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One Reader at a Time...

PUBLIC HEALTH ALERT

Insights Into Lyme Disease Treatment: 13 Lyme-Literate Healthcare Practitioners Share Their Healing Strategies Ginger Savely, DNP: Part 3



by **Connie Strasheim**

Available from
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**Chapter 4: Ginger Savely, DNP
Part 3 of 3**

About this article:

The following is an excerpt from the book, *Insights Into Lyme Disease Treatment: 13 Lyme-Literate Health Care Practitioners Share Their Healing Strategies*, by Connie Strasheim. The book is 443 pages and retails for \$39.95; it is available from BioMed Publishing Group by calling 530.573.0190 or online at www.LymeBook.com. The book is based on interviews

with 13 Lyme-Literate health care practitioners. Each doctor is given their own chapter in which to explain their Lyme disease treatments. This chapter focuses on the treatments of Ginger Savely, DNP, of San Francisco, CA. Note: This book excerpt has been broken up into multiple issues of Public Health Alert due to space constraints, so be sure to visit the PHA website to read the first two installments! (continued from previous issue of PHA)...

Patient and Practitioner Challenges and Roadblocks to Healing

One of my greatest challenges as a practitioner is getting my patients to keep plugging away at their treatments, because they get very frustrated and want to give up. It's really hard, because when they don't see any change in their symptom picture, it's as if they can't "see the forest for the trees." If I can help them to get through their treatments, they are often then able to look back and realize that they are getting better, but in general, it's

very hard for them to "hang in there." Providing reassurance is one of the best things that practitioners can do for Lyme disease patients, however, and a great majority of their job involves being cheerleaders or psychologists.

Another challenge that I have is coming up with individualized treatment plans for my patients, because they are all so different and I never know what's going to work for them. For instance, I have some people for whom artemisinin makes all the difference in the world, and other people for whom it doesn't do a thing. There is so much that we as practitioners don't know about treating Lyme disease. Further complicating things is the fact that there are so many different strains of *Borrelia* and other infections going around that we don't know about, which means that we don't necessarily know how or what we are treating.

Patients don't always understand this, either. Occasionally, they will get really angry with me because they think that a treatment that worked for another per-

son should have worked for them, and it didn't. Lyme sufferers are constantly talking to one another and giving advice over the Internet, too. They are desperate and are constantly coming in to my office and telling me things like, "I heard on the Internet that this is the best method for treating Lyme, so I want you to do this treatment." This can sometimes complicate things because what works best for one person doesn't always work best for another.

So when patients write me angry letters and say things like, "You withheld this treatment from me. It would have helped me!" I want to tell them that they might be the one in million that that particular treatment would have helped. Interestingly enough, some of these people are intelligent and well-educated, and they do end up finding things that work better for them than antibiotics. Problem is, they end up accusing me of being incompetent, even though, as a health care provider, I am making decisions based on statistics all of the time. I have to first give patients the treatment that

PUBLIC HEALTH ALERT

works the best for the majority. I can't know whether the next person that I am treating is going to be part of the minority of people for whom a treatment isn't going to work, but some people get angry over this issue, anyway. Of course, when people are sick, they aren't at their best.

Really, though, it's so hard treating Lyme disease! It's no wonder that most doctors don't want to touch this disease with a ten-foot pole. It's a very iffy, wishy-washy disease, and most doctors are more comfortable with conditions that they know exactly how to treat, and in fact, the treatment approach to other maladies is often more standardized. I'm always telling nurse practitioners at national conferences that we (nurse practitioners) are actually the perfect type of practitioner for treating Lyme because our style of taking care of people is much more individualized and holistic than that of physicians'. It's a good area for us. We are more comfortable with this type of thing, whereas medical doctors tend to dislike situations where they are not sure what's going on.

If I knew of a remedy that was the "key" to everyone's healing, then yes, I would be shouting about it from the rooftops. This is the thing that drives me so crazy, though. Every time I think that I've found something that is "it" for everyone, I find patients for whom it doesn't work.

For example, I sometimes recommend the mushroom *Coriolus* to my patients, because I notice that it raises CD-57 levels like crazy. Some of my patients take it and say, "I feel so much better on this!", whereas it doesn't

seem to help others at all. It's always interesting how people respond differently to things. As another example, I have patients who use an herbal treatment called burbur, and some will swear that it ameliorates their Herxheimer reactions, while others claim that it doesn't do anything to improve their symptoms. For those that it helps, I don't know how much of it is the placebo effect, but I'm never going to tell people not to try something if it makes them feel better. I have a few things that I would always say "No" to, such as intravenous hydrogen peroxide, but for the most part, if patients ask, "Should I try this?" I will tell them, "Sure, go ahead, try whatever works."

