25	Are there any exposures in a person's surroundings (e.g., chemicals, pesticides, pollution etc.) that are associated with an increased risk of seizures?	Is there environmental factors or known causes for epilepsy? What types of secondary or external factors can cause epilepsy? What contributes to the development of epilepsy in youth who do not have and congenital epilepsy or a genetic predisposition to epilepsy. And what are the differences in brain activity between petit absence seizures, tonic-clonic seizures and partial or focal seizures. What environmental factors are important in the development of epilepsy? Why is it so difficult to identify the cause of epilepsy when it appears out of nowhere in so many cases? Why are there so many cases of refractory epilepsy? Are scientists looking at other areas for causes outside of the brain I.e viruses, bacterial infections, environmental? Where is the future of epilepsy research going? What effects do mercury and aluminum have on the brain Relationship between mecury/aluminum and seizures Is this hereditary? How did I contact Epilepsy ? What if any environmental factors have a role in contacting this disease? What genes and variants contribute to common and rare epilepsies? How do common variants contribute to causing epilepsy when the cause is acquired (such as TBI, malaria)? Why is epilepsy more common in socially deprived areas? What is the role of the microbiome in the cause of epilepsy? Why do some seizures fail to stop and cause status epielpticus? What other health conditions cause seizures? Are there any factors that make someone more likely to have seizures or epilepsy?	5	1	3	4	1			Nussbaumer-Streit, B., Yeoh, B., Griebler, U., Pfadenhauer, L. M., Busert, L. K., Lhachimi, S. K., . . . Gartlehner, G. (2016). Household interventions for preventing domestic lead exposure in children. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD006047.pub5
26	What is the best protocol for screening seizure patients for common comorbidities?	Why do so many patients with seizure disorders have cardiac problems/surgery? Why are their so many cardiac minics and what can be done to assure proper diagnosis? Why do some people with epilepsy develop post-ictal psychosis? Is there a way of identifying these patients and preventing psychosis before it manifests? When should someone with epilepsy look to obtain these diagnosis? When do physicians investigate/treat comorbidities like depression, anxiety, developmental disorders, etc.? How to detect and provide a holistic approach for co-existing conditions in children? Are programs available to overcome barriers like memory issues or stress? Can my neurologist help me determine if a co-existing condition is part of me? What questions should I ask? What are the top 5 co-existing conditions relating to epileptics? What blood tests should be performed and how frequently, to determine if medications are causing problems while distinguishing it from it being a new medical condition? Without seizure control, how can we test for any comorbid diagnosis? How are behaviours/challenges associated with epilepsy diagnosed and treated separately from co-existing conditions? Why aren't children diagnosed early on with epilepsy screened regularly for learning difficulties and mental health issues? Are there neurobiological markers that could help predict certain traits? epilepsy is a neurodegenerative disease with a psychiatric component - psychosis, depression, anxiety	4	3	2	4	1			Wilmshurst, J. M., Gaillard, W. D., Vinayan, K. P., Tsuchida, T. N., Plouin, P., Van Bogaert, P., . . . Cross, J. H. (2015). Summary of recommendations for the management of infantile seizures: Task Force Report for the ILAE Commission of Pediatrics. Epilepsia, 56, 1185-1197. doi:10.1111/epi.13057 Jackson, C. F., Makin, S. M., & Baker, G. A. (2015). Neuropsychological and psychological interventions for people with newly diagnosed epilepsy. Cochrane Database of Systematic Reviews(7). doi:10.1002/14651858.CD011311.pub2 Fountain, N. B., Van Ness, P. C., Bennett, A., Absher, J., Patel, A. D., Sheth, K. N., . . . Stecker, M. (2015). Quality improvement in neurology: Epilepsy Update Quality Measurement Set. Neurology, 84, 1483-1487. doi:10.1212/wnl.0000000000001448 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Mula, M., Kanner, A. M., Schmitz, B., & Schachter, S. (2013). Antiepileptic drugs and suicidality: An expert consensus statement from the Task Force on Therapeutic Strategies of the ILAE Commission on Neuropsychobiology. Epilepsia, 54, 199-203. doi:10.1111/j.1528-1167.2012.03688.x Kerr, M. P., Mensah, S., Besag, F., De Toffol, B., Ettinger, A., Kanemoto, K., . . . Wilson, S. J. (2011). International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. Epilepsia, 52, 2133-2138. Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
27	Aside from EEG and videoEEG, what monitoring devices can be used to reduce safety risks/complications related to seizures?	For those with families or who live alone, what processes can we take to ensure we are save if we have a seizure alone or with a young child, as no device has been invented to notify people of this. When will we have seizure monitors for nocturnal seizures to prevent SUDEP and other monitors for any time use to alert family when a seizure happens When will have monitors so people can feel sad and confident to go to school/ work/ be in the public How can a parent monitor nocturnal absence seizures?? 1) Why are there no very good seizure detection devices available in the world? Either seizure prediction or immediately when a seizure starts? There are wrist bands such as Embrace that are no where close to perfect. Is research being done on better devices? Are there incentives to better detection devices? It appears all seizure detection devices are created by small under-funded companies. Nothing truly professional. If we realistically can't stop seizures, we should surely be able to easily monitor them in real time to help prevent injury or death. In this day of Digital Transformation, what is the best epilepsy monitoring tool for nocturnal seizures? Secondly, given that in our experience, seizures are relatively sporadic, we would like a predictive tool to determine at any particular point of time whether our son is at a higher, or lower risk of having a seizure from his baseline activity. This would allow him to perhaps increase medicine (assuming we knew it would do something), but it would also allow us to arrange to be near him to help him if he is at a higher risk. This would allow him to live independently in times of low risk. It might also rule in or out his ability to drive on a particular day or engage in potentially dangerous tasks like skiing/swimming/fishing. Why can't we have better early detection so that people can feel like they can have a normal life - and then when/if a seizure is oncoming - they will be warned with enough time to take precautions? If we can prevent it from going off like walking on a surprise grenade, it will help people lead a more normal day. Why can't we develop better, cost effective, REAL TIME monitoring? I don't mean a watch that rings once a preson STARTS shaking. I mean a proper system like 'hey, your electrical charge is building up in your brain, you may have a seizure in a few moments' Is there a device to detect petit mal (absence seizures) for patients who live alone? Will we one day, have access to something that will be able to detect nocturnal epilepsy	3	4	5				1	Maguire, M. J., Jackson, C. F., Marson, A. G., & Nevitt, S. J. (2020). Treatments for the prevention of Sudden Unexpected Death in Epilepsy (SUDEP). Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD011792.pub3 Tatum, W. O., Rubboli, G., Kaplan, P. W., Mirsatari, S. M., Radhakrishnan, K., Gloss, D., . . . Beniczky, S. (2018). Clinical utility of EEG in diagnosing and monitoring epilepsy in adults. Clinical Neurophysiology, 129, 1056-1082. doi:10.1016/j.clinph.2018.01.019 Dash, D., Dash, C., Primrose, S., Hernandez-Ronquillo, L., Moien-Afshari, F., Ladino, L. D., . . . Téllez-Zenteno, J. F. (2017). Update on minimal standards for electroencephalography in Canada: A review by the Canadian Society of Clinical Neurophysiologists. Canadian Journal of Neurological Sciences, 44, 631-642. doi:10.1017/cjn.2017.217 Beniczky, S., Neufeld, M., Diehl, B., Dobesberger, J., Trinka, E., Mameniskiene, R., . . . Ryvlin, P. (2016). Testing patients during seizures: A European consensus procedure developed by a joint taskforce of the ILAE – Commission on European Affairs and the European Epilepsy Monitoring Unit Association. Epilepsia, 57, 1363-1368. doi:10.1111/epi.13472 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Labiner, D. M., Bagic, A. I., Herman, S. T., Fountain, N. B., Walczak, T. S., & Gumnit, R. J. (2010). Essential services, personnel, and facilities in specialized epilepsy centers-Revised 2010 guidelines. Epilepsia, 51, 2322-2333. doi:10.1111/j.1528-1167.2010.02648.x Scheltens-De Boer, M. (2009). Guidelines for EEG in encephalopathy related to ESES/CSWS in children. Epilepsia, 50, 13-17. doi:10.1111/j.1528-1167.2009.02211.x

		Will we one day, have access to something that will be able to detect nocturnal epilepsy effectively?								Gaillard, W. D., Chiron, C., Helen Cross, J., Simon Harvey, A., Kuzniecky, R., Hertz-Pannier, L., & Gilbert Vezina, L. (2009). Guidelines for imaging infants and children with recent-onset epilepsy. Epilepsia, 50, 2147-2153. doi:10.1111/j.1528-1167.2009.02075.x Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
28	How does understanding where seizures originate affect the outcome of treatment?	Is there a difference in the types of seizures, depending on where they originate in the brain? What are the main triggers of seizures? Where in the brain are the seizures initiating? If that area can be identified is there some further treatment options? What contributes to the development of epilepsy in youth who do not have and congenital epilepsy or a genetic predisposition to epilepsy. And what are the differences in brain activity between petit absence seizures, tonic-clonic seizures and partial or focal seizures. Can an EEG tell what part of the brain seizures come from. If you have tonic clonic seizures that spread everywhere, it is really hard to figure out in what part of the brain it originates. I am very interested in understanding more about all brain function and its relationship to the location of the seizure focus. I have found that behaviour and mood can be a predictor of seizures and can change for the better, once the seizure has passed. Why is it so difficult to diagnose or map where seizures are starting? Where in the brain is the cause of the seizure?, and can it be removed if it's scar tissue.? Understanding how networks trigger seizures 1) could the seizures be caused by another neurological syndrome? 2). If so, what tests should be done to determine if this is the case and how to better manage them? 3). Do I have a rare kind of epilepsy given that I have abnormal seizure types?	5	2	2	2	1			Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
29	Why and how does abnormal brain organization (i.e. cortical dysplasia, enlarged ventricles) cause seizures?	1. Is focal cortical dysplasia a genetic disorder? Does this mean it can be inherited if the sibling of someone with cortical dysplasia has children? What causes cortical dysplasia and what preventative measures can be taken? It took over a year and many hospital trips and tests to identify the cause of my child's seizures...a cortical dysplasia. However her seizures only began at 6 years of age and initially occurred only at night. After a functional MRI revealed her seizure activity traveling along thalamic pathways, a new medication was introduced (ethuxomide/zarontin) and immediately had a positive effect where other medications had failed. Many years and medications later, her EEG shows seizure activity only during light sleep. What causes cortical dysplasia? How prevalent is cortical dysplasia in Canada? Why does cortical dysplasia cause seizures? 2. What is the natural history of cortical dysplasia? How does it affect cognition and learning? What are the causes of epilepsy, particularly Cortical dysplasia. Why does cortical dysplasia not show symptoms at birth and appear at a later stage in life? Can cortical dysplasia change as the patient ages, or does it remain in the same region of the brain at the time of diagnosis? My Daughter (3 years old) has had Infantile spasms and focal seizures since she was 36 hours old. She has had multiple tests including 2 MRI scans, with another one scheduled for fairly soon. In these scans we've noticed her ventricles are enlarged, so I am curious to see what this MRI has to show. My question to you that has never been answered is, would the cause of her spasms and focal seizures be caused my enlarged ventricles? I have cortical dysplasia in my right frontal lobe however I present with seizures that look like they come from my right temporal lobe; why is that? 7 years running and we still don't know the cause of my 8 year old daughter's seizures. We have been told it may be because of focal cortical dysplasia, however she randomly stopped having seizures and so we not been able to identify whether her GTC's are originating in that area. I am told that my 2 year old daughter, diagnosed three weeks ago, is epileptic because of a dysplasia of the brain which would have developed in-utero ... In this case, how is it that she had her first attack at 2 years old? Also, why are the seizures, albeit very intense, rare? What triggers them then? Why did my child get absence seizures? Where does it come from? What could I have done differently to prevent this?	2	4	5	1				Blümcke, I., Thom, M., Aronica, E., Armstrong, D. D., Vinters, H. V., Palmini, A., . . . Spreafico, R. (2011). The clinicopathologic spectrum of focal cortical dysplasias: A consensus classification proposed by an ad hoc Task Force of the ILAE Diagnostic Methods Commission. Epilepsia, 52, 158-174. doi:10.1111/j.1528-1167.2010.02777.x Ayuga Loro, F., Gisbert Tijeras, E., & Brigo, F. (2020). Rapid versus slow withdrawal of antiepileptic drugs. Cochrane Database of Systematic Reviews(1). Marigold, R., Günther, A., Tiwari, D., & Kwan, J. (2013). Antiepileptic drugs for the primary and secondary prevention of seizures after subarachnoid haemorrhage. Cochrane Database of Systematic Reviews(6).
