PORTRAIT OF A MARRIAGE
Becky and Joe Salacki

IN SICKNESS AND IN HEALTH

"When love exists, nothing else matters—not life's predicaments, not the fury of the years, not a physical winding down."

—ISABEL ALLENDE

WRITTEN BY Stephanie Booth
PHOTOGRAPHS BY João Cenriani
At the time we got married, we were on top of the world. Our careers were in high gear. And we had found our soul mates.

Every marriage begins with vows. But what happens when these vows are put to the test? For Joe, 54, and Becky, 56, of St. Louis, that’s the challenge they’ve faced in the decade since Joe was diagnosed with multiple sclerosis (MS), a chronic disease in which the immune system attacks the brain and the spinal cord. Becky has gone from being in a union of equals to one in which she is both the primary caregiver and the sole breadwinner. That change has rocked their daily lives and even caused them to question their roles in their 20-year marriage. But one thing hasn’t altered: their shared love for and commitment to each other.

In the beginning
Joe and Becky first met in 1990. Both were restaurant managers for a chain of restaurants headquartered in North Carolina. At the time, they were unapologetically married to other people.

BECKY: My husband of 16 years and I were still friends but no longer in love. We had nothing in common anymore.

JOE: After eight years, my wife and I had grown apart, too.

BECKY: I wasn’t crazy about Joe early on. He griped about the restaurants I overviewed.

JOE: That’s true, but I admired the way that Becky worked. I appreciated her commitment to her job—and, you know, I thought she was beautiful.

BECKY: We spent many hours together, and over time we found ourselves talking. We both loved NASCAR and baseball.

JOE: And football!

BECKY: I’ll choose baseball over a reality show any day.

JOE: That was exciting for me.

BECKY: Eventually we confided in each other about our failing marriages. Within the next year, both of us separated from our spouses and we began dating.

JOE: In the spring of 1995, both of our divorces were final.

BECKY: Joe was so romantic. I had never experienced that before in my life. He wrote me poems and sent me cards. When we were apart, we talked on the phone for hours. That’s how I knew I was in love.

JOE: Because Becky and I got together as our marriages were ending, a lot of people thought—or maybe even wished—that we wouldn’t stay together.

BECKY: But we did. That July I threw a birthday party for Joe. He stood up in front of the guests and read a poem [seen on opposite page] in which he asked me to marry him. It still gives me goose bumps when I think about it. Four months later, we were standing before the justice of the peace.

JOE: Not that it was smooth sailing from that point on. My son, Trey, who was six at the time, accepted Becky, but her daughters—Stefanie, then 12, and Kim, 14—had a tough time with me as their new stepdad.

BECKY: That was a challenging time.

JOE: Still, we were on top of the world. Our careers were in high gear. And we had found our soul mates.

Ignore it—maybe it’ll go away
Years earlier, when he was in his 20s, Joe sometimes felt the fingers on his right hand turning numb, but doctors never discovered anything wrong. In his mid-30s, a few years into his marriage with Becky, he began having issues with his right leg. The muscles occasionally swelled without warning, causing him to struggle when walking long distances or rise his balance. But Joe and Becky explored every possible option. Joe had been sitting too long in front of his computer screen at work or just been exhausted.

STEFANIE WHITE, 32, BECKY’S DAUGHTER: My sister and I lived with Joe and my mom. As a kid, I remember Joe coming into the house after work walking funny—just kind of dragging his leg. I didn’t think it was anything bad. I thought it was just Joe.

BECKY: When he was tired, Joe walked with a stiff leg. But he didn’t talk about it, and I didn’t bring it up. I was in denial.

JOE: Then I was at work one day and suddenly felt a tightening sensation below my brachioradialis that stretched around my arm.

BECKY: Now we know that’s a symptom: called the “MS hug.”

