



8 TIPS ON MAKING TREATMENT DECISIONS FOR LYME DISEASE

by Kerry Lang

TheLymeTree.org

When Researching Your Options:

1) Look at SOLID research- This includes double-bind studies, peer-reviewed research (Google Scholar is a great source for academic articles and research), and get the FACTS from websites that you trust. Be mindful of who the authors are and what their intentions might be. It also helps to find out what the writers' credentials are. There are many articles out there about Lyme disease that are not evidence based, and often times writers use false information to sell a product. There are also many sources with a personal bias against certain treatment approaches or physicians, often due to someone's personal experience (which might end up being different from yours!).

2) Read about others' experiences, especially with specific protocols or new therapies....but don't dwell on the horror stories or failed treatments of just a few people. Be mindful that a lot of the people who attend support groups and those who post on online forums are likely still sick, and that people are more likely to post about negative experiences than positive ones. Those who got better are likely out and enjoying the world. Although we don't hear as often from those who have healed, they DO exist and there is hope!

3) Remember that everyone is unique! What works for one person isn't necessarily the cure-all for everyone. Not only are there many strains of Lyme disease in addition to various co-infections and opportunistic infections, every one of us has a different immune system and genetic factors that cause us to respond to treatment differently. It is very tempting to seek out the "magic cure" for those who have recovered from Lyme disease, but many who have healed will tell you that there were various factors that led to their recovery. If someone is trying to sell you a magic bullet that they claim will cure all Lyme patients, be vigilant! and do your research (see #1 above). It is certainly worthwhile to listen to the success stories (see #4 below), but remember your own healing journey will be just as unique as you!

4) Read and follow stories of those who HAVE healed from Lyme disease. Learn about what worked and what didn't work, especially for those with similar co-infections or symptoms as you. Pay attention to protocols and diets, but also to the emotional outlooks, spiritual journeys, and other lifestyle changes these former "Lymies" had to make. Most people who have healed from Lyme disease got through it by surrounding themselves with positivity, by maintaining a strong spiritual outlook, and by focusing on self-care strategies like sleep and saying "no" when they need to. These people learned to love themselves and didn't give up even after multiple treatment failures! Examples of great resources of those who have recovered or are in remission from Lyme disease are:

- Facebook Group- "Lyme Success Stories"
- Books-
 - ★In a Heartbeat by Neil Spector
 - ★Out of the Woods- Katina Makris
 - ★Bite Me- Ally Hilfiger
- Documentaries

- ★[LymeLight](#)- the story of professional freeskiier Angeli VanLaanen
- ★[Under Our Skin 2- Emergence](#) follow up documentary to [Under Our Skin](#)
- Blogs-
 - ★Jennifer Crystal's blog which documents her healing journey and lessons learned along the way, can be found on the website of [Global Lyme Alliance](#) and [Lymedisease.org](#).

5) Analyze Benefits Vs. Risks

Because there is so much to be considered when beginning a new protocol, it may help to make a list of the pros and cons to help you decide on the right treatment. Some things to consider when making your list: insurance coverage, ability to afford treatment, risk of side effects/herxheimer reactions, ability to work or to take time off, long term risks, responses to prior treatment, things you learn during research, etc.

Consider your circumstances- talk with loved ones on how you can best be supported in whatever treatment protocol you choose. Maybe you will need some extra help with finances, maybe you will need to prepare to take time off.

It might also be helpful to decide under what circumstances you will pursue a specific treatment- and to write these guidelines down. For example, you might not want to pursue IV treatment until your daily functioning becomes significantly impaired, or you may not want to pursue herbal protocols until you've tried several different antibiotic regimens. It helps to write these guidelines down on paper so that you aren't likely to give in or give up based on how you feel in the moment (many people discontinue treatment that is working because of difficult herxheimer reactions, for example).

6) Take the time to process and absorb.

Too much information can actually be overwhelming and can get in the way of making the right decision. Just like an artist sometimes needs to step back from their painting in order to proceed, we, too, need to step back from information overload in order to listen to inner gut. Remember the value of intuition and instincts- we all have it! The best decisions are often made through meditation and taking quiet time to reflect, while the worst decisions are made when under stress or pressure. After you've taken the above steps, meditate, spend time relaxing, and take a break from thinking about Lyme disease for a few days. Then ask yourself and your body what feels right for you.

7) Understand that healing doesn't just happen on a physical level.

Most of those who have recovered from Lyme disease will likely tell you that their healing was a multifaceted approach- that they had to heal themselves mentally, emotionally, and spiritually before attaining complete physical remission. They learned to love themselves. They learned to say "no" to others' demands and "yes" to self-care.

To address these other crucial aspects of recovery, it is helpful to invest in a god therapist who can help you work through some deeper issues that might be holding you back from healing. You may also want to consider seeking out a Lyme literate therapist, or a counselor who specializes in chronic health issues. These professionals are trained to NOT give advice, but to guide patients towards making decisions that are right for them.

8) See the Light

Making treatment decisions is very difficult when it comes to a disease as complex and mysterious as Lyme disease. Being able to give meaning to your experience and to grow spiritually from a trauma like Lyme disease will enable you to heal from the inside out.

Many people who have survived hardships such as cancer or other life-threatening circumstances report having a greater appreciation for life and stronger relationships than they ever had before. Knowing that life can not only improve for you, but that it could also result in more fulfillment, can help guide you in a path toward healing and recovery. (look up the term Post Traumatic Growth!)

No matter how difficult things get, always try to look towards the light at the end of the tunnel and that which gives meaning to your life here on earth. What will motivate you to complete this marathon of recovery? For some, its their children and family. For others, its the desire to help others suffering from Lyme disease. And for a few people, its the hope that something beautiful is waiting for them at the finish line of this challenging journey. <3

