CH-04 Epilepsy: the ketogenic diet, bromides and the care of seizures

HEALING after the FALL, research library, CH-04

Researched 10 October 2026 by Claude Opus agent for THRIVING after the FALL, Book Four. Library document, unverified.

Findings by section

This report covers recurrent fits: epilepsy. Febrile convulsions and the fit that means meningitis are in IN-02, which this report builds on without repeating (THRIVING library, IN-02). Head injury is in WO-07, pork tapeworm in IN-08, and the shelf life of salvaged antiepileptics in ME-09. Psychosis belongs to MI-05, not yet written. The social life of epilepsy is treated only as far as the brief asks. Each section separates tradition, record and inference.

Three corrections to the brief. ME-08 has no bromide section, so the bromide material here is new (THRIVING library, ME-08). The figure of about 40 per cent seizure-free in Ecuador comes from Placencia's 1994 paper, not the 1992 Brain paper, and it is a cross-sectional count, not a measured remission rate. Friedlander's 2000 history of bromide could not be reached.

1. The untreated course: how many remit, how many die

How common. About 50 million people have epilepsy, nearly 80 per cent in low and middle income countries, with up to three times the risk of premature death (WHO 2024). At the active prevalence ME-09 used, 6.38 per 1,000, a village of 300 holds about two people with active epilepsy and a district of 3,000 about 19 (THRIVING library, ME-09). Five African surveillance sites covering 586,607 people found active convulsive epilepsy at 7.0 to 14.8 per 1,000 (Ngugi and colleagues 2013), so a parasite-heavy district may hold 30.

The treatment gap. More than 75 per cent of people with epilepsy in low income countries were untreated, against under 10 per cent in many rich countries. The gap was twice as high in rural areas (relative risk 2.01) and did not narrow over twenty years (Meyer and colleagues 2010). After the Fall every village is in the rural, low income column.

Spontaneous remission. Placencia and colleagues screened 72,121 people in the Ecuadorian Andes and found active prevalence of 6.7 to 8.0 per 1,000 (Placencia and colleagues 1992). Of 1,029 people who had ever had epilepsy, only 37 per cent had ever taken a drug, yet 44 per cent were seizure-free in the past year, and nearly two thirds of those inactive cases had never been treated (Placencia and colleagues 1994). That is a snapshot, not a follow-up. In rural Malawi, Watts found fewer and fewer untreated patients with long-standing epilepsy and read this as frequent spontaneous remission (Watts 1992). Kwan and Sander put spontaneous remission at up to 30 per cent (Kwan and Sander 2004). Perhaps a third of people with epilepsy stop fitting without a drug, and no one can say in advance who. For a village with a finite stock, that is the most important single fact.

How many die. In low and middle income countries people with epilepsy died at 19.8 per 1,000 a year, a weighted median standardised mortality ratio of 2.6. Status epilepticus caused a median 13 per cent of deaths, sudden unexpected death in epilepsy (SUDEP) 13 per cent and drowning 15 per cent (range 3.3 to 45). In rural Kenya people who did not take their drugs died at 3.37 times the rate of those who did (Levira and colleagues 2017). Across 51 cohorts

people with epilepsy drowned at 18.7 times the expected rate, and at 96.9 times in institutions (Bell and colleagues 2008). SUDEP runs at about 1.2 per 1,000 adults and 0.22 per 1,000 children a year, driven by frequent tonic-clonic fits (Harden and colleagues 2017).

Burns. At Edendale Hospital in KwaZulu-Natal, 39 of 197 adults admitted with burns (20 per cent) had epilepsy. Two thirds were women, wood or coal fires were the usual source, and half were burnt during a seizure (Faurie and colleagues 2015). The post-Fall hearth is the same hearth.

Status epilepticus. The ILAE defines two times for convulsive status. At 5 minutes a fit is unlikely to stop alone and should be treated. At 30 minutes long-term brain injury becomes a risk. Both are best estimates from incomplete data (Trinka and colleagues 2015). In Richmond, Virginia, status killed 22 per cent, 3 per cent of children and 26 per cent of adults (DeLorenzo and colleagues 1996). Low drug levels are among the commonest causes of status and carry a relatively good prognosis (Neligan and Shorvon 2010). The village can prevent that cause: the drug that stops.

2. The care of the fit: hands first

Tradition. Hesperian has met first aid that throws water on the person or makes them smell onions or leather shoes. In Ituri, a plant is put in the nose of the fitting person (Dolo and colleagues 2018). The European spoon between the teeth lasted into living memory.

Record. Stay close, move the person away from fire, stairs and sharp objects, put something soft under the head, loosen the collar, time the fit, and roll them into the recovery position. Nothing goes in the mouth and no one holds them down. Water only once they are fully awake. Help is needed after 5 minutes or if a second fit follows (Hesperian, first aid). IN-02 gives the same rules (THRIVING library, IN-02).

Inference. The tongue cannot be swallowed, and biting happens in the first seconds, so an object in the mouth protects nothing and breaks teeth or fingers. The killers are fire, water and the airway after the fit. No trial tests prevention, but the drowning ratio, the Edendale burns and Levira's 15 per cent drowning share all point to guards round the hearth, raised stoves, bucket washing instead of baths, and company near water. These cost nothing at any rung.

The rescue benzodiazepine. This is the one drug for the fit itself, and a salvage item.

