

IN SICKNESS, IN HEALTH, IN LOVE

After several blissfully easy years of marriage, my wife was struck with an incurable illness. On our eighteenth Valentine's Day together, a look at how love and commitment survive the toughest times. By Stephen Fried

This month is the eighteenth anniversary of the first time I laid eyes on my wife, Diane. We met at a Valentine's Day party that I threw with several single friends, all in our twenties. Diane came to the "Passion Bash," as we optimistically named it, as the guest of one of my best buddies from college. But then she and I danced together. And their date, and everything else that came before it in our romantic lives, was history.

It took a while to tie up the loose ends of our social lives, but we both knew right away this was going to be *it*. I'd never met anyone so beautiful and smolderingly sexy yet so loving and lovable (which are not the same thing); so smart, talented and focused yet willing to draw another into her artistic and intellectual passions. We love a lot of the same movies and music, and when we disagree, the discussions are epic and fascinating. Diane also has a great giggle.

I waited until the next Valentine's Day to propose only because it seemed like nice romantic symmetry, popping the question in front of the building we had rented out for the Passion Bash. That night it was being used for a concert of Ukrainian string music. So on bent and shivering knee—it was about eight degrees outside—with the sound of a balalaika quartet in the background, I asked Diane the question we had both known the answer to for so long.

Back in the car, I put on a mix tape I had prepared: every version I could find of "My Funny Valentine." We sat for a long time listening to it and making out.

Eighteen years later, we both still tell this story as if it happened just a few weeks ago. And people often

At a dinner
dance less
than a year
after we
met; we fell
in love on the
dance floor.

ask us how we hooked up, because we seem like we never really got over the astonishment of falling in love at first sight. They also ask because we are pretty open about how hard we work on our relationship—and how hard our relationship has worked on us.

We have survived professional setbacks in our lives as writers and teachers, and we've even survived professional successes, which can be as dangerous to a marriage as setbacks. We have survived the stunning early death of a parent. We have survived medical catastrophes. And we continue to survive the chronic siren of mental illness, which cannot be cured but is treatable—with a cocktail of medication, therapy and love.

When I listen today to that mix tape I made 18 years ago, it turns out to be a prescient soundtrack for the life we made for ourselves. The renditions of "My Funny Valentine" are remarkably diverse, everything from Miles Davis and Sarah Vaughan to Elvis Costello. And some of the versions aren't really romantic at all. They're dark, mysterious, challenging.

Together, however, these tracks reinforce what I have come to understand about being and staying in love: A great marriage is a song that is both brilliant and resilient, one that can be performed over and over, with different nuances being discovered, or rediscovered, on every take.

In the fall of 1992, Diane and I were preparing to go to New Mexico to celebrate our fifth anniversary. She was, of course, almost completely packed a week before departure, all her best underwear already neatly sealed in Ziploc bags; I was planning to pack, as I always do, two hours before the plane left.

Then Diane took that pill. It was a sample of a newly approved antibiotic her gynecologist had given her for a UTI so minor she didn't even know she had it until it showed up in a routine test. Six hours later, I was bringing her; delirious, to the emergency room. Her jaw ached from clenching during a seizure. Her pupils were fixed and dilated, like blobs of black ink. And she was bobbing in and out of lucidity. Only seconds after cracking a joke to a nurse, her mind would be sluggish and she would barely respond when I stroked her cheek or her shoulder-length brown hair.

Since married people can afford to be scared only one at a time, I pretended I was not frightened as Diane was tested for condition after condition I could not even bear thinking about. The tests were all negative. Eventually she was diagnosed with a severe central nervous system reaction to the medication and sent home to wait for the symptoms to go away. But they didn't.

Days, weeks, months later, we were still sorting out all her symptoms. She had really aggressive, buzzy insomnia, visual distortions that made the world seem six-dimensional, and, periodically, a strange sensation that something was "melting" behind her eyes. She also had intermittent aphasia: We'd be sitting at the kitchen table and, halfway through a sentence, she wouldn't be able to say the next word in her thought.

Diane's moods also became tortuously unstable. A fiction writer and painter, she had always had an "artistic temperament." Her passion for her work (and for me) was one of the things I'd loved about her. But now her moods were severe. There were depressions, dark and weepy—(I have never quite adjusted to sound of my wife's

"After Diane got sick, sex was more important than ever — proof that our most primal connection was intact."

voice when I can tell she's been crying). Then there were moments more on the manic side, which began as creative, giddy, even sexy fun but rarely ended well. When she was low-level manic, Diane's brain seemed to be making connections faster than usual, like an upgrade to the mental micro-processor. But eventually, everything started racing too quickly.

