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Late Stage Lyme Disease, Patient Information

Can't lie to ya. Rough road ahead. In fact, getting well may be about the hardest and most difficult thing you'll ever do. But it's worth it! Stick with it! Never give up hope!

The first thing you should know is that it gets worse before it gets better. It can in fact get a lot worse before it gets better. It depends on how long you've had it, how much of the bacteria has built up, what strain you have, and many other factors as well.

The Lyme bacteria gives off a chemical toxin when it dies. When the antibiotics start killing them, the toxin levels in your body will soar and the symptoms can become intense. Physical symptoms include pain, numbness, swelling, tremors, and a myriad of others if internal organs are significantly affected. The toxin affects your mind as well. Typical symptoms include insomnia, confusion, disorientation, depression, anxiety and panic attacks. These will all go away as you get well!

As if the toxin effects weren't good enough, another fact about the Lyme bacteria is that it grows and reproduces slowly. At first that may seem a good thing, except that antibiotics are generally able to kill it only during certain stages of it's life cycle. The end result being that it takes a long time to get well. usually months. There have been cases of "miracle" cures in just a couple weeks, but these are rather rare. Just don't give up hope! Keep at it! Keep trying! It takes a long time, but being happy and healthy again is worth it!

Of course we'd all probably like to have our mind functioning properly again as the first step in getting well. Unfortunately, that won't happen. Your mind returns last, when just about all the bacteria are dead. Physical symptoms like pain and numbness go first, then the bacteria that didn't cause pain, and then, finally, your head begins to clear up. This can be very disconcerting when your body feels good but your head is still reeling. Hang in there!

When you first start on effective antibiotics, you'll be in for quite an unpleasant surprise. Within a day or two you'll feel like you've been hit by a fully loaded military cargo jet flying at full throttle. Your symptoms, including the ones you didn't even know you had, will flare up intensely. Try hard to tough it out. But if you find that you absolutely positively can't, and this is not too unusual, ask your doctor about lowering the dosage for a while, or pulsing on and off until you get through the worst of it. Sticking on the medication as prescribed, always taking them right on time, is your best bet for getting through it as quickly as possible. Don't give those nasty little bacteria an inch! This can be really tough, because it takes at least a few weeks (6-8), and sometimes much more to get through the brutally hard part.

If when you start your antibiotics, your symptoms don't flare severely, including ones you didn't know you had, then you may have a strain that is resistant to that particular antibiotic. Or, perhaps, your body is fighting the antibiotic and not letting it do its job properly. This is one reason that two antibiotics are often used at the same time. It is a judgment call between you and your doctor as to whether the antibiotics are being effective, and what might need to be done if they aren't.

Which set of symptoms, the physical or the psychological, will be the most difficult to handle is entirely up to the individual. Are you more physically oriented? Or are you a thinker? Some people are so happy-go-lucky and full of faith that nothing at all bothers them. In fact, many people are. You can be like them too. Just don't bother to worry about it! You're on the right road. The road to being happy, healthy and normal again!

Is it contagious? The answer is: no one knows. Spouses and siblings tend to all travel in the same places, so it is hard to tell if the disease was transmitted person to person or just infectious bites by different ticks. The long answer is: that since it's a blood-borne disease, as long as you don't go around biting people and bleeding on them, then no, it's not. As always though, better safe than sorry.

A few annoyances you may encounter along the way, and should be made aware of if you're the worrying sort:

1. Confusion/Disorientation. Your short-term memory will probably be taking a nice long vacation. You may find yourself confused about where you are and what you're doing every time the scenery changes. Like when walking from one room to another, or driving (DON'T!). Sometimes even when just sitting or lying around doing nothing. It could also be even more intense, with temporary bouts of amnesia. But it's a fact of life that vacations do end. This one tends to be about the most disconcerting psychological symptom for most people. Again though, it's caused by the toxin release from the dying bacteria. It will get better and eventually go away!
2. Numbness. Various parts of your body, both those you knew were infected and those you didn't, may go numb for a period of time. Quite often it's just for a day or so, but can also last for many weeks, until enough of the bacteria in that location have been killed that the toxin level finally drops. Don't panic! They all come back! (The numb body parts, that is!) They'll eventually switch from numb to painful, and then finally to normal.
3. Pain. Same as 2), but may be sporadic pains instead of numbness.

