

KNOWLEDGE IS POWER...

UNPROVEN THERAPIES: WORTH THE RISK?

Unproven therapies are any therapy for which no reputable scientific proof of efficacy (effectiveness) exists. The Internet is the wild, wild west of unproven therapies for many diseases, not just ALS. By googling 'laetrile for cancer' or 'liberation therapy for MS' you will find evidence of how unproven therapies can prove costly in so many ways for those who put their (unfounded) trust in them.

It is understandable that when faced with a terminal illness for which no cure exists and existing approved therapies are not universally effective, persons will search for something that might help them stave off the inevitable. But there are risks to unproven therapies.

- Unproven therapies offer false hope. Hope is essential to living with any disease and no one knows when a breakthrough will occur. False hope- hope that has no basis in truth – is morally wrong and can lead to unrealistic expectations. When false hope is dashed and those unrealistic expectations are proven false they are replaced by misery, defeat and loss of hope.
- Unproven therapies are almost always costly, either for the purchase of the treatment or for travel costs to access these 'therapies'. Canada is a first world country with scientists working around the clock to improve our lives. If we do not trust Canadian scientists who are our family, friends and neighbors, why would we trust people or groups who are completely unknown to us and who live and work in places in the world where standards of care and scientific rigor are not the equivalent of our own? When life is short, choose wisely; spend your money on living life to the fullest at the very best quality you can afford. Make memories for your family and ensure that you are not leaving an overwhelming debt. Your family will have enough to deal with.
- These 'therapies' are untested. You do not know, or have any way of finding out, the effect on you. You do not know how these 'therapies' will interact with other, proven therapies you are receiving.
- Each unproven therapy will have testimonials from persons purporting to have ALS. Some may have the disease and truly believe that the unproven therapy has helped them. It is difficult if not impossible to find records of long-term survival data, or true records of sustained improvements in disease state. In truth, the power of the placebo effect (essentially mind over matter) is strong and very real.

- Not every professional is knowledgeable about the scientific method which is the process of objectively establishing facts through testing and experimentation. Many have no real knowledge of or experience with medical evidence and the basics of science. News writers and broadcasters, for example, are not trying to harm you and may truly mean to be helpful but they too can be purveyors of false hope.
- Your doctor has your best interests at heart. They know you. Purveyors of unproven therapies do not know you, and they probably know very little about ALS. Talk to your doctor before putting your hope and trust in the unknown.

If, after talking to your trusted physician and weighing the evidence, you are still uncertain about the benefits of an unproven therapy, visit ALSuntangled.com. The mission of this organization is to help patients and families make informed decisions about Internet alternative and off label treatments. The group has been in existence since 2009.