

*Even after years of struggles with lupus and three lupus-induced strokes, Katy still finds joy and love in her life and still looks for the good in people and circumstances.*

## **Love and Lupus:**

**A love story around one woman's lifelong struggles with Lupus**

By Ken Conklin

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K E N   C O N K L I N

# Love and Lupus

**An inspirational story of a couple's love  
and their struggles with lupus**

*"I'd stay married to you even if I didn't love you because you  
always make me laugh!"*



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Print ISBN: 978-1-958889-33-6

Ebook ISBN: 979-8-88531-475-6

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Published by BookLocker.com, Inc., Trenton, Georgia.

Printed on acid-free paper.

BookLocker.com, Inc.

2023

First Edition

Library of Congress Cataloguing in Publication Data  
Conklin, Ken

Love and Lupus: A love story around one woman's lifelong struggles with  
Lupus by Ken Conklin

Library of Congress Control Number: 2023903505

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*Ken Conklin*

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## **Chapter 1: The Beginning**

“Will you marry me?” I asked Katy as we danced at the New Years Eve party at my niece’s home in Denver.

“We know we love each other, and my lease is up in February.”

Katy laughed. “Well, of course I will, you silly goose. Especially since your lease will be up anyway and you’ll need a place to live.”

We first told my brother, Rob, and his wife Shirley about our marriage plans. Shirley said, “I’m so glad you asked her, Ken. Remember what Rob and I told you at the Thanksgiving dinner, to not let this one get away.”

We then announced our news to the rest of the party goers who also had a chuckle over my proposal. We received a lot of congratulatory remarks, and everyone was happy that I had found Katy, even though it had only been two months since we met at a pre-Thanksgiving party.

The occasion had been a progressive dinner hosted by the local Parents Without Partners (PWP) organization. I was recently divorced and had two children, Tammy and Kenny, that I regularly saw on weekends. A friend from my workplace, who was also a divorced man with children, asked me to join him at the PWP Thanksgiving party that coming weekend. I first said no.

I wasn't into groups like that. However, when he said the gals in the group were really good cooks, I thought of the frozen dinners in the fridge at my apartment and decided to go.

Katy liked to tell the story of our first meeting at that dinner in her own good-natured way not to embarrass me but just to share a funny incident. She wouldn't intentionally hurt my feelings or anyone else's.

"It must have been his smile," she would begin. "Because his sense of style was sorely lacking. "He wore a moss-green corduroy sports coat with patches on the sleeves (like a college professor), orange and brown plaid pants, a cream-of-grape-soup color denim shirt, and engineer boots."

I would counter with, "It was the seventies after all, and I could have worn my striped leisure suit."

She would laugh and say, "It was the seventies alright, but remember he's also colorblind. He thought he was wearing a brown coat to go with his brown slacks, and he swore his shirt was blue."

I would laugh at my own style sense along with everyone else. That was one of our mutual bonds, the fact that we could laugh at ourselves.

As the party progressed to the next course, and then the next, we consumed excellent dishes as we moved from house to house, Katy and I found ourselves sitting next to each other at every table. In our conversations, I learned that she was an English



teacher and department chairman at the local high school; and I told her that I was a technical writer for high-tech company.

After dessert, at the last home, the hostess had music going and room for dancing. Katy and I danced every dance, except one, when an interloper asked her to dance while I was getting a couple of drinks. I sat our drinks down and cut in on the guy, who reluctantly relinquished Katy's hand.

“The nerve of that guy,” I said, “trying to get my girl!”

“Oh, so I'm your girl already?” You move pretty quickly there, Mr. Conklin.

We both had a chuckle and finished dancing together to Neal Diamond's *Hot August Night* album, singing along to the words from “Play Me”. “You are the sun, I am the moon; you are the words, I am the tune, play me.” Needless to say (but I'm saying it anyway) “Play Me” became Our Song. We were literally falling in love.

While at the PWP party, we had a chance to talk and learn more about one another. She told me that she had just moved to Colorado two years prior from Illinois. She said that she too, was recently divorced, had a 2 ½ year old daughter and was teaching at Longmont High School; and that she had also not been intending to come to the PWP party but that a friend had dragged her along.

Could this be providential? I thought to myself.

Thanksgiving was coming up the following week, and when I learned that she was going to be alone for Thanksgiving, I told her that I had been invited to join my brother, Rob, and his family for their Thanksgiving dinner and would she like to come along. I knew Rob and Shirley wouldn't mind a bit, so Katy said that would be lovely. Katy was a trusting soul. She had just met me and now I was going to take her to meet some of my family in Denver. We could have been a gang of bank robbers or cattle rustlers for all she knew.

It turned out great. Everyone loved Katy.