4. It's in more places than you know. While you are on effective antibiotics the bacteria are NOT spreading. Never had a problem with your back, but now it hurts? Forearms maybe? Wrists? They hurt now because the bacteria were there all along, and now that they're dying they're releasing toxins. It's the toxin from the dying bacteria that causes the numbness and pain. Dead bacteria is a good thing!
5. Insomnia. And not just at night either. You may find it impossible to nap during the day at all. You may get to enjoy every last minute of the worst part. As the toxin levels fall though, you'll be able to sleep better and better.
6. Hallucinations and voices. These can occur during times when your mind and body are exhausted but the toxins won't let you sleep. You may be trying to rest, but your brain gets stuck halfway between sleep and awake, dreams and reality mix. Better sleep at night, along with less activity during the day, should help these symptoms disappear. Ask your Doctor about sleeping aids you can use if necessary. However, if you get these symptoms while you're wide awake and have gotten reasonable sleep, consult your doctor immediately.
7. Tremors, shakes, and spasms. Can occur in various places to varying degrees. The length of time they last varies as well. These may be caused by bacteria dying near, and hence irritating, a nerve which controls motion.
8. Sweats, hot, cold, day and night. Get used to them. You might consider adding just a bit of extra salt to your diet so that you don't become salt/sodium deficient.
9. Fireworks, popcorn, or pin-cushion pains. These tend to feel like someone has picked a part of your body and decided to jab it with a pin a few times. Then they go and pick another spot. These are probably just irritations of pain nerves, or perhaps bacteria dying inside a nerve itself. You might notice that they tend to occur in your most affected areas, and that more effective antibiotics cause more of them.
10. Heart palpitations or irregularities. Notify your doctor immediately so that they can determine if the irregularities are severe enough to be dangerous. In some extreme cases, people have been put on a temporary pace maker until the worst of the symptoms have disappeared.
11. Dizziness and Vertigo. It's everywhere else, why be surprised that it's in your ears? Symptoms here can range from a feeling of "walking through jello" to complete loss of orientation.
12. Temporary Amnesia. Really this is just an extension of memory loss symptoms, except that instead of just losing your short-term memory, mid and sometimes long-term memory can go for a hike as well. These symptoms can last anywhere from just a few minutes, to a few weeks, and will probably only occur during the first month or so of treatment.
13. Aliens Under My Skin. usually felt in the forearms or shins, but can occur anywhere, this feels for all the world like little turtle-shaped aliens crawling around in the affected area. These are actually associated with an attack by your own immune system against the bacteria, and are probably the result of localized swelling and toxin releases from the bacteria dying under the attack.
14. Sudden bouts of weakness and symptoms flares. Your body is fighting the bacteria alongside the antibiotics. But your body isn't always a nice steady predictable stream. Occasionally, and even frequently during the first cycle or two, your body will attack. Sometimes with an all-out-vengeance that will literally leave your knees weak and you panting for breath. In extreme cases, this can actually cause fainting. This can be very disconcerting if you're not expecting it. As long as your heart rate and blood pressure are OK, then you're probably fine. Go over your drug allergy checklist and consult your doctor if you think it might be a delayed reaction to antibiotics. Normally, this feeling will drop in intensity within a few minutes.
15. Headaches. Can range from not at all if you're really lucky, to some really intense head-splitters. Do whatever you can to survive them.
16. Disconnection. Close your eyes, now where is your arm? OK, look at it now. Doesn't really feel like it looks where it is, does it? The extreme of this symptom is a complete out-of-body experience. As toxin levels fall, you should become more and more re-connected to your body again. And there you were thinking that you were just getting really good at your Yoga exercises.....
17. Panic Attacks. You don't want to get these, really, you don't. It's a feeling of "Oh my God, I'm going to be like this forever, I can't take it please, somebody just kill me and get it over with..." The only possible good thing about this symptom is that it goes away.
18. Bright Colors. Your pupils may dilate a bit. Indeed, you may find yourself wearing sunglasses, inside!
19. Hypersensitive Hearing. Your ears may become hypersensitive to sound. In extreme cases, sound, even very quiet ones, can become painful.
20. Mood Swings, Irritability/Short Temper, Erratic Behavior. Again, all due to the toxin's effect on your mind. These will all clear up as you get well. These symptoms can be especially difficult for those around you to deal with.
21. Yo-Yo. You'll be feeling like one. Up one minute, down the next. You might wake up feeling great one day, only to find that a couple hours later you're back feeling horrible again. UP, down, up, down, all around. Slowly, month after month, the downs will stop being quite so low, and eventually go away.
22. Whatever Else. Everyone is different, and the disease is quite well known these days for just how differently it affects different people. Any other significant symptoms that you are concerned about should be discussed with your doctor.

