



THE DANGERS OF UNPROVEN THERAPIES

Fact Sheet

All of those involved in ALS/MND, be they health professionals, care-givers and, most of all, patients with ALS/MND are only too aware of the grave significance and implications of the disease. This results in a variable degree of desperation which makes all three vulnerable to “try anything” for “what is there to lose”?

There are several categories of drug therapy. They include:

1. Conventionally approved drugs.
For ALS/MND there is presently only one - Rilutek.
2. Therapies that have shown promise in ALS/MND animal models, in particular SOD1 mutant mice. Numerous examples of such medications can be quoted (complex Q10, celebex, minocycline, creatine are just a few). Thus far none of these and others have translated into the same efficacy in the human disease. I would recommend an excellent web site www.alstdf.net which is dedicated to analysis and discussion of these animal model therapies.
3. Off-label drugs. Off label drugs are drugs that have been approved for treatment of other diseases that may have some rationale in ALS/MND. In some respects these are the most problematical since

they are readily prescribed by family physicians and others not always familiar with ALS/MND. The problem with off-label medications is that there is no knowledge of the correct dose or of interactions with other medications used in ALS/MND. Combination poly-therapy for ALS/MND is very much an accepted approach but it remains to be seen what are optimal combinations and drug doses. Other off-label medications, such as the “AIDS cocktail” are potentially dangerous and extremely expensive. Even in countries where there is subsidized provision of pharmacological products it is invariably for medications specifically directed.

4. Non-conventional (alternative medicine) medications. These list in the hundreds and they too are readily available over the counter, without a prescription. There is thus far no evidence that any are beneficial for ALS/MND. However, there have been few formal trials involving these medications. Most ALS/MND patients take some or many of these. For the most part they do not appear to do harm, which is important. However, many are expensive and there is no regulation as to their exact content

or concentration of compounds that they contain.

5. Stem cell therapy. Hardly a day goes by without a press release on some form of stem cell therapy. The whole science of stem cells is extremely complex apart from the ethical issues raised in some forms of stem cell treatment. The diffuse nature of ALS/MND raises particular difficulties of stem cell therapy in this disease. A recent, excellent, article by Silani and Leigh “Stem Cell Therapy for ALS: Hope and Reality” (http://www.als.ca/_media/docs/hopeandreality.pdf) highlights the problems. Uncontrolled, non-approved stem cell therapy is offered in certain parts of the world. One has to be extremely cautious about these. They usually make false and ridiculous claims.

In recent years, the pressure to treat has been heightened and hyped by the popular press (newspapers, TV and the internet). They, increasingly and vigorously, report news regarding health, medical therapies and indulge in disorders that are much rarer than ALS/MND such as mad cow disease (Bovine spongiform encephalopathy).

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The increased dispersion of medical news has not necessarily been matched by an increase in competent professional “health” news writers and broadcasters. The combination of growing demand for health information by the public and an almost vertical drop in the skill base in the media called upon to meet this request, can be very detrimental in its effect. At best it raises “false hope” but worse is the pressure placed on physicians by ALS/MND patients and their families who with very good reason demand access to the new “cure”

However, the worst portrayer of misinformation, information taken out of context and plain quackery, is to be found on the internet. Even if one limits an internet search to ALS/MND using a popular search engine no less than 732,000 sites are available, many have link-outs to other sites. The vast amount of internet information on ALS/MND is anecdotal and it certainly cannot be assumed that it was produced by a patient with ALS/MND or even anyone interested in the disease. However, there are a few reputable, well-organized sites that are educational. It is important for ALS/MND health care workers and ALS/MND Societies to direct patients and their families to such sites.

The World of ALS/MND health professionals is rather small (<1000) but very dedicated and communicates frequently and well. ALS/MND patients should be assured that they will not miss out on meaningful therapy as long as they maintain membership of or contact with a recognized ALS/MND clinic or

ALS/MND Association or Society. Unfortunately there are those who prey on the vulnerability of people with serious disease. Their ethics are questionable or non-existent and the up-front fees they charge underscores the scam in which they are involved. One of the roles of the ALS/MND team and ALS/MND Associations is to protect patients from this totally unacceptable behavior.

Let me conclude by plagiarizing a small section from an excellent article published in the Italian newspaper IL SOLE24ORE “The Scientific Journalists” that resulted from the Di Bella “debacle” claiming to treat numerous types of cancer in the late 1990’s “Every piece of information concerning a scientific issue relating to ALS/MND must clearly indicate the factual elements and the sources it refers to, favouring as much as possible the distinction between existing data and opinions. Information must not confuse science with faith and hopes with facts, which is the essence of journalism. And this also applies to opinion leaders”.

Information to make patients fully aware of all the details of treatments cannot be minimized!

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