- Rectal diazepam (MSF): children 1 month to 11 years 0.5 mg per kg, maximum 10 mg. 12 years and over 10 to 20 mg, 10 mg in the old. Repeat once after 5 minutes, never more than 2 doses (MSF, diazepam). Hesperian gives slightly lower age bands for children and the same rule, and says diazepam into muscle is too slow (Hesperian, rescue medicines).
- Buccal or nasal midazolam: 0.2 to 0.3 mg per kg, maximum 10 mg, adults 10 mg (MSF, midazolam). MSF repeats after 5 minutes, Hesperian after 10. The safer reading is 10.
- Buccal midazolam stopped 56 per cent of children's fits against 27 per cent for rectal diazepam, with no more breathing problems (McIntyre and colleagues 2005).
- Both can stop breathing, more so with phenobarbital, alcohol or opioids on board (MSF, diazepam). Diazepam ampoules keep their content about ten years, yellowing (THRIVING library, ME-09).

3. The ketogenic diet

Tradition. Fasting as a cure for fits goes back to at least 500 BC (Wheless 2008).

Record of the 1920s. In 1921 Geyelin and Wheatley in New York reported that the osteopath Hugh Conklin had stopped fits in 3 patients by fasting, then fasted 26 patients themselves: 20 improved and 3 became seizure-free (Goswami and Singh 2014). Secondary accounts give other numbers, and the original was not read [VERIFY]. The same year Russell Wilder at the Mayo Clinic proposed that a diet rich in fat and very low in carbohydrate would raise the same ketones without starvation, and named it the ketogenic diet. Peterman fixed the proportions in 1925 at

about 1 g of protein per kg and 10 to 15 g of carbohydrate a day [VERIFY]. Nine papers in the 1920s covered more than 400 patients, and interest fell after phenytoin arrived in 1938 (Goswami and Singh 2014).

The Johns Hopkins series. In 51 children with more than 10 seizures a week despite two drugs, 54 per cent had their fits halved at 3 months. At one year 47 per cent were still on the diet and 10 per cent were seizure-free (Vining and colleagues 1998). Of 150 children followed 3 to 6 years, 13 per cent became seizure-free and 14 per cent had 90 to 99 per cent fewer fits (Hemingway and colleagues 2001).

The randomised trial. Neal and colleagues randomised 145 children aged 2 to 16 with daily fits despite at least two drugs. At 3 months the diet group had 62 per cent of baseline seizures against 137 per cent in controls. 28 diet children (38 per cent of 73) had fits more than halved against 4 controls (6 per cent of 72). Six withdrew for intolerance. Constipation, vomiting, lack of energy and hunger were common (Neal and colleagues 2008). The brief's figures are confirmed.

The Cochrane verdict. Thirteen randomised studies with 932 people, 711 of them children, all unblinded. In children the diet raised seizure freedom (risk ratio 3.16, 95% CI 1.20 to 8.35) and halving of seizures (risk ratio 5.80, 3.48 to 9.65), all at low or very low certainty. No adult became seizure-free and adults dropped out up to five times as often (Martin-McGill and colleagues 2020).

Ratios and the modified Atkins diet. The classic diet gives 4 g of fat for each 1 g of protein plus carbohydrate, about 90 per cent of calories as fat, with 3 to 1 for infants. Starting with a fast is unnecessary (Kossoff and colleagues 2018). The modified Atkins diet allows 10 to 15 g of carbohydrate a day, later about 20 g, with no limit on protein or calories, and suits settings with few dietitians (Kossoff and colleagues 2018). In New Delhi, 102 children with daily fits despite three drugs were randomised. At 3 months 52 per cent on the diet against 11.5 per cent had fits halved, and 30 per cent against 7.7 per cent had them cut by more than 90 per cent (Sharma and colleagues 2013). A later Indian trial found the diet beat adding levetiracetam, 52.9 against 22 per cent responders (Archna and colleagues 2022). In infantile spasms it matched the classic diet (Sharma and colleagues 2023). These trials were run on Indian food in a poorer setting.

Harms. Kidney stones in 3 to 7 per cent, slowed growth, raised blood fats in 14 to 59 per cent, mild acidosis, and fatal crises in rare inborn errors of fat metabolism that a village cannot test for. Every child needs a carbohydrate-free multivitamin, calcium and vitamin D. Judge after 3 months, stop after about 2 years if it worked, and step down over 1 to 3 months (Kossoff and colleagues 2018).

Feasibility after the Fall (inference). A 20 kg child needing about 1,200 kcal a day [VERIFY] at 90 per cent fat needs about 120 g of fat a day, about 44 kg a year, the fat of several pigs for one child [VERIFY]. The classic diet needs every meal weighed, and Hesperian warns against estimating by eye (Hesperian, ketogenic recipes). Without ketone strips the village can watch only weight, vomiting, drowsiness and the fit diary. The modified Atkins diet is the version a household can run. The first failure to expect is a family that cuts calories instead of carbohydrate, and a thin child who gets thinner.

4. Bromide

History. On 12 May 1857, in the discussion of a paper by Edward Sieveking in London, Sir Charles Locock was reported to have said that potassium bromide had stopped fits in all but one of 14 or 15 women with "hysterical" or menstrual epilepsy. Eadie found the reports of that remark shaky and credits Samuel Wilks in 1861 with the first sound evidence (Eadie 2012). Bromide was the only effective drug until 1912 (Gouveia and colleagues 2024). In 1930 Wagner and Bunbury found bromide in 77 of 1,000 consecutive admissions to a Colorado psychiatric hospital (JAMA 1939, secondary), because bromide was sold freely as a sedative.