30	In addition to medication adherance, what causes seizures to change in presentation and/or severity?	Why does epilepsy sometimes 'resurface' after years of no activity? How can someone have a certain type of seizure as a child and suddenly change to more severe seizures as an adult? None. Perhaps I have an intrinsic lack of curiosity. I just have it. I've had it since I was two. It became worse when I turned 32. I don't have nearly as severely as some people do. My only interest is in how to manage it. Perhaps, why does a diagnosis change in one's life. My epilepsy was thought to be one type as it started when I was two. I had a grand mal seizure when I was 13 and was told that it now couldn't be guaranteed that my seizures would end as it did for many people with a pre-school diagnosis. Fair enough. But at 32 I started have grand mal seizures as well as petit mal. Why do some people's manifestations of seizures change along the way? Why are my seizures changing with time? What prompted my seizures to happening very rarely and then to almost daily? Does epilepsy get worse with age ? Is it degenerative for most? INW: Does it get worse with age? can a person develop more seizure types the longer they have epilepsy? What causes epilepsy? Why after 42 years I take 3 grand mal seizures? Why were they the worse ones then I took when I was 12 - 23 years old? Why are there so many different types of seizures and why is it so rare to come across those with epilepsy to have the exact same symptoms? What causes status epilepticus Can they be treated again when you go for year without having any than start to occur than?	10	1						Al-aqeel, S., Gershuni, O., Al-sabhan, J., & Hiligsmann, M. (2017). Strategies for improving adherence to antiepileptic drug treatment in people with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD008312.pub3
31	Why do some seizure disorders resolve?	- Why did I all of a sudden develope seizures in my late thirties with no past hx or family hx? - What percentage of people do they go away in ? -To what age do seizures normally last ? Will it ever stop? Do children in fact grow out of epilepsy or have it their whole life? Is it true some people with epilepsy will have seizures all of their life? is the diagnosis for life? There is conflicting information about this. If seizures stop, you might still have spikes and waves on an EEG which means you still have epilepsy? Why do they (Doctors) say that your child can grow out of these episodes ?seizures Will I have seizures all my life and what could have caused them	6	2	3					Evidence Not Identified

		We do not yet know whether the form of epilepsy will remain or disappear as we age. We also don't know what causes epileptic status, or whether migraines are related to epilepsy itself or the medication How is it that for some patients the seizures stop permanently? Have we made associations with age, lifestyle or others? What can help the brain heal and make new neurons? Is age 58 too old for this healing? Is there any treatment that is effective in totally eliminating seizures? How do patients outgrow epilepsy?								
32	Are sleep disorders linked to developing seizures and are people who experience seizures at an increased risk of sleep disorders?	My main ones are to do with memory, sleep, and anxiety. At times have fogginess and forget things. Also want to know if my epilepsy affects my sleep and does it cause anxiety or are they all bound together in one single ball. Is there a link between epilepsy and sleep disorders Does sleep apnea affect seizures? 1 - When my teen (non verbal with autism) has a seizure day she is unable to sleep at night. She seems tired but is unable to settle herself. She is literally up the whole night. Do seizures cause insomnia? Is it normal for someone with adult onset epilepsy for their personality to change? Is it normal for people with epilepsy to lose their energy more quickly or to be more tired even with a sufficient amount of sleep? Currently my son is on multiple medications to manage the mental illness, learning disabilities, sleep and epilepsy. Can we initiate research for more understanding for the root cause of the deficits and therefore be able to provide targeted treatment for the defect instead of the symptoms? Why isn't there more research and development in the areas of Sleep & Seizures (direct relationships) and then Hormones & Seizures (primarily puberty and menopause)?	5	2	3					Michaelis, R., Tang, V., Wagner, J. L., Modi, A. C., LaFrance Jr, W. C., Goldstein, L. H., . . . Reuber, M. (2017). Psychological treatments for people with epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD012081.pub2 Brigo, F., Igwe, S. C., & Del Felice, A. (2016). Melatonin as add-on treatment for epilepsy. Cochrane Database of Systematic Reviews(8). doi:10.1002/14651858.CD006967.pub4 Maguire, M. J., Weston, J., Singh, J., & Marson, A. G. (2014). Antidepressants for people with epilepsy and depression. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD010682.pub2 Epilepsy: a public health imperative. Geneva: World Health Organization; 2019. Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
33	How can access to resources/supports for people who experience seizures be optimized?	Why are resources so difficult to access? As an exhausted parent I always felt like I had to fight for everything. It is a condition that is invisible but can be extremely difficult to manage. Service areas that seem to be missing are things like supporting patients in getting to medical appointments when fearful of taking public transit and can't drive. Child care or respite for parents with epilepsy. Companion or respite for spouses of individuals with epilepsy when afraid to leave the individual alone. More information about effective seizure alert devices like the watches. Always, people are looking or financial help in many different areas. If a person is born with epilepsy due to 'encephalitis' or a form of it who's can that person receive help at different phases of our lives. As outlined in my answer to question 1, I am a limbo-epileptic; I don't know if I'm in or I'm out. I have taken anti-seizure drugs for nineteen years, have done volunteer work, have attended a zillion seminars and lectures, have completed a few more courses toward my Master's degree - but the entire process has been a 'do it yourself, sink or swim' deal. With no follow-up from the hospital that I was taken to, and enormous abuse from the landlady where the accident happened (she and her psycho-son hired a couple of guys to kill me, frightened me out, then kept all of my belongings) my life has been bleak. And in 2006 I was still in seizure mode - and they were whoppers - landing me in hospital numerous times. **Again, the hospital where I was sent should have had follow-up/outpatient/outreach services to help people like me.** Many hospitals do very little with providing personalized mental health care plans for patients due to their short visits in inpatient EMUs and outpatient clinics. These are excellent opportunities to engage this group of patients that are facing coexisting mental health conditions especially anxiety, depression, bi-polar disorder, OCD, PTSD and with it a tendency for violence both trauma related and post-ictal violence. Every time the issue is raised with organizations, very little is done to combat the issue because it's 'mental health'. Combating this issue is much more simpler than most think. The availability of a Advanced Practice Nurse or Nurse practitioner specializing in a psychiatric speciality can help counsel patients and make appropriate referrals during their visits or length of stay in the hospitals. Facilities with such services tend to have greater patient satisfaction and help serve as a bridge that prevent patients from falling into the systems's gaps. My son has cortical dysplasia and he started seizures when he was 7 yrs old. He was seizure free for 5 years but has recently had 3 grand mals in the last year (2019/2020). Its very hard as a single parent who works two jobs to go to work and not wonder if your child has had a seizure alone. He has fallen and hit his head both times and the 3rd seizure thankfully he was sitting in a chair and was safe. **It would bring peace of mind as a parent if service dogs were more accessible and if there was funding for such thing.** My son would also be safer as well. I have found very little support for dealing with my recent diagnosis. nothing was provided at the time of diagnosis, ie. transport alternatives, safety considerations, medic alert bracelet etc. Counseling or group meetings could help. There is a lack of local support services in our area. It may be helpful to run public events like 5k walk/runs, to bring patients and families together. There should be automatic and regular follow-up (once a year minimum) with a psychology department to see the effects on the morale of people affected	4		3	1	1			Elliot, V.L., Morgan, D., Kosteniuk, J., Froehlich Chow, A., Bayly, M. Health-related stigma of noncommunicable neurological disease in rural adult populations: A scoping review (2019) Health and Social Care in the Community, 27 (4), pp. e158-e188. https://www.scopus.com/inward/record.uri?eid=2-s2.0-85058424682&doi=10.1111%2fhsc.12694&partnerID=40&md5=5d3691f58897ce7bfe9498170511105d Didsbury, M. S., Kim, S., Medway, M. M., Tong, A., McTaggart, S. J., Walker, A. M., White, S., Mackie, F. E., Kara, T., Craig, J. C., & Wong, G. (2016). Socio-economic status and quality of life in children with chronic disease: A systematic review. Journal of Paediatrics & Child Health, 52(12), 1062–1069. https://doi.org/10.1111/jpc.13407 Williams, F., McCafferty, A., Dunkley, C., & Kirkpatrick, M. (2018). A UK survey of the experience of service provision for children and young people with epilepsy. Seizure, 60, 80–85. https://doi.org/10.1016/j.seizure.2018.06.007 Falcone T., Rivera E., Blanks M., Butler R.S. & Kotagal P. (2012). Knowledge and access to care in families of youth with epilepsy in Ohio. Epilepsy Currents, 12(1 SUPPL. 1), no pagination. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed13&NEWS=N&AN=70830056. Catalao R., Eshetu T., Tsigebrhan R., Medhin G., Fekadu A. & Hanlon C. (2018). Implementing integrated services for people with epilepsy in primary care in Ethiopia: a qualitative study. BMC health services research, 18, 372. https://doi.org/10.1186/s12913-018-3190-y