JOE: My doctor ordered a stress test on my heart, which came back normal. So I had no diagnosis. A few months later, each time I stood up, I took my body a minute to get into gear when my brain said, “Walk.” I still didn’t panic, though. I figured, I’m in a high-stress job, never taking my foot off the gas. Maybe my body is simply reacting to that.

Things fall apart
In 2000, after accepting a promotion, Joe moved with Becky and Stefanie to St. Louis. (They remained with his mother in North Carolina, and Kim was working in Virginia.) At first things went well: Becky found a new position overseeing a group of restaurants.

But Joe’s imbalance and fatigue become impossible to ignore. Unseen surfaces made him trip. He couldn’t make it down an airport concourse without stopping to rest. Then, the following year, he was abruptly downsized.

STEFANIE: Joe was a corporate hobo. He loved his job. When he lost it, I’m sure it felt like his life was crumbling. On top of that, it had to have been scary not knowing what was wrong with himself physically.

JOE: I saw four doctors, underwent numerous tests, and even had brain surgery in 2003 because a neurosurgeon believed that my symptoms were caused by pressure on my brain stem. When that didn’t help, I was upset. I just wanted an answer.

Then, in February 2002, my neurologist ordered a lumbar puncture, a test to check my spinal fluid. She called while Becky and I were cooking dinner several nights later and matter-of-factly explained that I had multiple sclerosis. Six months later, we learned that it was the primary-progressive type.

BECKY: There are four types of MS, and this is considered one of the worst, because there are no periods of remission. Like all MS, it causes a huge array of debilitating symptoms, from terrible vision problems to memory loss to paralyzing, and it has no cure. In rare cases, it can be fatal.

JOE: All of a sudden, I was out of work and had this diagnosis?

I remember thinking, What the hell am I going to do? I was in shock. And I felt guilty. My disease was going to affect not only my life but Becky’s, too. I mean, I went from a six-figure job to applying for disability insurance.

BECKY: I was at a loss. I felt so helpless. With Joe not working, we couldn’t afford health insurance. It took all of our money just to maintain a normal standard of living.

JOE: I isolated myself a lot that first year. I didn’t want to share my diagnosis except with my loved ones. I didn’t want pity, or help. But Becky never pulled away from me. Never.

BECKY: I knew other couples dealing with MS who seem so bitter, with the caregiver always yelling at her spouse, who suffers from the disease, for things that aren’t his fault. I vowed not to let that happen to us.

TREY SALACCI, 26, JOE’S SON: I was 16 when my dad was diagnosed. At first I worried because I didn’t know what was going to happen. And then, as I learned more about the disease, I worried because I did.

The struggle for independence
For MS patients, it’s a constant battle to find a medication that can reduce relapses, slow progression of the disease, or relieve specific symptoms, even temporarily. The initial course of treatment that Joe

Above: Becky and Joe on a cruise to celebrate their fifth anniversary, in 1997. Left: Joe’s backup wheelchair.

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was given—a series of infections—did little more than make him feel fatigued. During the first year following his diagnosis, Joe’s condition rapidly declined, and he suffered from depression.

Joe: I didn’t know what to do with myself. I spent hour after hour in front of the TV, watching CNN. Not until Becky came home each night did I feel that everything would be fine. We just talked about your day at work, vaguely about my condition.

Becky: I was angry—not at Joe, but at the disease and the life it was taking away from us. We used to be spontaneous, going to stock-car races, taking road trips. That was all over now. When I felt down, I took long walks, trying to cheer up by listening to Eric Clapton.

Joe: That first year was tough. I went from using a cane to a walker to mostly using a wheelchair. But I still wanted to do everything myself.

Becky: I’m a fast-paced person, going 100 miles per hour. As soon as I saw Joe struggling with something, I would try to do it for him.

Joe: I wasn’t bashful about saying, “Stop! I want to do it myself!” Becky didn’t always appreciate that. She would give me the “task.”

Becky: When I get mad, my voice goes up an octave. Joe: I still get the “task” a lot.