Modern use. It is still used in resistant childhood epilepsy, chiefly in Germany and Japan. In 36 resistant children, 6 of 19 with mainly tonic-clonic fits became seizure-free and 9 more halved them, at 50 to 80 mg per kg a day. Acne,

poor appetite and fatigue affected a third (Ernst and colleagues 1988). In 60 resistant patients 58 per cent had tonic-clonic fits halved and 27 per cent became free of them (Steinhoff and Kruse 1992). In 42 Japanese children the dose ran from 20 to 80 mg per kg, mean 50 (Kodama and colleagues 2019). In Dravet syndrome 81 per cent of 32 improved at 3 months (Lotte and colleagues 2012). It does not help absences (Ernst and colleagues 1988). There is no randomised trial.

Pharmacology and dose. Bromide replaces chloride in body fluids and competes with it in the kidney (Vetbromide SPC 2026). Its human half-life is about 12 days, so a steady level takes 6 to 8 weeks (Birmingham bromide reference ranges, Gouveia and colleagues 2024). The brief's 12 days is confirmed. The clinical series centre on 50 mg per kg a day of potassium bromide, within 20 to 80 (Ernst and colleagues 1988, Kodama and colleagues 2019). Potassium bromide is about two thirds bromide by weight [own calculation]. Human serum targets are 9.4 to 18.7 mmol per L, potentially toxic above 15.6 and seriously toxic above 35 (Birmingham bromide reference ranges), and toxicity has been seen as low as 5 (SAS Centre bromide). In Dravet syndrome drowsiness forced a stop in 41 per cent (Pringsheim and colleagues 2025).

Salt changes the dose. A low-salt diet raises bromide levels and risks poisoning. A sudden rise in salt lowers them and lets fits return. The veterinary licence tells owners to keep salt intake steady (Vetbromide SPC 2026, Birmingham bromide reference ranges). After the Fall salt supply rises and falls with trade, so a household on bromide must keep its salt constant. This is the most practical finding in the bromide literature.

Bromism. Slow onset: tiredness, poor appetite, unsteadiness, tremor, slurred speech, confusion, hallucinations, psychosis, stupor, and an acne-like rash on face and trunk (Thornton and Haws 2020, Coelho-Silva and colleagues 2025). A German woman took about 60 g of bromide over 6 weeks, reached 325 mg per L and was confused and unsteady. She was well 8 days after stopping and taking salt (Steinhoff and Paulus 1992). Bromide crosses the placenta and reaches breast milk (Coelho-Silva and colleagues 2025). Laboratories read it as chloride, giving a negative anion gap (Thornton and Haws 2020).

Treating bromism. Stop it and give salt and water. Oral sodium chloride 2 to 3 g three or four times a day with plenty of fluid is an alternative to intravenous saline (Thornton and Haws 2020). Fits may return as the level falls [inference].

Veterinary use. Potassium bromide is licensed for dogs, at 30 mg per kg twice daily alone, and must not be stopped abruptly (Vetbromide SPC 2026). Veterinary practices are a salvage source.

Can it be made? Balard discovered bromine in 1826 at Montpellier, in salt-marsh residues, freeing it with chlorine. Seawater holds about 65 parts per million bromide and the Dead Sea up to 50,000. Industry treats bromide-rich brines with chlorine gas, and elemental bromine is toxic and corrosive (Bromine encyclopaedia entry). A village would need a bromide-rich brine, a chlorine source, the means to handle a corrosive poison, a way back to a pure salt and a purity test. That is industrial chemistry, and this report gives no method. Sea salt is useless, since its chloride outweighs its bromide by about 300 to 1 and would wash the bromide out [own calculation, VERIFY]. The honest answer is salvage. [OWNER] whether the book says more.

5. Phenobarbital and the salvaged drugs

History. Bayer marketed phenobarbital as Luminal in 1912. That year Alfred Hauptmann in Freiburg gave it to epileptic patients sleeping badly on bromide and found their fits fell (Hauptmann 1912, secondary). Hauptmann, a Jew, was held in Dachau after Kristallnacht, emigrated, and died in Boston in 1948.

Dose. MSF: adults and children 12 and over start at 1 mg per kg (maximum 60 mg) at bedtime for 2 weeks, then add 15 to 30 mg a week as needed up to 3 mg per kg, maximum 180 mg. Children 1 month to 11 years start at 2 to 3 mg per kg at bedtime, adding 1 to 2 mg per kg a week up to 6 mg per kg. Levels settle after 2 to 3 weeks. Do not stop abruptly (MSF, phenobarbital). Sander gives maintenance of 60 to 240 mg and a target level of 10 to 40 mg per

L (Sander 2015). The village should use MSF's 180 mg ceiling. The adult half-life averages 79 hours and the child's 110 (DailyMed phenobarbital label), so one dose a day suffices and a missed day does little harm.

Effect. Rural Chinese doctors with basic training treated 2,455 people with convulsive epilepsy using phenobarbital alone. Of those completing 12 months, 68 per cent had fits at least halved and a third were seizure-free. At 24 months the figures were 72 per cent and a quarter. 76 per cent were still on treatment at 2 years and 1 per cent stopped for side effects. No formal cognitive testing was done (Wang and colleagues 2006). The brief's figure is confirmed. The Cochrane comparison found no difference from carbamazepine in remission, though people stayed on carbamazepine longer (Nevitt and colleagues). Kwan and Brodie found few efficacy differences from other drugs and consistent tolerability in poor countries (Kwan and Brodie 2004). In rural India, 94 children on phenobarbital showed no more behaviour problems than on phenytoin (Pal and colleagues 1998, secondary).