34	Are there lifestyle factors (e.g. diet, vitamin deficiency, amount of exercise) associated with an increased risk of seizures?	Are there certain lifestyle choices/health choices that make you more likely to have epilepsy? Why is it less common for adults to be diagnosed with epilepsy and why do they? Can we limit seizures by avoiding certain situations? Why did my child get absence seizures? Where does it come from? What could I have done differently to prevent this? What other health conditions cause seizures? Are there any factors that make someone more likely to have seizures or epilepsy? Why is it so difficult to identify the cause of epilepsy when it appears out of nowhere in so many cases? Why are there so many cases of refractory epilepsy? Are scientists looking at other areas for causes outside of the brain I.e viruses, bacterial infections, environmental? Where is the future of epilepsy research going? Doctors does blood works, MRI, CT scan, EEG, ECG and other test for the heart but didn't find any problem. Why they don't check if the patient have deficiency on nutrients. is vitamin deficiency a cause of epilepsy?	5	2	2					Evidence Not Identified
		How to educate children on how to cope living with epilepsy?								Ontario Epilepsy Guidelines. (2018). Guidelines Summary - Patients and Families. Available from: https://ontarioepilepsyguidelines.ca/guidelines-summary-paf/

35	What are the best methods to provide information about seizures to patients and their caregivers?	Upon diagnosis are physicians providing proper education to patients about their specific type of epilepsy, treatments,and prognosis vs just prescribing medications? How can we better educate patients on the resources they have available to them when they have co-existing conditions? How do I help my son understand that his anxiety is most likely caused by his epilepsy disorder A Canada wide website that provides information to patients. A good model to follow would be the National site in the UK epilepsy .org. In the medical field, there is a lack of transparency regarding epilepsy's effects on day to day life. Why? Is there a fear of creating symptoms in people by telling them about the possibilities? Why are we left to feel like we can't contribute to society instead of being told, 'you're normal'? In that regard I think we should focus on more research oriented ways to measure education in epilepsy. How comprehensive epilepsy clinics deliver education to families to facilitate learning about the condition, resources and treatment options. We are doing a study about it here in London Health Science Centre What are risk for missed doses of medications? How to explain that to a patient?	3		1	4				Edmonton Epilepsy Association. (2011). Epilepsy: A guide for professionals and caregivers. Available from: https://www.edmontonepilepsy.org/wp-content/uploads/2020/07/documents/Epilepsy%20-%20Guide%20For%20Professionals%20&%20Caregivers.pdf Pandey, D.K., Dasgupta, R., Levy, J., Wang, H., Serafini, A., Habibi, M., Song, W., Shafer, P.O., Loeb, J.A. Enhancing epilepsy self-management and quality of life for adults with epilepsy with varying social and educational backgrounds using PAUSE to Learn Your Epilepsy (2020) Epilepsy and Behavior, 111, art. no. 107228, . Coster, S., Li, Y., Norman, I.J. Cochrane reviews of educational and self-management interventions to guide nursing practice: A review (2020) International Journal of Nursing Studies, 110, art. no. 103698, Luedke, M. W., Blalock, D. V., Goldstein, K. M., Kosinski, A. S., Sinha, S. R., Drake, C., Lewis, J. D., Husain, A. M., Lewinski, A. A., Shapiro, A., Gierisch, J. M., Tran, T. T., Gordon, A. M., Van Noord, M. G., Bosworth, H. B., & Williams, J. W. (2019). Self-management of Epilepsy: A Systematic Review. Annals of Internal Medicine, 171(2), 117–126. https://doi-org.myaccess.library.utoronto.ca/10.7326/M19-0458 Jackson CF, Makin SM, Marson AG, Kerr M. Non-pharmacological interventions for people with epilepsy and intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD005502. DOI: 10.1002/14651858.CD005502.pub3 Wasilewski A, Serventi J, Ibegbu C, Wychowski T, Burke J & Mohile N. (2020). Epilepsy education in gliomas: engaging patients and caregivers to improve care. Supportive Care in Cancer, 28, 1405-1409. https://doi.org/10.1007/s00520-019-04968-x, 10.1007/s00520-019-04968-x Albert DVF, Moreland JJ, Salvator A, Moore-Clingenpeel M, Haridas B, Cole JW, et al. (2019). Seizure Action Plans for Pediatric Patients With Epilepsy: A Randomized Controlled Trial. Journal of Child Neurology, 34, 666-673. https://doi.org/10.1177/0883073819846810, 10.1177/0883073819846810
36	Do environmental factors (e.g., changes in weather patterns, moon phases, and seasons) affect the frequency of seizures?	what is the relationship between the phases of the moon and seizure activity what is the relationship between atmospheric pressure and seizure activity what is the relationship between excitement and seizure activity why do I have more seizures during certain time of the year? What research has there been surrounding weather and environmental stimuli as triggers for seizure activity? How come my daughter seizes more in colder weather? What are the factors that make it so that certain days my daughter does not have a seizure and then the next day, she has ten? Are there any factors that make someone more likely to have seizures or epilepsy? Why is it so difficult to identify the cause of epilepsy when it appears out of nowhere in so many cases? Why are there so many cases of refractory epilepsy? Are scientists looking at other areas for causes outside of the brain I.e viruses, bacterial infections, environmental? Where is the future of epilepsy research going?	4	1	1			1		Evidence Not Identified
37	What is the relationship between seizures and the human microbiome?	From my personal experience, I also think more research about the gut-brain relationship can help us understand seizures and may contribute to their treatment. Following a seizure I have a lot of gut and bowel related symptoms, very similar to a flare-up of irritable bowel syndrome. Is it possible that a treatment lies in the relationship between my brain and my gut? Can seizures be related to other systems in the body, for example the gut? With the diagnosis of general idiopathic we have no definite cause of consensual diagnosis amongst folks in the medical community to remedy. I wonder about end of life, medication reliability, is there a potential more specific diagnosis that needs further research into the black box of GI What genes and variants contribute to common and rare epilepsies? How do common variants contribute to causing epilepsy when the cause is acquired (such as TBI, malaria)? Why is epilepsy more common in socially deprived areas? What is the role of the microbiome in the cause of epilepsy? Why do some seizures fail to stop and cause status epielpticus? How connected is gut bacteria to epilepsy/seizures? Is this also why many women with epilepsy have catamenial seizures? Can epilepsy be genetically transmitted? hy did my child get absence seizures? Where does it come from? What could I have done differently to prevent this?	3	2		2				Evidence Not Identified
38	Apart from anterior thalamic and responsive neurostimulation, does deep brain stimulation prevent seizures?	How does DBS work? How does therapy impact treatment? What are the differences for men and women? many questions - mechanisms of drugs, mechanisms and efficacy of brain stimulation both intracranially and extracranially Have 'Deep Brain Stimulators' been placed in any Epilepsy patients in Canada as of 2019? How many patients in Canada have had a Deep Brain Stimulator (DBS) implanted to treat their seizures, and how effective is it? Is CBD oil being officially tested in Canada for treatment of seizures? Are some Epileptologists in Canada starting to prescribe CBD oil if the patients' seizures are uncontrollable? Has Deep Brain Stimulation been tested in Canada for seizure treatment? Is CBD oil soon to be medically tested to treat seizures in Canada? It is being used in other countries, and some Canadian patients are trying it on their own, but my neurologists are fully against it as they say it hasn't been tested in Canada. 2. Has deep brain stimulation (DBS) been tried in Canada yet? If so, what are the statistics on how many patients had positive results, how many had negative results? How effective is DBS?	5			1	1			Sprengers, M., Vonck, K., Carrette, E., Marson, A. G., & Boon, P. (2017). Deep brain and cortical stimulation for epilepsy. Cochrane Database of Systematic Reviews(7). doi:10.1002/14651858.CD008497.pub3
40	How can sleep quality be monitored for people who experience seizures?	How to manage sleep issues and the postictal period? Will short naps throughout the day help my productivity long-term? How can we improve quality of sleep in patients with epilepsy? How much those problems impact in the seizure control? How to attend school? How to manage sleep? Monitoring? Is there any help for a child who is no longer sleeping since the onset of their first seizure? I also have trouble sleeping & suffer from chronic migraines. What can I do to manage that? Since sleep deprivation is often a trigger for seizure activity, what actions can be taken to monitor sleep quality in children with epilepsy/seizures?	2	4		1				Michaelis, R., Tang, V., Wagner, J. L., Modi, A. C., LaFrance Jr, W. C., Goldstein, L. H., . . . Reuber, M. (2017). Psychological treatments for people with epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD012081.pub2 Al-aqeel, S., Gershuni, O., Al-sabhan, J., & Hiligsmann, M. (2017). Strategies for improving adherence to antiepileptic drug treatment in people with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD008312.pub3 Bradley, P. M., Lindsay, B., & Fleeman, N. (2016). Care delivery and self management strategies for adults with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD006244.pub3 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
67	Are vaccinations safe and effective while one is taking anti-seizure drugs? Can vaccinations cause seizure disorders?	Can remote head injury (over 20 years ago) contribute to developing epilepsy? Can vaccines cross the blood-brain barrier and cause inflammation that contributes to epilepsy? What tests can be done to rule out autoimmune epilepsy? Can seizures stop spontaneously? If yes, in what type of person/seizure? I am still correlating my daughter's seizure with the MMR VACCINATION she had when she was 13 months after a week she had a seizure.	2		1					Di Pietrantonj, C., Rivetti, A., Marchione, P., Debalini, M. G., & Demicheli, V. (2020). Vaccines for measles, mumps, rubella, and varicella in children. Cochrane Database of Systematic Reviews(4).

