

# My Lupus

Author Arnold Ytreeide  
Shares His Journey with a  
Chronic Disease





# **My Lupus**

by

Arnold Ytreeide

**My Lupus**  
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**About the Cover, Arnold Ytreeide writes:**

"I chose the image of the old shoe for the front cover because that's exactly how my lupus makes me feel - old, torn, and tattered. But I like the image of the footprint for the back because my attitude is that this disease will *not* get me down. Even if I'm tired and hurting, I'm going to "make tracks"; I'm going to live my life."

For all those who have helped make  
My Lupus  
bearable.



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## Why My Lupus?

Every person who suffers from lupus has a different set of symptoms – a unique grouping of manifestations of the disease (actually, *diseases*). That’s why I’m calling this little book *My Lupus* – because I can only talk about my particular experiences and circumstances. I am not an expert on lupus, but I *am* an expert on *my* lupus.

And yet, among us sufferers, there are some commonalities. It’s my hope that, by sharing my experiences, others can benefit – especially those who are recently diagnosed. When I first received my own diagnoses, my wife and I went immediately to the web and to the book store. We found bits and pieces of information – some of it helpful, much of it not – but could find nothing comprehensive that fit my particular experiences. So I’m hoping this little volume will help others in their own search for information.

But why *me* in particular? There are a few concrete reasons, and a couple abstract ones:

- I’m a man, and it’s hard to find information about male victims
- I’ve recently been through those first frightening years, so have a fresh perspective

- I have a middle-of-the-road variety of lupus, so am not focused solely on SLE
- I've found the medical community grossly inadequate at explaining and preparing me for what lies ahead, so want to help others in a similar situation
- I often start doubting that my symptoms are real, and find great solace when I hear the stories of others going through similar experiences; I want to be that solace for others.

I must stress from the beginning that I am not a doctor of any kind, I have no special training and no expertise in anything but my own experiences. So, please, take anything you read in here not as medical advice, but as possible avenues of exploration with your doctor, and perhaps a bit of inspiration.

You are not alone!

## My Discovery

My wife and I remodeled our master bedroom in June of 2005. We did a great job, at least in our own minds. I'm a professor at a university, so have the summers off for such projects.

About a week after completing the job, I became very sick with flu-like symptoms. For eight weeks – most of my summer – I had fevers of 104 to 105, as well as aches, a rash, and other symptoms. I went to several doctors, mostly of the “quick care” variety since my own physician was on vacation. I was tested for everything imaginable, including West Nile Virus, but everything was negative.

Finally my own doctor came home and, in about 20 minutes, properly diagnosed me: I had a strange bacterial infection *and* a strange viral infection at the same time. An antibiotic cleared out the bacteria in just a couple days, and the virus soon followed.

Just before school started in August, I noticed a peculiar lesion in the middle of each of my earlobes. I say peculiar because I couldn't figure out why identical lesions would appear “bilaterally.” They went away, but returned again later, as did other lesions on my face. They also itched, sometimes severely.

During those fall months, I seemed to be getting more and more tired. I remember commenting many times to my wife, “I don’t know what’s wrong with me! I just have no energy!” Usually this

was said as I was headed to the couch to lie down. Being tired wasn't unusual – school life is very busy, with many extra-curricular activities as I teach film and television production. But this was different: it was pervasive, constant, and deep.

I'm very passionate about my teaching, which means I'm also very animated. I move a lot, and use a lot of energy. But that winter I found myself sitting down during more and more of my lectures. I also had trouble concentrating, and sometimes felt like I wasn't making sense.

Finally, with the bilateral lesions on my earlobes again and another lesion on my temple, I made an appointment to see my doctor.

## My Diagnosis

It took some weeks to get in to see my primary physician, but when I did he took one look at me and sent me to a specialist – a dermatologist. He didn’t say why, or what he suspected, for which I don’t blame him.

It took another few weeks to get the second appointment. The dermatologist turned out to be an abrupt and insensitive man. He looked at the lesion on my temple and said he need to take a biopsy. I’d only ever heard the term *biopsy* in relation to cancer, so assumed that’s what he was looking for.

The biopsy itself wasn’t that bad – I’ve been through much worse – but was still a bit uncomfortable: he used a sharp, round device like a small cookie cutter to take about a 1/2 inch chunk out of my face. Then, just before he left the room, I asked him what he suspected. “I think it’s lupus,” he said. And then he was gone.

I grew up in the sixties, and had only heard the term “lupus” a few times. But every time I heard it, it was associated with someone dying. I remember a movie where someone announced they had lupus, and all their friends and family stood in shock, then three scenes later were standing by the casket.

So the doctor’s remark that he thought I might have this disease I knew nothing about, drove my wife and me to the internet. There we learned about the different forms, and the fact that lupus is

almost never fatal anymore. That was a relief, but still, the descriptions we read left me frightened about my future.

A week later I was back at the specialist's office. After waiting the usual 45 minutes, I was eventually taken to an exam room, where I waited another half hour. Finally, the doctor walked in the door, his face stuck in my chart. Without looking at me he said, "Pathology confirms you have lupus," then he turned and started to leave.

This time I was ready: I had decided he wasn't just going to ignore me. I literally chased the doctor down the hall and into another treatment room - with another patient - and demanded he answer some questions . Having no other option than to talk to me or call security, he gave me about a minute of his time.

It turns out that, based on his experience, I had only the discoid type of lupus - not the more serious SLE form. From my research I knew this was a good thing, at least relatively speaking. I would need to see a rheumatoidologist, he said, and gave me a name. In response to my question about the lesions on my face, and those that were now appearing on my scalp as well, he reluctantly told his nurse to give me samples of some creams. I think he did this more to get rid of me than to help me.

I say all this about the doctor not to complain or whine or just tell war stories, but rather to make a point: your health is your responsibility. If faced with a doctor like this - one who doesn't care, doesn't give you complete answers, or doesn't seem to know what he's talking about - ask questions! Don't let him or her leave the room until you are satisfied you have all the information you need. Chase him down the hall if you need to (But try not to get arrested).

Back to my story.

All through the fall and winter I had been developing more and more symptoms, and a deepening of the symptoms I'd started with. Clearly the disease was not yet fully developed, or perhaps not yet fully manifested.

