

Very nearly a disaster as a bride

My eyes were too swollen for me to walk down the aisle, and it wasn't from crying

Modern Love

BY IBBY CAPUTO

The morning of my wedding, I woke up looking grotesque.

I could hardly open my eyes because my eyelids were so swollen. In despair, I called out to Damian, my soon-to-be-husband. Then we called my doctor, who said, "Looks like your bone marrow transplant came to your wedding."

I had received a bone-marrow transplant several years earlier, which vanquished the leukemia in my blood and saved my life. But my new immune system sometimes went haywire. Submerging myself in the hotel bathtub the night before with a moist, fragrant washcloth over my eyes had probably been a bad idea; it likely vexed my sensitive system.

Or maybe this was stress? It hurt to look at myself. Why did my body have to go rogue today of all days?

Just two and a half years before, I didn't think this day would happen. At lunch with my mother, I said, "Mom, I'm probably not going to find a partner." I was 30 then and full-body irradiation had made me infertile. "I'm not what guys are looking for."

I wasn't sad about this. On the contrary, I felt relieved. Finally free from hope and longing. But my mother couldn't stop crying.

"I'm going to be O.K.," I said. The next day, I boarded a plane for Arkansas and a Buddhist retreat center in the Ozark Mountains I had been to before. When I was ill, my parents worried I wasn't turning to Jesus, but Buddhism seemed to make more sense. My life had become an education in impermanence and suffering.

After releasing the pressure of needing to partner, after making my mother cry, I arrived at the retreat center. And there was Damian, wearing tan cargo pants, a beige button-down shirt and a Tilley hat. He looked Australian, but I knew he was British.

I knew because I had heard about him during a visit when I met his then-wife, Angela. Damian's green card had expired and he was stuck in England, unaware that Angela was lusting after a new guy. I actually advised her to ditch the new guy and stay with her husband, because he sounded so awe-



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some. I even emailed her afterward to encourage her again, and I was sad when I learned they had divorced.

"So, you're the Damian I've heard so much about," I said.

With a new green card, he was there for the same retreat and was helping build cabins for the center. I knew from Angela that he was in his late 40s, but he looked closer to my age.

Damian would later say that after he met me, he kept thinking, "Where's Ibbby?" I did get the sense he was always finding me around the center, but not in a creepy way — more how a Labrador greets you at the door, tail wagging, ready to receive you.

I wanted to prove to myself I could handle rugged conditions, so I chose to camp the first night, but I didn't know how to set up my borrowed tent, so Damian set it up with me.

As I organized my things, Damian lay half in the tent staring at the stars. He later told me he kept thinking he should leave, but he felt remarkably comfortable. I kept thinking he should stay, because I was afraid to camp alone. But I decided that sharing a tent with a stranger wasn't the best way to start a meditation retreat.

And this was a silent retreat, or meant to be. The first day, I was eating lunch on the ledge of a cabin. With no room next to me, Damian plopped on the grass directly in front, grinning. I found the obviousness of his interest refreshing, but I couldn't say anything, so I stood up and moved next to him on the grass and we ate our lunch quietly, staring at a cabin wall.

The second day, eating lunch under a tree, we watched a cricket jump onto

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another cricket and they started mating. Talk about an awkward silence!

We went for a walk to a swimming hole, where we skipped rocks. Then I broke the silence. I had been sick, I told him, and I didn't want to waste my time or his, so I asked him everything I could think of. Do you like your mother? What about children? Would you get married again? Do you mind that my ovaries don't work?

All those questions, and not one red flag.

Damian wasn't fazed by my cancer-survivor status, either. I was healthy by then, with a negligible chance of relapse, but my immune system could be wonky. I have already been through menopause, and I can no longer make tears — all side effects of the treatment that gave me more time on earth.

Illness changes you in nonphysical ways, too, aging your spirit. It can make you wiser but also more aware and scared of life's potential for pain.

"Well," Damian said, "you seem fearless to me."

On the third day, he kissed me. Then he told me he loved me.

"No, it's too soon!" I said. Then I remembered the meditation instructor told us to "be spacious." Maybe that meant, don't freak out?

What I wanted was a man I could admire and a love that was abundantly clear. Damian was unafraid, attentive, generous and compassionate. It seemed as soon as I had let go of my hope and longing, he appeared.

By the end of the retreat, I knew that while there had been life before Damian, now there could only be life with him.

My parents, however, were not happy when I told them about him and us, concerned about our age difference and Damian's previous marriage.

My father, an attorney, said, "When one of my clients wants to marry a divorced man, I tell her to talk to the ex-wife first."

"But Dad, I did that." He also worried that Damian, who designs, builds and remodels homes, wasn't a college graduate. I had an answer for this, too.

The year Damian was sorting out his green card, the BBC interviewed him about the benefits of meditation. Because he had meditated for more than 10,000 hours, neurologists figured his brain activity might look different from the brain of an average person, so they put him into an M.R.I. machine.

"Meet Damian, a man who can seemingly turn happiness on," the reporter, David Sillito, said, adding that the neurologist who read Damian's M.R.I. had called his brain "beautiful." I sent the link to my father.

"No one's ever said that about my brain," he replied.

But the morning of our wedding, not even Damian could turn on my happiness. I had become Buddhist, found the retreat center and met the man I love because I once had cancer. Still, if ever there was a day that I didn't want to be reminded of this, it was today, and it was staring me in the face.

My doctor prescribed antibiotics, Benadryl and steroids. Damian and I sat on the edge of the bed and meditated for an hour, which was our practice at the time. Then he went off with his best man and I tried to pull myself

together. At the salon, as my hair was being twisted into a bun, my mother begged me to stop being so upset, saying it would only make my eyes worse.