Her speech couldn't keep up with her thoughts; her restlessness and irritability became unbearable.

I can describe this all quite clinically now because I've had more than a decade to process and understand it. At the time, however, Diane's combo platter of symptoms just scared me to death, as did the fact that her very good doctors could not agree on her diagnosis or course of treatment. Diane also had to contend with the side effects of all the different medications doctors were using to counteract the adverse reaction triggered by that one damn pill. Her health became a combination roller coaster and Tilt-A-Whirl.

Three months into our crisis, she had a particularly terrifying experience on my birthday. She had walked the three blocks over to Isgro's bakery to pick up my cake, and then got lost while carrying it home. She found herself standing at a corner a half block away from our house, unable to figure out which direction to go. She was so embarrassed about the incident that she didn't tell me what had happened until days later.

Soon after that episode, we took a long weekend in St.

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Diane in St. Thomas, 1993. I'm still amazed that she could look so good when she felt so lousy.

In Diane's office, 1998: A stolen kiss is one advantage of working together.

The last day of our honeymoon, 1987: a little tipsy in Venice.

Thomas, which didn't turn out quite as romantic as we hoped. After several days in the tropical sun, Diane wasn't able to keep up with the amount of water she needed to drink with one of her medicines. She ended up dehydrated and terribly sick, and had to change medications yet again as soon as we returned.

The worst side effect caused by most of her meds was sedation. I am an earlier riser than Diane. It is our custom for me to get up first, make coffee and bring her a cup in bed. She used to sit up, take a few sips and then join me for breakfast, where we would tussle over who got to read "the ladies' section" of the newspaper first. Instead, when she heard me come in saying "special coffee delivery," she often just half opened her eyes, mumbled a thank-you, pointed to where she wanted me to put down the cup and rolled back over.

I assured Diane that I could handle the pressures of her illness. And even to my closest friends, I rarely admitted how difficult it was to see my wife sometimes battling her meds just to stay awake. This was a woman who for years had to be literally dragged away from her desk because she was so engaged in her writing or drawing.

For the most part, I was able to keep my frustration and heartache about her health to myself. But it still seeped out in less conspicuous ways. There was this strange recurring dream in which thousands of brightly colored pills dropped from a conveyor belt into a huge vat. Suddenly a hand, a woman's hand, burst through the surface of the pills, and then the other hand, and then her head, momentarily gasping for air before sinking entirely. When I blasted awake from the dream, I felt the need to make sure Diane was still alive, but without waking her up. If she was sleeping on her back, I'd put my hand under her nose to feel for breathing; if she was on her side facing away, I'd brush my lips across her neck and wait for the quick reflexive sigh I knew would come.

Some of Diane's symptoms

were horrendous—but none of them would last long. And we'd spend hours, even days together in a subdued version of what we used to think of as normal—until some symptom we had just managed to forget about would present itself again. Diane tried her best to shrug it all off—she comes from one of those stoic "it's just a flesh wound" families—but I could always tell by the look on her face when something unpleasant was happening in that finely tuned brain of hers. For couples who really observe each other,

the eyes betray everything. Depressed eyes are droopy, a little softened at the edges, but especially just below; manic eyes are a little too open, and they dart around too much.

Diane's doctors continued trying many different cocktails of medication to help combat and explore all her symptoms, which we still believed—or hoped, or prayed—were temporary. Eventually, the aphasia receded and the neuro-ophthalmologist told her she would just have to learn to live with the visual distortions. She even figured out how to adjust (or "climatize" as they say in the trade) to the side effects of her medications—which many patients (and spouses of patients) find themselves unable to do. But while the mood symptoms began to respond well enough to a combination of medication and supportive therapy, they clearly were not going away. Diane was formally diagnosed with manic-depressive illness. She accepted the fact that she had a major mood disorder more gracefully than I did. At the time, I was still looking in vain for the "antidote" to that pill she took for the UTI.

Now, it is probably fair to say that almost every marriage is, to some degree, mood disordered. The cycles of mania and depression are all apt metaphors for what happens in the emotional lives of couples. In theory, I suppose there is even some advantage for a couple to have mental illness as a common enemy, because it can be blamed whenever friction arises between them.