I find that my patients almost always respond positively to my Lyme disease treatments, but the question is, how much? For those that only improve somewhat, the reasons are multiple. They might have a resistant strain of the organism, a genetic predisposition that blocks their healing, or other infections that are primary in their symptom picture. As well, there may be other unknown factors involved and which keep them from healing fully.

Patients often ask me about the importance of treating viral infections, and if I were to check viral titers on most of my Lyme patients, I would find that they all have high titers for other infections, but I think that such infections are opportunistic. That is, they are infections that show up in test results and become active because of Lyme disease. I then tell my patients that these will tend to go away once we treat their Lyme.

Lyme Disease vs. Chronic Fatigue Syndrome

There is some debate in the chronic fatigue world about whether Lyme disease itself may be the primary cause of chronic fatigue syndrome. The question is very hard to answer. Sometimes, a person may have chronic mold, or another issue that is causing their symptoms, even if Lyme is present as a background problem.

On the other hand, I used to be very involved in the chronic fatigue world, and at some point, I began to realize that CFS was caused, in many cases, by Lyme disease, and for that reason, I became more involved in treating Lyme disease.

Those who present with classic CFS symptoms such as chronic fatigue and brain fog are often the most difficult to treat. There is sometimes very little response to treatment in this type of patient, so who knows what this really means?

In the end, however, I'm a big proponent of presenting every treatment to my patients as though it was going to work, even though I have colleagues who disagree with this approach. They say that doing this is akin to "pulling the wool over someone's eyes," and think that it's better to be frank with patients, but I look at the matter differently. I think that patients' healing is aided significantly when they believe that they are going to get better. A practitioner who says, "Do this, and you will get better" will have patients who tend to get better. A practitioner who tells patients: "You have a 50/50 chance of heal-

ing" might end up discouraging them. Besides, what's the worst that can happen if the person doesn't get better? People don't tend to come back and scream, "You said this was going to work!" So in my practice, I look my patients in the eye and tell them, "We're going to do this treatment and you are going to get better." And I can do this and say with all honesty that I feel they are going to get better, because most of the time, they do, and in hindsight, they will often say, "That is the best thing you could have said to me." People need hope, and I don't believe in false hope. You have to give people hope. That's what gets them through this.

Patient Roadblocks to Healing

I find that my toughest patients are those with PTSD (post-traumatic stress disorder). There's a lot going on with them emotionally and their healing is complicated. Sometimes they don't seem to get well, and I don't know how much of this is tied into their emotions. All Lyme doctors have patients that don't seem to get better, but in reality, these are few. It is unfortunate, though, because I hear about a lot of negative conversation on the Internet Lyme disease support groups. People ask, "Is it worth it to treat Lyme? I have read that people don't get better, anyway."

Are you kidding? I wouldn't treat this if people didn't get better-it would be cruel and unfair to take their money and time! Not to mention depressing. The fun and wonderful part of treating Lyme disease is seeing people get their lives back. It's a very

exciting and powerful thing, and I think that's what keeps me doing this (fighting the regulatory boards and administering difficult treatments) because I get to watch my patients come back to life before my very eyes.

So people do get better. As for healing and my protocols, I find that those who have been sick for less than a year tend to get better after about a year. Most of my patients with chronic Lyme disease, however, need two years, at minimum, to heal, and on average, two and a half to three years, occasionally a little longer. A very small percentage, perhaps 5%, as well as those who have been sick for twenty years or longer need more time, sometimes five years or more, to heal. But those who have been sick that long do get better. It just takes time.

Do Antibiotics Work?

There is a perception on the Internet that people don't get better with antibiotics.

It seems to me, however, that the people on the Internet support groups are the ones who don't get better. They get a skewed view, or perception of the Lyme world. Those who heal from Lyme disease aren't on the Internet, because they move on with their lives once they get better. I often tell my patients that Internet chat rooms are beneficial in some ways, but they can also be depressing. Those who tend to linger there are those rare people who don't get better. Some are cynical and/or depressed, and so tend to bring others down. They are not a fair representation of those who heal

from Lyme—perhaps they represent a number as small as 1% of the Lyme disease population.

Again, all of us who treat Lyme disease wouldn't do it if patients didn't get better. I mean, how depressing! Imagine treating and treating and your patients never getting better. We do this because people do get better. It's unfortunate that those with Lyme who are just learning about the disease and trying to find answers on the Internet get discouraged by what they learn.