		Is it safe to get vaccines if I'm taking medication								
88	Are people who experience seizures at an increased risk of developing autoimmune diseases?	Is there a relationship between autoimmune diseases and epilepsy (either in the person themselves with epilepsy or a relative)?					1			Evidence Not Identified
41	Can approved pharmaceuticals (i.e. chemotherapy, Accutane) cause seizures?	How would chemotherapy (I have had breast cancer before epilepsy diagnosis) affect me? Relation of topical acutane use in first trimester of pregnancy in causing pediatric epilepsy? I was taking anti depressants before I was diagnosed. Did they cause my epilepsy? I was taking wellbutrin for depression when i started having seizures, was this the cause? I dont understand how my EEG is 'clear' yet I still have epilepsy. Do my seizures always start from the same cells, or just from the same general area of my brain? My neice has epilepsy. Is it genetic? Will my children get it? Why did my child get absence seizures? Where does it come from? What could I have done differently to prevent this? Is this caused by the medication?	4	2						Epilepsy: a public health imperative. Geneva: World Health Organization; 2019. Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444
42	Why are seizures stigmatized in society?	Will/should I learn how to drive? Why is there so much stigma around it? Why is epilepsy still not discussed in public very often? I have lost many jobs due to having a seizure at work because there is so much medical discrimination. Why is there no television programs that talk about epilepsy? I know we have it easy in comparison to other families but I would like a resource just for Absence Seizures in children. Why isn't there more positive dialogue around Epilepsy? When you get cancer people talk about fighting the disease, when you get an epilepsy diagnosis, all hope fades and you enter this world of fear, stigma and hused conversations. Why? Why is there little to no support in schools for students with epilepsy, seizures and accompanying learning disorders? Why are epileptic students treated 'special' when taking test, applying for work and volunteering? Are there associations that can help epileptic patients learn how to live life independently and comfortably. Why are people afraid when they learn your epileptic. Why is there stigma around neurological medications causing depression, mania and suicidal thought? Why are patients not immediately referred to psychologist and / psychiatrists when we know they need it? Why is there not more help in institutional settings for parents/caregivers? Why is there still so much stigma around this disorder? Why are people with epilepsy still being discriminated against for coming out with their disease? Why is epilepsy so stigmatised - my sister is asthmatic and is not worried about anyone finding out about that but people sure react differently when they find out I have epilepsy	4	2						Hansen B, Szaflarski M, Bebin EM & Szaflarski JP. (2018). Affiliate stigma and caregiver burden in intractable epilepsy. Epilepsy & Behavior, 85, 1-6. https://doi.org/10.1016/j.yebeh.2018.05.028, 10.1016/j.yebeh.2018.05.028 Seethalakshmi R, Krishnamoorthy ES. Depression in epilepsy: phenomenology, diagnosis and management. Epileptic Disord. 2007;9(1):1-10. doi:10.1684/epd.2007.0063 Sung, C., Chan, F., Ditchman, N., Chan, C., & Rumrill Jr, P. D. (2020). Evaluating the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) framework as an employment model for people with epilepsy. Journal of Vocational Rehabilitation, 52(2), 205–221. https://doi-org.myaccess.library.utoronto.ca/10.3233/JVR-201072 Elliot, V. L., Morgan, D., Kosteniuk, J., Froehlich Chow, A., & Bayly, M. (2019). Health-related stigma of noncommunicable neurological disease in rural adult populations: A scoping review. Health & Social Care in the Community, 27(4), e158–e188. https://doi-org.myaccess.library.utoronto.ca/10.1111/hsc.12694 Carrizosa-Moog, J., Salazar-Velasquez, L. V., Portillo-Benjumea, M., Rodriguez-Mejia, A., & Isaza-Jaramillo, S. (2019). Does public attitude change by labeling a person as epileptic, person with epilepsy or the acronym PWE? A systematic review. Seizure, 69, 273–278. https://doi-org.myaccess.library.utoronto.ca/10.1016/j.seizure.2019.05.011
43	How does the successful management of seizures improve the quality of life for children living with seizures?	How do parents of children with epilepsy balance caution and normal life in regards to their childrens' activities and health? What are the best programs for children, youth and adults to manage their daily life? More comments about balancing out being a kid or individual with epilepsy as opposed to the epilepsy dictating ones life or identify. How can you teach a child to detect seizures by themselves? As a mother of a child with epilepsy, how to grant independence to a teenager while staying intellectually responsible for that child? Do we let her live alone in University? Do we follow her everywhere to be close to respond? He has dyslexia, adhd and behavioural issues. The behaviour problems are often related to the medication. **How do we balance all of that while still treating him like a normal teenager? How do you give consequences when you know a lot of the behaviour issues are due to medication?**		5			1			Goodwin, S.W., Wilk, P., Karen Campbell, M., Speechley, K.N.; Emotional well-being in children with epilepsy: Family factors as mediators and moderators (2017) Epilepsia, 58 (11), pp. 1912-1919. Crudgington, H., Rogers, M., Morris, H., Gringras, P., Pal, D.K., Morris, C. Epilepsy-specific patient-reported outcome measures of children's health-related quality of life: A systematic review of measurement properties (2020) Epilepsia, 61 (2), pp. 230-248. Phillips NL, Widjaja E & Smith ML. (2020). Family resources moderate the relationship between seizure control and health-related quality of life in children with drug-resistant epilepsy. Epilepsia, https://doi.org/10.1111/epi.16602, 10.1111/epi.16602 Miller WR, Von Gaudecker J, Tanner A & Buelow JM. (2020). Epilepsy self-management during a pandemic: Experiences of people with epilepsy. Epilepsy & Behavior, 111, 107238. https://doi.org/10.1016/j.yebeh.2020.107238, 10.1016/j.yebeh.2020.107238
44	What is the best way to support caregivers of people who experience seizures?	How do parents achieve mental health for themselves when caring for a child with epilepsy? How can we stop issues with the sight, sound, feels, emotions, or mind or the epileptic and then the effects it has on caregiver or loved ones? It's the mind, body, spirit, soul and heart of an epileptic. Why are patients not immediately referred to psychologist and / psychiatrists when we know they need it? Why is there not more help in institutional settings for parents/caregivers? Why is there still so much stigma around this disorder? Why are people with epilepsy still being discriminated against for coming out with their disease? I have worked super hard to help my daughter live a courageous, rich life. To know her physical commitments required to stay healthy and do awesome self care and not to be limited by her condition. However, I had to do this pretty much alone. Every support group - online and in-person - that I joined was based on a victim mindset (it wasnt the people, they were all very kind, it was the context). I still speak to so many parents trapped in fear and protection and uncertainty. How can we help more parents and care givers step into this space and empower people with epilepsy? I want this for others and I also want my daughter to find a vibrant community. How to support parents/families living with epilepsy. Is PTSD reported for care givers? I jump at every loud sound, high alert all the time...what supports are out there for parents?	1	3	1	1				Karakis I, Morton ML, Janocko NJ, Groover O, Teagarden DL, Villarreal HK, et al. (2020). Caregiver burden in psychogenic non-epileptic seizures. Seizure, 81, 13-17. https://doi.org/10.1016/j.seizure.2020.07.007, 10.1016/j.seizure.2020.07.007 Karakis I, Montouris GD, Piperidou C, Luciano MS, Meador KJ & Cole AJ. (2014). Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures. Seizure, 23, 47-54. https://doi.org/10.1016/j.seizure.2013.09.011, 10.1016/j.seizure.2013.09.011 van Andel, J., Westerhuis, W., Zijlmans, M. et al. Coping style and health-related quality of life in caregivers of epilepsy patients. J Neurol 258, 1788–1794 (2011). https://doi.org/10.1007/s00415-011-6013-1 Hussain SA, Ortendahl JD, Bentley TGK, Harmon AL, Gupta S, Begley CE, et al. (2020). The economic burden of caregiving in epilepsy: An estimate based on a survey of US caregivers. Epilepsia, 61, 319-329. https://doi.org/10.1111/epi.16429, 10.1111/epi.16429 Lai ST, Tan WY, Wo MC, Lim KS, Ahmad SB & Tan CT. (2019). Burden in caregivers of adults with epilepsy in Asian families. Seizure, 71, 132-139. https://doi.org/10.1016/j.seizure.2019.07.008, 10.1016/j.seizure.2019.07.008 Teagarden D.L., Morton M.L., Janocko N.J., Groover O., Villarreal H.K., Evans L., et al (2020). Socioeconomic disparities in patients with psychogenic nonepileptic seizures and their caregivers. Epilepsy and Behavior, no pagination. https://doi.org/10.1016/j.yebeh.2020.107160
		My sexual health is never addressed by any physicians and I have a hard time asking about it, but I am pretty sure it has been affected - by something (sex drive, desire, early menopause, seizures related to cycle) Memory, depression, low sex drive, all of these are problems. are they caused by epilepsy, by the number of seizures i have had, by the meds, or are they just part of who i am?								Maguire, M. J., & Nevitt, S. J. (2019). Treatments for seizures in catamenial (menstrual-related) epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD013225.pub2 Weston, J., Bromley, R., Jackson, C. F., Adab, N., Clayton-Smith, J., Greenhalgh, J., . . . Marson, A. G. (2016). Monotherapy treatment of epilepsy in pregnancy: congenital malformation outcomes in the child. Cochrane Database of Systematic Reviews(11). doi:10.1002/14651858.CD010224.pub2 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Maguire, M. J., Weston, J., Singh, J., & Marson, A. G. (2014). Antidepressants for people with epilepsy and depression. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD010682.pub2 Bromley, R., Weston, J., Adab, N., Greenhalgh, J., Sanniti, A., McKay, A. J., . . . Marson, A. G. (2014). Treatment for epilepsy in pregnancy: neurodevelopmental outcomes in the child. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD010236.pub2 National Institute for Health and Care Excellence. (2013). Epilepsy in adults. Available from: www.nice.org.uk/guidance/qs26 National Institute for Health and Care Excellence. (2013) Epilepsy in children and young people. Available from: www.nice.org.uk/guidance/qs27

45	Aside from teratogenic effects, what are the impacts of anti-seizure drugs on the reproductive health of people who experience seizures, and how can their reproductive and sexual health be best supported?	What are the impacts on pregnancy? What are the impacts on pregnancy, childbirth and breastfeeding? Is there any specific follow-up to be done? Is it true that certain drugs make a man impotent or sterile? I would like to see more data on the effects of anticonvulsants on female reproductive health and fertility	3		2	1				Labiner, D. M., Bagic, A. I., Herman, S. T., Fountain, N. B., Walczak, T. S., & Gumnit, R. J. (2010). Essential services, personnel, and facilities in specialized epilepsy centers-Revised 2010 guidelines. Epilepsia, 51, 2322-2333. doi:10.1111/j.1528-1167.2010.02648.x Harden, C. L., Hopp, J., Ting, T. Y., Pennell, P. B., French, J. A., Allen Hauser, W., . . . Le Guen, C. (2009). Management issues for women with epilepsy - Focus on pregnancy (an evidence-based review): I. Obstetrical complications and change in seizure frequency: Report of the Quality Standards Subcommittee and Therapeutics and Technology Assessment Subcommittee o. Epilepsia, 50, 1229-1236. doi:10.1111/j.1528-1167.2009.02128.x Epilepsy: a public health imperative. Geneva: World Health Organization; 2019 Osbourne Shafer P. (2014). Epilepsy and Sexual Relationships. Available from: https://www.epilepsy.com/living-epilepsy/women/all-women/epilepsy-and-sexual-relationships Karan, V., Harsha, S., Keshava, B. S., Pradeep, R., Sathyanarayana Rao, T. S., & Andrade, C. (2015). Sexual dysfunction in women with epilepsy. Indian journal of psychiatry, 57(3), 301–304. https://doi.org/10.4103/0019-5545.166616 Petersen M., Kristensen E., Giraldi L. & Giraldi A. (2020). Sexual dysfunction and mental health in patients with multiple sclerosis and epilepsy. BMC Neurology, 20, no pagination. https://doi.org/10.1186/s12883-020-1625-7 Owczarek K., Rozenek H., Jedrzejczak J., Rysz A., Blaszczyk B. & Wlodarczyk D. (2015). Declared satisfaction with sexual life and the quality of life in patients with epilepsy. Acta Neuropsychologica, 13, 157-167. https://doi.org/10.5604/17307503.1168309 Egerod, I., Wulff, K., & Petersen, M. C. (2018). Experiences and informational needs on sexual health in people with epilepsy or multiple sclerosis: A focus group investigation. Journal of Clinical Nursing (John Wiley & Sons, Inc.), 27(13–14), 2868–2876. https://doi-org.myaccess.library.utoronto.ca/10.1111/jocn.14378 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