Side effects. Fatigue, hyperactivity and aggression in children, slowed memory and learning, depression, bone softening, folate deficiency (Sander 2015). Rare severe skin reactions begin with fever, rash or mouth ulcers. Malformations in pregnancy, so folic acid 5 mg and the lowest dose. It weakens contraceptive pills and implants (MSF, phenobarbital).

Overdose. One gram of most barbiturates causes serious poisoning in an adult and 2 to 10 g commonly kills (DailyMed phenobarbital label). A bottle of 1,000 tablets of 60 mg holds 60 g. It must be locked.

What happens when it stops. The label states that barbiturate withdrawal can be severe and fatal, with convulsions and delirium within 16 hours, lasting up to 5 days (DailyMed phenobarbital label). That describes barbiturates as a class. With phenobarbital's long half-life the danger probably comes later and lasts longer [inference, VERIFY]. Hesperian says sudden stopping raises the risk of death and a planned stop should take 2 to 3 months or longer (Hesperian, stopping medicines). Of patients seizure-free for two years and withdrawn slowly, 59 per cent stayed seizure-free at 2 years, against 78 per cent who continued (MRC Antiepileptic Drug Withdrawal Study Group 1991). The WHO allows stopping after 2 seizure-free years (WHO 2024). So a slow, planned stop succeeds in more than half, a sudden stop risks status and death, and a stop forced by an empty shelf is a sudden stop unless the keeper sees it coming months ahead.

Stability and stock. Phenobarbital kept its strength 28 to 40 years in the Cantrell cache, and ME-09 calls it the decade antiepileptic, with a district target of about 140,000 tablets of 60 mg (THRIVING library, ME-09). At 120 mg a day one patient uses 730 tablets a year [own calculation]. It costs about US$5 a person a year (WHO A68/12, secondary).

Phenytoin and carbamazepine. Phenytoin switches to saturation kinetics at therapeutic doses, so a small dose change causes a large swing, with drowsiness, slurred speech and unsteadiness on the way up and fits on the way down. It coarsens gums and features. Carbamazepine suits focal and tonic-clonic fits but can worsen absences and jerks, and rash affects up to 10 per cent (Sander 2015). Its tablets stop dissolving in humidity once out of the strip (THRIVING library, ME-09). Both are second line while they last.

6. Plants

Cannabis (Cannabis sativa, female flowering tops and resin). *Tradition.* Used for convulsions in South Asian medicine, in Victorian medicine, and in home-made oils by American families in the 2010s. *Record.* In 120 people with Dravet syndrome, pharmaceutical cannabidiol 20 mg per kg a day cut monthly convulsive fits from a median 12.4 to 5.9, against 14.9 to 14.1 on placebo. 5 per cent became seizure-free. Diarrhoea, sleepiness and abnormal liver tests were more common (Devinsky and colleagues 2017). Pooled trials give a number needed to treat of 8 and a risk ratio of 2.55 for serious adverse events (Stockings and colleagues 2018). Families who moved to Colorado for home oil reported success twice as often as local families (47 against 22 per cent), and 13 per cent of children had more fits (Press and colleagues 2015). Only 31 per cent of 84 products bought online were accurately labelled, and 21 per cent held THC (Bonn-Miller and colleagues 2017). *Inference.* The raw plant holds mainly the acid form, which

becomes cannabidiol only with heat (Journal of Cannabis Research 2024, secondary), and content varies between plants. A home oil cannot be shown to deliver 400 mg a day to a 20 kg child, and may deliver THC. Grade A for the pharmaceutical, D for the plant.

Valerian (Valeriana officinalis, root). *Tradition.* In 1592 Fabio Colonna wrote that the powdered root had cured his own epilepsy, and by the 19th century it was often thought the best treatment (Eadie 2004). Gairdner reported a 12-year epilepsy cured by it in 1828 (Gairdner 1828, title only). *Record.* No trial. *Inference.* It yields isovaleric acid, close to valproic acid, but its content is uncertain (Eadie 2004). Rare liver injury (LiverTox, secondary). The lookalike risk is poison hemlock (Conium maculatum), from a single herbal source [VERIFY]. Grade D.

Skullcap (Scutellaria lateriflora, aerial parts). *Tradition.* North American eclectic medicine used it for nervous disorders and fits. *Record.* No human seizure trial. Its liver injuries are often blamed on germander (Teucrium canadense or T. chamaedrys), a liver poison sold in its place because they look alike (LiverTox, secondary). Grade D.

Mistletoe (Viscum album, leaves and stems). *Tradition.* Sir John Colbatch called it in 1720 a "most wonderful specifick" for convulsions (Wellcome Collection). *Record.* No trial. American mistletoe (Phoradendron) caused no deaths in 1,754 poison-centre exposures (Krenzelok and colleagues 1997), but that is a different genus and the oral toxicity of Viscum album was not checked [VERIFY]. Grade D.

7. Preventable causes

Birth. In the African sites, children who had trouble breathing, crying or feeding after birth had 10.2 times the odds of active convulsive epilepsy, and antenatal and perinatal problems together explained a third of childhood cases (Ngugi and colleagues 2013). Midwifery and newborn resuscitation are epilepsy prevention.

Head injury. Among 4,541 people in Minnesota, mild brain injury raised later seizures 1.5 times, an excess gone after 5 years, and severe injury 17 times (Annegers and colleagues 1998). See WO-07 (THRIVING library, WO-07).

