

ALSUntangled Information Sheet

Alternative or off-label treatments (AOTs) are things advertised to slow, stop or reverse ALS without what most would consider “good scientific evidence.” They include things like coconut oil, blue green algae and stem cell clinics in China.

At some point in their illness, more than 50% of patients with ALS will try at least one AOT. Unfortunately the people selling AOTs are not always honest or accurate in the descriptions of their offerings. This flawed information makes it difficult for patients and families to choose wisely. AOTs are not without risk. Even in clinics that advertise their offerings as “perfectly safe” there are examples of patients suffering physical, financial and emotional harms.

In 2009, the North American ALS Research Group created a program called ALSUntangled to scientifically review the evidence on AOTs and help patients and families make more informed decisions. There are 3 parts to ALSUntangled: inputs, reviews and outputs. Inputs are the list of AOTs that patients and families want reviewed. Requests for reviews can be sent to ALSUntangled in a number of ways including Twitter (send a Tweet with the word “ALSUntangled” in it), email (send to bedla001@mc.duke.edu) or by asking your ALS neurologist to forward your request to us. Reviews follow a standard operating procedure that is described on a website (www.alsuntangled.org). There are currently 94 clinicians and scientists from across 10 countries involved in these reviews. Once the ALSUntangled review team is satisfied that they have all available information about an AOT, it is summarized in a short paper, published and available free on the website.

ALSUntangled encourages patients and families to discuss AOTs they might be considering with their ALS neurologist before buying them. ALSUntangled is always happy to get new requests for reviews as well.

Finally, ALSUntangled has come up with some “red flags” they suggest patients and families watch out for when it comes to AOTs. If any of the following are true, it means the AOT is likely to be bogus and not worth trying:

- Advertised as “dramatically effective” or “cure all” for multiple diseases with different causes
- Advertised as “perfectly safe”
- Non-MD or similarly unqualified person making medical recommendations
- Lack of IRB review/lack of consent form
- Lack of standardized protocol (different things done to different patients)
- Large up front out of pocket cost
- Subjective or no outcome measures
- Lack of follow up after treatment