46	Is emotional trauma (e.g. sexual abuse, Post Traumatic Stress Syndrome) associated with an increased risk of epileptic seizures?	Is sexual abuse at age of 6 a cause of seizures? How much is caused by trauma from childhood Prenatal? Birth trauma? Poisonings? Concussion? Post traumatic? Why do adults get idiopathic adult-onset epilepsy? What factors may play a cause in diagnosis ie. a history of trauma, PTSD, family violence, or grief? Are creative people more likely to be diagnosed? Also can the epileptic of a residential school survivor suffer the long term effect of the residential school survivors suffering caused in the residential schools?	4			1				Martlew, J., Pulman, J., & Marson, A. G. (2014). Psychological and behavioural treatments for adults with non-epileptic attack disorder. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD006370.pub2
		Should epilepsy in children be treated with the same drugs as adults or should specific drugs be developed for treating pediatric epilepsy? There must be a better medicine for children.								Shah, P. B., James, S., & Elayaraja, S. (2020). EEG for children with complex febrile seizures. Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD009196.pub5 Panebianco, M., Bresnahan, R., Ramaratnam, S., & Marson, A. G. (2020). Lamotrigine add-on therapy for drug-resistant focal epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD001909.pub3 West, S., Nevitt, S. J., Cotton, J., Gandhi, S., Weston, J., Sudan, A., . . . Newton, R. (2019). Surgery for epilepsy. Cochrane Database of Systematic Reviews(6). doi:10.1002/14651858.CD010541.pub3 Nevitt, S. J., Tudur Smith, C., & Marson, A. G. (2019). Phenobarbitone versus phenytoin monotherapy for epilepsy: an individual participant data review. 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Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD003032.pub4 National Institute for Health and Care Excellence (2019). Cannabidiol with clobazam for treating seizures associated with Lennox–Gastaut syndrome. Technology Appraisal Guidance, TA615. www.nice.org.uk/guidance/ta614 Panebianco, M., Prabhakar, H., & Marson, A. G. (2018). Rufinamide add-on therapy for refractory epilepsy. Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD011772.pub2 Panebianco, M., Al-Bachari, S., Weston, J., Hutton, J. L., & Marson, A. G. (2018). Gabapentin add-on treatment for drug-resistant focal epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD001415.pub3 Nevitt, S. J., Tudur Smith, C., Weston, J., & Marson, A. G. (2018). Lamotrigine versus carbamazepine monotherapy for epilepsy: an individual participant data review. Cochrane Database of Systematic Reviews(6). doi:10.1002/14651858.CD001031.pub4 Nevitt, S. J., Tudur Smith, C., & Marson, A. G. (2018). Oxcarbazepine versus phenytoin monotherapy for epilepsy: an individual participant data review. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD003615.pub4 Nevitt, S. J. Marson, A. G. Weston, J. Tudur Smith, C. - Sodium valproate versus phenytoin monotherapy for epilepsy: an individual participant data review Nevitt, S. J., Marson, A. G., Weston, J., & Tudur Smith, C. (2018). Sodium valproate versus phenytoin monotherapy for epilepsy: an individual participant data review. Cochrane Database of Systematic Reviews(8). doi:10.1002/14651858.CD001769.pub4 Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Martin-McGill, K. J., Jackson, C. F., Bresnahan, R., Levy, R. G., & Cooper, P. N. (2018). 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47	Compared to adults, what are the top treatments for children with epilepsy/seizures?	Is there any protocol in terms of AED's to be prescribed to children who have epileptic seizures?	1	2	2					Brigo, F., Igwe, S. C., & Bragazzi, N. L. (2017). Antiepileptic drugs for the treatment of infants with severe myoclonic epilepsy. Cochrane Database of Systematic Reviews(5). doi:10.1002/14651858.CD010483.pub4 Al-aqeel, S., Gershuni, O., Al-sabhan, J., & Hiligsmann, M. (2017). Strategies for improving adherence to antiepileptic drug treatment in people with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD008312.pub3 Rosenow, F., Bast, T., Czech, T., Feucht, M., Hans, V. H., Helmstaedter, C., . . . Strzelczyk, A. (2016). Revised version of quality guidelines for presurgical epilepsy evaluation and surgical epilepsy therapy issued by the Austrian, German, and Swiss working group on presurgical epilepsy diagnosis and operative epilepsy treatment. Epilepsia, 57, 1215-1220. doi:10.1111/epi.13449 Leone, M. A., Giussani, G., Nevitt, S. J., Marson, A. G., & Beghi, E. (2016). Immediate antiepileptic drug treatment, versus placebo, deferred, or no treatment for first unprovoked seizure. Cochrane Database of Systematic Reviews(5). doi:10.1002/14651858.CD007144.pub2 Jayakar, P., Gotman, J., Harvey, A. S., Palmini, A., Tassi, L., Schomer, D., . . . Kahane, P. (2016). Diagnostic utility of invasive EEG for epilepsy surgery: Indications, modalities, and techniques. Epilepsia, 57, 1735-1747. doi:10.1111/epi.13515 Glauser, T., Shinnar, S., Gloss, D., Alldredge, B., Arya, R., Bainbridge, J., . . . Treiman, D. M. (2016). Evidence-based guideline: Treatment of convulsive status epilepticus in children and adults: Report of the guideline committee of the American epilepsy society. Epilepsy Currents, 16, 48-61. doi:10.5698/1535-7597-16.1.48 Xiao, Y., Gan, L., Wang, J., Luo, M., & Luo, H. (2015). Vigabatrin versus carbamazepine monotherapy for epilepsy. Cochrane Database of Systematic Reviews(11). doi:10.1002/14651858.CD008781.pub3 Wilmshurst, J. M., Gaillard, W. D., Vinayan, K. P., Tsuchida, T. N., Plouin, P., Van Bogaert, P., . . . Cross, J. H. (2015). Summary of recommendations for the management of infantile seizures: Task Force Report for the ILAE Commission of Pediatrics. Epilepsia, 56, 1185-1197. doi:10.1111/epi.13057 Strozzi, I., Nolan, S. J., Sperling, M. R., Wingerchuk, D. M., & Sirven, J. (2015). Early versus late antiepileptic drug withdrawal for people with epilepsy in remission. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD001902.pub2 Panebianco, M., Rigby, A., Weston, J., & Marson, A. G. (2015). Vagus nerve stimulation for partial seizures. Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD002896.pub2
		As a person who had a bad history with seizure medications, why are some common medications that cause emotional numbness, stunted growth, loss in appetite, red blood cell death and epidermal syndromes consideted safe to give the young children? Are there other less detrimental treatments for youth with epilepsy?								Tan, H. J., Singh, J., Gupta, R., & de Goede, C. (2014). Comparison of antiepileptic drugs, no treatment, or placebo for children with benign epilepsy with centro temporal spikes. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD006779.pub2 Prasad, M., Krishnan, P. R., Sequeira, R., & Al-Roomi, K. (2014). Anticonvulsant therapy for status epilepticus. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD003723.pub3 Jayakar, P., Gaillard, W. D., Tripathi, M., Libenson, M. H., Mathern, G. W., & Cross, J. H. (2014). Diagnostic test utilization in evaluation for resective epilepsy surgery in children. Epilepsia, 55, 507-518. doi:10.1111/epi.12544 Morris, G. L., Gloss, D., Buchhalter, J., Mack, K. J., Nickels, K., & Harden, C. (2013). Evidence-based guideline update: Vagus nerve stimulation for the treatment of epilepsy: Report of the guideline development subcommittee of the american academy of neurology. Neurology, 81, 1453-1459. doi:10.1212/WNL.0b013e3182a393d1 Hemming, K., Maguire, M. J., Hutton, J. L., & Marson, A. G. (2013). Vigabatrin for refractory partial epilepsy. Cochrane Database of Systematic Reviews(1). doi:10.1002/14651858.CD007302.pub2 Hasan, M., Pulman, J., & Marson, A. G. (2013). Calcium antagonists as an add-on therapy for drug-resistant epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD002750.pub2 Hancock, E. C., Osborne, J. P., & Edwards, S. W. (2013). Treatment of infantile spasms. Cochrane Database of Systematic Reviews(6). doi:10.1002/14651858.CD001770.pub3 Hancock, E. C., & Cross, J. H. (2013). Treatment of Lennox-Gastaut syndrome. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD003277.pub3 Glauser, T., Ben-Menachem, E., Bourgeois, B., Cnaan, A., Guerreiro, C., Kälviäinen, R., . . . Tomson, T. (2013). Updated ILAE evidence review of antiepileptic drug efficacy and effectiveness as initial monotherapy for epileptic seizures and syndromes. Epilepsia, 54, 551-563. doi:10.1111/epi.12074 National Institute for Health and Care Excellence (2013). Partial-onset seizures in epilepsy: zonisamide as monotherapy. Available from: http://nice.org.uk/guidance/esnm17 National Institute for Health and Care Excellence. (2013) Epilepsy in children and young people. Available from: www.nice.org.uk/guidance/qs27
		What research is ongoing about improving treatment options for young people with epilepsy?								Mbizvo, G. K., Dixon, P., Hutton, J. L., & Marson, A. G. (2012). Levetiracetam add-on for drug-resistant focal epilepsy: an updated Cochrane Review. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD001901.pub2 Labiner, D. M., Bagic, A. I., Herman, S. T., Fountain, N. B., Walczak, T. S., & Gumnit, R. J. (2010). Essential services, personnel, and facilities in specialized epilepsy centers-Revised 2010 guidelines. Epilepsia, 51, 2322-2333. doi:10.1111/j.1528-1167.2010.02648.x Abba, K., Ramaratnam, S., & Ranganathan, L. N. (2010). Anthelmintics for people with neurocysticercosis. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD000215.pub4 Scheltens-De Boer, M. (2009). Guidelines for EEG in encephalopathy related to ESES/CSWS in children. Epilepsia, 50, 13-17. doi:10.1111/j.1528-1167.2009.02211.x Koch, M. W., & Polman, S. K. L. (2009). Oxcarbazepine versus carbamazepine monotherapy for partial onset seizures. Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD006453.pub2 Gaillard, W. D., Chiron, C., Helen Cross, J., Simon Harvey, A., Kuzniecky, R., Hertz-Pannier, L., & Gilbert Vezina, L. (2009). Guidelines for imaging infants and children with recent-onset epilepsy. Epilepsia, 50, 2147-2153. doi:10.1111/j.1528-1167.2009.02075.x Perucca, E., Albani, F., Capovilla, G., Bernardina, B. D., Michelucci, R., & Zaccara, G. (2006). Recommendations of the Italian League against Epilepsy working group on generic products of antiepileptic drugs. Epilepsia, 47, 16-20. doi:10.1111/j.1528-1167.2006.00871.x Glauser, T., Ben-Menachem, E., Bourgeois, B., Cnaan, A., Chadwick, D., Guerreiro, C., . . . Tomson, T. (2006). ILAE treatment guidelines: Evidence-based analysis of antiepileptic drug efficacy and effectiveness as initial monotherapy for epileptic seizures and syndromes. Epilepsia, 47, 1094-1120. doi:10.1111/j.1528-1167.2006.00585.x National Institute for Health and Care Excellence (2004). Vagus nerve stimulation for refractory epilepsy in children: Interventional procedures guidance. Available from: www.nice.org.uk/guidance/ipg50 Marson, A. G., Williamson, P. R., Hutton, J. L., Clough, H. E., & Chadwick, D. W. (2000). Carbamazepine versus valproate monotherapy for epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD001030 Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
49	What knowledge barriers do health care providers have about anti-seizure drugs and the potential adverse effects of anti-seizure drugs?	Also Why do doctors not know the side effects of Keppra with anxiety? This makes life harder. I have an anxiety disorder and Asperger's syndrome and they told me the medication causes 'hyper behavior' or had no clue.	2		2					Mirbaha, F., Shalviri, G., Yazdizadeh, B., Gholami, K., & Majdzadeh, R. (2015). Perceived barriers to reporting adverse drug events in hospitals: a qualitative study using theoretical domains framework approach. Implementation science : IS, 10, 110. https://doi.org/10.1186/s13012-015-0302-5
		Issues with quality of life and GPs lack of long term issues with AEDs: Epival and the side affects (depression is a key issue) including some GPs just don't get it regarding the over medication impact of AEDS - my husband had to be weaned off of Epival due to over medication of the Epival.								Cheema E, Haseeb A, Khan TM, Sutcliffe P, Singer DR. Barriers to reporting of adverse drugs reactions: a cross sectional study among community pharmacists in United Kingdom. Pharm Pract (Granada) [Internet]. 2017Sep.3 [cited 2020Jul.20];15(3):931. Available from: https://pharmacypractice.org/journal/index.php/pp/article/view/931
		Which treatments have the least cognitive impacts. Also why do doctors not use statistics and instead just guess medications.								Peterson, L. N., Peterson, R., Ho, K., & Olatunbosun, T. (2009, December 24). Barriers to Canadian physicians reporting of adverse drug reactions [G]. doi:http://dx.doi.org/10.14288/1.0055435
		How do family doctors learn about new drugs that are being used to treat various types of epilepsy?								Seyedeh Fereshteh Mansouri, Tahereh Khaleghdoost Mohammadi, Masoomeh Adib, Ehsan Kazemnejad Lili, Mostafa Soodmand (2019, June 12). “Barriers to Nurses Reporting Errors and Adverse Events”. British Journal of Nursing. Vol. 28, No. 11 Glauser T, Ben-Menachem E, Bourgeois B, et al. ILAE treatment guidelines: evidence-based analysis of antiepileptic drug efficacy and effectiveness as initial monotherapy for epileptic seizures and syndromes. Epilepsia. 2006;47(7):1094-1120. doi:10.1111/j.1528-1167.2006.00585.x
		Is the laser therapy a good or bad thing?								