By now it was April, and my wife and I were scheduled to go to Switzerland in early May, where I was taking classes for my Ph.D. I made the appointment with the rheumatoidologist, but when I got there I didn't actually see him. Instead I saw his associate, a Physicians Assistant. She was absolutely marvelous! As soon as she heard about my situation (and the name of the first doctor) she spent almost an hour with my wife and me, answering questions and giving possible solutions.

The situation was this: I was leaving for Europe in two weeks, and had no idea what it meant to have lupus or how to treat it. The PA carefully went over the possible symptoms, and talked with us about the importance of diet. She approved of the medications the first doctor had given me for the lesions, and told us how to manage the pain. I never did meet the real doctor at that clinic, but the PA was a tremendous boost to both my morale and my understanding of the disease.

We managed to get through six weeks in Europe okay, though I came home twenty pounds heavier than when I'd left. I needed constant snacks with salt and protein, and the only convenient things we could find at the little store in the Swiss Alps was peanut M&Ms and pretzels. Those became my hourly diet as I sat in class.

After returning home, we visited the PA again and she suggested we see a specialized specialist, so referred us to another doctor.

He was the first to actually do blood work and a full medical workup. When he was done, he informed us that I have subcutaneous lupus: not the milder discoid brand the first doctor had diagnosed, but not the more serious SLE either. He told me I'd have many of the symptoms of SLE (which was not news to me), but without the actual organ involvement. I'd also continue to exhibit the discoid-type lesions on my head and shoulders.

I should note here that subcutaneous lupus is not often talked about. It doesn't seem to be a recognized form of lupus, at least not often recognized. But I recognize it. It hurts. It makes me tired. It messes with my mind.

Other doctors have listed me with "Discoid lupus and fibromyalgia" or other variations. From what I've read and experienced, this doctor's diagnoses of subcutaneous is right on. Not that it much matters what we call it, but somehow knowing helps psychologically.

## **My Symptoms & Treatments**

As most of us with lupus know by now, there is no one set of symptoms that describes us all. Lupus can manifest itself in so many ways, and even imitate other diseases, such that my particular brand of suffering is not the same as yours.

Still, there are some common complaints, and I've found it very comforting to know that others have some of the same experiences I do with the disease. I hope that, by describing my own symptoms and treatments we've found to work, you might find some hints and clues as to how to treat *your* symptoms. But again, I am not a doctor and you should try no treatment without your doctor's approval.

### **Lesions**

These were the first indication that something was wrong, but mine are neither purely discoid nor the often seen butterfly type. My lesions occur on the face, scalp and shoulders. They're irregular in shape, and anywhere from a pencil width to a dime in diameter.

Lesions for me start as a small, itchy red spot, difficult to distinguish from a pimple, cold sore, or other eruption. They quickly grow into a scaly patch, at which point I can identify them as lupus. The itching is intense, and it takes all my will power not to scratch my skin off.

Most annoying is when the lesions appear on my nose or eyelid – the nose for reasons of vanity, the eyelid because the itching is intense and it's difficult, and dangerous, to treat.

**Treatment:** my doctor gave me a tube of Desoximetasone cream when I was first diagnosed, and this has worked well for me. He, and the manufacturer, warns about over-use, so I'm extremely careful about applying the cream only to the lesion, and in a small amount. In four years, I've used about one tenth of the tube, so I think I'm doing okay.

For the scalp, he gave me an aerosol can of Luxiq foam. This has been very effective: as soon as my wife can identify a lesion as lupus, one application of the foam – sometimes two – knocks it out.

## **Sun Sensitivity**

Of course, one cause of the lesions is exposure to the UV rays of the sun, or some kinds of lights (working in film I have to be careful about this). Not only does it cause lesions, being in the direct sun seems to sap the strength out of me.

**Treatment:** Stay out of the sun as much as possible, use high SPF sunblock every single day, and wear a wide-brimmed hat every moment I'm outside in the daylight. When it's necessary to be in the sun, I drink plenty of Gatorade, and sit as often as possible to conserve strength.

## **Fatigue**

Almost all sufferers of lupus can talk about this one. For me, dealing with fatigue is almost worse than dealing with the pain (especially since the discovery of my “miracle”).

At times, the fatigue is so bad that I just have to lie down on the floor – no matter if that’s in the supermarket, our living room, or the middle of the sidewalk. It hits fast, and it hits hard. A friend of mine in Switzerland, also a victim, described it this way: “You’re so weak that the floor isn’t low enough. You feel like your body isn’t strong enough to even support its own weight.” That’s exactly how it feels for me. The floor isn’t low enough.

As my disease fully bloomed after my diagnosis – or perhaps after I came out of a short remission – the fatigue would hit every day, and often three or four times a day. Slowly, as we learned to manage the disease and regulate my expenditure of energy, the frequency of these episodes lessened. Today I reach the extreme of fatigue only once or twice a week.

**Treatment:** Teaching at a university is the perfect job for me right now – it allows me the flexibility I need to monitor and adjust my activities for energy conservation. And that’s the key: conserving energy. I tell people that having lupus is a matter of resource management: I have a given amount of energy in a day, and a limited rate at which it can be consumed. If I use too much energy, or use it too quickly, I’m done for the day; I’ve used up my allotment.

But diet is also vital to managing my energy reserves. I must have protein, and sometimes carbohydrates, at a constant rate. For me, trial and error has determined the rate to be generally one ounce of protein every two hours. More if I’m expending more energy, less if I’m fairly dormant.

The type of protein also matters greatly. Generally it needs to come from meat, and often that meat needs to be beef. But I also use smoked almonds, ice cream, and peanut butter. I’ve learned to listen to my body and feed it the amount and

type of protein and carbs it needs on an hour-by-hour basis.

All of this means that I must eat less at regular meals, but I do still need to have a full breakfast, lunch, and dinner. The two-hour snacks get me through, but I must have the entire complex of nutrients at meal times.

Of course it's also important to rest when I start feeling fatigued. If I keep pushing, I quickly pass the point of no return and am down for the remainder of the day.

## Pain

As you know, lupus can cause a lot of pain – muscular, skeletal, joint. For me, the aches and pains are constant, and always in someplace new and exciting. Lupus means never a dull moment. Sometimes the pain is so bad I just want to lie down and cry, and men aren't supposed to do that.