To return the favor, Katy said she had been planning to go back to Illinois for Christmas and asked if I would like to come along and meet her family. Of course, I said yes, and added that the rest of her family must be okay; after all her dad's a minister, isn't he?

"Tell them that I have good hair and teeth." I said.

I was glad to meet her family and they seemed to accept me into their realm as well. We all enjoyed being together.

A new year was following close behind, and my niece invited Katy and I to her New Year's Eve celebration. It was at this party that I introduced Katy to more of my family and I asked her to marry me.

After the New Years Eve party, we decided to set our wedding date for Valentine's Day, continuing our trend of doing big things on holidays. Therefore, January was a flurry of activity

as we tried to get our ducks in a row. After conferring with our minister, Reverend Davis, we decided to ask Katy's father, a Methodist minister in Illinois, to assist Reverend Davis in the ceremony at our United Church of Christ church in Longmont, Colorado. Katy asked her sister Marge to be maid of honor and I asked my brother, Rob, to be my best man. His twin, Rich, had been best man at my first wedding so, I changed brothers for a change of luck. I also asked a friend from work, who was a cake decorator on the side, to make us a heart-shaped cake. To further add to the Valentine theme, Katy and I spent a couple of evenings making heart-shaped mints. Yes, we went for the schmaltzy for our Valentine's Day wedding.

Her parents and her sister came from out-of-town a few days before the wedding to help with the last-minute details. Katy's mother's task was to babysit Kirsten while we rehearsed the ceremony. However, an unexpected tragedy occurred earlier that day. My job was to drive fifteen miles to Boulder to pick up the cake. And a beauty it was. Three heart-shaped layers with pink frosting. each layer surrounded by rings of roses and some larger red roses on the top center.

After I picked up the cake from the cake decorator's apartment, I carefully sat it on the passenger side of my car which had bench seats (as most cars did in those days). Then, I carefully left Joan's apartment and headed out of Boulder to get on the Diagonal Highway, the main route from Boulder to Longmont. As it happened, there was only one traffic light on the highway at the exit road for the town of Niwot. I was only going about 45mph when the light turned yellow, and I carefully slowed down for a

stop. As I slowly applied my brake, I noticed a movement on the passenger seat. I felt my heart stop as our beautiful cake was sliding forward. How do you stop a three-tiered, unboxed cake from sliding off of a seat without trying to stop it with your arm? Too late, I watched in horror as all three layers slid onto the floorboard.

A few minutes later, I pulled into the driveway of Katy's house in Longmont. I'm sure there were tears in my eyes as I carried the damaged masterpiece into the house.

"I've ruined our cake!" I shouted as I entered the kitchen where the women were gathered.

"What happened," asked Katy.

"The cake had a wreck," I said.

Katy looked at the broken cake I carried in my arms and saw the horrified look on my face and said, "It's okay, honey, it's not about the cake. We'll manage."

As I explained the tragedy, Katy's mother took it from me and sat it on the table to assess the damage. "I might be able to repair it," she ascertained. "Get some powdered sugar, flour, and food coloring and I'll see what I can do."

Katy's mother was a clever, crafty sort, and so I was greatly relieved that she might be able to save the day and save my hide. She took the crumbly cake parts to the kitchen and went right to work while the rest of us got ready to go to the rehearsal. The downside of having Mary work magic on the cake was that she

wouldn't be able to babysit Kirsten at home, thus adding to our series of unplanned occurrences,

Because of the cake caper, we took Kirsten to the rehearsal. She had a good time running around the church and participating in the rehearsing of our wedding vows while Katy's mother stayed home and rebuilt the cake.

We were amazed at how well the cake reconstruction went. You couldn't tell it had been in a horrific accident. There were a few toothpicks inside to hold some pieces in place but otherwise it was a masterpiece. I felt delivered. The wedding itself wasn't as smooth but was just as memorable.

Our wedding was held in the United Church of Christ where Katy and I had been attending. The Reverend Newel Davis and Katy's Methodist minister father, Bert, officiated. My brother, Rob, was best man and Katy's sister, Marge was Maid of honor. The guest list consisted of some relatives and a few friends from Katy's school and from my workplace; about 50 in all. My children had been invited, but declined which was fine. We understood they were young and still hurting from the divorce.

Katy's mother was sitting with Kirsten as the ceremony began. After our two ministers said a few introductory words, Kirsten escaped from her grandmother and ran up to the pulpit to join in the action. Katy signaled to grandma that it was okay, just stay seated. So, as the ministers went through the wedding vows, Kirsten crawled around our legs and at one point Katy held her, then I held her, then Bert held her as we came to the I Dos. For

years after, Kirsten would tell people, “It was, “When we married Daddy.”