It's true, though, that there are some people who can't take antibiotics. These people might be "permanent Herxers." Their Herxing never stops and so they have to find other solutions for healing.

Also, no amount of treatment can bring people with irreversible damage in their bodies, such as those with ALS, back to full health. I must tell them that yes, it is possible that they have Lyme disease, and maybe Lyme was the initial trigger for their ALS, but the damage to their bodies has already been done. We may be able to halt progression of the disease temporarily, but we can't bring them back to full health.

I am, by the way, intimately involved with this disease. I have had Lyme, as have my two daughters and my mother. Also, my son has gestational Lyme and my sister died from Lyme and ALS. I have found that those practitioners who have had personal experience with this disease are more empathetic, and tend to "get it" more than those who haven't—and it turns out that most Lyme doctors or their family members have in fact dealt with Lyme disease

themselves. They may not admit it, but most of them have. That is why they are so ahead of the curve of conventional medical knowledge.

Treating Relapses with Dr. Burrascano's Pulse Protocol

Every now and again, my patients will relapse after I stop their antibiotic treatments. If they do, I apply Dr. Burrascano's pulsing protocol, which involves pulsing antibiotics for six to eight weeks. If patients are going to relapse, it is usually six months to a year after stopping treatments. Whenever that happens, I hit their infections again with another pulse treatment, but I must wait until they completely "crash", because Burrascano's theory is that patients have to wait until they hit rock bottom before practitioners can "hit" them again with another pulse treatment. They can't just have beginning signs of returning symptoms, or else the protocol won't work well; they must crash entirely. After my patients have gone into remission, if they relapse, I usually have to do only one pulse, and occasionally, two. Dr. Burrascano says that three is the maximum number of pulse treatments that are usually required for patients to get completely well and I have never had to do more than two of these pulses, because after that, I find that my patients are absolutely better.

Profiling the Person that Heals from Lyme Disease

Smokers will never get better. It's amazing how many Lyme sufferers drink, smoke and do drugs. When my patients do things that

tear down their immune systems, they don't tend to heal. Those who do what it takes, eat the right food, adhere to treatments and so on, are the ones who get better.

Also, I have consistently seen that people who are able to get rid of their anger heal. Those who are eaten up with anger and resentment, as well as those who get depressed and ask questions like, "Why me?" don't tend to heal. Those that have a calmer, less fatalistic perspective and say things like, "I know this happened for a reason. I may not know that reason, but I accept it", tend to do better. I have patients who are sick as dogs, but they maintain their sense of humanity and humor. They crack jokes and they laugh. They are the ones who heal. People go through grieving stages when they first get sick, and it's not until they finally arrive at a place of acceptance of their illness that they really start to heal. Those who are angry, those who are kicking, fighting and screaming, and living their lives as though the illness wasn't there, tend to be hindered in their healing. They push through their activities and think, "By golly, this isn't going to get me down". They continue to work full time and ignore their symptoms, but their symptoms don't go away. It's surprising how many people just keep pushing themselves in their daily activities, and yet they are sicker than dogs. It blows my mind. It's like they are in denial and running away from the disease. Teenagers are very much this way. They refuse to let it stop them. Those who accept their new situation, and say, "Okay, this is the new me. What can I do

in this situation?" get better. Once patients are able to relax and accept their illness, then they start to heal.

Stress Reduction and Behavior Modification

Western medicine is beginning to realize that it isn't possible to separate the mind from the body in the healing process. People have often been told that their illness is all in their head, and in a way, it is! Tick-borne diseases infect the brain and cause malfunction in the limbic system, a part of the brain that receives all kinds of inputs from the external world (emotional, physical and otherwise) and "translates" them into body functions. To say that stress reduction and behavior modification will help patients' physical condition does not mean that part of their problem is psychosomatic. It means that their limbic system is highly sensitive to stress, and, as is the case with many physical problems, will have a better chance of healing itself when the burdens of stress are removed from it.

Strategies for Stress Reduction Biofeedback

This therapy teaches those with Lyme to identify when and where their bodies are reacting to stress and how to let go of that stress. Mental health provider networks have information on practitioners and places where this type of therapy can be done.

Cognitive Behavior Therapy

This therapy helps those with Lyme to identify

the unrealistic thought patterns that cause them stress and anxiety and to adopt new mind sets that enable them to be easier on themselves. It can also teach them to set limits, let go of guilt, blaming and the need to be in control, as well as how to accentuate the positive aspects of their lives, and so on. Patients can call therapists in their insurance plan to see if any of them specialize in this type of therapy.

