Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration

ISSN: 2167-8421 (Print) 2167-9223 (Online) Journal homepage: https://www.tandfonline.com/loi/iafd20

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To cite this article: The ALSUntangled Group (2020): ALSUntangled 56: “ten red flags”-things to be wary of in alternative or off-label products, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, DOI: 10.1080/21678421.2020.1765518

To link to this article: https://doi.org/10.1080/21678421.2020.1765518

Published online: 28 May 2020.

Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2020; 0: 1–6

REVIEW ARTICLE

ALSUntangled 56: "ten red flags"-things to be wary of in alternative or off-label products

THE ALSUNTANGLED GROUP

Patients and families affected by disabling, life-shortening diseases such as amyotrophic lateral sclerosis (ALS) often turn to the Internet for answers (1). There they can find a large number of alternative and off-label treatments (AOTs, 2), most being sold or offered in "trials" with a large up-front cost (2). Proponents (persons advertising AOTs) sometimes make extraordinary claims such as "clinically proven", "guaranteed" and "no risk" (3). Unfortunately, the evidence backing up these claims can be flawed, inaccurate or altogether absent. Non-scientists may not always recognize the problems with such evidence (4) and thus may over-estimate the potential benefits of AOTs. They may also underestimate the risks of AOTs which can include financial harms (2) and physical harms (5) to the individual, and scientific harms to the community (6). Individual clinicians may not have time to perform the research required to educate themselves and their patients on the risks and benefits of AOTs.

In 2009, we started a program called ALSUntangled to help people with ALS (PALS) make better informed decisions about Internet AOTs (7). There are three components to this program: determining which AOTs are of interest to PALS, objectively reviewing each AOT using a standard protocol, and, finally, crowd-sourcing and publication of the reviews. In the first component, PALS or their caregivers nominate an AOT by mentioning it to their neurologist, by emailing ALSUntangled directly, or by tweeting about it along with the hashtag #ALSUntangled. Once a new AOT has been identified, we list it on the "Future Reviews" section of our website (8). We prioritize nominations by the number of votes from the public and a multiplier that is based on the amount of useful, disclosable information available. One clinician or scientist writes the first draft of a review using specific standard operating procedures we designed to make this as objective and transparent as possible. These include the use of a Table of Evidence by which every AOT is reviewed in five specific categories: mechanistic plausibility, preclinical models, cases, trials and risks. Within each category, a letter grade ranging from A to F is assigned according to the specific evidence found (9). The draft is then crowd sourced- sent to our team of 120 clinicians and scientists from 11 countries for their edits and comments. Once an agreement is reached, the report is published in a peer reviewed medical journal (*Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*) and on the "Completed Reviews" section of our website (10). All our reviews are "free open access", allowing anyone to access them without charge. As of this writing, we have published 55 reviews. Some individual reviews have more than 30,000 downloads and collectively the series is approaching 200,000 downloads. We have started podcasts to provide short audio summaries of each review (11) and these are being translated into other languages (12). ALSUntangled won the 2019 American Academy of Neurology Brainstorm Innovation Award for best use of technology to improve patient care (13).

While we have accomplished much with ALSUntangled, we recognize we are unable to keep pace with the number of new ALS AOTs that are emerging (8). We know of no similar program reviewing AOTs for patients with other diseases.

To try and help patients who may be considering AOTs we have not reviewed, we applied our experience from years of training, caring for PALS, and ALSUntangled writings to construct and

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DOI: 10.1080/21678421.2020.1765518

Table 1. "Ten red flags"—things to be wary of in alternative or off-label products.

	Large out of pocket cost
	Advertised as effective for multiple incurable conditions with different causes
	Lack of safety and scientific oversight
	Absent or limited informed consent process
	Lack of an evidenced mechanism by which the intervention might help
	Absence of regularly measured validated outcomes
	Vague or no plan to present outcomes for peer review
	The only evidence of benefit is anecdotes
	Proponents have no relevant training, presentations or publications
	Proponents portray themselves as victims, advise "divorce" from mainstream doctors

crowd-source a list of things to be wary of. We wound up with "ten red flags", which are listed in Table 1. In our opinion, all of the things on this list are problematic, and they tend to be associated with treatments we assigned lower grades to. The more of these "ten red flags" patients find associated with an AOT, the more wary we think they should be. We will now describe and explain each item on this list.

Large out of pocket cost

A high cost does not mean a treatment is more likely to work. For example, the "Stowe/Morales Protocol", a combination of stem cells, supplements, anti-toxins and energy healing, was one of the more expensive AOTs we reviewed, being offered at $120,000 dollars per cycle (14). We found no plausible mechanism for most of this protocol and no evidence that it ever helped anyone with ALS. Investigative reporters at the television program "60 minutes" found that the person in charge was lying to patients about his results and his affiliations with the FDA and American institutions (15). He was later convicted on related charges and sentenced to prison (16).

When unproven therapies in development are sold in trials or through "expanded access" programs, regulators like the FDA only allow companies to charge what it costs them to make the drug (17). Charging much more than that for unproven treatments raises serious ethical questions (18,19).

