

Consensus of the Fragile X Clinical & Research Consortium on Clinical Practices

**The Use of Complementary and Alternative Therapies
in the Treatment of Fragile X Syndrome**



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Introduction

Complementary and alternative medicine (CAM) therapies are defined by the National Center for Complementary and Alternative Medicine as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.” They are very widely used in the general population; there are many anecdotes of families exploring CAM therapies for their children with fragile X syndrome (FXS) although the rate at which this occurs is unknown.

Families usually choose CAM therapies because allopathic interventions have not resolved their concerns, and for philosophical and cultural reasons. There are many different types of CAM, with varying degrees of evidence for benefit or harm. Many CAM practitioners claim proven efficacy, but available studies tend to be poorly designed. Unfortunately, because of the lack of critical peer review, these studies are often able to be published or otherwise disseminated to practitioners and potential patients.

CAMs fall into a number of basic categories:

- Mind-body therapies such as yoga and meditation.
- Biological therapies such as special diets, vitamin and herbal supplements, homeopathy, chelation therapy, and physiological agents such as hyperbaric oxygen.
- Manipulative/movement therapies such as massage, craniosacral therapy, reflexology, and Alexander technique.
- Energy therapies such as Reiki, crystal, qi-gong, and magnetic therapy.

Discussing CAM Usage

The physician managing an individual with FXS must inquire if the family is using or planning to use CAMs. Failure to do so can complicate patient management, as there may be adverse effects or interactions with the allopathic treatment plan. In addition, awareness of a family’s interest in pursuing a CAM allows the physician to discuss alternatives and to guide the family away from potentially dangerous interventions such as chelation therapy, high-dose antifungal agents, and inappropriate dietary restrictions. Empathic dialogue regarding CAMs also serves to reduce parental antagonism toward allopathic treatment and may translate into better adherence to prescribed treatments.

Current Treatment Guidelines

Current treatment guidelines for fragile X syndrome do not specifically advocate any form of CAM therapy. However, if a family is considering one of these treatments, we strongly

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recommend that they review the treatment under consideration with the physician in charge of managing the child's FXS symptoms. Points for discussion with the family include the evidence of efficacy vs. possible adverse effects, financial burden of the therapy, and any emotional tolls of the treatment, including discomfort and time required.

Other specific concerns include adverse interactions of the CAM therapy with the rest of the patient's treatment regimen. Potentially toxic interactions are most often reported—but are obviously not limited to—herbal remedies and traditional Chinese and Ayurvedic treatments. This can be challenging as very often the “ingredients” have unknown pharmacological effects. In these instances, alternative therapists themselves may have at least some experience of treating individuals receiving the same orthodox medications/therapies. If trusted, and in conjunction with the primary care doctor, their experience may help guide decisions. This is clearly not ideal but may be better than no communication among involved parties.

There is currently no evidence for the effects of any of these therapies in fragile X syndrome and very limited data for their use in other populations. However, some studies have been performed in small populations with autism and cognitive impairments. No CAM therapy has been shown to be efficacious at a level of scientific rigor commensurate with an FDA-approved drug; indeed the therapies in which studies have been undertaken have shown conflicting results. This is not surprising, given the small size and low statistical power of these studies. Where sufficient number of such studies has allowed Cochrane review and meta-analysis, the results have shown either no benefit or not been conclusive. For those in which the data is unclear, there is thus a possibility that more powerful studies could show benefit.

Therapies with possible benefits: The best evidence currently available for therapies with potential benefits (cognitive and/or behavioral) includes music therapy, vitamin supplementation, dipeptides (carnosine and carnitine) and omega-3 fatty acids.

Therapies of unknown efficacy: Many therapies, including the traditional Chinese and Ayurvedic therapies, have simply not been studied to sufficient degree or in a manner that allows for risk-benefit assessment at this time. Although there is some questionable possibility for benefit from the casein and gluten-free diet, adherence to this diet does increase the risk for deficiencies in calcium, vitamin D and protein. It also presents a significant financial and social burden for the family. Families who choose elimination diets may find referral to a dietitian helpful. Therapeutic listening (auditory integration training) and yoga, like many other therapies, remains experimental for those with FXS, with no benefit having been proven.