50	Is laser surgery a safe, effective alternative to traditional surgical interventions to treat seizures?	Can laser surgery be performed on a 49 year old female in menopause who hasn't had a seizure in over a year but she has mixed epilepsy with temporal lobe epilepsy, mesial temporal sclerosis and one part of the brain hemispheres larger than the other side (right brain smaller than left) but works harder than the left side does and does both hemispheres of the brain? Is laser surgery safer than having your skull and brain actually cut open? Can VNS MACHINES help or work against us in thunder and lightning storms? Role of RNS or laser ablation as surgical alternatives.	3			1				Evidence Not Identified
51	Are hormone-based therapies effective in treating seizures (e.g. birth control pills for catamenial seizures)? How do hormone levels impact the effectiveness of anti-seizure drugs?	**I have questions as to hormonal treatments and if there is a potential for treating catamenial epilepsy**. I would also like to see more exercise and stress management built into treatment plans and covered by benefit plans. Do some medications cause IBS or other systemic issues in the long term? Do some cause vitamin deficiencies, perhaps depending on gender? More information on the long-term side effects would be helpful. How much of an affect does hormones/menstrual cycle have on the treatment of epilepsy? Will birth control help control catamenial seizures? How come there is not a medicine developed for female specific epilepsy and it's relation to estrogen metabolism?	4							Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
52	Are people who experience seizures at an increased risk of developing early-onset dementia?	Memory problems are the hardest to deal with and my spouse is in his 30's. And I am wondering what his memory will be like as he ages, will it get worse? is he at risk for dementia because of the drugs? 3. What is the prevalence of dementia in people older than 60 with refractory seizures? 'Do they get Alsiemers or Dementia at younger ages due to the seizures and surgeries they have gone through to treat the seizures? Can these memory problems ultimately lead to early onset dementia?	2	1	1					Liu, J., Wang, L. N., Wu, L. Y., & Wang, Y. P. (2018). Treatment of epilepsy for people with Alzheimer's disease. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD011922.pub3 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Gonzalez-Duarte, A. (2013). Evidence-based guideline: Treatment of parenchymal neurocysticercosis: report of the Guideline Development Subcommittee of the American Academy of Neurology. Neurology, 81, 1474-1475. Epilepsy: a public health imperative. Geneva: World Health Organization; 2019. Thurman, D. J., Logroscino, G., Beghi, E., Hauser, W. A., Hesdorffer, D. C., Newton, C. R., . . . Tomson, T. (2017). The burden of premature mortality of epilepsy in high-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy. Epilepsia, 58, 17-26. doi:10.1111/epi.13604
53	How does medication for other conditions effect the presentation of seizures in people who experience them?	Can your epilepsy ever become worse due to age, new medication being added for another disease (I.e. cholesterol, blood pressure,) Would be nice to know if co-existing conditions are because of of seizures, or underlying brain issue, or because of medications. A lot of people believe the medications are causing these other conditions. I have seen Keppra rage with my own eyes as Keppra was started, and disappear when Keppra was stopped. Is this caused by the medication? Which medications can impact these co-existing conditions? How do we measure or know how much each of or a combination of medications is impacting these conditions?	3	1						Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Kossoff, E. H., Zupec-Kania, B. A., Auvin, S., Ballaban-Gil, K. R., Christina Bergqvist, A. G., Blackford, R., . . . Wirrell, E. C. (2018). Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. Epilepsia Open, 3, 175-192. doi:10.1002/epi4.12225 Beghi, E., Carpio, A., Forsgren, L., Hesdorffer, D. C., Malmgren, K., Sander, J. W., . . . Hauser, W. A. (2010). Recommendation for a definition of acute symptomatic seizure. Epilepsia, 51, 671-675. doi:10.1111/j.1528-1167.2009.02285.x Abba, K., Ramaratnam, S., & Ranganathan, L. N. (2010). Anthelmintics for people with neurocysticercosis. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD000215.pub4 Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
54	How can chronic migraines be managed in people who experience seizures?	I also have trouble sleeping & suffer from chronic migraines. What can I do to manage that? Is there a way to improve learning styles for kids with epilepsy? I have no more seizures but I have very bad headaches post-op. I am still on epilepsy medication. Is it helping my headaches? What else will? Does VNS also help with migraine?	3	1						Evidence Not Identified
55	Do fevers cause epilepsy?	If a small child under 3 has a prolonged fever, can this cause seizures in young adulthood - 14-22 years Was it the high fevers when I was a baby that caused my epilepsy? What other health conditions cause seizures?	2	1						Evidence Not Identified
56	Apart for EEG used for non-convulsive status epilepticus, what is the best method for monitoring seizure patients to prevent side-effects and breakthrough seizures?	Is there a way to be more proactive in treatment to avoid a surprise breakthrough seizure without over-medicating (and resultant side effects)? How prevent problems or not to contribute to them inadvertently, as well as best models of practice to help Should the patient be more closely monitored while introducing medication to gauge moods with respect to their side effects , to be more proactive vs reactive?	1		1	1				Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
57	How can caregivers implement evidence-based support strategies for adults and children who experience seizures?	Fortunately we are both retired and can devote a lot of time and energy to being here for our son but yet we often feel helpless. How best can we help? How can I help my husband enjoy his life when he can't seem to do anything anymore? Physically, mentally, social results of his epilepsy and/or the brain tumour are huge. What approaches work to combat stigma in schools? What approacvhs work to prevent over-protection by parents?		1	1	1				Epilepsy Ontario. (2018). Getting Support With Your Health. Available from: https://epilepsyontario.org/living-with-epilepsy/9473-2/support-with-health/ About Kids Health. (2010). Epilepsy resources and support. Available from: https://www.aboutkidshealth.ca/Article?contentid=2123 Decker KA, Miller WR & Buelow JM. (2016). Parent Perceptions of Family Social Supports in Families With Children With Epilepsy. Journal of Neuroscience Nursing, 48, 336-341. https://doi.org/10.1097/JNN.0000000000000243 Hixson J.D., Barnes D., Parko K., Durgin T., Van Bebber S., Graham A., et al (2015). Patients optimizing epilepsy management via an online community: The POEM Study. Neurology, 85, 129-136. https://doi.org/10.1212/WNL.0000000000001728
58	How should caregivers plan for long-term support of a person who experiences seizures?	long term care for my son after i can no longer provide it How does a young man with no mental deficiencies and no physical deficiencies life his life? Where are the supports in place for him to manage day to day life after we, his parents, are no longer able to help him? How can parents and caregivers help advocate for their children to receive all the supports they need?		1	2					John Elliott, Bassel Shneker. Patient, caregiver, and health care practitioner knowledge of, beliefs about, and attitudes toward epilepsy, Epilepsy & Behavior, Volume 12, Issue 4,2008, Pages 547-556 Hansen B., Szaflarski M., Bebin E.M. & Szaflarski J.P. (2018). Affiliate stigma and caregiver burden in intractable epilepsy. Epilepsy and Behavior, 85, 1-6. https://doi.org/10.1016/j.yebeh.2018.05.028 Brook, R. A., Rajagopalan, K., & Smeeding, J. E. (2018). Healthcare Costs and Absenteeism Among Caregivers of Adults with Partial-Onset Seizures: Analysis of Claims from an Employer Database. American Health & Drug Benefits, 11(8), 396–402. Glauser TA, Sankar R, Glauser, T. A., & Sankar, R. (2008). Core elements of epilepsy diagnosis and management: expert consensus from the Leadership in Epilepsy, Advocacy, and Development (LEAD) faculty. Current Medical Research & Opinion, 24(12), 3463–3477. https://doi-org.myaccess.library.utoronto.ca/10.1185/03007990802561148
	In addition to having a safety plan, how can people who experience seizures and their caregivers	-I am unsure of how to manage safety. For example, is it dangerous for my daughter to be in a bathtub (rather than showering) in case of drowning during a seizure? -What do I need to know about SUDEP? We haven't had much (if any) info on this from our d 3). How to I decrease my risk given that I often have seizures where I leave the house and wander								Maguire, M. J., Jackson, C. F., Marson, A. G., & Nevitt, S. J. (2020). Treatments for the prevention of Sudden Unexpected Death in Epilepsy (SUDEP). Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD011792.pub3 Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Thurman, D. J., Logroscino, G., Beghi, E., Hauser, W. A., Hesdorffer, D. C., Newton, C. R., . . . Tomson, T. (2017). The burden of premature mortality of epilepsy in high-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy. Epilepsia, 58, 17-26. doi:10.1111/epi.13604 Michaelis, R., Tang, V., Wagner, J. L., Modi, A. C., LaFrance Jr, W. C., Goldstein, L. H., . . . Reuber, M. (2017). Psychological treatments for people with epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD012081.pub2 Levira, F., Thurman, D. J., Sander, J. W., Hauser, W. A., Hesdorffer, D. C., Masanja, H., . . . Newton, C. R. (2017). Premature mortality of epilepsy in low- and middle-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy. Epilepsia, 58, 6-16. doi:10.1111/epi.13603 Al-aqeel, S., Gershuni, O., Al-sabhan, J., & Hiligsmann, M. (2017). Strategies for improving adherence to antiepileptic drug treatment in people with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD008312.pub3

59	In addition to having a safety plan, how can people who experience seizures and their caregivers decrease their risk of injury due to seizures in their daily lives?	around **How vigilant do parents need to be when it comes to allowing their preschoolers to play in their own bedrooms alone when their child has a history of seizures and is on anti-seizure medications? How vigilant do parents need to be at night when it comes to allowing their child to sleep in their own bedroom?** Are doctors looking into, or aware of and promoting/prescribing seizure monitoring devices currently available on the market so that parents can have a chance at a night of sleep without worry of undetected seizures? Is there active doctor involvement in the testing or creation of any of these devices?	1	1	1					Glauser, T., Shinnar, S., Gloss, D., Alldredge, B., Arya, R., Bainbridge, J., . . . Treiman, D. M. (2016). Evidence-based guideline: Treatment of convulsive status epilepticus in children and adults: Report of the guideline committee of the American epilepsy society. Epilepsy Currents, 16, 48-61. doi:10.5698/1535-7597-16.1.48 Bradley, P. M., Lindsay, B., & Fleeman, N. (2016). Care delivery and self management strategies for adults with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD006244.pub3 Fountain, N. B., Van Ness, P. C., Bennett, A., Absher, J., Patel, A. D., Sheth, K. N., . . . Stecker, M. (2015). Quality improvement in neurology: Epilepsy Update Quality Measurement Set. Neurology, 84, 1483-1487. doi:10.1212/wnl.0000000000001448 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk National Institute for Health and Care Excellence. (2013). Epilepsy in adults. Available from: www.nice.org.uk/guidance/qs26 National Institute for Health and Care Excellence. (2013) Epilepsy in children and young people. Available from: www.nice.org.uk/guidance/qs27 Labiner, D. M., Bagic, A. I., Herman, S. T., Fountain, N. B., Walczak, T. S., & Gumnit, R. J. (2010). Essential services, personnel, and facilities in specialized epilepsy centers-Revised 2010 guidelines. Epilepsia, 51, 2322-2333. doi:10.1111/j.1528-1167.2010.02648.x Epilepsy: a public health imperative. Geneva: World Health Organization; 2019