But besides the usual rheumatoid-type pains that most lupus victims have, I get the additional fun of peripheral neuropathy. This means that – at any moment, and in any place in my body – I get a stabbing pain just exactly as if someone has driven an ice pick into my flesh. This is a crippling pain that, if it happens to be in my legs or feet, drives me to the ground. No matter where it is, the only relief comes from squeezing or pushing on the point of pain as hard as I can.

**Treatment:** For the general aches and pains, as well as other symptoms, my doctor put me on the anti-malarial drug Plaquenil. I filled the prescription, and have the bottle sitting on the shelf, but have never taken one of the pills.

I have no aversion to taking pills, but the thought of starting something I'll have to be on every single day for the rest of

my life worries me just a bit. I know this particular drug has been around for decades, and is completely safe, but still, I'd rather not be dependent. So I have thus far chosen to manage my pain solely with over-the-counter NSAIDs: aspirin, Tylenol, and Ibuprofen.

This, in itself, is not a great solution: NSAIDs have dangers of their own. And in fact, I have to take a Prilosec a day to keep the NSAIDs from eating a hole in my stomach (which they did once). But as long as I can, I want to stay off the more powerful drugs.

As for the peripheral neuropathy, nothing seems to help. In fact, it sometimes seems as if the Ibuprofen can cause one of the stabbing pains, but that might just be coincidence. Pressure applied for one to two minutes is my only relief from the ice pick.

In any case, I've always taken copious amounts of OTC anti-inflammatories for the general pain, and just put up with the neuropathy.

Until, that is, I discovered my "miracle." More on that later.

## **Cognitive Impairment & Loss of Balance**

At various times, and apparently for several reasons, I tend to lose focus in my thinking, and even become confused. I've seen this described as "lupus fog," and that description works for me.

Sometimes the fog comes in conjunction with the loss of energy or over-exertion. Sometimes it seems to be linked simply to the loss of electrolytes (see below). At other times it's linked to food intake: if I forget to eat, I lose focus.

Whatever the reason, the fog means I can hear someone talking and have absolutely no idea what the words they're saying mean. In fact, I have a kind of funny story about that...

While in Switzerland studying for my Ph.D., the Dean of the school was teaching us one day. This was a school of philosophy, which meant long discussions of things philosophical. The Dean made a long statement, then asked me what I thought of what he'd said. I looked him in the eye and said, "I'm sorry, sir, I have absolutely no idea what the words you just spoke mean."

"Finally!" the Dean yelled in his German accent, waking everyone up. "Finally someone understands! We don't even know what we don't know!"

He went on for quite some time about how my "insight" was brilliant. Chalk one up for lupus.

But the frightening fact is that often – not quite daily anymore, but almost – I have periods where I don't understand what's happening around me. When it's really bad, I won't even remember later what happened during those periods.

**Treatment:** Because of my problems with blood pressure (see below), we discovered that salt seems to help both my physical weakness and my cognitive impairment. At first, I would simply grab the nearest salt shaker and dump some in my mouth when I started feeling disconnected or weak. Then a friend told us about the electrolyte tablets used by athletes – tablets that include salt – and we started ordering these. They came in convenient packets of two that I could carry in my pocket and my wife could carry in her purse.

I was never quite sure about our home remedy, though, until I asked a colleague at the university who studies the brain for a living. I told her about my fog, and about taking electrolyte tablets (not mentioning the salt), and asked if that made any sense.

Absolutely! was her response. It's salt that allows the neurons in our brain to communicate with each other, she said. No salt, no communication.

This was further confirmed when my wife asked a pharmacist if they had electrolyte tablets. When she explained that I have lupus his response was, "Oh, of course, he needs the salt then."

Unfortunately, the company that made those convenient little packets of salt tablets decided for some reason to start making them "Salt Free" (an idea that seems idiotic to me). So now we can only buy bottles of the pills, and have to make up our own packets.

## **Electrolyte Loss**

Early blood tests indicated that, since contracting lupus, my body had started shedding electrolytes like they were poison. This, I'm assuming, aggravated the lupus fog problem. Tests have not uncovered a reason for this, only the fact of it.

**Treatment:** My doctor "prescribed" Gatorade for the loss of electrolytes. I was glad when they came out with G2, which has half the calories, since I drink at least a bottle a day.

But the Gatorade alone wasn't enough - or rather I couldn't drink enough of it to re-supply my body - so I use one to four of the electrolyte pills every day.

## Blood Pressure

Another by-product of My Lupus is that, at any given moment and for no apparent reason, my blood pressure will suddenly drop to much lower than normal – another good excuse to spend time on the floor.

I've been through a battery of tests, including a heart stress test, which have revealed no detectable cause for my blood pressure problem. It was only detected because I happened to have an episode while sitting in the doctor's office. I now have a home blood pressure monitor which has helped me learn to "read" the feedback my body is giving me when I feel weak.

**Treatment:** My doctor said that I'm the first patient in his thirty-year career for whom he has prescribed salt, but that seems to be the solution when my pressure drops. My BP is usually on the low side of healthy anyway, and I need salt for the fog problem, so in my case salt seems to be called for. It's one more reason to take the electrolyte tablets and drink Gatorade.

Even if you've ignored all the other WARNINGS, this is probably one you want to pay attention to: DO NOT USE SALT UNLESS INSTRUCTED BY YOUR PHYSICIAN. It can be deadly.

## The "Crash"

All of the above symptoms, in various combinations, can conspire together to create what our family affectionately calls a "crash." By Crash we mean a moment when I'm perfectly fine followed by a moment when I'm on the floor, completely unable to move, and incoherent. This can happen because I forget to eat right, because my blood pressure drops, because I just get weak, because I've over-exerted, when I've had a shot of adrenalin, or some

combination of these. It can even happen for no reason at all, when I've done everything right.

A good example of a crash is the day after we returned from Europe last year. We'd been home less than ten hours when my father had a problem and we had to have him taken to the Emergency Room. In the process of caring for my father, I forgot to care for myself. As a doctor and three others attended to him, I suddenly felt a crash coming on. I had only enough time to turn to my wife and say "Uh oh" and I was on the floor, out like a light. Of course the doctors were ready to shock me with the aptly named "crash cart," but my wife assured them that my behavior was normal, and all I needed was some salt and a bit of meat.