HELPFUL HINTS:

1. You may need help to get through this. You should not be left alone for long periods of time. Someone needs to be around to help encourage and reassure you along your rough road back to wellness. Your mind will not be working properly, and it's easy to become confused, terrified, and discouraged. Make sure you have someone to talk to when you need them. Just a phone call can help tremendously! Emotional release, if needed, can be good for you! Rare are the ones who can make the journey back to wellness without a few breakdowns along the way. Call around, ask around, find your local Lyme disease support groups. Talk to them. That's why they're there. They want to help!

2. Eat! When you finally get through this, you'd certainly like to enjoy life again as soon as possible, wouldn't you? Well you can't do that if you're a shriveled-up little mess. Solid food is best, but may prove difficult for a while. Liquid foods like "Ensure Plus" and "Instant Breakfast" can help keep your calorie intake up. Don't forget your basic "Multi-vitamin & Minerals" either. And eating does much more than just keep your weight up. It provides energy for: your own immune system so it can fight too, for all the healing that has to take place, and energy to help your body process the toxins out. Eat, and you'll be healthy and happy again that much sooner.
3. Move and Stretch. The worst thing you can do is just sit or lie around all day. Lyme Disease is a deep tissue bug as well as not-so-deep tissue. It likes to hide and live in places that are hard to reach, both for your body and the antibiotics. Stretching and moving around does a number of things: such as providing circulation going and flushing toxins out, you help prevent toxic build-up and subsequent possible permanent damage. So if it hurts, stretch it (gently), move it around, get some circulation in there! You should be gently stretching everything from your nose to your toes at least once an hour while you're awake. Go for a short walk... Even just up and down the driveway, or around the living room a few times will do a world of good. This is extremely important during the first few weeks or so when the toxin levels will skyrocket!
4. Sleeping aids. Do not use sleeping aids during the first couple weeks or so. As long as you have extreme pain or numbness somewhere that needs to be moved around occasionally you're probably better off rolling around and toying and turning all night. Once you feel like you can go the night without accumulating severe pain somewhere, then sleeping aids are OK. Naturally, use as little as possible. You do need sleep but you also don't want permanent toxin damage.
5. Take your medication on time, every time, religiously. Some bacteria takes days to kill. A missed dose may let them recover and restart the clock all over again. Unless, of course, you like suffering.....
6. Don't stop once you feel good. Lyme Disease is very slow growing, but the longer you've had it, the deeper into your system it gets. Deep enough such that even the "instant kill" family of cephalosporins antibiotics take time to kill it. Thus it is generally good practice for Lyme patients to continue effect antibiotics for a number of months after symptoms have (seemingly) disappeared. Taking medication when you feel good can be an annoyance, but when you consider what you're going through now, do you really want to do it again?
7. Lyme Disease doesn't just grow in the bloodstream. It tends to enter inside your cells and grow there too. Not all antibiotics can penetrate cell walls to effectively kill the bacteria there. Fortunately, there are a number that can: Suprax, Flagyl, and Biaxin for example. One might consider some time spent on these to help kill any bacteria which might have crossed inside the cell wall barrier.
