

Alternative Treatments

A diagnosis of ALS is devastating, as it is a rapidly progressive disease with no known cure and no effective treatment. Rilutek®, generally known as riluzole, is the only FDA-approved drug for use in treatment of the disease. It is a costly drug that may have significant side effects in some people, but has been shown to prolong the life of a person with ALS up to several months. No other drug or treatment besides Rilutek® appears to alter the course of ALS. Faced with the limitations of available treatment, people with ALS and their caregivers may be inclined to seek alternative treatments. It is important to be aware of the potential dangers in this pursuit, as there are some people who will take financial advantage of those who are desperate to find a treatment or cure. The global community of ALS/MND health professionals is a small but dedicated group that keeps abreast of current developments in ALS research and communicates frequently through scientific meetings, the internet and newsletters. Anyone who maintains membership or contact with a recognized ALS/MND association or society may be sure that they are receiving up-to-date information on the latest research and therapies.

While the internet provides an invaluable tool for communication among ALS professionals, it is also a source of a great deal of misinformation generated by unscrupulous or ill-informed sources of therapies and even ‘cures’ for this as yet incurable disease. Even respectable news sources, including radio, television and newspapers, contribute to the misinformation, as health news becomes a more and more marketable commodity among an aging population and competition among new agencies become fiercer. The gains in understanding ALS being made by the research community are not generally the headline-grabbing sort; and, there is a tendency among newsmakers to overstate such glimmers of hope as ‘miraculous breakthroughs’, creating false

hope in those who have ALS and placing pressure on the medical community to grant access to new therapies. The following information is intended to provide an overview of therapies either in development or on the market and to assist in making informed choices in the treatment of ALS.

Promising therapies

Coenzyme Q10, COX-2 inhibitors, minocycline and creatine are a few examples of drugs that have shown promise in the superoxide (SOD1) mutant mouse model that was created to mimic a pattern of familial ALS present in 20 per cent of inherited cases. None of these, or any other experiment drugs have translated into the same degree of efficacy in the human form of the disease.

Off-label drugs

‘Off-label’ describes the legal use of a prescription drug to treat a disease or condition for which the drug has not been approved. Such use of prescription drugs may present a problem because they are often prescribed by a physician who is not familiar with ALS. Without rigorous testing, there is no knowledge of the correct dose or of interactions with other medications used in the treatment of ALS patients. While the use of drugs in combination, or polytherapy, may be an approach to the whole treatment of ALS, without testing on specific drug combinations, optimal combinations and doses remain unknown. Most insurance companies will not reimburse people with ALS for the cost of a drug that is not specifically directed for use in the treatment of that disease.

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Non-conventional, alternative and 'natural' therapies form the broadest spectrum of available treatments and are the most likely to come from questionable sources. An online search for ALS treatments will turn up substances to 'target and reverse the brain and neurological imbalances', ways to 'beat the system' through nutrition, special supplements, detoxification and 'cures' that will help your body 'regain its natural state of health and vibrancy'. At best, some of these treatments may or may not be harmless; at worst, they hold out cruel hope for a cure that does not yet exist. On the less extreme end, many people with ALS use readily available over-the-counter treatments, nutrients, herbal supplements and natural therapies that they feel are helpful with managing symptoms. For the most part, these treatments do no harm. Since there are few formal trials involving these products, there is no evidence showing their benefits. In addition, many natural medicines contain the same molecules as chemical drugs, but produced from a plant source rather than synthetically. Therefore, it is necessary to discuss taking these with your medical doctor. Canada has recently passed legislation to govern the production, labelling and sale of natural health products (NHPs) under which manufacturers, importers, packagers and labellers of NHPs in this country will be required to comply with stringent regulations regarding medicinal and non-medicinal ingredients, source, potency and recommended use. Health claims for NHPs sold in Canada will require standards of evidence such as traditional references, observational studies, expert committee reports and clinical or trial data. These regulations should make it easier for people to make informed choices when using alternative medicines.

Stem Cell Research

Stem cell research presents hope for the treatment of many diseases, including ALS. While this research holds promise, it is in its early stages. Since ALS is a complex disease, it is unlikely that stem cell therapy will offer a simple cure in the near future. Uncontrolled, non-approved stem cell therapy is available in certain parts of the world and people have paid great sums of money for treatments that may be dangerous and have no guarantee of success or worse, show evidence of failure.

Complementary Therapies

Complementary therapies are not used as a replacement but in conjunction with conventional medicine. They are not meant as a cure but may provide relief from symptoms and make day-to-day life more comfortable for people with ALS. Complementary therapies include meditation, hypnosis, acupuncture, massage and other physical and mental therapies used to relieve anxiety, stress, stiffness, pain and discomfort. To learn more about these options, please refer to the ALS of Alberta's fact sheet, Complementary Therapies.

Useful Resources

International Alliance of ALS/MND Associations

www.alsmndalliance.org

The Motor Neurone Disease Association (UK)

www.mndassociation.org/index.html

The ALS Association (US)

www.alsa.org

Rilutek® ALS Info Web Site

www.alsinfo.com/iondex/jsp

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