In our research, we've only found a few references to others having similar experiences, so I'd love to hear from people who know what I'm talking about. I used to crash just about every day, but as we refined my daily regimen, that's diminished to a couple times a month.

**Treatment:** salt, protein, electrolytes, and/or aspirin, depending on the cause of the crash. I usually have to lie on the floor for ten to fifteen minutes before I'm able to sit up. It takes a little longer for my brain to really re-connect, so I often don't remember what happens during a crash.

## Adrenalin Coma

This is my name for a condition that occurs whenever I get a shot of adrenalin. Here's how we discovered it:

The second fall after I'd been diagnosed we noticed that, no matter how careful I was and how perfectly I observed my routines, every Sunday afternoon I would crash. Like clockwork. It didn't matter if I went to church or not, what I ate, or anything else.

Then one day – not a Sunday – I was riding in a car with someone and we were almost hit by a guy running a red light. This, of course, gave me a shot of adrenalin. At home twenty minutes later I crashed, and crashed hard. When we later tried to figure out what happened, I mentioned to my wife the close call in the car a few minutes before the crash. She got on the internet and, sure enough, found a link between lupus and adrenalin.

It seems that, for some reason I don't fully understand, lupus allows adrenalin to cross the blood/brain barrier (or perhaps it's the other way around), and enter the brain directly. Once there, it seeks and destroys helpless brain cells (this is my amateur and probably inaccurate description, but the result is accurate). So whenever I get a shot of adrenalin, we've learned from experience that sixteen minutes later I'll be on the floor. It's happened in the car several times, once when I was stung by six wasps, and any other time I'm suddenly frightened or excited.

But what about those Sunday afternoon crashes? Well, what I do every Sunday afternoon in the fall is watch the Seahawks play football. And I watch with passion. I get excited, jump up and yell, and am very tense. That is, I used to be. Now, when I watch, my family keeps saying, "It's just a game, Dad!"

**Treatment:** Other than trying not to get a shot of adrenalin, we've found no way to counteract the results. It does seem to help a little to take salt and aspirin right away, and to breath deeply for those sixteen minutes, but we've learned that, once the adrenalin is released, I'm going down. I don't usually feel 100% until I get a full night's sleep.

## Buzzing Feeling

Whenever I come close to crashing but don't, or often when I get fatigued, or am just having a bad day, my entire body will start to

“buzz.” That’s as close as I can describe it. Every cell of my body seems to do a throbbing, vibrating, buzzing dance. It borders on painful, but is mostly just disconcerting, and seems to rob me of energy.

**Treatment:** A full night’s sleep.

## **Twitching**

After a particularly stressful event, or sometimes “just because,” my muscles will start twitching. At its worst, every muscle in my body seems to twitch and it’s difficult to function. In milder episodes, it’s just my upper body, or random points throughout my body. While usually nothing more than annoying, at times it can make it difficult for me to control my muscles – to move voluntarily – as the muscle I’m trying to move is doing a dance of its own.

**Treatment:** A full night’s sleep.

## **The Flu**

Many victims of lupus have commented about flu-like symptoms, and I’m no different. Every once in a while, I get the flu. I have all the symptoms of chills, body aches, and so forth. But I don’t have a fever, and don’t really have the flu.

In fact, this was one of the early signs that something was wrong with me, before my diagnosis. I remember telling my wife on many occasions that I had a fever, only to be proven wrong. I’d swear to her that I had the flu, but the next day it was gone. It’s one of the things that drove me to the doctor.

**Treatment:** Initially this happened once a week like clockwork. Today, I only have “flu days” once every four to six weeks. We’ve discovered that following my diet routine

religiously keeps that annoying symptom at bay. But when it hits, we haven't found anything that cures it. I just have to plan to be down for 24 to 36 hours.

If you've just been diagnosed, all these symptoms might seem frightening to you. Remember, every lupus victim suffers different manifestations of the disease, so it's unlikely you'll get all of these.

Whatever form your lupus takes, it *is* manageable! It may make life tough at times, but it can't rob you of the *joy* of life unless you let it.

## My Routine

By nature, I'm a very random guy: if I do the same thing twice, I probably won't do it the same *way* twice. My life has always been spontaneous, unpredictable, and (to me) interesting.

Lupus has changed a lot of that.

Now, I'm on a strict routine of diet, sleep, and activity. I should also be on a strict routine of exercise – and always feel better when I am – but somehow life keeps getting in the way.

Waking up is my first routine of every day: I must wake up naturally and fully before getting out of bed, or it will probably be a bad day. This means no alarm clock, no one getting me up, no early morning meetings or classes.

As soon as I'm up, I must have breakfast immediately. If I'm going to exercise, breakfast comes first, not after. And it must be appropriate to the time and my planned activities: a bigger breakfast for busier days.

If it's a work day, I have to be careful not to over-exert myself in the morning. I'm usually feeling pretty good at this point, so it's easy to forget that I have limitations. I can't go bounding up the stairs at work, and if I'm carrying a load of books or papers, I take the elevator up the two flights.

I'm very animated when I teach, so if I have a morning class I have to fortify myself with Gatorade and almonds just before I go in. On weekends when I'll be working out in the yard or otherwise expending energy, I also need a mid-morning snack.

Lunch comes at 11:30, without exception. Even if I've had a snack, my body needs the full meal by this time. I don't necessarily have to be actually eating right at 11:30, but I have to be headed that direction, and must be consuming food before noon. This has a nice side benefit in that I always beat the rush at restaurants.

In the early afternoon I almost always need a nap. Five or ten minutes usually does it, but skipping this can mean a bad day later.

Between 2:30 and 3:30 I have another snack – almonds or ice cream, then have another nap before dinner.

5:30 is dinner time, though I can often stretch that to 6:00 or 6:30. If I know I'll be going to a late dinner that night, or eating late for some other reason, I still do better if I have a light but complete dinner at 5:30.

My last snack of the day comes between 9:00 and 10:00 p.m., depending on how I'm feeling. This is sometimes a bit of leftover dinner, but often is ice cream with almonds or peanuts. I should probably be asleep by 11:00, but I've always been nocturnal. Though we're usually in bed by 11:00, I usually work on my laptop until closer to 1:00 or 1:30.