But serious mental illness is neither metaphorical nor theoretical. It's the realest thing in the world, and its effects are harsh, brutal, never to be taken lightly.

I may have struggled with the idea that Diane would have manic depression for the rest of her life, but nonetheless, I became very noodgy about those medications she was sentenced to taking. Diane thought it was time for me to stop treating her like a patient, time to stop thinking I could minimize her suffering by controlling her life.

"I didn't die, you know," she would say. I heard her, but I'm not sure I listened.

Luckily, we had other ways of communicating. For years, we had always been such an intuitively together couple that it sometimes seemed we could mentally beam each other information. Now when her symptoms were at their worst, she was far away—sitting right next to me but lost in a world of melting brains, visual tricks and chaotic moods. So we became much more reliant on purely physical contact. A soft swipe of her hand across mine—not even a prelude to a squeeze, just a deliberate brush stroke—became an emotional Morse code message that she was still

there. Sex was more important than ever before, the best proof possible that our most primal connection was intact.

In the middle of all this, we made a decision to let some of our story go public in order to raise awareness of drug safety and mental illness. So besides support from our friends and family, we also got encouragement from people all over the world who learned about Diane's situation—and shared their own—after an article I wrote about adverse drug reactions got national media attention. First we discussed the antibiotic that triggered Diane's problems on *Good Morning America*. Several months later, we were on *Oprah*. Afterward, Diane joked that she had the most famous urinary tract infection in America.

The show came about because one of Oprah Winfrey's producers had experienced a similar adverse reaction to the same medication. But when I was introduced on the program, it was clear our story had resonated for another reason. Oprah leaned toward us. "I loved what you said about how you loved her more than anything," she commented, referring to a line in the story.

When I think back on that show, I must admit that Oprah understood something then that I did not. I believed that intense investigation, by me and by our doctors, was the key to maintaining Diane's health and our health as a couple. In fact, I spent the next four years writing a book that explored the entire pharmaceutical-industrial complex. But I now realize that we survived and grew as a couple only because we were able to honor our marriage vows—to remain, in sickness and in health, in love.

The biggest risk to any relationship is not taking risks together. And I realized that only when, during the thick of this, Diane dared me to take the biggest risk of all—to try to start a family together.

During the first five years of our marriage, we ignored making any major decisions about children. Then Diane had her adverse drug reaction, and it was hard to think about making any decisions about anything. At about the same time, our siblings and close friends began to have babies, producing a mess of enchanting kiddos who were like poster children for having children. I knew that if we wanted to take any more aggressive action on the procreation front, we couldn't push the snooze button on the biological clock radio for much longer. But I was too nervous to bring up the subject. I didn't want to put that kind of pressure on Diane and add to the fragility of her situation. *(continued on page 217)*

One Sunday when we were driving home from a day with our two eldest nieces, Diane confronted me about the "baby thing." She said she was worried that I wanted a baby more than I'd let on—which was true—and that if the issue got pocket vetoed by the passing of time and opportunity we might regret it, and that I might blame her. She proposed we give it a try (although since she hates the hoopla around couples who admit they are "trying," she insisted I say only that we were "not not trying.")

It has been nearly eight years since Diane made her modest proposal. We don't have children of our own—although we are, trust me, the greatest aunt and uncle ever. And our parenting situation will only change if we adopt, since fertility treatments are not an option. We decided early on that Diane's meds were difficult enough to balance without adding fertility drugs to the mix.

Adoption is a step both of us have been too ambivalent about so far to actually take. But the fact that Diane made me, made us, actually confront the issue of having children and wrestle with it—I even had some counseling just to get used to the idea that it wasn't going to happen biologically—still brings tears to my eyes.

She is so much more emotionally brave than me. And emotional bravery is everything in a marriage.

Even at its worst, Diane's illness has never impaired her ability to be an amazing wife and partner. That's a good thing, because we have always counted on each other for a lot more than marital love and affection—and frankly, I can be pretty high-maintenance myself.

For instance, not long after we met, Diane became my primary editor. Not someone who reads and pats you on the shoulder, "that's nice, dear," but a real, hands-on, fight-over-a-semicolon editor. Not everybody wants this level of professional intimacy with their spouse. Personally, I thrive on it. There are, of course, times when I don't want to hear (or believe) her brutally honest assessment of my first, second or tenth draft. But in my work, I have always trusted Diane with my life. And I still find it hard to believe that she has been able to maintain this role in my professional life even when she was most ill.