8. Know the signs of a drug reaction for those drugs you haven't had before. Sometimes it can be difficult to distinguish between a drug reaction and standard Lyme symptoms. Discuss any concerns or unusual symptoms with your doctor.
9. Avoid any anti-inflammatory and anti-pain medication. Mostly at the start of treatment. Inflammation is your body's way of increasing circulation to affected areas. Circulation is what brings the antibiotics in to where they need to go and takes the toxins away. Pain is your body's way of saying "Hey stupid! Move this part around a bit!" You might actually find that anti-inflammatories, though, during the first month or so of treatment, will tend to make joint pains worse. Once past the hard part though, a bit of anti-inflammatory and anti-pain medication is OK.
10. Antibiotic Soap. For shower or bath. Not proven to actually do anything, but may help to kill the bacteria hiding in the pores of your skin.
11. Contact Lenses. Take them out! Never nap or sleep with your contacts in! It is just as likely that the bacteria is in your eyes, as well as everywhere else. A die-off in your eyes can raise the local toxin levels, but with your contacts in your body, is hindered from flushing it away. The result build-up may cause damage to your eyes. Better safe than sorry! Dig up that dusty old pair of glasses!
12. Depression. Nobody likes feeling depressed. Problem is, that a fair number of people just get that way after fighting the disease for a seeming eternity and still not feeling a whole lot better. Try to find things you can do to occupy yourself and keep your mind off it. Do whatever you can, naturally, to lift your spirits and keep them up. Failing that, it is not out of the question to ask your doctor for a little help. Make sure to avoid anti-depressants that can add to your insomnia!
13. B-Complex Vitamins. These have been shown to significantly help psychological symptoms. They also help the brain repair and protect itself from toxin damage.
14. Injuries. Try to avoid them. The Lyme bacteria thrive on injured body parts. Bruises, sprains, etc., are a feast with an open all-you-can-eat invitation. You might, to amuse yourself once you know the exact length of your cycle, try mapping back specific short-lived pains to the event which caused them!
15. Exercise. Gentle stretching and low-level workouts are OK. But remember that strenuous exercise and hard workouts are actually controlled injury...and injury feeds the bacteria.
16. Yeast Infections - in throat and/or digestive tract. Some antibiotics are more prone than others to causing yeast infections by killing off all your good bacteria. Your doctor should question you about sore throats and intestinal problems each time you visit. These infections can be cured with yet more drugs, or avoided all together by simply asking your pharmacist for "good tummy bacteria", the live ones". Lactobacillus Acidophilus (they're non-prescription) Live Culture yogurt does essentially the same thing, as it contains the very same live bacteria. In either case, make sure to rinse your mouth and throat with water immediately after you eat or drink anything, then swish a bit of your live good bacteria around in your mouth and swallow.
17. Antihistamines. No. No. No. No. No. And most especially not when on one of the cyclene family of antibiotics. Your immune system is one of the biggest factors in your recovery, one of the big superpowers in the war against disease. The antibiotics will kill some percentage of the bacteria each cycle while your immune system kills off the ones that were weakened. Together, the antibiotics and your body create a team to defeat the bacteria. Antihistamines, like Benadryl, turn off your immune system! All they do is make sure that you suffer longer! Further, the cyclene family of antibiotics doesn't actually kill the bacteria, but rather just stops them from growing and relies on your immune system to kill them.