So that's my daily routine, developed by trial and error over the last four years. We've learned that much deviation from this

schedule can make it a bad day very quickly. Once that day turns bad, there's no getting it back until I've had a full night's sleep.

But what about days when I *can't* be normal? Here are some special circumstances:

## Travel

No matter what, getting on an airplane is tough. Well, not so much the getting on, but sitting inside as it goes up and down. I assume it's the slight pressure change that affects my body.

I love to fly, have no fear of flying, but since I developed lupus, flying does not like me. Even a short hop of 45 minutes, or a couple thousand feet up in my friend's small plane, almost always means I'm down for the rest of the day.

But long hours in the car are also tiring for me, and mean the end of my day. So, when I travel, we just plan to do nothing once we reach our destination.

This also means that I never travel alone anymore. In my former life I used to go to conferences and conventions by myself, but now either my wife or son must accompany me. This is mostly because of my "crash" syndrome.

Two other new things lupus has brought to our travel are refrigerators and room service. Hotels will often have room refrigerators available – either free or for a small fee – and we keep Gatorade, breakfast food, beef stick, and other perishables there. And I now often use room service for late night snacks or to be sure I have breakfast when I need it.

## Overseas Travel

We've been to Europe and Great Britain three times since I developed lupus. The first year, I was down for four or five days when we got there, before I could function normally. A lot of this has to do with jet lag, of course.

So the next two years we developed a system which I'd patent if lots of people hadn't already thought of it.

For a week or ten days prior to traveling to Europe, I start adjusting my internal clock, one hour at a time. I also use melatonin – the substance that tells your brain when it's time to sleep – to reset my brain.

Melatonin can be a dangerous drug, though, so be sure to ask your doctor before trying it. Basically, you take a tablet at the time your brain should think is sleep time at your destination.

So a week or ten days before we leave, I go to bed an hour early (taking a melatonin tablet), then set my alarm for 7:00 am (knowing it will be a bad day, but planning for that). I'll do that for two days.

Then I'll go to bed yet another hour earlier, set my alarm for 6:00, and do this for another two days. Eventually I'm going to bed at 8:00pm and getting up at 3:00am. Then, when I arrive in London or wherever, it's only another few hours of time adjustment and I'm ready to go.

Using this system I overcame almost all feelings of jet lag, and was able to function normally in Europe from the first day.

Of course, for that week or ten days I was getting up early, I didn't have great days. But I'd much rather suffer a little at a time over here at home, than suffer severely for four or five days in Europe, where I'm paying to have a good time.

Traveling westward is much easier, and I don't do any special preparations. I'm tired when we get home, of course, but then so is everyone else.

Using this system, as well as sticking to my strict routine, has allowed me to travel all over Europe having no worse days than I do here at home. The real key is to plan ahead for meals and snacks: the same foods are not always available in other countries.

The eight to ten hour flight can also be a problem if you're not careful. We've learned to always pack peanut butter and crackers, as well as some beef stick, when we travel by air. Airline service and food are unpredictable.

But the day we returned from Europe in 2007 was the day *after* there was a bombing at the Glasgow airport: all UK airports were under tight security. Though we thought we left plenty of time, it took 2-1/2 hours to get through security, *and* security took away all of our food and Gatorade. When we finally got through, we literally had moments to get on the plane, so no time to stop and buy more food.

Once airborne, I tried to explain my circumstances to the flight attendants, but they wouldn't listen. I explained that I needed food more often than just the one dinner and pre-landing snack, and that I'd be unconscious and on the floor if I didn't have my snacks.

The flight attendant's response? "That's okay, we'll just step over you."

I practically begged them, saying that on a flight of almost 500 people, surely someone would skip dinner, leaving an extra meal available. Absolutely not, the flight attendants insisted – there wasn't an extra meal anywhere on the plane.

Sure enough, two-thirds into the flight I crashed. The flight attendants freaked. The pilot started to divert to the nearest airport, and called ahead for an ambulance. But finally the chief flight attendant came back from First Class and my wife told her that all I needed was some meat.

"Well why don't we just give him another meal?" she said. "We have lots of extras." So they did – and got two in fact – and my wife forked the meat into my mouth. Half an hour later I was at least coherent, if not fine.

That's when the head flight attendant gave me a lecture about alerting them to my medical needs in the future! I told her – rather acidly I think – the whole story, and she was shocked to hear how her staff had treated me.

So now, when we travel by air, we're sure to always carry some form of protein besides meat and peanut butter – both of which we've had taken away by security (though not always, and usually not if we explain why I need it). But a bag of almonds accompanies us wherever we go.

Oh, and the pilot un-diverted the plane and cancelled the ambulance.

## Work

Again, I'm very fortunate to have a job that allows me some flexibility. As long as I can prop myself up during class if I need to, I can rest in my office or go home afterwards if I'm having a really bad day. In the last two years I believe I've only missed two class sessions because of lupus.

Even so, I need the support of others. I have four Teaching Assistants that help run the department, and one is assigned to every class I teach. They know the signs of lupus, and know to get whatever I need if I start feeling fatigued or start crashing.

Likewise, my colleagues in my office cluster know where I keep my stash of salt, drugs, Gatorade, etc.

With all that help, I'm able to carry on a fairly normal schedule at work. I can't teach early morning classes, and can't do two classes back-to-back or a meeting followed immediately by a class, but given the proper routine, I can function almost as normally as I ever did.

A friend of mine with full-blown SLE was in a different situation, but she had very understanding superiors, who allowed her to go home when she needed to, or lie down in her office. As long as the work eventually got done, they were accommodating. Unfortunately, even their flexibility wasn't enough, and the affects of the lupus eventually put her on disability.

At the other end of the scale is one of my phlebotomists (blood draw-ers): she's had SLE lupus for 22 years and is still working full time.

## **Church**

The fact is that standing is harder – more exhausting – than walking, and standing while singing is harder yet. After numerous Sunday-morning crashes, we finally developed a routine that works: I bring some beef stick and Gatorade to church and have a snack just as the sermon starts.

I always feel weird doing this, and always wonder what people think, but I figure that eating is better than lying down on the floor in the middle of the sermon. No one has ever said anything, and this routine allows me to attend and participate.