Pork tapeworm. In endemic areas a quarter of people with seizures have neurocysticercosis (25.2 per cent, 95% credible interval 19.5 to 32.2), a share falling since 2008 (Jalal and colleagues 2026). Seizures occur in 78.8 per cent of clinic patients with it (Carabin and colleagues 2011). In northern Peru, mass treatment of people and pigs with pig vaccination across 107 villages left 105 with no infected pig (Garcia and colleagues 2016). Worm tablets can provoke fits in undiagnosed brain cysts (THRIVING library, IN-08). The village measures are latrines, penned pigs, pork cooked through and hand washing. The WHO judges a quarter of epilepsy preventable (WHO 2024).

8. Possession, contagion and the life of the epileptic

Traditions on their own terms. Among the Hmong of Laos the condition is *qaug dab peg*, "the spirit catches you and you fall down": the soul has fled and must be called back. Fadiman's account of Lia Lee in Merced, California, from 1982, shows parents turning to sacrifice and the shaman while doctors changed her drugs. The illness carried honour as well as grief, because shamans are often people who fall (Fadiman 1997, summaries only). In Togo the local names mean "the disease that makes you fall" and are taboo to speak. Healers cut scars at the hairline, small if fits are rare, large and visible if frequent. More than 80 per cent of epileptics bore them (Grunitzky and colleagues 2000). In Ituri, epilepsy is blamed on spirits and witchcraft and treated with church sprays, the plant dodoi, river bathing and sacrifice, and many believe it spreads through saliva or touch (Dolo and colleagues 2018). The Hippocratic writer of *On the Sacred Disease* called it "nowise more divine nor more sacred than other diseases" and placed it in the brain (Hippocrates, Adams translation).

Record. Fear of saliva leaves the fitting person unturned and near the fire, which fits the Edendale burns [inference on the link]. In Cameroon, deaths were proportionally more common after traditional plus modern treatment than after modern treatment alone (Levira and colleagues 2017). In Ecuador, work was the area most damaged, and fear of the next fit persisted after drugs controlled them (Farmer and colleagues 1992). In Ituri, disclosure could cost

a marriage, and a box of phenobarbital cost about US$20 (Dolo and colleagues 2018). In the 1950s about a third of American states restricted epileptics' marriages (Harvard Undergraduate Law Review 2024, secondary), and the WHO still notes laws allowing annulment on that ground (WHO 2024).

Inference. Epilepsy is not contagious. The Hmong and Togolese practices place a frightening event inside a story a community can act on. The book can respect that and still say the fit is a brain event that soul-calling does not stop and turning on the side makes survivable. A healer can call the soul beside a person in the recovery position who takes phenobarbital at night. Burning, cutting and beating are harms and are graded X.

Marriage and work. People with epilepsy marry and work. Proposed rules: no working alone at heights, open fire, deep water or machinery until 2 seizure-free years [OWNER], no bar on marriage [OWNER], and a duty to teach a spouse and work partner the first aid [OWNER]. A couple should hear the pregnancy risks of phenobarbital before pregnancy (MSF, phenobarbital).

Evidence grades

Remedy or practice	Record	Grade
Recovery position, timing, nothing in mouth, no restraint	Hesperian and IN-02 agree, no trial	B
Fire and water precautions	Drowning 18.7 times, 20% of Edendale burns	B
Buccal midazolam, rectal diazepam	Midazolam 56% vs diazepam 27%	A
Phenobarbital	2,455 rural Chinese patients, parity with carbamazepine	A
Carbamazepine, phenytoin	Effective, harder to run	A
Classic ketogenic diet, children	38% vs 6% halved, Cochrane low certainty	A (low certainty)
Modified Atkins diet, children	52% vs 11.5% halved	A (small trials)
Ketogenic diets, adults	Uncertain, high dropout	C
Potassium bromide	Series of 36 to 60 resistant patients	B
Pharmaceutical cannabidiol, Dravet	Randomised trials, NNT 8	A
Home cannabis preparations	Parent report, mislabelling	D
Valerian, skullcap, mistletoe	No trial	D
Water thrown, onions or shoes to the nose, object in mouth	No benefit, injury	X
Scarification, burning, beating	No benefit, wounds, stigma	X
Abrupt phenobarbital stop	Withdrawal convulsions, death	X
Penned pigs, latrines, cooked pork	Transmission ended in Peru	B

Means ledger

Remedy	Hands	Hearth	Garden and still	Village dispensary	District infirmary	Hospital reference
Fit first aid	Side, time, protect	Hearth guard, no baths	Same	Teach every house	Same	Same plus oxygen

Remedy	Hands	Hearth	Garden and still	Village dispensary	District infirmary	Hospital reference
Status	Time, side	Same	Same	Rescue benzodiazepine, 2 doses	Injectable phenobarbital or phenytoin if trained	Intensive care
Phenobarbital	None	None	Scale to split tablets	Start, titrate, register, lock	Decade stock	Blood levels
Bromide	None	Steady salt	Scale	Only with salvage and approval [OWNER]	Salt-water rescue	Serum levels
Ketogenic diet	None	Modified Atkins with local fat	Classic diet with a gram scale	Plan, weight chart, vitamins	Ketone strips if salvaged	Dietitian, labs
Cannabis	None	Unknown dose	Unknown strength	Not advised	Not advised	Pharmaceutical cannabidiol
Prevention	Hand washing	Cook pork	Pens, latrines	Treat carriers, safe births	Mass treatment rounds	Scans, surgery

Hands and hearth prevent deaths from fire, water and the blocked airway. The dispensary, with phenobarbital and a rescue drug, is where seizure counts and deaths fall. The district adds injectable drugs. The hospital adds levels, scans and newer drugs that for most patients work no better (Kwan and Brodie 2004).