Trev: becky had to be very patient, allowing my dad to try to get a glass of water or pick something up if he dropped it, rather than jumping in to fix the situation.

Joe: I didn’t like having to give up control. It took me a while to learn to depend on other people.

Redefining marriage

In 2000 Joe and Becky realized that he could no longer handle the stairs in their house. They reluctantly sold it and moved into a one-story, wheelchair-accessible home in a retirement community in the hopes that Joe would feel more independent. However, the move didn’t solve all their problems.

Becky: In 2008 I was away on a business trip. When I called Joe from the Orlando airport, he acted like everything was fine. Only when I called back, as I drove from the local airport to our house, did I hear tears in his voice. Joe said, “You have to get home.”

Joe: I had fallen while getting out of bed that morning. I thought I could walk to the bathroom, grab one of the assistance bars, and pull myself up. But I couldn’t make it.

Becky: He had been lying on the floor for seven hours. I said, “Why didn’t you call 911?” Joe told me he needed to preserve his dignity. That’s when I decided never to travel again unless someone was there to stay with Joe.

Joe: I hated limiting Becky’s options. I hated hearing the fact that her colleagues often said things to her like “How do you do so much? I couldn’t do it.”

Becky: I became more of a loner at work. I assumed people didn’t want to hear about the life of a caregiver.

Joe: I started acknowledging that there were things I couldn’t do anymore—from driving and lifting heavy objects to taking care of household repairs. Becky had to take over many of those roles in the marriage. My ego could have been bruised, but Becky never acted as though I was her patient. She just treats me like her husband, with love and respect.

A different kind of together

Over the last few years, Joe’s condition has continued to deteriorate. He’s determined to adapt. His wheelchair is fully motorized, and he uses a voice-activated device to type e-mails, use the phone, and make video slide shows. Still, he needs more physical assistance than ever before.

Becky: On weekdays we both rise at 5 A.M. I don’t have to leave for work until 7:15, but we like to have coffee together and watch the news. Also, Joe can’t get out of bed on his own.

Joe: I’m like a Weeble Wobble.

Becky: I help Joe into his wheelchair, then assist him as he gets in the shower. I wash his hair and bathe him.

Joe: Taking a shower is the worst part of my day. It takes a while to get all my damp body parts working.

Becky: Afterward I brush his hair, put on his deodorant, and put on his clothes. I make his breakfast. Then, finally, I leave for work.

Joe: Our evening routine has its own challenges.

Becky: I have to put our dog outside, charge his wheelchair, get him undressed, get his medicines, and help him to the restroom.

Joe: We try to watch TV together in the evenings, but Becky often falls asleep on the couch. I feel badly that I have to wake her up to get us both into bed. She’s so tired.

Stefanie: I told my mom, “I’ll never understand what you’re going through.” It makes me want to cry. Joe can’t cut his own food, he can’t dress himself. When Mom is home, she has to help him to the bathroom, get him to bed, wrap his feet up so they don’t get cold. And I’ve never heard her complain, even when I’ve given her the opportunity.

Becky: I try to stay upbeat. Of course, I do sometimes feel envious of friends who don’t have caregivers that I have very little—if any—to myself. And I have concerns over money; we have so little saved. But mostly I worry about Joe. He never leaves my thoughts.

Joe: She comforts me every day, with her words and actions.

Becky: We used to make love several times a week. I miss it, but it’s especially difficult for Joe.

Joe: Not being able to show Becky my affection is my greatest struggle. It’s the worst thing this disease has taken from me. Becky: It’s hard for us to hold hands anymore, but I still try to put my fingers in between his.

Joe: I feel that love, whether we’re touching or not.

Becky: We don’t talk about the future. It scares the hell out of me. My biggest fear is that something will happen to me and I won’t be able to care for Joe.

Joe: I’m afraid of being separated from her. I’ve had a few nightmares where Becky pulls our van over to the side of the road and makes me get out.

Becky: Whatever happens, Joe is my soul mate. He is stuck with me for life.