



Unproven therapies for MND and the internet

With the internet being as accessible and unregulated as it is, MND Associations often receive calls and e-mails from people regarding treatments being offered both here and overseas that claim to treat or cure MND. Often, these treatments are promoted on websites that feature in internet search results when people search for information about MND. It is very difficult for people living with MND and their families, desperate for effective treatments and a cure, to sort fact from fiction, and paid advertising from good quality health information.

Stem cells, in particular, are still considered a relatively new form of science, and with the range of claims being made every day about new cures, it's not surprising people are confused. There are many success stories related to unproven therapies and unproven stem cells therapies posted on the internet. Unfortunately there are just as many stories where these therapies have not been successful or where the improvement is for a very short time only. This highlights the need for properly conducted research trials to assess the effectiveness of any therapy offered.

Information about current research and alternative and unproven treatments will help people to make informed decisions regarding any treatments being offered via the internet. Talking to your doctor, neurologist or MND association will also help you to make informed decisions. There are a number of resources available on the MND Australia website to help you decide about any claims being made about treatments or cures for MND:

Links to the International ALS/MND Alliance Statement on Alternative and Unproven Treatments and the MND Australia Research Policy:

<http://www.mndaust.asn.au/policies/>

Links to the Australian Stem Cell Centre Patient Handbook and Latest Research Updates:

<http://www.mndaust.asn.au/latest-research/>

Treatments for any health condition can be:

- **beneficial or**
- **have no effect or**
- **cause harm through side-effects, adverse events or life-shortening effects.**

There are many steps that must be taken before any treatment or medication can be offered to people living with MND. It is imperative that any intervention is proven to be safe and proven to improve outcomes for people living with MND. At present we know that there is no evidence to suggest that the therapies, such as the stem cell treatments being offered by various clinics, improve outcomes for people with MND and they could in fact be harmful.

MND Australia keeps abreast of the latest research and will support and promote any new treatments that have been proven through research and scientific peer review to improve survival or symptom management for people with MND. Research has increased and improved dramatically over the last few years and many researchers both in Australia and overseas are working collaboratively to better understand MND so that effective treatments and ultimately a cure will be discovered.

Please contact your MND Association for more information.

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