Unproven treatments can come in various shapes and sizes from Bee Venom to Coconut Oil. But how can we tell if there’s any proof that these treatments actually work? Kelly Edwards from our research team explains.

The lack of reliable evidence shrouding unproven treatments makes it difficult to know whether a potential treatment should be pursued. Not only is evidence important for people with MND who want to make an informed decision about what they take, but also in terms of researchers pursuing potentially promising substances. We understand the eagerness and determination of people with MND to search for an effective treatment now, while researchers search for a cure for tomorrow.

An international group of leading MND clinicians known as ALSUntangled are leading the way by objectively reviewing unproven and off-label treatments (see panel opposite) that are of interest to people with MND, in addition to being full-time clinicians and researchers. We acknowledge the importance and value of this work and have granted $10,000 to ALSUntangled to ensure that they can continue to unravel unproven treatments.

Those living with MND play an integral role in ALSUntangled by suggesting unproven treatments to be investigated through the social media tool, Twitter. After carefully reviewing the facts behind these chosen treatments, ALSUntangled publish their results in a journal article, where people affected by MND can find out the facts about unproven and off-label treatments.

So far, ALSUntangled has investigated 16 unproven treatments ranging from Bee Venom to Coconut Oil and Blue Green Algae to Goat’s Serum.

To bee or not to bee?

One unusual treatment that has been investigated is Bee Venom therapy. This is a painful procedure involving the injection of Bee Venom, with serious risks reported, including loss of sight and even death.

By reviewing studies where Bee Venom had been tested on mice, ALSUntangled estimate that a person would need an astonishing 70,000 bee stings twice a week to replicate the benefits found in mice.

Going nuts for coconuts

Not all unproven treatments are as painful, or as invasive, as Bee Venom therapy. Nevertheless, it’s still important to gain an understanding of the risks versus potential benefits, and discuss these with doctors or neurologists before trying them.

Although there is a theoretical justification for how it could potentially work in MND, this has not yet been proven. To be proven, rigorous studies would be needed to explore whether Coconut Oil could be beneficial in MND. ALSUntangled supports further careful study of Coconut Oil.

Dr Rick Bedlack from Duke University USA founded ALSUntangled in 2009. He said: “I saw a need to help patients understand all the aspects of different alternative and off-label treatments which were being touted for use in MND. “At the time the only people putting information out there on these things were the ones selling...
them, and their descriptions tended to be incomplete and sometimes frankly inaccurate.

“The most rewarding part of being involved with ALSUntangled is seeing the large number of people that are reading our articles. Last year, ALSUntangled reviews comprised all of the top five most downloaded articles in the ALS Journal and we are on pace to do this again. To me it means that all the hard work is paying off… that we have created something useful.

“Our program is successful because of participation! Keep sending us ideas for reviews and keep reading the ones we finish.”

“there is a wealth of high quality information on the web. Unfortunately, it’s also a source of anecdote and misinformation”

Our Director of Research, Dr Brian Dickie commented: “There is a wealth of high quality information on the web. Unfortunately, it’s also a source of anecdote and misinformation. ALSUntangled is fast becoming a very important resource to people with MND, helping to separate the ‘wheat from the chaff’ and providing the sort of objective information that helps people to come to an informed choice on whether or not to pursue alternative approaches to treating their disease.”

What makes a treatment proven?

Not only do clinical trials determine whether a treatment works, but they are also important to determine the safety of a treatment in a controlled setting. The most reliable evidence comes from rigorous, ‘gold standard’ clinical trials that contain the following elements. We only fund trials that meet this ‘gold standard’.

**Placebo group:** A ‘dummy drug’ control group made up of participants who do not take the active substance.

**Blinding:** Neither doctors, nurses nor participants know who is on the active substance, or who is on the active treatment.

**Randomisation:** Participants should be assigned to either the placebo group or active substance group randomly – which is usually carried out by a computer.

**Large numbers:** Only by including large numbers of people in trials can researchers be sure that the beneficial effect is not occurring by chance.

**Published results:** The results of successful trials are usually shared in reputable research journals – this means that their results will have been independently scrutinised by leading experts in the field.

What’s the difference?

- **A treatment** is the application of medicines, surgery, etc, to a patient or to a disease or symptom. Riluzole (Rilutek™) is the only drug to be licensed for the treatment of MND and is available on the NHS. It is not a cure.

- **Complementary therapies,** such as aromatherapy and massage, do not aim to treat the disease or symptom, but to help people cope with the disease. They should be used alongside, but never replace, the treatment offered by doctors.

- **An off-label treatment** is a term used to describe a medical drug that is used for a different purpose than the one it was originally intended for.

- **An unproven treatment** is an aspiring treatment that has not gained scientific evidence for its effectiveness or safety.

- **Alternative medicine,** including homeopathy, is not acknowledged in conventional medical practice, due to the potential risks involved, and a lack of clinically qualified results.

**more information:**

If you are considering taking an unproven treatment, please discuss this in advance with your doctor or neurologist

**ALSUntangled:** [www.alsuntangled.com](http://www.alsuntangled.com)

Our Research Development team: [research@mndassociation.org](mailto:research@mndassociation.org) Telephone: 01604 611880

MND Connect: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) Telephone: 08457 626262

Forum: [https://forum.mndassociation.org](https://forum.mndassociation.org)