18. Natural herbs and such. A stroll through your local herbal and natural foods shop will provide you with an amazing array of itmes which claim to do all sorts of good things. Anything that says "boosts your immune system" might be a good idea. Purely optional, although a number of herbal concoctions have actually been shown to do as they claim.
- 19.Caffeine. Surpresses the immune system, which is very bad. Give up that morning coffee and that afternoon coke.
20. Alcohol. Worse for you than caffeine. Unless you just want to be sick longer, no alcohol!
21. Smoking. Haven't you been lectured about this enough yet? Now would be a really good time to quit.
22. Rest. You're going to need a lot of it. Even after you begin to feel better, remember your body is still fighting off a rather nasty infection. Don't overdo it. Without sufficient rest, recovery just takes longer.
- 23.Hot drinks. Let them cool off to luke-warm first. Hot fluids tend to make the dead layers of cells on your tongue rather thick to protect them from the scalding heat. This means more stuff for yeast infections to grow in.

Chart it!

Make a chart of your symptoms! Get some graph paper, on the left-hand column list your symptoms and various affected body parts, and then across the top number the days. Each day, fill in the appropriate squares with the severity of your symptoms. Hurts like crazy? Fill that square in. Hurts just a little? Maybe just put a line across the bottom of the square. Record the worst of each symptom each day. You'll notice that some move gradually up and down, some might appear constant, and others can blink in and out in just a day. Now you have a record. With this record, you can help you and your doctor figure out exactly what to expect when, and even make a prediction on when you'll feel 100% normal again! Instead of being at the mercy of the disease, waking up each morning and wondering "whats the torture of the day going to be?", or wondering "When is it ever going to end?", you could be looking at your chart and knowing exactly what to expect and when! Of course, you still have to map that first cycle, but from there on out you're not just blindly muddling along!

Sometimes interpreting your chart can be difficult. For instance, some body parts may feel fine during the first month or two, only to become painful later on. Reason being, is that they started out numb, and as the bacteria died away the feeling came back to that area. Physical symptoms that started out painful should show themselves fading away with each cycle. Basic energy level should rise each month, although there may only be a slight increase between the first two cycles. Neuro symptoms should also improve slightly each month, but they will be the last ones to finally clear up.

The Lyme bacteria appears to stick very tightly to its cyclical schedule. These cycles tend to be about 21 days in men, 30 days in women. If your symptoms don't appear to be going down with each cycle, then consult your doctor about increasing the antibiotic levels, adding another, switching, or whatever the attack plan they might suggest.

Because the physical symptoms disappear first and the psychological ones are sometimes difficult to measure, your doctor may ask you to begin recording your temperature a few times a day once your symptoms are nearly cleared. When you've gone through a few full cycles without sign of a fever, you're done!

The Lyme bacteria will typically have a peak intensity sometime during its cycle each month. Beginning, middle, or end is a matter of chance and at what point you start your charting. But it can be very frustrating to start your antibiotics on the low end of a cycle, only to find yourself feeling worse and worse as the days go by. Which is why you are keeping a chart! It is completely irrelevant to use day-to day or even week-to-week comparisons for whether you are improving. The only reliable way to tell is to compare each months chart and see if the symptoms are improving overall. Again frustraintg, because you really can't tell if you're improveing for at least one full cycle. Unless of course, you're one of those miracle Rocephin cures, which is rare. The rest of us suffer for a month, and then begin comparing each month's date to the previous to see if there is improvement.

Typical uncomplicated recovery. Before starting your antibiotics you might find yourself feeling pretty bad, or at the least, not very good. Once you start though:

Oh my God, I'm gonna Die.

Ugh, I feel horrible.

Feeling bad.

Feeling much better.

Wow! I feel pretty good!

Symptoms gone!

Now Cycle 1 Cycle 2 Cycle 3 Cycle 4

This chart assumes many things, mostly that nothing goes wrong, that the choice of antibiotic and its level are correct from the start, etc..It is intended to be an example of how a typical recovery might feel.

The Lyme Disease Cycle. Is not really 30 days precisely. Rather, in women it tends to match their menstrual cycle in number of days. In men the cycle is usually around 21 day. But again, these vary from person to person. The only way to know for sure is to make a chart of your symptoms and then begin looking for patterns.