Harm test

First aid. Objects in the mouth break teeth and block the airway. Restraint dislocates shoulders. Poured water is inhaled (Hesperian, first aid). Watch for noisy or absent breathing and blue lips after the fit.

Rescue benzodiazepines. Slow or stopped breathing, especially with a third dose or with phenobarbital or alcohol on board (MSF, diazepam). Never more than 2 doses. Count breaths for an hour.

Phenobarbital. Sedation, behaviour change in children, depression, bone disease, malformations, failed contraception, rare severe skin reactions (MSF, phenobarbital, Sander 2015). Overdose brings deep sleep, slow breathing and coma. The abrupt stop brings convulsions and can kill (DailyMed phenobarbital label). Never for absences (MSF, phenobarbital). The greatest harm is a population stabilised on a drug that runs out.

Bromide. Bromism, caused by raising the dose before 6 to 8 weeks, a drop in salt, kidney failure, an added sedative, or dosing on the wrong weight. Not in pregnancy or breastfeeding [inference from placental and milk transfer]. Stop, give salt and water, watch for returning fits.

Ketogenic diet. Low blood sugar, acidosis, vomiting, dehydration, kidney stones, poor growth, deficiency. Fatal in rare metabolic disorders a village cannot detect (Kossoff and colleagues 2018). Not for children under 2, thin children or children who vomit [inference]. Watch weight, urine colour and drowsiness.

Cannabis. Unknown dose, THC, more fits in 13 per cent (Press and colleagues 2015). Not for children.

Valerian, skullcap, mistletoe. Liver injury, germander substitution, hemlock confusion. Not in pregnancy.

Traditional practices. Scarification risks infection and tetanus [inference], burning causes burns, beating injures. The worst harm is delay: the child kept from phenobarbital while the soul is called.

Red flags

1. **A fit lasting 5 minutes, or a second before waking.** Rescue drug, airway. Past 30 minutes brain injury becomes likely (Trinka and colleagues 2015).
2. **Fit with fever and stiff neck, a non-fading rash, or not awake within an hour.** Treat as meningitis (THRIVING library, IN-02).
3. **A first fit in an adult with headache, one-sided weakness or personality change.** Abscess, cyst, tumour or bleed. The village can treat fits but not diagnose.
4. **A fit after head injury, or with one pupil larger** (THRIVING library, WO-07).
5. **A fit in late pregnancy or after birth.** Eclampsia: magnesium, not phenobarbital (THRIVING library, ME-09).
6. **A fit in a diabetic, a starving child, a child on the diet or a heavy drinker.** Sugar by mouth if awake. Alcohol withdrawal fits come 1 to 2 days after the last drink [VERIFY].
7. **A fit after a worm tablet.** Brain cysts likely. Do not repeat it (THRIVING library, IN-08).
8. **Fever, rash or mouth ulcers on phenobarbital or carbamazepine.** Stop and switch (MSF, phenobarbital).
9. **Sleepiness, unsteadiness, confusion or acne on bromide.** Bromism.
10. **Slow breathing after a rescue dose.**
11. **Stock for less than three months.** A district red flag (Protocol 4).

What to do anyway. Turn, time, protect, give what the shelf holds, and stay with the family. For status that continues after two doses with no further drug, keep the airway open, keep the person on their side and warm, and let the family hold their hand. Many fits stop late. If one does not, the family should hear that nothing they did caused the death, and that it was not a spirit's punishment.

The case against

Against the hospital. Kwan and Sander dismantled the view that untreated epilepsy only worsens (Kwan and Sander 2004), and Placencia's untreated Ecuadorians show the same (Placencia and colleagues 1994). For most patients newer drugs beat phenobarbital in tolerability, not in efficacy (Kwan and Brodie 2004, Wang and colleagues 2006). The modern ketogenic revival came from families, after hospitals neglected the diet for decades (Wheless 2008).

Against phenobarbital. Sander writes that it is seldom used in rich countries because of its effects on memory, mood and behaviour (Sander 2015), and the Chinese trial did not test cognition (Wang and colleagues 2006). The harms are real. They are smaller than the harm of untreated tonic-clonic fits.

Against the diet. Martin-McGill and colleagues rate every outcome low or very low certainty and the adult evidence uncertain (Martin-McGill and colleagues 2020). The 38 per cent is a three-month result in children whom drugs had failed, and most children who start do not last a year (Vining and colleagues 1998). After the Fall the diet competes for the scarcest food, fat.

Against bromide. Eadie doubts Locock's famous remark rested on real evidence (Eadie 2012). Ryan and Baumann note bromide fell from use for its toxicity (Ryan and Baumann 1999). There is no randomised trial, and toxicity occurs inside the "therapeutic" range (SAS Centre bromide).

Against the herbal. Eadie's verdict on valerian fits all the old specifics: possibly active, impossible to dose (Eadie 2004). Press, Knupp and Chapman's Colorado data carry the signature of hope rather than pharmacology (Press and colleagues 2015).

Against the romance of tradition. The Togolese scars mark a patient for life and the contagion belief leaves people to burn. The meaning a community gives to the fall is its own, and the turn onto the side and the bedtime tablet are owed to every person regardless.

