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The ALSUntangled Group

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RESEARCH ARTICLE

ALSUntangled 41: "Eric Is Winning"

THE ALSUNTANGLED GROUP

ALSUntangled reviews alternative and off label treatments (AOTs) for people with ALS (PALS). Here, in response to 771 requests (1), we evaluate the regimen described in the book "Eric Is Winning" by Eric Edney (2). We will refer to this regimen as EIW.

Overview

Eric Edney, an insurance agent, reportedly experienced his first symptoms of ALS in 1990 and was diagnosed with ALS in 1993 at age 64 years (2,3). In 1996, after 'gathering all of the available information, putting it together, and applying some common sense' he developed a multi-phase health regimen for himself (2). His EIW regimen (Table 1) included detoxes, exposures to avoid, dietary changes, nutritional supplements, cleansing treatments, hormone therapy, prayer, and meditation. He continued to tweak his EIW regimen over the years and he felt strongly that his regimen prevented further decline and may even have reversed some of his ALS symptoms. He reportedly died at 85 years of age from complications of a heart attack and stroke – not from ALS (4).

Eric's website sells a book about his regimen, and another he wrote called 'Surviving Without Your MD.' The website also endorses specific suppliers and practitioners who provide products and services in the EIW regimen. In our opinion, such sales and endorsements create a potential conflict of interest.

Mechanisms

There is no convincing evidence that the mercury from dental amalgams, or any other metal exposure, can trigger ALS. Thus, there is no plausible way that amalgam removal or chelation would help. We know of no scientific mechanism by which clean air, colon hydrotherapy, daily bowel movements, foot soaks, mineral baths, laser beams, fasting, alkaline pH, any of the suggested dietary changes, use of testosterone, prayer, meditation or massage would slow ALS progression. None of the 'toxins to avoid' have been shown to play a role in ALS progression.

The most mechanistically plausible part of the EIW regimen is the use of injected B12. We have previously discussed the multiple ways injected B12 could work to slow ALS progression, and assigned it a TOE 'Mechanism' Grade of A (5). Our mechanism grade for EIW was determined by investigating whether or not it might do more than B12 alone. Vitamin D (6), vitamin E (7), alpha lipoic acid (8), injected glutathione (9), caloric restriction (10), and exercise (11) could theoretically add to the antioxidant or antiinflammatory activity of vitamin B12, but this additive effect has never been proven. Growth factors (12), including human growth hormone (HGH), could theoretically slow ALS progression by improving the health of motor neurons and/or muscle (neurotrophic/myotrophic mechanisms, 13). One study suggests that a positive mental attitude in patients with ALS correlates with their survival (14); of course, this correlation does not prove that attitude can influence ALS progression. Based on all this, ALSUntangled assigns a Table of Evidence (TOE) 'Mechanism' Grade of C.

Pre-Clinical Models

We found no studies of EIW in pre-clinical models of ALS. Thus, ALSUntangled assigns a TOE 'Pre-Clinical' Grade of U (Table 2).

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Table 1. EIW Regimen.

1. Detox
   a. Remove dental amalgams because they contain mercury
   b. Obtain a comprehensive set of blood tests and hair analysis to identify toxins
   c. Chelation
   d. Move to a place with 'clean air'
   e. Colon hydrotherapy
   f. Daily bowel movement
   g. Bionic hydrotherapy foot soaks
   h. Bathing in Bentonite clay
   i. Hot mineral water baths
   j. Laser beam treatment
   k. Fast 36hours each week
   l. Maintain an alkaline pH
2. Exposures/Toxins to avoid
   a. Mercury
   b. Tap water (w/chlorine and fluoride). Drink distilled water from a glass
   c. Plastic bottles
   d. Pesticides and food preservatives (eat washed/rinsed organic whole foods)
   e. Insecticides
   f. Gasoline
   g. Ceramic pottery (containing lead)
   h. Toothpaste
   i. Prescription drugs
   j. Flagyl
3. Dietary Changes
   a. Avoid the following foods:
      i. Sugar
      ii. MSG
      iii. Aspartame
      iv. Milk
      v. Coffee
      vi. Alcohol
      vii. Meat (especially beef and fish)
      viii. Dairy
      ix. Wheat
      x. Canned goods
      xi. Salt
      xii. Cysteine
   b. Drink plenty of water (distilled, drink from a glass)
   c. Drink Starbucks Chai Latte with Soy
4. Nutritional Supplements
   a. Probiotics (Ultraflora or buttermilk)
   b. Natural antibiotics
      i. Olive leaf extract
      ii. Raw garlic
      iii. Oil of oregano
      iv. Colloidal silver
   c. Vitamin B-Complex, B1, B12 (daily injection is preferable to oral)
   d. Vitamin A
   c. Vitamin C
   f. Vitamin E
   g. Vitamin D
   h. Calcium
   i. DHEA 300 units
   j. Flax seed oil
   k. Glucosamine and Chondroitin
   l. Alpha Lipoic Acid
   m. NADH
   n. Selenium
   o. Multigenics powder
   p. Ultra Clear Sustain
   q. Raw Vegetable juice
   r. Glyconutrients
   s. Vitamin/mineral IV with Glutathione
5. Live Cell Therapy (use of processed tissues from animal embryos, foetuses or glands)
6. Hormone Therapy
   a. Human Growth Hormone injection (daily)
   b. Testosterone injection (every 2-3 weeks)
7. Mental Health
   a. Positive Mental Attitude ('PMA')
   b. Prayer
   c. Meditation & deep breathing exercises
8. Exercise & Massage

Table 2. TOE Grades for EIW in ALS.