Sometimes having lupus means not worrying about what the neighbors think.

## **Driving**

When I'm feeling good, driving is no problem at all. But when the lupus symptoms hit hard, my cognitive functioning does not allow me to drive: I'm simply too confused or "floaty ."

Fortunately, I'm able to tell this before I get behind the wheel, and I've learned to live with the fact that my wife has to do much of the driving. This was a very hard adjustment for me: I spent ten years as a cop, and like to be in control of any vehicle I'm in.

But I've made that adjustment, and now actually enjoy being the passenger. The alternative – driving while incoherent – is unthinkable, as it puts too many people at risk.

What this means for my routine is that I never go very far alone in the late afternoon or evenings. Short trips are okay, because we can always manage to get both cars home if I'm unable to drive

and my wife has to come and get me. But for longer trips, I never go alone.

It's just part of the disease, and a change I've had to learn to live with. Sometimes lupus means giving up what was and learning to enjoy what is.

## **Alone in Public**

Ever since we started figuring out my needs and responses with lupus, I've had a fear of being alone in public: if I crash, the first thing someone's going to do is call 911. I don't need 911, I just need salt/protein/whatever. I crashed once outside the St. Louis airport, right on the sidewalk, and if my wife and friends hadn't been there, I would have been in the hospital.

So now, if I'm going somewhere public where I don't know anyone, and I won't have my wife, child or friend with me, I - okay, this is going to sound silly, but there's no way around that - I carry a 3x5 card in my shirt pocket that says "DO NOT CALL 911!" It also has a packet of salt stapled to it, and instructions to whomever finds me about the problem and how to deal with it, along with my wife's phone number.

My plan is that, if I ever feel myself starting to crash, I'll pull the card out of my pocket on the way to the ground. I haven't actually had to use this yet, but am comforted by the fact that it's there if I need it - I always have at least a few seconds warning of a crash, enough to pull out the card.

And if that sounds really strange to you, then here's another story: I was at the lab having a glucose tolerance test - the one where they draw blood from you about a hundred times in the span of an

hour (I exaggerate). This is a fasting test, so I was already feeling low. Sure enough, after one of the draws, I crashed to the floor. The phlebotomists freaked out, called nurses, who called doctors, who called for a crash cart. I wasn't totally out, but don't remember the incident, and was later told that I kept mumbling "I'm not dead! Don't zap me!"

So now I carry the card. Just in case.

## **Explanations**

Part of life for me now involves explaining my condition to others. Most friends want to know all the details. Others – like my dental hygienist just this morning – only need to know that it's okay if I lie down on the floor.

A couple weeks ago I had just gotten a haircut and was paying the bill when I felt a crash coming on. I calmly (I think – I really don't remember the incident) told the hair stylist, "I'm going to be on the floor and unconscious in a minute, but it's okay." As I said this I, apparently, was able to dial my cell phone and tell my wife I was crashing. Ten seconds later (in my mind; I have no idea how long in reality) I woke up to see my wife hovered over me. The quick explanation I was able to give prevented the hair dresser from calling 911.

I've tried not telling people about my condition, but eventually that just makes things harder. Sooner or later I'll have some manifestation of the disease and then the explanation is tougher to give. So now I just tell anyone I'm with right up front that I have this condition, and not to be alarmed if I suddenly need help.

The result, of course, is that I'm often asked, "How are you doing?" It's not like I have a cold and am getting over it - lupus is forever. So my standard answer is, "Good days, bad days." That usually answers their concern, without spending my whole life giving detailed explanations.



## My Diet

The biggest routine I have is my diet. I've already described much of this, but let me recap. The absolutes are:

- breakfast as soon as possible after I get up
- protein (meat or nuts) every 2 hours
- a full lunch, with carbohydrates, at 11:30 am
- a full dinner, with carbohydrates, at 5:30 - 6:00pm
- a snack, usually ice cream with nuts or leftovers from dinner, somewhere around 9:00pm
- Gatorade and/or salt tablets throughout the day

Probably the most important part in this, other than sticking to the routine religiously, is listening to my body: Biofeedback.

Over the years I've come to recognize and interpret the messages my body sends me about what it needs. At the first sign that something's wrong, I ask myself (or my wife or TA literally asks me), "How are you feeling? What do you need?"

Almost always, I can tell whether it's protein from nuts that I need, protein from meat, the dairy or whatever in ice cream, or if it's salt or drugs or a nap.

I say “almost” always because sometimes I read my body wrong, and take the wrong treatment. Sometimes, lupus is just going to have its way with me no matter what.

But most of the time, I can tell. As I said, it took years to figure this out, but it’s this paying attention to the biofeedback that has taken me from having constant crashes to having only a crash every once in a while.

## **Carb/Protein Ratio**

One of the saddest days of my lupus life was when I came to the realization and conclusion that I can only eat two brownies in a sitting.

Prior to lupus, I’d eat half the batter and then half the pan of baked brownies without a second thought. Experience has proven, though, that I must be careful how many carbs I consume at any one time.

We all need carbs, of course, just as we need some fat and salt in our diets. I used to cut way back on carbs to lose weight, but lupus no longer allows me that: I have to have sufficient carbs at each meal, but I can’t have too many. And when I eat carbs, they need to be balanced by the proper amount of protein.

This carb/protein ratio is critical to my feeling well at any given time on any given day. Again, it’s a matter of biofeedback, and a matter of finding the right ratio for the day and the meal.

Protein is by far the most important, and I always eat a large portion. But I have to be careful with the carbs. For instance, if I’m having Fettucini Alfredo at Olive Garden, I eat all the chicken

but only about a third of the pasta. It's hard to send it away, but I know if I don't the day will go bad very fast.

If having a hamburger for lunch, I'll eat the entire meat patty but only about half the bun.

The side benefit of this is that I do lose weight when I need to: fewer carbs, and fewer calories overall, means (for me) weight loss.

## **Ice Cream**

For whatever reason, ice cream works for me. Often I'll have a dixie cup or milkshake in the afternoon, and the rest of the time one in the evening (rarely both times on the same day). I'm guessing my body needs the dairy (calcium?), but it's also carbs and protein in a good ratio for me.