The reception went well, and everyone admired the beautiful heart-shaped cake, never guessing that it had been the victim of a dreadful accident. After the reception, Katy and I said our goodbyes and left for our short honeymoon (we both had to be back at work on Monday). As we left the church, we found that 12 inches of snow had fallen during the ceremony. This was February in Colorado.

As we left the church, I reached for Katy’s hand, noticing that she didn’t have her gloves on. As I closed my hand on hers, she uttered an “Ouch, my fingers are sore! Must be some arthritis,” she said. “I’ve been noticing more pain lately.”

She put on her gloves, and I helped her into the car. Little did we know at the time that this arthritic episode may have been the forerunner to a more severe problem. A wolf was sneaking up on her.

Our one-night honeymoon was to be at a nice hotel in Boulder. As we left the church, we realized that the entire landscape was covered with a foot of new snow. When we reached the road to Boulder, we saw that it was covered with snow.

“Looks like we’ll be plowing our way to Boulder,” I said. “They haven’t cleared the road yet.”

“Well, our adventure continues,” said Katy. “At least we can look forward to some champagne when we get there.”

I drove slowly and carefully so a normally 30-minute drive took well over an hour and when we arrived at the hotel, we parked and made our way into the lobby. After we checked in, I asked about some champagne. “Oh, we’re sorry. The bar closed 15 minutes ago.” Katy and I looked at one another and laughed.

The next day, we had a nice breakfast and then drove to Denver. Why? You may ask. Well, this was my weekend to be with My kids. So, to help ease my son Kenny’s trepidation about my marriage, we decided to take him bowling. We had a good time bowling and then we made arrangements to take Tammy to dinner later that week. Even without a new marriage, Katy wanted to try to ease into Kenny and Tammy’s lives.

And so, my life with Katy as my wife began.

## **Chapter 2:**

### **We meet the Wolf**

Her fingers were turning blue, and she said they felt cold. I reached for her hand and felt her cold fingers. This was the middle of July. I also noticed her cheeks were looking like she had a reddish blush on. These body changes went on for several days, sometimes with less discoloration and cold feelings, but continually recurring. She also experienced an increase in pains in her joints and arthritis in her hands. We knew it was time to check in with our doctor in Longmont, Colorado, where we were living at the time.

After a preliminary exam, Doctor A, our internist, said that he had seen some similar symptoms and that they might be indicative of an autoimmune disorder. Your cold fingers appear to be Raynaud's Syndrome. He said, "Raynaud's Disease is what happens when the blood vessels contract and restrict the flow of blood to the hands or feet, or both. It happens to many patients who have an autoimmune disease."

He ordered a complete physical, including several lab tests. When the results came back from the lab, he said that they showed some high ANA numbers, antinuclear antibodies, which could indicate lupus. Therefore, he recommended that we see a rheumatologist because her tests revealed there were some problems with her immune system. He referred us to a prominent rheumatologist he knew at a large hospital in Denver.



Needless to say. We were more than a little concerned.

“What does this mean?” I asked the doctor.

“That’s why you need to see a specialist,” said Doctor A. “There are several possibilities for your problem, including rheumatoid arthritis. This is a great research facility, and they can perform all the tests you need to narrow down the possibilities.”

Driving home from the doctor’s office, I told Katy that this hospital had a great reputation, and I was glad we were being sent there.

“I’m glad too,” she said. “But should I be concerned. This is kind of scary?”

I just shrugged my shoulders and reached to grasp her hand. She said that she really appreciated Dr. A being so thorough and careful. In hindsight, we realized that not every GP (General Practitioner) would have checked her ANA numbers, let alone even run those labs. So, looking back, we felt very fortunate.

We met with Dr. B, a renowned rheumatologist, at the hospital, who ran his own set of labs to verify and augment what Dr. A had tested. The results were not what one would want to hear.

“All the lab tests and your physical exam point to SLE or Systemic Lupus Erythematosus,” he told us.

We looked at each other and shrugged, not really knowing what that was.

“Sorry,” he said. “Systemic lupus erythematosus (SLE) is the most common type of lupus. “Now you’re wondering what lupus is. Unfortunately, it’s an autoimmune disease where the immune system attacks its own tissues, causing widespread inflammation and tissue damage in the affected organs. It can affect the joints, skin, brain, lungs, kidneys, and blood vessels.”

“What can we do about it?” asked Katy. I squeezed her hand and we both looked at Dr. B.

He looked right at Katy and said, “I’m sorry to say that it’s incurable, but the better news is that it can be managed with some lifestyle changes and medication.”

With further discussion, we learned that she would have to take daily doses of Plaquenil (Hydroxychloroquine), to help alleviate the immunosuppressive effects. He further added that this medicine was initially used to treat malaria but has proven to be effective for treating lupus. He added that one of the side effects of Plaquenil can cause damage to the vision, so she would need to have her eyes checked yearly by an ophthalmologist.