60	Are people who experience seizures at an increased risk of cardiovascular problems (e.g., heart attack)?	Why do so many patients with seizure disorders have cardiac problems/surgery? Why are their so many cardiac minics and what can be done to assure proper diagnosis? Can epileptic seizures cause heart problems or stroke? I also have heart disease and I am concerned epilepsy and the medications could have an affect. As in the answer above, counseling, both specific to epilepsy and in general would help me.	3							Maguire, M. J., & Nevitt, S. J. (2019). Treatments for seizures in catamenial (menstrual-related) epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD013225.pub2 Thurman, D. J., Logroscino, G., Beghi, E., Hauser, W. A., Hesdorffer, D. C., Newton, C. R., . . . Tomson, T. (2017). The burden of premature mortality of epilepsy in high-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy. Epilepsia, 58, 17-26. doi:10.1111/epi.13604 Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
61	Aside from Severe Myoclonic Epilepsy, Psychogenic Nonepileptic Seizures, and Lennox-Gastaut syndrome, are seizures associated with significant personality changes in people who experience them?	How or will my personality change because of the seizures or medicine? Is it normal for someone with adult onset epilepsy for their personality to change? Is it normal for people with epilepsy to lose their energy more quickly or to be more tired even with a sufficient amount of sleep? Does epilepsy determine my personality?	2		1					Brigo, F., Igwe, S. C., & Bragazzi, N. L. (2017). Antiepileptic drugs for the treatment of infants with severe myoclonic epilepsy. Cochrane Database of Systematic Reviews(5). doi:10.1002/14651858.CD010483.pub4 Lafrance, W. C., Baker, G. A., Duncan, R., Goldstein, L. H., & Reuber, M. (2013). Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: A staged approach: A report from the International League Against Epilepsy Nonepileptic Seizures Task Force. Epilepsia, 54, 2005-2018. doi:10.1111/epi.12356 Hancock, E. C., & Cross, J. H. (2013). Treatment of Lennox-Gastaut syndrome. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD003277.pub3
62	Can seizure control decrease the severity of developmental delays in people who experience seizures?	If we can get seizures under control, will there be a positive impact on developmental disorders/delays? With co-existing conditions, for instance, developmental disorders and behavioral issues, what are the resources available? Can the conditions get better or improve? From my experience, neurologists are careful not to overprescribe medication. However, when behavior is causing isolation, loneliness and lack of connection in adult life, are their specialists, programs or resources to tackle these cases? Can biofeedback help with behavior? Once the seizures are under control, will my daughter catch up on her developmental delays?		1	2					Wilmshurst, J. M., Gaillard, W. D., Vinayan, K. P., Tsuchida, T. N., Plouin, P., Van Bogaert, P., . . . Cross, J. H. (2015). Summary of recommendations for the management of infantile seizures: Task Force Report for the ILAE Commission of Pediatrics. Epilepsia, 56, 1185-1197. doi:10.1111/epi.13057 Hancock, E. C., Osborne, J. P., & Edwards, S. W. (2013). Treatment of infantile spasms. Cochrane Database of Systematic Reviews(6). doi:10.1002/14651858.CD001770.pub3 Hancock, E. C., & Cross, J. H. (2013). Treatment of Lennox-Gastaut syndrome. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD003277.pub3
63	What is the best method for treating developmental delays in people who have seizures?	How do you balance trying to advance a person with global development delays with epileptic drugs that cause drowsiness/makes your brain more loopy? How do I help my child continue to develop cognitively. She has developmental delays due to her seizures that are now under control. All of the above: what do we know about standard of treatment for mental health and developmental comorbidity in those with epilepsy?			2	1				Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Wilmshurst, J. M., Gaillard, W. D., Vinayan, K. P., Tsuchida, T. N., Plouin, P., Van Bogaert, P., . . . Cross, J. H. (2015). Summary of recommendations for the management of infantile seizures: Task Force Report for the ILAE Commission of Pediatrics. Epilepsia, 56, 1185-1197. doi:10.1111/epi.13057 Jackson, C. F., Makin, S. M., Marson, A. G., & Kerr, M. (2015). Non-pharmacological interventions for people with epilepsy and intellectual disabilities. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD005502.pub3 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Kerr, M. P., Mensah, S., Besag, F., De Toffol, B., Ettinger, A., Kanemoto, K., . . . Wilson, S. J. (2011). International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. Epilepsia, 52, 2133-2138. doi:10.1111/j.1528-1167.2011.03276.x
64	What are the best strategies to disseminate information regarding co-existing conditions to healthcare providers and the general public?	How often are guidelines including these comorbidities is information disseminated to front line care providers? What mechanism is in place? What can we do to create more awareness for all of these conditions as being in addition to seizures? What can be done so people understand epilepsy is not just seizures? Are memory problems after meds and seizures discussed as well as they should be? (ie. I was a family doctor and I was having memory/cognitive issues, which was not considered as a risk for my patients until I demanded cognitive testing.) My anxiety increased and therefore considered to be the problem. Although it was the impaired cognition that was causing the increased anxiety. I believe that all of these things above are hard to tease out; maybe it is all interlinked.	1	1			1			Iida K., Kagawa K., Katagiri M., Seyama G., Okamura A., Hashizume A., et al (2020). Establishment of an epilepsy medical network to facilitate cooperation in community practice. Journal of the Japan Epilepsy Society, 37, 795-802. https://doi.org/10.3805/JJES.37.795 Herrmann L.K., Welter E., Berg A.T., Perzynski A.T., Van Doren J.R. & Sajatovic M. (2016). Epilepsy misconceptions and stigma reduction: Current status in Western countries. Epilepsy and Behavior, 60, 165-173. https://doi.org/10.1016/j.yebeh.2016.04.003 Paschal A.M., Hawley S.R., Romain T.St., Liow K., Molgaard C.A., Sly J., et al (2007). Epilepsy patients' perceptions about stigma, education, and awareness: Preliminary responses based on a community participatory approach. Epilepsy and Behavior, 11, 329-337. https://doi.org/10.1016/j.yebeh.2007.06.007
65	Can using illegal drugs cause non-withdrawal seizures? (Illegal drugs do not include cannabis products or alcohol)	How does the diagnosis of epilepsy differ when the onset occurs shortly after or with the use of illegal drugs? Is there a definitive way to differentiate when brought on with substance abuse?				2				Beghi, E., Carpio, A., Forsgren, L., Hesdorffer, D. C., Malmgren, K., Sander, J. W., . . . Hauser, W. A. (2010). Recommendation for a definition of acute symptomatic seizure. Epilepsia, 51, 671-675. doi:10.1111/j.1528-1167.2009.02285.x
66	Does dehydration cause seizures?	Can seizures be caused by deyhydration/exhaustion? What other health conditions cause seizures?	1	1						Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
68	What causes Mesial Temporal seizures?	What causes Mesial Temporal Sclerosis? what is the cause of mesiotemporal seizures	1			1				Pandey, S., Rathore, C., & Michael, B. D. (2016). Antiepileptic drugs for the primary and secondary prevention of seizures in viral encephalitis. Cochrane Database of Systematic Reviews(5). doi:10.1002/14651858.CD010247.pub3 Jayakar, P., Gotman, J., Harvey, A. S., Palmini, A., Tassi, L., Schomer, D., . . . Kahane, P. (2016). Diagnostic utility of invasive EEG for epilepsy surgery: Indications, modalities, and techniques. Epilepsia, 57, 1735-1747. doi:10.1111/epi.13515 Blümcke, I., Thom, M., Aronica, E., Armstrong, D. D., Bartolomei, F., Bernasconi, A., . . . Spreafico, R. (2013). International consensus classification of hippocampal sclerosis in temporal lobe epilepsy: A Task Force report from the ILAE Commission on Diagnostic Methods. Epilepsia, 54, 1315-1329. doi:10.1111/epi.12220
69	Are there sex or gender differences in seizure frequency?	Is there research done on how epilepsy is reflected across various genders. Do women experience it more than men do?	1							Maguire, M. J., Jackson, C. F., Marson, A. G., & Nevitt, S. J. (2020). Treatments for the prevention of Sudden Unexpected Death in Epilepsy (SUDEP). Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD011792.pub3
70	In people with Sunflower Syndrome, what causes involuntary handwaving?	What causes the involuntary hand waving in 'Sunflower Syndrome'		1						Evidence Not Identified
71	Is Type 1 diabetes associated with an increased risk of seizures?	Can type 1 diabetes (which is often accompanied by neuropathy) cause epilepsy?	1							Evidence Not Identified
72	What causes idiopathic temporal lobe epilepsy in adults?	How is idiopathic temporal lobe epilepsy caused? Most common type of epilepsy in adults and we still don't know.	1							Blümcke, I., Thom, M., Aronica, E., Armstrong, D. D., Vinters, H. V., Palmini, A., . . . Spreafico, R. (2011). The clinicopathologic spectrum of focal cortical dysplasias: A consensus classification proposed by an ad hoc Task Force of the ILAE Diagnostic Methods Commission. Epilepsia, 52, 158-174. doi:10.1111/j.1528-1167.2010.02777.x
73	For people with brain lesions, are there early indicators of seizure development?	If born with a lesion on the temporal lobe, how is it possible it goes undetected, I.e. no seizures until adulthood? E.g. well into 30s or 40s. What trips it to show up out of the blue? Are there early signs that may have gone undetected?	1							Evidence Not Identified

74	How can algorithms be improved to increase the reliability of EEG-based seizure detection tools?	Why don't I have to have any eeg or mri occasionally. What if something has changed or if you missed something since my original diagnosis? I		1						Tatum, W. O., Rubboli, G., Kaplan, P. W., Mirsatari, S. M., Radhakrishnan, K., Gloss, D., . . . Beniczky, S. (2018). Clinical utility of EEG in diagnosing and monitoring epilepsy in adults. Clinical Neurophysiology, 129, 1056-1082. doi:10.1016/j.clinph.2018.01.019
75	Are reduced doses of anti-seizure medications effective at controlling seizures?	Side effects of medications can be both unpleasant and/or affect mental and physical abilities. Is there more research on reduced dosing and effectiveness? One dose does not always fit all. I am very sensitive to any medications and typically cannot tolerate full doses of many things.						1		Evidence Not Identified
76	Does individual metabolism impact the effectiveness of anti-seizure drugs?	How much is known about metabolism of medication and how that affects the effectiveness of drug therapy? For example, if a body metabolizes medication quickly or slowly does that make a difference?			1					Evidence Not Identified
78	Do supplements (e.g., daily multivitamins) impact the effectiveness of anti-seizure drugs?	Need more shared info on how common vitamins and supplements can affect or reduce efficacy of epilepsy meds.			1					Ranganathan, L. N., & Ramaratnam, S. (2005). Vitamins for epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD004304.pub2
