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REPORT

ALSUntangled No. 6: Investigating Marty Murray's Method

The ALSUntangled Group

ALSUntangled has been in existence for 15 months. We currently have 209 twitter followers, and have sent 44 tweets. Our NING consists of 67 ALS clinician scientists from across six countries, participating in 32 active discussions. New discussions open since our last publication include ampyra and low dose naltrexone. We have published five investigations on six different alternative and off-label treatment options. We have received our second financial grant, this time from the Packard Center (1). We have a new website under construction (www.alsuntangled.com) which we hope will make it easier for clinicians, scientists and PALS to find us and to interact. At the request of multiple PALS, we here investigate Marty Murray's method of 'solving ALS'.

The Marty Murray Method

Our group had a difficult time deciding whether to investigate Marty Murray's (MM) approach. When we first contacted him to better understand what he was offering we got the following e-mail response: "You have referred to what you have termed my treatment. That word does not really fit this paradigm…rather than treating patients, maybe some more appropriate terms would be working with, teaching or coaching people." However, it is clear that those he solicits see this as a treatment. PALS he has contacted have stated that he "claims to cure rare diseases like MS and ALS" (2). Furthermore, he has implied that his method can produce dramatic results. On an internet discussion board (3), he posted the comment "That's what I am saying. In a sense there is a cure for ALS. Not a medical cure, a way to solve it. Just many people are not aware that that way exists." In an e-mail to one ALSUntangled investigator MM writes "It is a great feeling to call someone you last saw sitting in a wheelchair and have her use the words 'complete remission'." Thus, it appears to us that what MM is offering qualifies as an alternative or off-label ALS treatment, indeed one being touted as potentially curative, and thus it meets our criteria for investigation.

MM has no formal medical training or degrees. He has a B.S in Political Science, Economics and is a Chartered Financial Analyst. In e-mails to ALSUntangled he stated that these experiences have prepared him to treat patients with ALS because "both political science and economics involve studying motivations, choices, behavior, consequences of choices and factors and patterns underlying the creation of situations."

MM's theory of ALS pathogenesis is delineated in e-mails to ALSUntangled. "ALS is essentially behaviorally created." It is "just another stress triggered reaction, much like hair loss that can be solved by changing reactions and resolving the underlying issues." He has no formal protocol. He describes his approach, again in e-mails, as follows: "This has three key aspects. One aspect could be considered educational. I help them learn to attain and maintain wellness, which is something they and most people are not that educated in. The second aspect is that I help them do the work needed to attain and maintain wellness. For instance, I help them figure out how exactly it came to be that they developed ALS, which, by the way, is never really about genes. The third aspect is the interactive aspect. I deal with them in a way that is conducive to attaining and maintaining wellness. For instance, if someone is complaining about an illness, I don't coddle the person. I more indicate that if the person does not like what is going on that he needs to make changes. There are many other parts of this. The basic idea is that just by interacting with me people tend to heal. Within that framework is this idea. Certain things people do can gain them relief from issues without working to help them attain and maintain wellness. For instance, a common factor contributing to the development of ALS is emotional repression. While repressing emotions can help a person get through the day, doing so does not create a healthy situation. So I help people learn to handle emotional issues in ways that create and maintain wellness. Another thing people do that gains them relief without real resolution is the use of medication. When a person's system is out of balance, the person can experience problems. One possible response to

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that situation is using medication, which blocks mechanisms in a person's system without dealing with the underlying issues. In addition to not dealing with underlying issues, medications, because of the way they work, inherently have a variety of deleterious effects. Now here is another key thing. By using medication, a person allows himself to function, even though his system is out of balance. For instance, marathon runners use painkillers to keep going when otherwise the pain might make them stop. So they use medication to help them strain their systems past the breaking point and that is another contributing factor in the creation of ALS."

In light of the above highly controversial statements, especially those pertaining to medications, ALSUntangled asked MM what he tells patients about proven ALS therapies. He was careful to point out to us that he does not make specific suggestions about drugs, bipap, feeding tubes, multi-disciplinary clinics, or research studies.