It's much more impressive than what I, unimpaired, have done for her. The honest truth is that sometimes in a marriage it is easier to save than to be saved. Trusting your spouse to save *you* is harder.

I know this because four years after Diane's drug reaction, something happened that put all our problems in perspective. Too much perspective. My father was diagnosed with stage IV colon cancer at the age of 61. I had to take care of him and my mom. And, suddenly, Diane had to take care of me. And I had to let her. I am 6'2"; my wife is 5'1"—I am not accustomed to falling backward into her arms and expecting her to catch me. But with her support, I was able to drop almost every responsibility in my life to spend with my dad whatever time he had left—which turned out to be only six months. That time together is probably the only reason I was able to cope with his death.

My father died just before sunup on a Sunday morning in February. I was holding his hand, which I used to wipe my tears. And when he was gone, I went to Diane, waking her from a sound sleep, and hugged her as if it were the first time.

It was a difficult year for me, mourning my father and trying to finish a book. But we had achieved a new equilibrium in our marriage: Diane had been there for me so much that I no longer feared her illness would define us. In fact, she was back at work on her own writing, and she was going to have a first novel published.

Then we had another medical reality check. Early one fall evening, Diane got a call from the health club where I work out. "Your husband just collapsed," the voice said, "and they took him to the emergency room in an ambulance."

While riding an exercise bike, I collapsed and had what's called a grand mal seizure and swallowed my tongue. The only reason I lived was because an anesthesiologist was working out nearby and unblocked my airway. All my tests ended up normal, and I never had another seizure, but since that day in 1998, Diane has had the same fear that I could suddenly be taken away as I have had about her. It's a mutual paranoia with one major benefit—we never take each other for granted.

Today, I'm no longer certain our health problems were our biggest tests. In many ways it was harder when, just after my seizure, I took an executive job that drastically cut back our time together for nearly two years. That was followed immediately by a year we both spent writing at home together, racing to meet simultaneous book deadlines. We were in the same crowded house every minute of every day, but had almost no energy for one another. When the projects were done, we were left with a feeling that maybe we had pushed ourselves and our relationship too far. On the eve of our fifteenth wedding anniversary—

which we marked with a trip to the Northwest that turned out to be too much business and not enough pleasure—I was more nervous about our marriage than I ever had been during Diane's illness.

I decided to do something drastic: I found us a new house, a place we could work in more comfortably, and work on together until it reflected our tastes and a new set of dreams. I arranged for Diane to see it for the first time on the very day of our anniversary. Sitting in the living room in front of the big bay window, she turned to me and said, "I could live here." And so we do. And, again, we are renewed.

Several weeks ago, Diane and I were lounging in a cool South Beach hotel room watching *Oprah*. We don't normally do this, but we were on our anniversary trip, and *Oprah* just happened to be on TV when we were getting dressed to go out for yet another stone-crab dinner.

Sting was the guest, plugging his memoir of pre-Stinghood. But a good bit of the hour program was spent marveling over the fact that he and his longtime wife, Trudie, adored each other—as if such couples deserve an exhibit at a zoo or a museum. As *Oprah* pressed them about how they stayed so together, we recognized the bemused look on Sting and Trudie's faces.

When people hear that Diane and I have been happily married for 16 years, they often ask how this is possible. For Sting and Trudie, of course, it's those eight-hour tantric sex marathons—which frankly sound a little dangerous to me (do roadies rehydrate them periodically or what?) For us, well, maybe we were just more in love when we started and had more emotion and commitment to access when times got hard.

I think what we have works because we still have huge ambitions for ourselves individually and together. And if we feel momentarily distracted, dissipated or distressed, we work hard not to blame this on each other or on our marriage. We blame ourselves or we blame bad luck. But then we're able to remind ourselves of how much good luck we still have, starting with the fact that we found each other.

Marriage isn't supposed to be the problem. It is supposed to be the solution. I know too many people who are sick of their marriages and treat them as some source of illness. To me, every day, my marriage is the antidote. ©

Contributing editor Stephen Fried's latest book, The New Rabbi, was recently published in paperback, as was Other Girls, the first novel by his wife, Diane Ayres.