10-line summary

1. Active epilepsy affects 6 to 10 per 1,000 people, two in a village of 300 and 20 to 30 in a district of 3,000.
2. Perhaps a third remit without drugs. 44 per cent of a largely untreated Ecuadorian population were seizure-free at survey.
3. In poor countries people with epilepsy die at about 20 per 1,000 a year, from status, sudden death, drowning (18.7 times normal) and burns.
4. Turn, time, protect, nothing in the mouth. Fire and water kill more than the fit.
5. A fit at 5 minutes is status, and brain injury becomes likely by 30. Buccal midazolam beats rectal diazepam.
6. Phenobarbital, 60 to 180 mg at bedtime, halved fits in two thirds of 2,455 rural Chinese patients for about US$5 a year.
7. Phenobarbital must never stop suddenly. Withdrawal brings convulsions and can kill.
8. The ketogenic diet halves fits in about four in ten children whom drugs failed, at low certainty, and needs fat, scales and supervision.
9. Bromide at about 50 mg per kg a day works on tonic-clonic fits, has a 12-day half-life, poisons slowly and moves with salt intake.
10. A quarter of epilepsy in endemic places is pork tapeworm, and a third of African childhood epilepsy follows a hard birth.

Open questions

- The true spontaneous remission rate. Placencia is cross-sectional and Watts indirect.
- When withdrawal fits come after an abrupt phenobarbital stop in people with epilepsy, as opposed to barbiturate users.
- Whether a village can sustain the modified Atkins diet on local food, and at what cost in fat.
- A safe bromide regimen without serum levels.
- Whether phenobarbital stored hot for decades keeps its dissolution as well as its content.
- The oral toxicity of European mistletoe.
- Whether teaching first aid cuts drowning and burn deaths.
- How healers' soul-calling and drug treatment can run side by side.

Sources to read in full

1. Neal and colleagues 2008, Lancet Neurology, the ketogenic diet trial.
2. Martin-McGill and colleagues 2020, Cochrane review of ketogenic diets.
3. Kossoff and colleagues 2018, Epilepsia Open, dietary management guideline.
4. Wang and colleagues 2006, Lancet Neurology, phenobarbital in rural China.
5. Placencia and colleagues 1994, untreated epilepsy in Ecuador.
6. Levira and colleagues 2017, Epilepsia, mortality in low and middle income countries.
7. Kwan and Brodie 2004, Epilepsia, phenobarbital in the 21st century.
8. Eadie 2012 on Locock and bromide, and Eadie 2004 on valerian.
9. Hesperian, Epilepsy and Seizures.
10. Fadiman 1997, The Spirit Catches You and You Fall Down.

At the bedside after the Fall

Household. Everyone in the house knows the first aid. The hearth has a guard. The person with epilepsy never bathes in deep water or works alone near fire, water or heights. A diary records each fit: date, time, length, what came before. The tablets are locked and counted. To start: a timing method (counting slowly to 300 is 5 minutes), a notebook, a locked box. First failure to expect: the tablets run out because the person has been well for months.

Village of 300. One trained keeper holds a register of the two or so patients, with weights, doses and diaries, a stock card for phenobarbital and rescue doses, and teaches every household the first aid. For a child still fitting on phenobarbital, the keeper may start the modified Atkins diet with a family that has fat. Pigs penned, latrines used, pork cooked. To start: about 1,500 phenobarbital 60 mg tablets for two adults for a year plus taper [own calculation], 4 to 10 rescue doses, a scale, the protocols below. First failure to expect: a dose raised too fast, so the patient sleeps through the harvest.

District of 3,000. A nurse or trained healer, a register of 20 to 30 patients, ME-09's decade stock, carbamazepine and phenytoin as second line, injectable rescue drugs, newborn resuscitation, a pig-and-latrine programme, and a yearly training day for keepers and traditional healers together. First failure to expect: phenobarbital diverted as a sleeping drug, or every single first fit started on lifelong treatment until the stock is gone.

Protocols

Protocol 1. The fit (any household)

- ☐ Note the start time, or start counting slowly.
- ☐ Move fire, pots and tools away. Pull the person clear of fire or water by the clothes.
- ☐ Something soft under the head. Loosen the collar.
- ☐ Nothing in the mouth. Do not hold the limbs. No water poured, nothing held to the nose.
- ☐ When the jerking stops, roll onto the side, top leg bent, chin up.
- ☐ Count breaths. Fewer than 8 a minute in an adult, or noisy breathing that does not clear with the chin lifted, is an emergency.
- ☐ Stay until fully awake. Water only then.
- ☐ Write in the diary: date, time, length, what came before (missed dose, no sleep, fever, drink).
- ☐ At 5 minutes, or a second fit before waking: Protocol 2.
- ☐ Not awake in 1 hour, fever, stiff neck, rash, one-sided weakness: IN-02 Protocol 1.

Protocol 2. Status (a fit at 5 minutes)

- ☐ Keep the person on the side. Note the time.
- ☐ First dose by a trained person:
  - Buccal midazolam 0.2 to 0.3 mg per kg, maximum 10 mg, adults 10 mg, between gum and cheek.
  - Or rectal diazepam 0.5 mg per kg in children, maximum 10 mg, adults 10 to 20 mg (10 mg if old). Syringe without needle, 1 to 3 cm in, buttocks held together 1 minute.
- ☐ Still fitting 5 minutes after diazepam or 10 minutes after midazolam: same dose once more. Never a third.
- ☐ Count breaths every 5 minutes for an hour. Fewer than 8 a minute in an adult: open the airway, stimulate.
- ☐ Ask when the last tablet was taken. Restart the usual dose once the person can swallow.
- ☐ Still fitting at 30 minutes: injectable drugs only at the district. Otherwise airway, warmth, side, family.