He also told her to avoid too much sunlight, take daily doses of an anti-inflammatory like Tylenol, and minimize stress and fatigue as they will exacerbate the lupus symptoms. He added that she might need to use prednisone on occasion if lupus flare ups become too severe. He explained that lupus flare-ups occur when the body overreacts to SLE, causing achiness, joint soreness, a lupus rash, and fatigue. However, he added, “We need to be careful with steroids, like prednisone because they may interfere with your immune system and cause other problems.”

“We also know that lupus is a disease of opportunity in that we can’t predict where it will decide to attack. It’s like its namesake, the wolf, a predator that stalks the weakest link. It may hit your lungs, your kidneys, your skin, your blood system, anywhere at any time. Also, they call the disease lupus because the rash, or markings on the cheeks, resembles the facial appearance of the wolf, and it can cause your immune system to attack your entire body like a pack of wolves.”

“Can I still have a life?” asked Katy

“So far, it appears that your lupus is affecting your joints and skin similarly to rheumatoid arthritis. Based on what I’ve seen, your lupus appears to be fairly mild, and it could stay in remission for several years if you take your Plaquenil and anti-inflammatory medicines.”

“The best way to handle a chronic disease is to always take good care of yourself,” he added. “That means seeing your GP, your ophthalmologist, and your rheumatologist on a regular basis. And maintain that positive attitude that you have.”

“By the way,” he continued. “Lupus is related to rheumatoid arthritis, and you said you have an aunt with Sjogren's disease, which is another autoimmune disease, and she has some arthritic symptoms. Also, your mother has some arthritis. Some forms of autoimmune disease often show up with relatives. So, I would suggest checking with your family members to see if anyone else has some similar symptoms.”

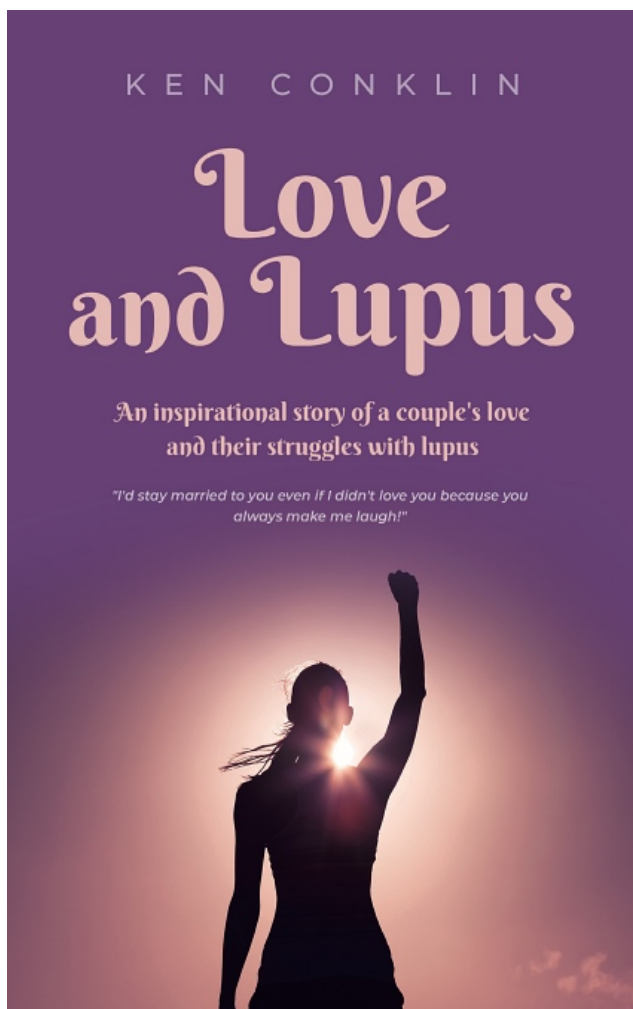
With our newfound knowledge of her disease, we left Denver and drove back to Longmont and between some tears and discussion, we decided that we would fight this wolf disease with all the resources we had. We thought that we should first develop a battle plan and we began making a list of what we would need to do.

Being the positive person that she was, she said she would not let this disease ruin her life. And, being a faithful person, she felt that God would help her get through it. “God won’t give me more than I can handle,” she said.

One day early on in, she said to me, “You know what. I’m really pretty lucky. A lot of people have worse problems than I have. The doctor said I could live a normal life and may never have a bad time with the lupus.”

I nodded and agreed. But, deep inside, I was a bit afraid of what the future held for us.

“I want to keep working and just take care of my body as best as I can,” she said. “I’ve never been one to just sit around and twiddle my thumbs. I need to keep busy and feel worthwhile.”



*Even after years of struggles with lupus and three lupus-induced strokes, Katy still finds joy and love in her life and still looks for the good in people and circumstances.*

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