I must emphasize again that my responses to lupus work for *me* but may not work for *you*. Talk to your doctor before making ice cream a regular part of you diet!

## **Doggy Bags**

I made an amazing discovery after developing lupus: one does not have to eat everything on one's plate at a restaurant: they'll send the leftover home with you.

This has become important because I must eat more and smaller meals than I used to. But restaurant portions are notoriously large (they give us far more food than our bodies require). So I've really come to enjoy doggy bags – it's better for my lupus and better for my overall health to not eat all that food at once. Besides, I then get to enjoy a good meal twice, and save some money.

So now I *plan* for the doggy bag: I divide most restaurant meals in half as soon as I get them, and only allow myself to eat half. The other half makes a great snack later, or a great lunch tomorrow.

## **Beef Stick**

Sometimes I need a large amount of protein from meat very fast, and beef stick usually does the trick. I discovered this early in my lupus career when I was at the grocery store alone and started to crash. I was next to the deli and they had free samples of beef stick. I grabbed several, and in a couple minutes was fine.

For a long time we carried one-ounce slices of beefstick wherever we went. There are a few drawbacks, however.

First, beef stick is not only high in protein, it's high in fat. So a constant diet of it would probably not be recommended by most doctors.

Second, beef stick is really disgusting if it's warm, and even worse when it's hot.

We finally discovered that almonds make a good substitution for beef stick, and are actually good for your body instead of bad. So now I use much less beef stick than I used to, but at times it's still a great option.

## **Bedside Snacks**

I keep Ritz crackers and jar of peanut butter on my night stand for middle-of-the-night emergencies. Several times I've dreamt that I was crashing, only to wake up and discover I really was. A Ritz cracker dipped in the peanut butter is just the right combination of protein and carbs to bring me back quickly.

## **My Miracle**

For the first few years of my disease I was in constant and nearly unbearable pain. One of my doctors prescribed the anti-malarial drug Plaquenil to ease these symptoms, but I was really trying to avoid using any powerful drugs. Plaquenil has been around for decades, and has been proven safe, but I didn't want to be on a prescription drug if I could in any way prevent that.

Instead, I relied on NSAIDs – Ibuprofen, Tylenol and aspirin – to manage my pain. I rarely used more than 50% of the daily allowed dosage of any of them, but I used all three every day to ease the pain. It allowed me to be functional.

It didn't take long before all those NSAIDs ate a hole in my stomach, though, so my primary care physician put me on Prilosec to treat and prevent ulcers. Together, those four drugs kept me functional for the first few years.

But then, in the summer of 2008, I started needing fewer and fewer NSAIDs. I only ever took them when I felt actual pain, and I was feeling less and less pain as the summer wore on. That is, I felt less *severe* pain – pain is always there, but I've come to accept a certain baseline as “normal” now.

At the same time, I noticed I was getting far fewer lesions than previously.

Prior to that summer, I normally had six to eight lesions on my shoulders, face and scalp at any given time. It would take five to seven days of Desoximetasone to eliminate each lesion, and sometimes more. During the summer of 2008, though, I rarely had *any* lesions, and when I did, one or two applications of Desoximetasone was all it took to wipe them out.

"What's going on here?" I remember thinking toward the end of summer. As the fact of my fading symptoms reached my conscious, I was perplexed. "I guess this must be what a remission is like," I told my wife.

Then in the fall of 2008 I read in an email from the Lupus Foundation of America about two studies that had shown a significant reduction in symptoms by taking fish oil.

Fish oil! I had started taking fish oil as a general heart disease preventative in the spring of 2008. I took one each day that whole summer. The results reported in the LFA studies matched exactly my own results. It was a miracle!

Immediately I started taking *two* fish oil capsules per day. Three is allowed, but again, I try not to take more of anything than I need to. With two a day, my pain has remained at a constant, but bearable, level ever since. I rarely have any lesions now, and they are almost always wimpy - about all I have to do is show them the tube of Desoximetasone and they retreat.

As with all things lupus, there are still bad days and exceptions of course. Even as I write this, I've had a stubborn lesion on my eyelid for two weeks. I'm also having a flu day, with lots of pain. And even on "normal" days, the pain is omnipresent. But it has

been so drastically reduced that, in comparison, it feels like I'm healed.

Now, instead of constant NSAIDs all day, I take one or two doses. Many days, I take none at all.

Is it just a long remission? I don't think so. If we go out for dinner and I forget to take a fish oil capsule, the excruciating pain returns that evening, until I realize I missed a dose. And some days I need to take that third allotted capsule for particularly nagging pain. So there seems to be a direct correlation.

Fish oil does nothing for all the other symptoms of lupus, but simply reducing the amount of pain and the number of lesions has made my life much easier.

But I'll say this one more time: every lupus victim has different manifestations and responds differently to treatment. Fish oil may not be the miracle for you that it has been for me. That said, I'd run out and buy a bottle if I were you.



## My Faith

Popular media and culture have painted a bleak picture of Christians as narrow-minded, hateful, and exclusionary. The behavior of many “Christians” hasn’t helped at all. But the Christ of Christianity was nothing if not inclusive, accepting, and loving. You could say that he was the perfect God. And I believe he is.

My relationship with that God began when I was five. I gave God a test, to prove his existence, and when he failed that test I decided to believe in Him anyway: I knew that the presence I felt in my soul was real. I’ve been a Christian ever since.

Though I’ve doubted many times in my life, researched both the empirical and spiritual evidence, and refined my understanding and belief of what it means to be a Christian, I always come to the same conclusion eventually – the unshakeable belief that there *is* a God, and that he cares about me personally.

So why doesn’t he heal my lupus?

I’ve asked, of course. Begged, even. Why doesn’t God listen?

In the immaturity of my youth I expected God to be something like a servant: snap my fingers and I get what I want. Maturity has led me to the realization that God doesn’t exist to right all the wrongs in my life, He exists to have relationship with me. Sometimes that relationship results in miracles of healing or

opportunity or protection. Sometimes it simply means He weeps with me through the pain.

Sometimes it means fish oil pills.

But, as I told the student body at the university one day, not knowing is the whole point of faith, and the whole *point* of faith – when you reach the point where you can say, “I don’t understand, Lord, but I believe in you anyway.”