Advertised as effective for multiple incurable conditions with different causes

Some Internet AOTs are being advertised as effective against not just one but large numbers of the world's most devastating diseases. For example, we found bee venom therapy being advertised as effective against: "arthritis, gout, bursitis, tendinitis, Lyme disease, multiple sclerosis, lupus, shingles, Bell's palsy, neuropathy, sciatica, carpal tunnel, fibromyalgia, Raynaud's disease, chronic fatigue, psoriasis, eczema, asthma, ALS, cancerous tumors, melanoma and carcinoma, bone fractures, herniated disks, surgical scars, internal scarring, phantom limb pain, torn ligaments and tendons, pulled muscles and cramping, numbness and poor circulation, spasms, mood disorders, and injuries to ankles, shoulders, knees, elbows, hips and wrists" as well as Parkinson's disease, Alzheimer's disease and stroke (20). The cause and biology of all these different conditions are not the same. It is therefore not plausible that one treatment could work against all these. The claim is "too good to be true". An "overly optimistic" description of potential benefits has been previously identified as a "red flag" in a paper outlining the risk of patient exploitation in research studies as well (21).

Lack of safety and scientific oversight

When mainstream researchers expose PALS to an investigational product, they always have independent oversight. This usually includes a governmental agency like the FDA as well as an institutional agency like an institutional review board (IRB, 22). The purpose of this is mainly to ensure thorough, systematic and transparent monitoring of patient safety. Historically, this oversight has been key to preventing or at least minimizing patient harm (23).

Many of the AOTs we have reviewed lacked appropriate oversight. This means patients had to trust that the person selling the product was carefully monitoring and reporting on safety. Often we were unable to confirm such monitoring. For example, in our review of stem cell transplants at the Hospital San Jose Tecnologico de Monterrey (24), we found a paper published on this treatment that concluded it was "safe and well tolerated" (25). But the paper described no systematic safety monitoring and included no table of adverse events. The paper mentioned that 1 out of 10 patients transplanted died within 10 days of the procedure. In our opinion, a treatment associated with a 10% risk of death in the first 10 days is not safe or well tolerated.

Absent or limited informed consent process

Following terrible historical examples of patient abuse, many countries passed recommendations and/or laws governing research (26). Fundamental among these is the need for informed consent, and this has now been adopted by all mainstream clinical researchers. Informed consent means:

- adequate information disclosed to
- a person with intact decision-making capacity
- who makes a voluntary (non-coercive) decision

Most of the AOTs we reviewed described no formal consent process. The safety and effectiveness information provided to patients on many of the AOTs we reviewed was, in our opinion, inadequate. The proponents of most of the AOTs we reviewed made no attempt to determine the decision-making capacity of their consumers. This is especially important in ALS since 30-50% of all PALS have cognitive abnormalities which can affect their decision making (27).

Lack of an evidenced mechanism by which the intervention might help

When considering a nontraditional therapeutic option, it is important to review its mechanistic plausibility (in other words, how it is supposed to work, and whether that makes any sense based on what we know about biology). In mainstream drug development, mechanisms are typically demonstrated in pre-clinical models using tissue and/or animals, prior to testing in humans. These important steps ensure the therapeutic has a justified scientific rationale. Academic and pharmaceutical companies go to great lengths to ensure this scientific justification. Importantly, the tissues and/or animal models that are needed for such mechanistic testing are commercially available to any individual or company.

Lack of an evidenced mechanism was a problem for several AOTs we reviewed. "Mary Murray's Method", for example, proposed that ALS is caused by emotional repression and that coaching patients into a different way of thinking can be curative (28). There is no evidence that people can think their way into having ALS or any neurodegenerative disease, or think their way out of it. "Dean Kraft", another example, proposed that healing energy could come out of his hands and reverse ALS. (29) Such energy has never been convincingly demonstrated to occur in any person and there is no known biological principle that would allow such.

Sometimes the problem with a proposed mechanism is more subtle and has to do with the dose or route of administration. In our review on sodium chlorite (30), we found that intravenous forms of this drug modulated the activity of macrophages and thus had plausible mechanisms for

influencing ALS progression. Conversely, more popular oral formulations were rapidly neutralized by saliva into breakdown products that could not affect macrophages and in fact were potentially very toxic.

Absence of regularly measured validated outcomes

Legitimate researchers want to see how their products perform in terms of effectiveness and safety, so they will ask patients to have tests (outcomes) measured at regular intervals. An experimental treatment that is being offered with no follow up measures should be regarded with caution. We have seen this situation with many of the AOTs we have reviewed, including for-profit stem cell clinics such as Precision Stem Cell (31).

The best outcomes have been validated; in other words they have been proven to measure something meaningful. An example of a validated outcome measure in ALS is the revised ALS Functional Rating Scale (ALSFRS-R). The ALS ALSFRS-R is a free, universally available, quickly administered (five minute) rating scale used to determine patients' assessments of their capability and independence in 12 relevant functional activities (32). Changes in ALSFRS-R scores correlate with changes in strength over time, and are closely associated with quality of life measures, and predicted survival (32–34). The measure can reliably be conducted over the phone (35) and, with training, patients can even measure this accurately themselves (36,37).