Protocol 3. Starting phenobarbital (village dispensary)

- ☐ Start only after two or more unprovoked convulsive fits at least 24 hours apart [VERIFY]. Not for one fit, fever fits in small children or absences.
- ☐ Check the stock rule (Protocol 4) first.

- ☐ Weigh and record.
- ☐ 12 years and over: 1 mg per kg at bedtime, maximum 60 mg, for 2 weeks.
- ☐ 1 month to 11 years: 2 to 3 mg per kg at bedtime for 2 weeks.
- ☐ If fits continue, add 15 to 30 mg (adults) or 1 to 2 mg per kg (children) once a week. Ceiling 180 mg or 3 mg per kg for adults, 6 mg per kg for children.
- ☐ Write the dose in mg and in tablet fractions.
- ☐ Teach: every night, never stop suddenly, never share, keep locked.
- ☐ Women who may conceive: folic acid 5 mg a day if held. Pills and implants fail.
- ☐ Review at 2 weeks, 1 month, 3 months, then every 3 months: fits, sleepiness, behaviour, rash, mouth ulcers.
- ☐ Fever with rash or mouth ulcers: stop and switch to carbamazepine if held.

Protocol 4. The stock rule [OWNER]

- ☐ Tablets per patient per year: daily mg divided by 60, times 365. At 120 mg, 730.
- ☐ Count stock monthly and write the months of supply left for the whole register.
- ☐ Rule A: no new long-term patient unless 12 months plus a 3-month taper is held for them [OWNER].
- ☐ Rule B: below 6 months of stock, begin planned tapers in those most likely to succeed: 2 or more years seizure-free, one drug, no tonic-clonic fits in 2 years [OWNER].
- ☐ Rule C: below 3 months with no resupply certain, taper everyone, lowest risk first, rather than let the shelf empty [OWNER].
- ☐ Taper: cut 15 mg (adults) or about 1 mg per kg (children) every 2 to 4 weeks, so 120 mg takes 2 to 4 months to stop [own schedule, VERIFY].
- ☐ During a taper the family holds a rescue dose and the patient keeps away from water, fire and heights.
- ☐ If fits return, go back to the last dose that held them.
- ☐ On a new lot, watch for drowsiness or returning fits (THRIVING library, ME-09).
- ☐ Count in pairs. Record every tablet out.

Protocol 5. Bromide, only where salvaged and approved [OWNER]

- ☐ Only for convulsive fits not controlled by phenobarbital, or when phenobarbital is gone.
- ☐ Not in pregnancy, breastfeeding, kidney failure or children under 2 [VERIFY].
- ☐ Potassium bromide 30 mg per kg a day in two doses with food.
- ☐ Keep daily salt the same. Write it down: a level teaspoon is about 5.9 g (THRIVING library, ME-08).
- ☐ Wait 6 to 8 weeks before judging. If fits continue and no bromism, raise to 50 mg per kg a day. Never above 80.
- ☐ Each visit: sleepier, unsteady, slurred, confused, odd behaviour, voices, acne, poor appetite? One sign: cut the dose by a third.
- ☐ Two signs or confusion: stop. Salt 2 to 3 g three or four times a day with plenty of water for several days. Rescue dose at hand.
- ☐ Never stop a working bromide suddenly except for bromism.

Protocol 6. Modified Atkins diet for a child still fitting

- ☐ Only for a child over 2, not thin, in a family with steady fat, eggs or meat, still fitting on phenobarbital.
- ☐ Weigh. Keep a fit diary for 4 weeks first.
- ☐ Carbohydrate 10 to 15 g a day for 1 to 3 months: no grain, bread, porridge, potato, sugar, honey, fruit or sweet roots. Leafy greens in measured amounts [VERIFY: local carbohydrate table needed].
- ☐ Fat at every meal: butter, lard, oil, fatty fish, eggs, cheese, meat. No limit on protein or water.
- ☐ Multivitamin, calcium and vitamin D if held.
- ☐ Weigh weekly for a month, then monthly. Step back if weight falls more than 10 per cent [VERIFY].

- ☐ Vomiting, drowsiness, blood in urine, back pain: water, a little sugar water if drowsy, ease the diet.
- ☐ Judge at 3 months. Fits not halved: stop over 4 to 6 weeks.
- ☐ If it works, continue up to 2 years, then step down over 1 to 3 months.
- ☐ Do not change the phenobarbital meanwhile.

Numbers to carry

1. **5 minutes.** A fit this long is status: give the rescue drug.
2. **30 minutes.** Beyond this, brain injury becomes likely.
3. **2 doses.** The most rescue benzodiazepine ever given.
4. **1 mg per kg, up to 3 mg per kg, maximum 180 mg.** Adult phenobarbital at bedtime.
5. **2 to 3 months.** The shortest safe taper. Never stop suddenly.
6. **730 tablets.** One year of phenobarbital at 120 mg a day.
7. **12 days.** Bromide half-life. Judge after 6 to 8 weeks and keep salt steady.
8. **4 to 1, or 10 to 15 g.** Classic diet ratio, and daily carbohydrate on the modified Atkins diet. Judge at 3 months.
9. **18.7.** How many times more often a person with epilepsy drowns.
10. **A third.** Roughly how many remit with no drug.

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