

Epilepsy Checklist- Supporting information for professionals when speaking to families:

SUDEP The risk of **Sudden Unexpected Death In Epilepsy** is very low in children with epilepsy **without** a neurological deficit comparable to the risk of death in an RTA.

A Nova Scotia population based cohort study followed up 692 children with epilepsy over 15 years. 26 died of whom 22 had a severe disorder with a functional neurological deficit. One of the four remaining died of possible SUDEP. If children with a functional neurological deficit (22 times more likely to die than the children without it) were subtracted, the risk was 0.88% which is close to the reference population. Death in children with epilepsy: a population-based study. Camfield CS, Camfield PR, Veugelers PJ *Lancet* 2002; 359: 1891–95

A retrospective study of death certificates found the risk of unexplained and unexpected death in children with idiopathic epilepsy around 65 per 100000 child-years, note! very different for non idiopathic epilepsy. Risk and causes of death in children with a seizure disorder. Nesbitt V, Kirkpatrick M, Pearson G, Colver A, Forsyth R. *Dev Med Child Neurol.* 2012 Jul;54(7):612-7

Driving DVLA: You may drive after 1 year: if no seizures awake, asleep only seizures, after 6mo, after withdrawal AED, provoked versus unprovoked ! etc. New! Focal seizure without impaired consciousness guidance, seizure during medication switchover-check before advice, see www.gov.uk/current-medical-guidelines-dvla-guidance-for-professionals-neurological-chapter-appendix

Careers Restrictions (not many) e.g. army, drivers, airline pilot

Organisations/Websites/Apps Recommended: Young epilepsy (youngepilepsy.org.uk) has app, see also epilepsy action, (www.epilepsy.org.uk), , epilepsy society (www.epilepsysociety.org.uk)

Triggers Lack of sleep (avoid, compensate later), mod. Alcohol- interaction AED, avoid drugs. Illness, menstruation. Photosensitivity (strobe lights, TV- cover one eye, 2,5 m distance, well lit room, computer, other)

Safety Bathing : shallow water, taps off, doors not locked, open outwards, somebody near by, best to shower

Active seizures: Don't carry hot pots or kettle, microwave safer than other cookers, special equipment available. fire guard, bed not next to radiator, protected radiators etc. etc. see epilepsy action website

Sports and recreation. Contact individual organisations e.g. r 5 year seizure freedom for diving etc. Individual risk assessments necessary. Cycling, no official guidance but if on public highway, use DVLA guidance, always use helmet. No swimming alone. High risk: some water sports e.g. canoeing.

Contraception and AED

CBZ, LTG (progesterone only), Oxcarbazepine, Phenobarbitone, Phenytoin, Topiramate and Rufinamide reduce blood levels of contraceptive drugs (including postcoital contraception!) via enzyme induction. Only Depo-provera® and Mirena® coil (+ other IUD) are unaffected by enzyme inducing AED's. Combined hormonal contraceptive pill lowers lamotrigine level significantly. (rebound high lamotrigine) .

C O'Brien MD, Guillebaud J. Contraception for women taking antiepileptic drugs. *J Fam Plann Reprod HealthCare* 2010; 36(4)239-242

Plan pregnancy! , high dose folic acid (5mg) recommended

Pregnancy and AED:

AED in pregnancy have an up to 6% increased risk of major malformations in offspring (2,2 % healthy controls, 2,8% epileptic women without AED),worse when polytherapy, aim for lowest dose(no"safe" dose) . Levetiracetam so far safe, LTG , Topiramites and CBZ? small risk.

Sodium valproate 1-2% risk of neural tube defect(10-20 risk of general population), but also risk of neurodevelopmental delay, reduced verbal abilities, poor attention span.

Antiepileptic drugs and pregnancy outcomes Wlodarczyk BJ, Palacios AM, *Am J Med Genet A*. 2012 Aug;158A(8):2071-90

Uk and Ireland Pregnancy register, update

MRHA Drug safety update,Volume 7, Issue 4 , November 2013 Sodium valproate: special reminder on risk of neurodevelopmental delay in children following maternal use—not for use in pregnancy unless there is no effective alternative:

A prospective multicentre study conducted in the UK and USA" Neurodevelopmental Effects of Antiepileptic Drugs study" suggests that of the 224 children followed whose mothers took valproate-related drugs had IQs at age 6 years that were between 8 and 11 points lower than children exposed to other antiepileptic drugs. Meador KJ, Baker GA, Browning N, et al. Fetal antiepileptic drug exposure and cognitive outcomes at age 6 years (NEAD study): a prospective observational study. *Lancet Neurology* 2013; 12 (3): 244-52.

A population based studying Denmark of over 650000 children born to mothers on AED from 1996 over 10 years showed an absolute risk for children exposed to valproate for ASD of 4,42% , for childhood autism of 2,5 % respectively. Jakob Christensen, PhD et; Prenatal Valproate Exposure and Risk of Autism Spectrum Disorders and Childhood Autism *JAMA*;309(16):1696-1703.

A prospective study of children of WWE over 6 years in the UK showed an increase in risk of neurodevelopmental disorders in children exposed to monotherapy sodium valproate (VPA) (12.0%) and in those exposed to polytherapy with sodium VPA (15.0%) compared with control children (1.87%). Autistic spectrum disorder was the most frequent diagnosis.The prevalence of neurodevelopmental disorders in children prenatally exposed to antiepileptic drugsBromley R, et al. *J Neural Neurosurgery Psychiatry* 2013; 0: 1-7.

Vitamin D MHRA 2009 available data suggest that long-term use of carbamazepine, phenytoin, primidone, and sodium valproate is associated with decreased bone mineral density that may lead to osteopenia, osteoporosis, and increased fractures in at-risk patients. Vitamin D supplementation should be considered for at-risk patients who are taking these medicines long term including patients who are immobilised for long periods,have inadequate sun exposure or inadequate dietary calcium intake

References

- The epilepsies: diagnosis and management of the epilepsies in children and young people in primary and secondary care. National Institute for Clinical Excellence (NICE) Clinical Guideline 137, NICE ,2012
- Diagnosis and management of epilepsies in children and young people. Scottish Intercollegiate Guidelines Network (SIGN), 2005.
- BNF medicines for children

Disclaimer: The information given is not a literature review