While the ALS community welcomes new, rigorously tested outcomes (38), some of the AOTs we reviewed used outcome measurements that were not validated nor in our opinion useful. An example can be found in our review of the XCell-Center (39). This for profit-stem cell clinic telephoned PALS 1-6 months after treatment and asked for their opinion on how they were doing. One concern with this measure is the potential for "placebo effect (40)". A person who traveled all the way to this clinic in Germany, had a bone marrow biopsy, a spinal tap, and paid 7500 Euro likely wants to believe all this effort is helping them. Their desire to believe may be so strong that it impairs their attempts to objectively assess their function.

Vague or no plan to present outcomes for peer review

Mainstream researchers share their results at meetings or in publications. In doing so, they give others in the field a chance to critique it. This is called peer review and has always been one of the fundamentals of good science (41,42). Beyond science, there is also a humanitarian reason: someone who has really discovered something that helps patients should want their technique to be adopted and widely used. Many of the poorly graded AOTs we reviewed in the past decade (3,14,28,29,31,39) have never been presented for peer review.

The only evidence of benefit is anecdotes

Many AOTs claim to benefit people with ALS. The most common "proof" of such benefit is called an "anecdote". Anecdotes are stories of people who tried something and then experienced an effect (usually a positive one) they attributed to it. There are several problems with anecdotes in ALS. First, it can be difficult to prove that an anecdote even represents a real person. There are examples of companies having fabricated anecdotes to sell their products (43). It is even more difficult to prove that the person in the anecdote had ALS, and to prove that something important actually changed in them in an objective way. Finally, when interpreting anecdotes, non-scientists often fail to account for the non-linear natural history of ALS. PALS can have periods where their function stops worsening (called plateaus) and it is not uncommon to spontaneously recover a small amount of lost motor function for short period of time (ALS reversals, 44). This can lead to the false assumption that the AOT caused the plateau or reversal. We found such false assumptions in several of our reviews including Dean Kraft (29), Deanna Protocol (45), GM604 (46), and Accilion (47).

Proponents have no relevant training, presentations or publications

Nowadays, it is usually possible to trace the background of a person offering an AOT. When that person has a history of scientific training and experience, and has relevant peer-reviewed presentations or publications in the field, then we think it is more likely that what they are offering may have promise for PALS. At the same time, when someone has no medical or scientific training and no record of ever presenting or publishing anything relevant, then it is less likely that they will have discovered something useful for PALS. In our review of Marty Murray's Method (28), for example, the proponent had no formal medical training or degrees. He had a B.S. in Political Science, Economics and was a Chartered Financial Analyst. It is not clear how that background would prepare someone to develop an effective ALS treatment. Sometimes this problem can be more subtle. In our review of a mineral cream called Accilion (47) we found a botanist associated with this product who had scientific publications about

plants. While he had training, experience and publications in botany, it was not clear to us how these were relevant to developing an ALS treatment.

Proponents portray themselves as victims, advise "divorce" from mainstream doctors

The authors of the book "When ALS is Lyme" wrote of a vast conspiracy among doctors, non-profits, pharmaceutical companies and the government to try and withhold information about Lyme testing and treatment that could help sick people (48). Proponents of the Rife Machine said similar things about their device (49). No credible evidence of such conspiracies exists and, as we have previously explained, these are not even plausible (48). Proponents of RCH4 claimed their submissions for publications and presentation were always rejected (50); in fact they had been invited to present at a recent scientific meeting and failed to appear (50).

The scientific method is straightforward and objective (51): make an observation, come up with a theory about it, design good experiments to test the theory, interpret and then report on all the results at a meeting or in a journal where peer review takes place. This pathway does not discriminate: it is open to anyone and everyone, and every legitimate researcher in history can and has used it to advance their field. We have not yet found any product that bypassed this pathway and was useful for patients with ALS.

Some proponents took this theme a step further, advising patients to keep pursuit of their AOT a secret from mainstream doctors, or even to "divorce" from mainstream doctors altogether (52,53). There is no credible rationale for this advice. Mainstream doctors have many years of training and experience qualifying them to help PALS make more informed decisions about treatments they are considering. Mainstream doctors can also provide evidence-based options that are proven to improve the quality and length of patients' lives (54).

Conclusions

In conclusion, PALS and those with other incurable diseases often self-experiment with AOTs they find on the Internet. Information about these can be incomplete or inaccurate, leading patients to overestimate the potential benefits, and underestimate the potential risks. Individual physicians and ALSUntangled can be valuable resources for helping patients make more informed decisions about Internet AOTs. When these resources are not available, patients can look for the "ten red flags" described in this paper. In our opinion, the more of these that are present, the more wary patients should be.

Declaration of interest

ALSUntangled is sponsored by the ALS Association. Richard Bedlack has research support from ALSA and Orion, and consulting support from ALSA, Biogen, Brainstorm Cell, ITF Pharma, Mallinkrodt, New Biotic and Woolsey Pharma.

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