There are many different strains of Lyme Disease. Fortunately there is also a variety of antibiotics. The trick is to find the antibiotics which your strain is susceptible to and that your body will tolerate in high doses. This can be extremely discouraging, to spend weeks or months on a particular antibiotic, only to figure out that it isn't working. This is one reason that Lyme Disease is frequently treated with two different antibiotics at the same time. Another is that doubling up provides a much higher kill rate. If the first set of antibiotics you try doesn't seem to be doing much, don't be afraid to ask your doctor for a few short trials of some others. Try each one for three days. Remember how you felt each third day. Continue with the one/ones which hit you the hardest.

Cephalosporins - When they work, they work extremely well. This family is effectively an "instant" kill, meaning that it can kill the bacteria regardless of the stage of its life-cycle. Naturally, like everything else, they're more effective during the reproductive cycle. But, essentially, this class of antibiotics pokes holes in the bacterial cell wall and causes the little buggers to bleed to death.

Penicillans - This class blocks cell wall formation during the reproductive cycle of the bacteria. They are a slow-kill antibiotic, but usually highly effective.

Cyclenes - Generally gum up the DNA of the bacteria. Without functioning DNA, the bacteria can't reproduce or grow.

Advanced Macrolides - Block protein synthesis in the bacteria. Without proteins, the bacteria have a difficult time doing much of anything.

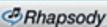
Metrodizanol - Does three things: gums up the bacterial DNA, suffocates the bacteria that may be in an anaerobic mode, and breaks their little legs so they can't run and hide (almost literally! The bacteria use their flagellum to escape attacking white blood cells, but without functioning flippers, they become easy targets). One possible problem with this antibiotic, is that it may be a tad too useful. By enabling the immune system to see and catch the bacteria the body is suddenly hit with the realization that there is tremendous infection going on. The immune system response can be intense. Possibly a great choice for "mop-up" later in treatment.

Antibiotics dosage and duration. Typical bacteria have very short cycle times, usually measured in hours or minutes. This means, that an antibiotic that is given at a standard rate to produce an effective 10-20% kill rate can kill a typical infection in just a matter of a few days. With each cycle the antibiotic kills some percentage of whatever bacteria are still left. When the numbers get low enough your body cleans up the stragglers, thus keeping the "percentage of what's left" from becoming one of those "limits that never reach zero" problems that you dreaded back in high school algebra. The Lyme bacteria behaves the same way. With each cycle the standard rate of antibiotics will kill some percentage of whatever is there. Except that the Lyme bacteria has a cycle time measured in weeks! (3-4) It could take years to kill the infection at standard rates! Antibiotics are dosed quite high, and often combined, in order to achieve the highest kill rate possible without killing the patient (you) in the process. But even forcing a very high kill rate can still take 4-6 months before the levels are brought down far enough for your body to overwhelm the stragglers. The other reason that antibiotic levels are kept very high for Lyme Disease treatment is that the bacteria isn't just in one or two easy-to-reach places. It's everywhere. That includes the central nervous system (CNS) and inside cells, joints, etc, etc.... Many antibiotics have a difficult time reaching these places in concentrations high enough to effectively kill the disease in these areas. Don't let your doctor underdose treatment options and effective dosage rates. Duration, or how long you stay on the high rate of antibiotics is just as important. A typical infection by a typical bacteria is beaten to death for many cycles past when it should have all been dead, just to make sure. Why not the same with Lyme? Currently, you'll be lucky if your doctor agrees to one full cycle symptom-free. Press for one full cycle fever-free. If you manage to stay on antibiotics for anything after that, consider yourself blessed. But 3-4 fever-free cycles, assuming that you're back living a healthy lifestyle and doing what you can to keep your immune system pumped up in top condition, well, that should do it. Time to stop and see if it's really as dead as we all hope it is.

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