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Therapies with no benefits: There are numerous CAM therapies that have no evidence supporting their use in symptoms related to fragile X syndrome. This includes homeopathy, crystal therapy and Reiki.

Dangerous therapies: The following therapies should never be used as they are dangerous and have no benefit: Chelation therapy, high-dose antifungal agents and severe dietary restrictions.

Common Q&A

What should I tell my patients?

There is limited evidence for CAM effectiveness, and the primary problem is that many such therapies overplay anecdotal evidence. In allopathic medicine, there is a mechanism in place which gradually resolves the use of unsupported treatments, while in CAM practice each therapy operates in a completely or partially autonomous manner to other therapies. As a consequence, CAM therapists may not be able to appraise treatment efficacy in an unbiased manner.

What are the expected benefits/side effects of CAM treatment?

CAM therapies often offer a holistic approach in which the therapist is able to spend more time with the family; this involvement itself may have therapeutic benefits. A good CAM practitioner should be willing to work with mainstream medical practitioners; indeed, one who advocates against allopathic treatment should raise the family's concern. Similarly, a medical practitioner who is not willing to listen to the family's interest in CAM and to evaluate a given therapy in an objective manner may not be ideal for that family.

What to do in an acute situation?

If the child is acutely ill, the family should contact their physician, or should take the child to the emergency room. The Poison Control Center may be able to assist physicians dealing with unknown agents.

Are there therapies other than those discussed here?

Yes, the therapies mentioned in this article are by no means comprehensive. The National Center for Complementary and Alternative Medicine (NCCAM) has information on many (see below for website). No list, however, is exhaustive. Even greater care should be taken pursuing particularly esoteric options, as there will be less experience of potential harmful effects than in the more well-known options.

Additional Resources

www.nccam.nih.gov/health/ (This is the NIH-based center for complementary and alternative medicines.)

Useful reference articles:

Akins RS, Angkustsiri K, Hansen RL. Complementary and alternative medicine in autism: An evidence-based approach to negotiating safe and efficacious interventions with families. *Neurotherapeutics*. 2010 Jul;7(3):307-19.

Boehm K, Raak C, Vollmar HC, Ostermann T. An overview of 45 published database resources for complementary and alternative medicine. *Health Info Libr J*. 2010 Jun;27(2):93-105.

Hanson E, Kalish LA, Bunce E, Curtis C, McDaniel S, Ware J, Petry J. Use of complementary and alternative medicine among children diagnosed with autism spectrum disorder. *J Autism Dev Disord*. 2007 Apr;37(4):628-36

Ernst E. Homeopathy: What does the "best" evidence tell us? *Med J Aust*. 2010;192(8):458-60.

Levy SE, Hyman SL. Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child Adolesc Psychiatr Clin N Am*. 2008 Oct;17(4):803-20, ix. Review

Sikand A, Laken M. Pediatricians' experience with and attitudes toward complementary/alternative medicine. *Arch Pediatr Adolesc Med*. 1998 Nov;152(11):1059-64.

Weber W, Newmark S. Complementary and alternative medical therapies for attention-deficit/hyperactivity disorder and autism. *Pediatr Clin North Am*. 2007;54(6):983-1006; xii.

Zhang J. A review of autism spectrum disorders (ASD) from A perspective of classical Chinese medicine (CCM). *J Tradit Chin Med* 2010 Mar; 30(1):53-9.

Author note: This guideline was authored by Jonathan Picker, MD, PhD and was reviewed and edited by consortium members both within and external to its Clinical Practices Committee. It has been approved by and represents the current consensus of the members of the Fragile X Clinical & Research Consortium.

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***The Fragile X Clinical & Research Consortium** was founded in 2006 and exists to improve the delivery of clinical services to families impacted by any Fragile X-associated Disorder and to develop a research infrastructure for advancing the development and implementation of new and improved treatments. Please contact the **National Fragile X Foundation** for more information. (800-688-8765 or www.fragilex.org)*