To an atheist, agnostic, or secular humanist that sounds like nothing more than religious babble, something akin, perhaps, to the brainwashing by cult leaders that has destroyed so many lives. But to one who has honestly assessed the possibility, probability, and presence of God, it’s the only response that makes any sense.

I’m not preaching here – you have your beliefs and I have mine, and that’s okay. But for me and my house of lupus, I could not survive without knowing there’s one greater than me who is holding my hand through all this.

## My Support

I also can't imagine going through the last four years without more terrestrial help. My family, friends, colleagues, and TAs have kept me going through all my various manifestations of the disease. But it is my wife, Elsie, who deserves the vast majority of the credit.

I know that not everyone who reads this will have the kind of super-spouse I do. And I know that, statistically, many lupus spouses walk out on this tough situation. It is not my intent to rub salt in marital wounds here, but rather to encourage the spouses of lupus victims that partnering in the "bad" of life makes the "good" of life so much sweeter.

Here are just a few of the things my wife has had to put up with:

- We can make plans, but can never know if I'll really be able to go through with them
- She has to keep track of what and how much I eat
- She has to be ready to change plans in mid-stream if my condition changes
- At any moment I can be on the floor, sidewalk, or road, and she has to be there to care for me
- She has to constantly explain to others why I'm not making sense, why I can't remember, why I can't lift/carry/load something
- For any kind of physical labor, such as carrying suitcases,

she has to do far more than her share, so I don't become exhausted

- Abandoning the purse she loved, she has to carry a purse large enough for all my needs: Gatorade, drugs, snacks, etc.
- She has to be ready to come and get me if I'm driving and suddenly can't concentrate
- She has to put up with me spending much of my time at home on the couch taking a nap, suffering with flu symptoms, or just being too weak to move.

As I said, my wife is a super-spouse, and these are just a few of the things she must endure.

But the literal care and feeding of Arnie falls on other shoulders as well. I've found it's best to teach a few close friends and colleagues what lupus means to my functioning, and how they can help me when the need arises.

My TAs have been especially good at this, since they spend so much of the day with me. It's not unusual for them to bring me a cup of ice cream or a salt tablet in the middle of class, when they see I'm having trouble getting my thoughts out. They've had to carry my books, bring me a chair to sit in, bring me my snacks, and help me up the stairs. They've been great.

Of course, my own family is just as willing to help. My children also "force" salt in me at times, often bring me snacks, and fill their own refrigerators with Gatorade for when I visit. At first, seeing me on the floor, semi-conscious, was a bit frightening to them I think. But after a while it became almost routine and they'd just step over me, continuing their conversation, without a second

thought.

I've been very blessed with the support I've had, and it's literally made all the difference for me; it allows me to do what I do.

If you don't have that kind of support, I hope you'll find some. Show this booklet to your family, if you have any. Ask a friend to be your "lupus companion." It's not glamorous, to be sure, but I think, in a sense, it is fulfilling. Doing something selfless usually is. Don't be afraid to ask: it could turn out to be as much a blessing to them as it is to you.



## My Life

My Life changed forever in June of 2005. Though we wouldn't know if for another ten months, it was then that the first infection that would eventually lead to lupus entered my body. I have no idea where I picked it up.

Once I was diagnosed, I entered the grieving process. Though I don't think I ever denied the reality of my disease intellectually, I was angry, and I was depressed, over the loss of my health. And I denied the reality in my behavior: I thought I could still do all the things I used to do, thought I could "tough it through" and beat this thing by force of will. Eventually, I came to accept that I now have limitations on my life.

But still, I have vowed not to give in to lupus, which means I have vowed not to let it ruin my life. The facts of life now are that sometimes I really can't get off the couch, but most the time, if I make myself, I can get up and do the things I want to do. Often I'll be feeling poorly as we're getting ready to go out and my wife will say, "Let's just stay home." Sometimes that's necessary. But most times I say, "No. We're going. If we only do things when I'm feeling perfect, we'll never do things."

Maybe it's a matter of attitude.

So life now is regulated, regimented, restricted. But it's not over. In the four years since I've been diagnosed I've been to Europe three times. While there I hiked in the Alps, walked all of Venice,

stood at the top of the Eiffel Tower, and explored Dublin on foot. I've climbed a waterfall in Oregon, driven across the country in a moving truck, taught 1500 classes, and spent dozens of 14 hour days on the sets of films and TV shows.

And I'm planning to go skydiving with my son.

None of that is as easy and free as it used to be, but that doesn't mean it's impossible.

Living with lupus is living moment-by-moment. For me – and again, I recognize that many people have it much worse than I do – it means constantly monitoring my body and responding to its needs. It means walking slowly up the slightest incline, sitting and resting often, not being embarrassed to ask others for help, and knowing where the nearest salt tablet is at all times.

It means admitting that I am sometimes not safe to drive, and monitoring my cognitive functions to know when it's one of those times.

Lupus means a lot of things, and it means a different set of things for each of us who suffer from the disease. But though the severity and manifestations of our symptoms differ, there is one thing that is true for all of us, something that has given me hope, and at times even brought me to tears:

I am not alone.

I am not crazy.

I am not making this up – it's not all in my head.

Others are experiencing exactly the same things I am.

I am not alone.

My Lupus is unique, but in one important way My Lupus is exactly the same as yours: it cannot destroy me. Even if it kills my body, it cannot kill who I am, how much I'm loved, or my potential for doing good in this world.

My Life is not my disease.

## One Man's Lupus

Writer, producer, director, university professor - Arnold Ytreeide has led a busy life. Add to that list "twenty-four hour caregiver" for three parents with Alzheimer's Disease, and Arnold's days left little time for anything but church, family, and work.

It certainly left no time for a chronic disease.

But in the summer of 2005, a chronic disease is exactly what he got - the autoimmune disease lupus.

Diagnosis did not come quickly, though, and neither did an understanding of the disease and its treatment. With the help of his wife Elsie, Arnold has spent four years learning what lupus means for him, and how to manage the symptoms for the best possible quality of life.

And now he's sharing what they learned.

*My Lupus* is about the unique manifestation of the disease in Arnold's life. With the understanding that every lupus victim faces a different set of symptoms, but knowing there are also many similarities among those victims, he shares in this short text the story of his journey, his symptoms, and what he's found that works.



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