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Above it all
The author on a hike
in Jackson Hole,
Wyoming; (below)
with husband, Scott,
at their 1988 wedding



Close to the heart

The miracle transplant that saved my life also forced me to hide my real self. **By Amy Silverstein**

It was a fairy tale come true: A groom waited at the end of the aisle for his bride. Rows of seated guests looked expectantly at me, the radiant woman in the gown. All was not as idyllic as it seemed, however. My dearly beloved knew about the scar dividing me from neck to navel, even though it was concealed by opalescent beads. They also knew about my MedicAlert bracelet inscribed with the words *Heart transplant. On cyclosporine, prednisone, other medications.* And yet there I stood, picture perfect. Who could blame them for thinking of me as a miracle on my wedding day?

Only I knew the truth: That beneath layers of finery, my hard-won heart pumped erratically. That with each step, I struggled with nausea brought on by the medications keeping me alive. Exactly one year after receiving the heart of a 13-year-old donor, I was determined not to present myself to the world as a complainer. I sensed that even my nearest and dearest preferred to dwell on the success of the transplant, not

the injustice of having needed one in the first place nor the ongoing health problems that followed in its wake.

My so-called miracle was complicated. When several friendships dried up in the months leading to the wedding, I was forced to admit that all my hospitalizations had taken their toll. Many people wanted to believe my transplant was a happy ending to heart failure when it was in truth only the beginning of life with a different set of complications. I was beyond lucky to have a reprieve from the death sentence that had been hanging over my head, but once the elation wore off, I found myself resenting the healthily beating hearts around me. The one step forward, two steps back rhythm of my recovery was more than many people could bear. As the concerned visitors tapered off, I realized that the only surefire way to hang on to my friends was to protect them from the grisly details of posttransplant life. I walked down the aisle with this discovery in mind, smiling broadly in spite of my physical and psychological struggles.

And now, nearly two decades later, I continue to make the same choice. I'm aware that I've outlasted the 10 years doctors predicted I would live after my transplant at 25. But hardly anyone knows how that life has really been because, when >>>

someone asks how I am, I say I'm fine. If I tell the truth—about the fatigue, wild heartbeats and the many medications that wreak havoc on my immune system—I fear I will try the patience of even my most loving supporters. Believe me, my illness tries my patience, too!

I've learned, over time, that honesty about my health woes can be perceived as ingratitude. Here's how it goes: A friend calls after I've spent a day at the hospital for a series of invasive tests. I tell her the news is good; it's year 19, and my heart is doing well, but it was a trying time for me on the exam table. I'd woken up sick that morning, which amplified the pain of every poke and cut. My friend's reply? "But you got a great result. Be happy for that." I am happy.

And grateful, too. But I'd had a day from hell. Rather than explain myself, I shelve the truth. "You're right." Once again, I put on what I've come to think of as "the mask."

Having a heart transplant has prodded me to tap into my inner actress. Highlights of *The Amy Show* include me, in low-rise jeans, showing no trace of the trademark prednisone potbelly; or me dashing off to volunteer at the library in spite of a medicine-induced fever and sore throat. I might put on my mask at a baby shower as I sit beside a pregnant friend celebrating another rite of passage my transplant has ruled out for me. The mask comes in handy when an acquaintance suggests I wouldn't contract so many infections if I would only think positively. Once, I reached for it during a conversation with a 35-year-old friend who had realized he should visit an internist. He hadn't seen a doctor since breaking his wrist in college. (I see nearly a dozen doctors, and I have several on speed dial.)

I hide my maladies and resentment in order to spare my friends discomfort, but I also do it to be kind to myself. I want to enjoy uncomplicated friendships as much as the next person. I want to blend in with the gang, even if this requires herculean effort.

I was striving for that recently, when my husband and I went to the Bahamas with friends. While everyone else sipped martinis, I nursed a club soda, hoping it would quell the nausea that followed my daily medications. One pal, who had just jogged five miles, leaned forward to massage her sore hip and cried, "My body is not cooperating!" And I thought, Wanna trade?

As if she'd telepathically heard what had passed through my mind, she swiftly added, "Amy, you sure look great. I wish I had your abs."

Wish I had your heart. Mask time.

Or maybe not. Something in me softened. My knee-jerk envy gave way to appreciation for my friend's sensitiv-

ity. And there was truth in her compliment; thanks to my strict fitness routine, my muscles are taut. Because I'd hidden my sickness and exhaustion behind each mile I jogged and each pound lifted,

my friends saw only the visible results of my effort, and these were real.

Suddenly, it occurred to me that keeping up appearances has power. Perhaps playing the role of the healthy transplant survivor actually turns me into a healthy transplant survivor. *Maybe there's something to this mind-over-matter stuff after all.* But there was more to it than that. I looked up at what I was sure was the other force behind my longevity: my husband, Scott. He'd returned from playing golf and stood above me now, beaming.

"Not a great morning?" he said, gesturing toward my club soda. There's no hiding from Scott—and no need to try.

He squeezed in beside me on the chaise longue and took my hand. Immediately, a memory flashed, bright and vivid. There was Scott, years younger, tuxedoed, his gaze locked on mine as I approached the altar. I looked into his eyes and, as he lifted the veil away from my face, the mask I wore floated away with it. In that small moment, I was not sick or well, masked or unmasked. I was, simply, adored. ■

“Maybe there's something to this mind-over-matter stuff after all.”