

# Alternative Therapy - Will it work for me?

*A Guide for you and your rehab team in making  
Informed decisions about your care.*

**This guide is designed to help you and your rehab team to talk and think about alternative therapy so you and your family can make an informed decision about complementary and alternative brain injury rehabilitation services.**

When recovering from a brain injury, clients and their families often learn about therapies or treatments offered outside of GF Strong from a friend, television commercial, magazine article, or other sources. These treatments may aim to improve physical and/or mental abilities by going to a private clinic, doing home-based exercises/training, or taking a medication or supplement. They may promise results that standard treatments do not, making them appealing. Although some alternative therapies may be as effective, others have little hope of helping and may even cause harm. By asking the right questions, you can do a lot to figure out whether a particular therapy will likely benefit you.

This guide is designed to help you be an informed consumer of such complementary and alternative brain injury rehabilitation services.

In order to answer the question “Will it work for me?”, you will need to consider:


## 1. To see if the claims are true...

### ○ Testimonials

Personal success stories and anecdotes can be encouraging, but often it highlights the most positive cases, rather than typical treatment experiences. And testimonials usually do not provide enough information to evaluate “What the treatment really do” (see below).

*Question(s) to ask:* Were these testimonials spontaneous or solicited? How do the experiences and results described in these testimonials compare to the “average” patient?

*Examples of an acceptable answer:* The providers recognize that testimonials have limitations and the treatment may not produce the same results for you.

 *Red flags:* They use the testimonials as the sole basis for their claim, deny receiving any negative feedback from former patients, or say that the outcomes in unsolicited testimonials are typical.


## ○ Clinical Expertise

If the claim is based on the experience and wisdom of a treatment provider, you will want to find out more about:

- a. His/her credentials.** The expert should have registration with the professional body that regulates his/her health discipline (i.e., an agency that oversees services by this discipline to protect the public). This only assures that he/she is competent to practice his/her discipline generally and that there would be consequences for his/her malpractice, but you may want to also ask about any specialty training and experience with regard to the particular treatment.

*Question(s) to ask:* If a patient wanted to make a formal complaint about the service they receive from you, who would they make the complaint to?


*Examples of an acceptable answer:* A professional body (or “college”) that is covered under the Health Professions Act, for treatment provided in British Columbia.

 *Red flags:* He/she is not in a regulated health discipline, or is in a regulated health discipline but is not a member of the professional body that oversees that discipline.

- b. Potential for bias.** Opinions are rarely neutral. If there is an incentive for the provider to present the treatment in the most positive light possible, his/her claims should be taken with some caution.

*Question(s) to ask:* What alternative treatments are available? What do critics of this treatment say?

*Examples of an acceptable answer:* He/she presents you with other treatment options, allowing you to make an informed choice.

 *Red flags:* Your only option is the treatment option he/she is offering.

## ○ Research

If the claim is based on scientific research (sometimes referred to as “clinical studies” or “clinical trials.”), it is important to learn more about the quality of this research. Because research can vary greatly in quality, it can be very compelling or of little value. Appraising the quality of research is quite complicated, but look out for (or ask about) these few characteristics:

- a. Published in a peer-reviewed journal.** Although scientific journals have variable quality standards, having research reviewed and critiqued by independent scientists helps.
- b. A comparison group.** Problems after brain injury can improve naturally over time. Because most treatments take weeks to months to complete, a good research study would have checked that improvement in the patients who got treatment was not simply due to passing time. Comparing them to patients who did not get the treatment is a common way of doing this.
- c. Randomization.** If participants in the study had an equal chance of receiving either the treatment of interest or some other treatment (through what is called “random assignment”), we can be more confident that the treatment of interest actually caused the reported improvements.
- d. Size of the study.** In general, the larger the number of people in the research study (or the more studies that are done), the more confident we can be in the findings.

## 2. What the treatment claims to do...


It is not the case that treatments either work or don't work. To judge how well they are likely to work for you, we will need to understand what is meant by "work" and the factors that are related to good/poor treatment outcomes. (Not all of these will apply to every treatment.)

### a. Definition of Outcome

The first step is to clarify what treatment success looks like. When an outcome is described in terms of a score on a scientific scale or test, you will need to ask what this score means for you, personally.

*Question(s) to ask:* How will I know when I have improved? How will others know when I have improved? What kind of improvement is typical?

*Examples of an acceptable answer:* No longer need physical help from another person to get dressed, 25% reduction in average pain levels, able to grasp and pick up a pen, etc.


 *Red flags:* "Improved mental clarity", "sharpened thinking", or other vague outcomes that can't really be measured. Demonstrated "statistically significant" effects of the treatment without studying how it makes any real-life difference.

### b. Success rate

No treatment works 100% of the time. Research studies may report various confusing statistics to describe a treatment's success rate. These can be translated into numbers that make sense to you.

*Question(s) to ask:* How likely is this treatment to work for me? What are my odds of getting the desired effect?

*Examples of an acceptable answer:* A number within the range of about 30% to 80%, based on consecutive people who were offered the treatment (as opposed to only those that accepted and stuck with it).


 *Red flags:* Success rates much higher than 80% are rare even among conventional rehabilitation treatments, and therefore should be considered suspicious. Guaranteed outcomes are almost certainly false.

### c. Comparability

If a treatment "works," the question becomes: compared to what? It may be better than nothing, but similar to or not as good as alternative treatments.

*Question(s) to ask:* Has this treatment been shown to work better than no treatment? Better than a placebo (an intentionally ineffective treatment that appears credible, such as a sugar pill that looks just like a medication)? Better than well-established treatments?