	Grade	Explanation
Mechanism	C	Some parts of EIW theoretically act on oxidative stress and inflammation, but these have never been shown to add to the effects of injected B12 alone on such mechanisms
Pre-Clinical	U	We found no studies of EIW in ALS models
Cases	D	Eric Edneys medical records suggest that he did have ALS, but he had very slow progression even before he started his EIW regimen. It is not clear to us that this regimen resulted in slower ALS progression or reversal
Trials	U	We found no trials of EIW in PALS
Risks	D	Chelation (a component of EIW) is associated with serious adverse events including death in less than 1% of patients in non-ALS studies. Nutritional deficiency as can occur from prolonged fasting is linked to more rapid progression of ALS. Several vitamins, if taken in excess, can lead to toxicity.

Cases

Eric Edney's daughter, Karen Tusler, was kind enough to provide us with his medical records and authorisation to discuss them. These show that the patient had a history of gradual onset right upper extremity weakness starting in 1993. It was in 1993 that a neurologist first diagnosed him with ALS. This slowly progressed, and by 1996 he had bilateral upper and lower extremity weakness, dysarthria and dysphagia. His ALS Functional Rating Scale (ALSFRS) score in 1996 was 30. Exams by multiple neurologists including ALS expert Carmel Armon at Loma Linda University demonstrated upper and lower motor neuron signs in the arms and legs. MRI of the brain and spinal cord failed to show any explanation for his presentation. EMG at Loma Linda showed a motor axonopathy affecting cervical and lumbar segments. Based on these records, we conclude that the patient likely did have ALS. His progression between 1993 and 1996 (before he started his protocol) was very slow (decreased by 10 ALSFRS points over 36 months) compared to the average PALS (decrease of 1 ALSFRS point per month (15). Unfortunately, we do not have more recent records to be able to confirm the stability or improvement in his neurological function that he reported between 1996 and the time of his death. His 21-year survival with ALS is unusual, but not unheard of; 1–5% of PALS have been reported to live this long (16,17). Based on the very slow progression before he started his regimen, and the fact that other PALS who were not on this treatment have had similarly slow progression, we cannot conclude that the patient's regimen improved his disease course. We were unable to find any other PALS who reported using the entire EIW

regimen in our Google and PatientsLikeMe searches. Based on all this, ALSUntangled assigns a TOE 'Cases' Grade of D.

Trials

We found no trials of EIW in PALS. Thus, ALSUntangled assigns as TOE 'Trials' Grade of U.

Risks and costs

We know of no series of patients on the entire EIW regimen in whom safety data were systematically gathered. Chelation therapy alone for conditions other than ALS has resulted in serious adverse events (SAEs) including pancreatitis (18) and death (19). The frequency of SAEs in trials using chelation for other conditions is less than 1% (18). Vitamin toxicity is another risk associated with the EIW regimen. For example, B6 can be neurotoxic at high doses (20). Vitamin A toxicity can cause cerebral oedema, osteoporosis, hypercalcaemia, liver damage, teratogenesis and hypotension (21). Vitamin E toxicity can cause coagulopathy, gastric distress, and weakness (20). The EIW regimen recommends fasting for 36 h each week. Research has shown that weight loss and caloric restriction in ALS patients results in worsened ALSFRS, accelerated ALS progression, and shorter survival (22,23). EIW suggests PALS avoid prescription medications; by doing so, they would miss out on agents that have been proven to slow ALS progression and improve quality of life (24). Finally, there is a risk of psychological harm to patients and caregivers. Such an expensive, time-intensive, and complex regimen may be difficult for patients to adhere to and may cause a sense of guilt and failure in patients who are unable to comply with the guidelines of EIW. Based on all this, ALSUntangled assigns a TOE 'Risks' Grade of D.

The cost of the EIW regimen is difficult to calculate. There are no specific dosages or frequencies given for many of the components, and others (such as moving to an environment with clean air) might vary substantially across different locations. In 2009, a rough estimate for the EIW regimen was calculated at $40,000 per year (25).

Conclusions

In conclusion, we find few plausible mechanisms by which components of the EIW regimen might impact ALS progression, and no pre-clinical or clinical evidence to support using this complicated, expensive and potentially risky treatment. Mr. Edney appears to have had very slow ALS progression even before he started his protocol, and there is no convincing evidence that the EIW regimen slowed, stopped or reversed his disease.

Disclosures of interest

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