

POSITION STATEMENT

Alternative therapies and people diagnosed with MND

Background:

There is ongoing and growing interest in alternative, off label and unproven treatments within the ALS/MND community globally. For the purposes of this Position Statement these terms refer to treatments or interventions that have not been scientifically proven via clinical trials to be safe and to improve outcomes for people with ALS/MND.

Those with ALS/MND have always been interested in alternative therapies. It is understandable that when you have been informed that you have a terminal illness and conventional medicine cannot provide effective therapies or a cure that you will look to alternatives which may provide you with some hope.

The internet and social media makes the promotion and marketing of alternative therapies easy and widespread.

MND Associations are often contacted 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.

Developments in stem cell research in particular are still considered to be experimental 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 a range of unproven, off label and alternative 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 for people with MND.

Resources currently available to assist people to make informed decisions about alternative, off label and unproven treatments include:

- [ALS Untangled](#) investigates alternative and off-label MND treatments
- International ALS/MND Alliance [Statement on Alternative Treatments](#)
- [The Australian Stem Cell Handbook](#) this handbook, updated in 2015, has been created to help people to understand the status of stem cell research and treatments in Australia and overseas.
- [The International Society for Stem Cell Research Patient Handbook on Stem Cell Therapies 2016](#)
- [The National Health and Medical Research Council](#) (NHMRC) have two resources on stem cell treatments. These resources provide medical practitioners and patients with a quick guide to stem cell treatments and the risks involved in undergoing unproven treatments.
- The [MND Australia website](#) provides latest research updates and information.
- [MND Australia position statement on Development and Approval of drugs to treat MND](#)



MND Australia believes:

Trusted information about current research and alternative, off label and unproven treatments is vital to assist people to make informed decisions regarding any treatments being offered.

Treatments for any health condition can be:

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

Any intervention must have been proven through rigorous scientific testing and clinical trial to be safe and to improve outcomes before it is made available outside of a clinical trial.

People living with MND have the right to accept, refuse, or discontinue treatment or intervention within the legal framework of the person's state or territory to ensure choice, control and the best quality of life possible, including access to preservation of personal dignity and to humane care, without discrimination.

MND Australia calls for:

- Doctors, neurologists, MND association and governments to support the development and provision of trusted and up to date information to assist people living with MND to make informed decisions
- The resources currently available to assist people decide about any claims being made about treatments or cures for MND to be updated regularly and promoted and disseminated widely
- Improved regulation of the increasing number of unproven experimental therapies and stem cell treatments being offered in Australia and overseas
- Research to be adequately funded to discover the causes, effective treatments, better care and ultimately a cure
- Access for Australians living with MND to properly conducted clinical trials
- Prioritised government approval once a drug has been through the appropriate clinical trial process and has been proven to be safe and improve outcomes for people with MND

On behalf of the MND Australia board and state MND Associations

Signed: David Ali (President)

Dated: 31 August 2017