

Background

Given the lack of approved and effective treatments for ALS, people diagnosed with the disease may seek out options that are not offered by their physician. Determining the difference between true and false information regarding ALS treatments can be difficult.

The internet has many websites that promote effective ALS treatments for purchase. Often they are well designed, boast treatments available for multiple diseases and ailments, and provide reassurance through online testimonials from previous clients. In nearly all of these cases, there is no evidence of safety and in all of them; there is no proof of benefit. Furthermore, these treatments are often extremely expensive, capitalizing on desperation and hope, and many people with ALS spend critical life savings or raise funds through family and friends for an opportunity to save their life.

Examples of such treatments include, but are not limited to; stem cell clinics, holistic/naturopathic/homeopathic/traditional medicine, and dietary or physical therapy regimens.

Resources like ALSUntangled (www.alsuntangled.com) can be valuable for balanced, open-access information about such alternative treatments and www.clinicaltrials.gov is a resource for determining whether a particular treatment is being tested in a legitimate clinical trial.

A forthcoming ALSUntangled podcast/review entitled ““ten red flags”-things to be wary of in alternative or off-label products’ provides helpful guide to the warning signs to look out for in an advertised potential treatment. Click [here](#) for the “ten red flags” article.

Recommendation

The SAC recommends that Alliance members defer all medical advice regarding unapproved/unproven/off-label treatments to an individual’s own clinician. This may be accompanied by objective information about the specific treatment, which may be provided by the SAC. Providing links to resources like ALSUntangled and clinical trials databases like www.clinicaltrials.gov are encouraged. Accompanying information can be especially important in situations where an individual does not have access to an ALS specialist physician and it may assist their clinician in making a medical recommendation. It can also be important to relay that there are thousands of researchers around the world who are dedicated to understanding ALS and finding effective treatments, and if there was anything, anywhere, that actually worked, we would know and we would do everything we could to get it to people living with the disease as soon as possible.