MM obtains the names and contact information of prospective clients by "doing web searches" for people affected by ALS. He then cold-calls them, offering his approach. In e-mails to ALSUntangled he stated that he will "simply tell them about what I am doing and offer to help. If they ask for more information I send it. If they say they are not interested, they generally do not hear from me again." PALS contacted by him have a different impression (2). One wrote "he talks nearly non-stop. If you refuse him, he will call you back, over and over again." Another said he "called me repeatedly after seeing my husband on the news (he has ALS)." It is clear that many PALS are upset by being contacted in this way, and also with his idea that they themselves or their loved ones might be responsible for the disease (2). One wrote "the thought of you + your practice turns my stomach." On another web page (4), TPP wrote "what you are saying is ridiculous and offensive."

When asked via e-mail how many potential clients MM has contacted, he responded "two to three hundred. Could be even fewer. Could be closer to four hundred, though I doubt that." He admitted that he does not attempt to confirm a client's ALS diagnosis. He reported working "to some significant degree with 13 people who told me they had ALS." He does not appear to use any specific outcome measures. ALSUntangled requested detailed information on MM's ALS best successes. We were given three names. One did not have contact information. Of the other two neither had typical ALS. Both had very slow progression prior to starting with MM. Case 1 was diagnosed with 'atypical motor neuron disease' in 2003 and is not being followed by an ALS Clinic. He has been working with MM for seven to nine months and reports improved motivation. Case 2 was diagnosed in 2004 and has been utilizing several alternative and off-label treatments. He added MM's approach to these in 2008. Case 2 reports that together these approaches have given him a "new way of thinking" and that his "life has changed for the better." We contacted Case 2's ALS clinician who noted clear evidence of worsening motor function over the past year.

MM reported in e-mails that he charges $70 per 60–90 min session, and "maybe $2100" every six months. It is unlikely that any insurance carrier would pay for this treatment.

Conclusion

In our opinion there are many serious problems with MM's approach. First, ALSUntangled is aware of no evidence to support MM's theory on ALS pathogenesis. No case of ALS has ever been shown to be caused or exacerbated by emotional repression. Statements that patients may have somehow caused their own ALS by repressing their emotions are not only completely unfounded but potentially hurtful, as pointed out by the numerous angry patient and caregiver posts cited. MM's statement that ALS development "is never really about genes" demonstrates that he has a shocking lack of awareness of more than a decade of ALS scientific literature.

Despite his claim that he is not offering a treatment, rather merely "teaching or coaching", it is clear that some of those he contacts see his program as a potential therapy. It is also clear that MM has implied to clients that his method can lead to dramatically effective results, potentially 'solving' their ALS problem. Reticence to call an intervention a 'treatment' is a strategy sometimes used to avoid laws that restrict the practice of medicine without a license. In our opinion, degrees in political science, economics and finance are not qualifications to provide medical advice, medical teaching or medical treatment. In the future, we hope that MM will clarify his lack of medical training, and the fact that he is offering 'teaching or coaching' and not medical treatment, to prospective clients.

We find no evidence that MM has ever 'solved' or cured ALS. Of his few reported 'successes' the two we could contact reported improved attitudes and motivations. It is not clear whether these had anything to do with his approach, or to one of the other alternative or off-label approaches being utilized, or (most likely) to the benign natural history of their unusual motor neuron diseases. We could confirm no definite motor improvements and Case 2's neurologist documented worsened motor function over the past year. Thus, terms like 'solved' and 'cured' should not be used by MM in describing his offering to patients.

Finally, MM's practice of cold-calling patients with ALS and their families is morally and ethically questionable, and is clearly disturbing to many. Patients and families who receive harassing phone calls should be aware that they can take action against the caller (5).

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Note: this paper represents a consensus of those weighing in. The opinions expressed in this paper are not necessarily shared by every investigator in this group.

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