Humor

It has been said that laughter is the best medicine. It's good for those with Lyme to surround themselves with light-hearted people, to find humor in their current situation and to not take themselves or their illnesses too seriously. It's also beneficial for patients to watch funny TV shows or movies, while avoiding the "heavy" ones.

Lifestyle Adjustments

Those with Lyme should analyze their life situation and list all of the things in their lives that are causing them stress, and then decide to eliminate as many of these things as possible. If they can reduce their work schedule to part-time, for example, this can be beneficial, as can quitting their job if they are financially able to (See below).

Financial Support

For many people with Lyme, financial worries are at the top of their list of stressors. It can be beneficial for them to file for disability payments through their employer's disability insurance program (if the employer has one) or file for disability benefits under the Social Security Disability Income program

(SSDI). The SSDI process is difficult and there are many roadblocks. I highly recommend that those with Lyme enlist the help of a disability counselor if they decide to apply for this income. The standard fee charged by disability lawyers is 25% of what the client wins in back pay, with a maximum fee of \$5,300. This is the standard fee for all disability lawyers and counselors and is regulated by the Social Security Administration. There is no fee charged to clients if they don't win their case, except for a small service fee because the lawyers work on a contingency basis.

Balancing Rest and Physical Conditioning

People with Lyme are often perplexed because they feel as though they're getting two opposite messages from their health care provider: rest, but get up and move! The fact is, they need to find a balance between both. Too much rest can lead to de-conditioning of the body, which will make them feel even weaker, as well as more tired and depressed. Too much activity, however, will lead to an exacerbation of their symptoms and longer recovery time. Ideally, those with Lyme should try to do some form of mild to moderate exercise every day. Some Lyme disease sufferers who are reading this might be thinking, "I barely have enough energy to get through the day, let alone exercise!" The idea is to do daily reconditioning, but starting off slow and easy, and progressing so gradually that they never become frustrated or exhausted. They should never exercise aerobically, but

research has shown that those with Lyme improve by doing other forms of mild to moderate exercise.

Activities That People with Lyme Should Do

1. Every day, take a half-hour (no more!) nap in the afternoon. More than a half-hour leads to grogginess, due to the body coming out of a deeper sleep.

2. Pay attention to the body! Learn to recognize signs of fatigue and then get some rest before becoming drop-dead tired.

3. Plan a regular time every day to do "movement therapy". (I don't use the "E" word!). People should do this even if they can only manage a few stretches, and they should make it a habit. Also, it's important that they keep their expectations low, and forget the motto, "No pain, no gain!" They should start their first week of "movement therapy" with a very low goal in mind (i.e.; walking to the mailbox and back). It's also beneficial to do some mild stretching before the "movement therapy", as well as afterwards. Beginning yoga is great for those with Lyme, but they shouldn't sign up for a challenging class! I taught myself to do yoga with Richard Littleman's, Yoga 28-Day Exercise Plan. Swimming is also an ideal, gentle exercise to try.

Other activities that those with Lyme can do for their daily "movement therapy" include walking, Pilates, working with light hand weights, and cycling on flat surfaces at a slow to moderate pace. They should avoid running, jogging, aerobic classes, heavy weights, or any sport

that increases the heart rate.

What Friends and Family Members Can Do to Help the Sick

While it's important for loved ones to be there for sick friends and/or family members, it's also important for caretakers to be supported because it's really hard to be a parent or spouse of someone who has Lyme disease. They suffer, too. For instance, one thing that's hard about taking care of Lyme patients is that they are so sensitive to everything. You want to hug your loved ones with Lyme, but they are so hypersensitive that

it hurts for them to receive a hug or be touched.

Also, it would help if loved ones could try to learn as much as they can about Lyme disease, so that they know what their sick family members are going through. Because the biggest problem with this disease, unlike any other illness such as cancer, for instance, is that people wonder, even if it's just a little, if the Lyme sufferer is really sick. People think, "Well, c'mon, can't you just snap out of it? Can't you just push yourself a little?" I see relationships break up over this and I see dissention in families,

because family members refuse to believe that there is anything wrong with the sick person. He or she just looks so normal!

Last Words

While treating Lyme disease is a great challenge, for me, it's so exciting to watch people get their lives back. There's nothing like it. Watching the transformation of those who once lost it all, were in the dumps, couldn't function and who felt like their lives were over, is wonderful and what makes my job worth the sacrifice.

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