80	Is stem cell therapy an effective treatment for seizures?	No one was comfortable talking with me about stem cell treatment options. 6-7 of the popular and usually effective drugs in various cocktails only made things worse and brought on undesirable side effects.	1							Evidence Not Identified
81	Is intravenous immune globulin (IVIg) therapy effective at preventing seizures?	What is IVIg therapy and how does it work to help reduce seizures? Is there work being done to create more comfortable and portable EEG leads and monitoring devices? Can there be increased funding to EEG monitoring units to allow for more patient privacy - eg. less patients per room? Is there a standard of care regarding medical followup of persons with epilepsy?	1							Geng, J., Dong, J., Li, Y., Ni, H., Jiang, K., Shi, L. L., & Wang, G. (2019). Intravenous immunoglobulins for epilepsy. Cochrane Database of Systematic Reviews(12). doi:10.1002/14651858.CD008557.pub4
82	Is ultrasound therapy an effective treatment for seizures?	Is the research on focused ultrasound therapy suggesting it may be a less invasive alternative treatment to epilepsy surgery in the future?		1						Evidence Not Identified
83	Is use of a hyperbaric chamber an effective treatment for seizures?	Can a **hyperbaric chamber hel**p, cbd oil, and food cure epilepsy?			1					Evidence Not Identified
84	If we study prodrome and post-ictal states closely, can we use our findings to develop effective treatments for prodrome and post-ictal states?	Can more knowledge of and closer study of the prodrome and post-ictal states tell us more about how to control seizures?	1							Evidence Not Identified
85	What are the best supplumental therapies for treating epilepsy/seizures that can be provided in a community setting (e.g., community agency)?	Are there treatments outside of the hospital that can be done through community organizations?					1			Fleeman, N., & Bradley, P. M. (2018). Care delivery and self-management strategies for children with epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD006245.pub4 Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Kossoff, E. H., Zupec-Kania, B. A., Auvin, S., Ballaban-Gil, K. R., Christina Bergqvist, A. G., Blackford, R., . . . Wirrell, E. C. (2018). Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. Epilepsia Open, 3, 175-192. doi:10.1002/epi4.12225 Michaelis, R., Tang, V., Wagner, J. L., Modi, A. C., LaFrance Jr, W. C., Goldstein, L. H., . . . Reuber, M. (2017). Psychological treatments for people with epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD012081.pub2 Al-aqeel, S., Gershuni, O., Al-sabhan, J., & Hiligsmann, M. (2017). Strategies for improving adherence to antiepileptic drug treatment in people with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD008312.pub3 Bradley, P. M., Lindsay, B., & Fleeman, N. (2016). Care delivery and self management strategies for adults with epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD006244.pub3 Jackson, C. F., Makin, S. M., & Baker, G. A. (2015). Neuropsychological and psychological interventions for people with newly diagnosed epilepsy. Cochrane Database of Systematic Reviews(7). doi:10.1002/14651858.CD011311.pub2 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Martlew, J., Pulman, J., & Marson, A. G. (2014). Psychological and behavioural treatments for adults with non-epileptic attack disorder. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD006370.pub2 Gloss, D., & Vickrey, B. (2014). Cannabinoids for epilepsy. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD009270.pub3 van Ginneken, N., Tharyan, P., Lewin, S., Rao, G. N., Meera, S. M., Pian, J., . . . Patel, V. (2013). Non-specialist health worker interventions for the care of mental, neurological and substance-abuse disorders in low- and middle-income countries. Cochrane Database of Systematic Reviews(11). doi:10.1002/14651858.CD009149.pub2 National Institute for Health and Care Excellence. (2013). Epilepsy in adults. Available from: www.nice.org.uk/guidance/qs26 National Institute for Health and Care Excellence. (2013) Epilepsy in children and young people. Available from: www.nice.org.uk/guidance/qs27 Labiner, D. M., Bagic, A. I., Herman, S. T., Fountain, N. B., Walczak, T. S., & Gumnit, R. J. (2010). Essential services, personnel, and facilities in specialized epilepsy centers-Revised 2010 guidelines. Epilepsia, 51, 2322-2333. doi:10.1111/j.1528-1167.2010.02648.x Epilepsy: a public health imperative. Geneva: World Health Organization; 2019. Cheuk, D. K. L., & Wong, V. (2014). Acupuncture for epilepsy. Cochrane Database of Systematic Reviews(5). doi:10.1002/14651858.CD005062.pub4 Panebianco, M., Sridharan, K., & Ramaratnam, S. (2017). Yoga for epilepsy. Cochrane Database of Systematic Reviews(10). doi:10.1002/14651858.CD001524.pub3 Ranganathan, L. N., & Ramaratnam, S. (2005). Vitamins for epilepsy. Cochrane Database of Systematic Reviews(2). doi:10.1002/14651858.CD004304.pub2 Martin-McGill, K. J., Jackson, C. F., Bresnahan, R., Levy, R. G., & Cooper, P. N. (2018). Ketogenic diets for drug-resistant epilepsy. Cochrane Database of Systematic Reviews(11). doi:10.1002/14651858.CD001903.pub4
86	What is the best method to manage substance abuse (other than alcohol withdrawal) for people with epilepsy or other seizure disorders?	Having to deal with paranoia (like thinking news stories and people walking by are saying negative things about you). Dealing with memory problems and being a slow learner. Also how to avoid self-medicating with alcohol & pot. I am Addicted to those but I don't want to tell people because I'll get chastised for it (esp. by medical professionals). People don't tend to talk about addiction in epilepsy because it's assumed that we don't drink or that pot is not addictive.	1							Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk
87	How does air travel affect those who are experience seizures?	How does air travel affect my brain and, seizures?	1							Evidence Not Identified
89	Are anti-seizure drugs associated with an increased severity of breathing disorders	AED affect the breathing disorders and over development of the child, are there any AED which have minimal side effects on these disorders?			1					McTague, A., Martland, T., & Appleton, R. (2018). Drug management for acute tonic-clonic convulsions including convulsive status epilepticus in children. Cochrane Database of Systematic Reviews(1). doi:10.1002/14651858.CD001905.pub3 Glauser, T., Shinnar, S., Gloss, D., Alldredge, B., Arya, R., Bainbridge, J., . . . Treiman, D. M. (2016). Evidence-based guideline: Treatment of convulsive status epilepticus in children and adults: Report of the guideline committee of the American epilepsy society. Epilepsy Currents, 16, 48-61. doi:10.5698/1535-7597-16.1.48 Booth, D., & Evans, D. J. (2004). Anticonvulsants for neonates with seizures. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD004218.pub2
90	Is use of anti-seizure drugs associated with an increased risk of Irritable Bowel Syndrome?	I would like to see more information on the links between TLE, catamenial seizures and depression/anxiety and IBS symptoms from medications and if that can be used to inform better individual treatment plans. I would like to see public education about the effects of co-existing conditions, combined with stigma, ableism, the lack of awareness and/or discrimination experienced by those with invisible disabilities. (FYI: for Section 2; I am a person with epilepsy and also a Health Care Provider and Health Policy Analyst - would be nice if more than one bullet could be captured).	1							Evidence Not Identified
91	Are people who experience seizures at an increased risk of losing their sense of smell?	Can lack of smell and epilepsy be related?	1							Evidence Not Identified
										Ayuga Loro, F., Gisbert Tijeras, E., & Brigo, F. (2020). Rapid versus slow withdrawal of antiepileptic drugs. Cochrane Database of Systematic Reviews(1). doi:10.1002/14651858.CD005003.pub3 Brigo, F., Igwe, S. C., & Bragazzi, N. L. (2018). Stiripentol add-on therapy for focal refractory epilepsy. Cochrane Database of Systematic Reviews(5). doi:10.1002/14651858.CD009887.pub4

92	Is use of anti-seizure drugs associated with an increased risk of other neurological conditions (e.g. Tourette's)?	Medication side effects and seizure side effects are hard to differentiate. Comorbiditys such as depression, anxiety can be as a result of seizure disorder and medications. **Can meditations cause other neurological conditions such as Tourette syndrome? If not, then do the seizures trigger the onset of tics once they start?**			1					Brigo, F., Igwe, S. C., & Del Felice, A. (2016). Melatonin as add-on treatment for epilepsy. Cochrane Database of Systematic Reviews(8). doi:10.1002/14651858.CD006967.pub4 Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults. Edinburgh: SIGN; 2015. (SIGN publication no. 143). [May 2015]. Available from URL: http://www.sign.ac.uk Sykes, L., Wood, E., & Kwan, J. (2014). Antiepileptic drugs for the primary and secondary prevention of seizures after stroke. Cochrane Database of Systematic Reviews(1). doi:10.1002/14651858.CD005398.pub3 Marigold, R., Günther, A., Tiwari, D., & Kwan, J. (2013). Antiepileptic drugs for the primary and secondary prevention of seizures after subarachnoid haemorrhage. Cochrane Database of Systematic Reviews(6). doi:10.1002/14651858.CD008710.pub2 Guidelines on Neonatal Seizures. Geneva: World Health Organization; 2011. Booth, D., & Evans, D. J. (2004). Anticonvulsants for neonates with seizures. Cochrane Database of Systematic Reviews(3). doi:10.1002/14651858.CD004218.pub2 Leach, J. P., Marson, A. G., & Hutton, J. L. (2002). Remacemide for drug-resistant localization related epilepsy. Cochrane Database of Systematic Reviews(4). doi:10.1002/14651858.CD001900 Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
93	Are people who experience seizures at an increased risk of developing involuntary twitching of voluntary muscle groups, such as arms or fingers (severe benign fasciculation)?	how are severe benign fasciculations connected to epilepsy, beside just being 'connected'	1							Liu, J., Wang, L. N., & Wang, Y. P. (2019). Topiramate for juvenile myoclonic epilepsy. Cochrane Database of Systematic Reviews(1). doi:10.1002/14651858.CD010008.pub4 Tan, H. J., Singh, J., Gupta, R., & de Goede, C. (2014). Comparison of antiepileptic drugs, no treatment, or placebo for children with benign epilepsy with centro temporal spikes. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD006779.pub2
94	Are people who experience seizures at an increased risk of developing joint inflammation (bursitis)?	Could repeated seizures cause bursitis in shoulder?		1						Evidence Not Identified
95	In addition to reducing stigma and improving employment and social supports, how can depression/anxiety be prevented in people who experience seizures?	Is it possible to prevent anxiety and behavioural issues?				1				Michaelis, R., Tang, V., Goldstein, L. H., Reuber, M., LaFrance, W. C., Lundgren, T., . . . Wagner, J. L. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. Epilepsia, 59, 1282-1302. doi:10.1111/epi.14444 Jackson, C. F., Makin, S. M., & Baker, G. A. (2015). Neuropsychological and psychological interventions for people with newly diagnosed epilepsy. Cochrane Database of Systematic Reviews(7). doi:10.1002/14651858.CD011311.pub2 Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
96	Aside from reducing the time from infantile spasms onset to commencement of therapy, how can behavioural issues be prevented in people who experience seizures?"	Is it possible to prevent anxiety and behavioural issues?				1				Wilmshurst, J. M., Gaillard, W. D., Vinayan, K. P., Tsuchida, T. N., Plouin, P., Van Bogaert, P., . . . Cross, J. H. (2015). Summary of recommendations for the management of infantile seizures: Task Force Report for the ILAE Commission of Pediatrics. Epilepsia, 56, 1185-1197. doi:10.1111/epi.13057