*Examples of an acceptable answer:* Some indication of how better or worse off you would likely be if you chose another treatment option instead.

 *Red flags:* The treatment has never been directly compared to another. If the success rate is low (less than 40%) and the treatment has not been compared to a placebo, it may only work because people expect that it will.

#### d. Amount Needed

Treatments can only be shown to work at specific amounts or intensities. This can be thought of as the “dose”, like with taking medications.

*Question(s) to ask:* How much of the treatment is needed to achieve the desired outcome and in what time frame? At what stage would we conclude that the treatment is not working (i.e., when would we stop it)?

*Examples of an acceptable answer:* Take 400 mg of herbal supplement once per day for six weeks; Play video game for two hours per day for four weeks.


 *Red flags:* Extremely broad ranges or the need for indefinite treatment sessions.

#### e. Candidacy

The greater similarity between the characteristics of your injury (e.g., type, severity, and time since injury) and the people for who research has shown the treatment to be effective, the more confident you can be that the treatment will work for *you*. As well, certain characteristics may be associated with a better or worse treatment response, making the treatment more or less likely to work for you.

*Question(s) to ask:* Why do you think this treatment will work for my condition? What would change your mind?

*Examples of an acceptable answer:* “This treatment has been shown to work for people with traumatic brain injury of at least ‘moderate’ severity, which is what you had. As well, the treatment seems most effective for people who were injured less than six months ago, like you.”


 *Red flags:* Treatments that claim to work for everyone almost certainly do not. Treatments that seem to work in laboratory animals, but have not yet been studied in humans. Treatments based on research studies that you would have been ineligible for (you meet one or more of the “exclusion criteria”).

#### f. Adverse Effects

Most treatments that have a positive effect also have some negative effect, or harm. Some non-medication treatments may, at the very least, cause fatigue and frustration. Natural herbs and supplements cannot be assumed to be safe simply because they are natural.

*Question(s) to ask:* What are the common adverse effects? What are the rare but serious adverse effects? Why did some people stop the treatment part way through?

*Examples of an acceptable answer:* They can tell you some possible adverse effects and how common they are.


 *Red flags:* The treatment is merely assumed to be safe. Longer-term (beyond 1 to 2 years) adverse effects have not been studied.

#### g. The Mechanism

An explanation of how the treatment works. Your family doctor or specialist can probably help you understand if the way it is said to work makes sense, or is plausible. (Note that not all explanations that seem to make good sense are actually medically plausible.)

*Question(s) to ask:* How does this treatment cause the desired outcome? How does doing \_\_\_\_\_ lead to an improvement in \_\_\_\_\_?

*Examples of an acceptable answer:* This treatment improves your memory by helping you learn to make use of the parts of your memory system that are relatively unaffected by your injury.

 *Red flags:* The provider doesn’t have a clear idea of how it works. Popular terms such as “neuroplasticity” don’t actually explain the mechanism. The provider gives an explanation that, according to your doctor, is implausible.

Note that not all conventional treatments meet these standards. For example, we don't know exactly why many common medications work the way they do or what kind and how much training is optimal to improve driving safety after brain injury. These standards are the "ideal." Although they can be applied to any treatment, there is a greater need to carefully evaluate treatments that have not been adopted into mainstream healthcare.

### 3. Putting it all together...

- The type and strength of evidence that you'll need will differ for treatments. For example, evidence of adverse effects is most important for treatments that involve ingesting a substance. Evidence for the amount or dose may be most important for costly ones. Common sense can also be a guide. You probably wouldn't need research studies to convince you that parachutes save lives when jumping from an airplane, or that a calendar helps to keep track of dates. The less common sense the treatment makes, the more important it becomes to have reliable research evidence.
- If you have unanswered questions, talk to your family doctor or specialist.
- Don't forget the golden rule: "If it sounds too good to be true, it probably is!" Other general consumer concerns apply here too. Being required to pay in full up front for a lengthy course of therapy, for example, suggests the need for caution.
- Your final decision should be based on an overall comparison between the costs (time, effort, expense, assistance required by caregivers, conflicts with your conventional treatments) versus benefits (likelihood of helping you, enjoyment, etc.). For example, although there is little research evidence that doing Sudoku puzzles improves concentration after brain injury, they are inexpensive and have almost no potential for harm. If you enjoy them, why not go for it? If you find them tortuous, it's probably not worth toughing it out.

### TO RECAP, HERE IS A QUICK OVERVIEW OF THE QUESTIONS YOU MAY WANT TO ASK YOUR COMPLEMENTARY AND ALTERNATIVE THERAPY SERVICE PROVIDER:

- 1) Testimonials are great but what should an "average" patient expect from your service? How long would it take to achieve that?
- 2) What is your training and experience working with a client with \_\_\_\_\_ (your diagnosis and/or symptoms)?
- 3) How does this treatment work?
- 4) Has this treatment been shown to work better than no treatment? Better than well-established treatments?
- 5) What are the common side effects to this? What are the rare but serious problems?
- 6) I want to learn more about your service, where can I get more information?
- 7) What evidence supports this treatment? Are there formal studies that were done? What do they say? What do critics of this treatment say?
- 8) How will I know when I have improved? What kind of improvement is typical?
- 9) How much of the treatment is needed to achieve the desired results and in what time frame? At what stage would we conclude that the treatment is not working (i.e., when would we stop it)?
- 10) What makes me a good candidate for this treatment? Why do you think this treatment will work for me? What would change your mind?

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