Damian says that my family, which is prone to stress-induced squabbles, didn't have a chance to fight that day because my eyelids elicited such sympathy. That's a very Buddhist interpretation. All I can say is I wish my eyelids had asked permission before sacrificing themselves to keep the peace.

But later, as my mother and sister and sister-in-law helped me into my wedding gown, I looked in the mirror and thought, "Wow, I actually look pretty!" One — or all three — of the drugs had worked. The swelling had left in its wake a burnt orange color that looked like makeup on my eyelids.

Still, I didn't really arrive to my own wedding day until the doors to the chapel opened and I saw my niece dropping petals on the path I was about to walk. Everyone I love was there, staring at me, smiling. Some were crying. I just kept walking.

We had a Tibetan Buddhist ceremony in a glass and wooden chapel in the woods of Eureka Springs, Ark. We included a Bible reading about love, since our families are Catholic, but most of the ceremony was in Tibetan: chants sung by a monk, accompanied by the ringing of a bell. Damian and I sat together silently, soaking it all in, as I experienced firsthand how suffering can transform into something beautiful.

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What are my obligations to my disabled parents?

The Ethicist

BY KWAME ANTHONY APPIAH

A little over two years ago, my family was involved in a catastrophic car accident overseas. My younger sibling was killed, and my parents survived but are severely disabled. My father is quadriplegic, while my mother has a traumatic brain injury resulting in severe cognitive impairment.

My spouse and I were overseas for several months with my parents before they were evacuated back to the United States. Then, over the next year (we don't live in the same city), we traveled to their city often to help manage transitions from the hospital to rehab, to where they are now (both live with 24-hour care). My extended family lives entirely abroad and, for the most part, does not speak English. Therefore, I also help (and plan to help for the rest of my parents' lives) to manage all of their financial and administrative matters, including trusts that I helped set up, applying for benefits, taxes, etc.

My father's parents have reacted to his disability with the attitude that it is my duty to do everything he is unwilling to do (or ensure that someone else does it), and they believe it is appropriate for me to move to his city to manage his day-to-day affairs and for me to care-take emotionally for him to spare him further pain (e.g., for me to arrange all matters relating to my sibling). They have not expressed gratitude for my actions over the past two years except to praise my paperwork and administrative skills.

My feeling is that I have put on hold my own grief and emotional needs (not to mention the money and time spent

and career opportunities lost) to manage this situation and also try to arrange for my father the best quality of life possible. Yet he refuses to come to terms with his disability, including refusing to use assistive devices and skills he learned in rehab.

My question is: What duty do I owe my father and grandparents? My father and I were not close before the accident, and while it is true that he has sacrificed a lot, as an immigrant, to ensure that my sibling and I had opportunities, he has always resented us for having a much easier life than he did. Given a lack of emotional closeness in our relationship (and my difficult childhood as a result), I don't feel inclined to sacrifice my current life more than I already have. My grandparents (and, I suspect, my father) feel differently. To boil my question down: Assuming a parent-child (or grandparent-child) relationship that lacks genuine warmth (which I think would create more genuine desire to help), what framework should I use to think about what duties I nonetheless owe? Name Withheld

THE CULTURAL DIVIDE you describe is more common than it used to be. Most of your family lives in a place with one conception of family responsibility; you live in a place with a very different one. Let me add that, even if your grandparents think everything you have done is a matter of filial duty, they owe you gratitude for it. (I don't know your family's culture of origin, but this is quite likely to be true over there as well.) In the end, however, you must live by the conception of duty that you yourself subscribe to. As John Stuart Mill put it, "If a person possesses any tolerable amount of common sense and experience, his own mode of laying out his existence is the best, not because it is the best in itself, but because it is his own mode."



TOMI LINN

Your life matters, and part of the challenge of making a good life is to balance your own needs, projects and interests against your obligations to others. Plainly, you have done a great deal for your parents, and, despite their ideas about the Dutiful Child, they are not entitled to further derail your life. Perhaps if you and your father had a better relationship, as you say, you would have been willing to do more. But your father has played a role, then and now, in your disaffection. The accident has dealt your parents' lives a devastating blow; if your own life were to be sacrificed in service of their care, the accident would have claimed another victim.

I am a college science professor, and over the past decade, I've noticed a proliferation of students who request extended time on exams through our office of disabilities. In math and science in particular, the time limit on exams functions as an important part of the test, i.e., making sure that students can manage their time well and complete their calculations quickly and efficiently. As a result, extended (usually double) time confers a significant advantage on the test taker. I have nursed some doubts about the legitimacy of some students' requests for extended time, but that is beside the

point; I am obliged to grant them. My question regards what to do when students who have benefited from such accommodations ask me for letters of recommendation, as many of them eventually do. Academic performance on exam-based assessments typically constitutes the heart of my recommendation letters; however, for students with academic accommodations, it should be important to convey a caveat about extended time, as this will affect performance and efficiency in jobs or graduate school. Is it ethical (or legal) to mention academic accommodations in recommendation letters? Name Withheld

THE FACT THAT a student has a disability is shared with the professor on a confidential basis, and you shouldn't disclose confidential information about students without their permission. On the other hand, you're not under an obligation to write undergraduate recommendations for everyone who asks. So if you're convinced that the conditions of test-taking are relevant to interpreting a student's grades, I suppose you could say that you'll write a letter of recommendation only if you're permitted to mention the academic accommodation.

If that's your position, though, you should alert students at the start. You would do well to confer with a lawyer at the start, too. Bear in mind that federal law generally forbids prospective employers to ask about mental disabilities, and similar restrictions apply to educational programs. (Exceptions are made when applicants request accommodations.) You may be entering a legal gray zone here.

And an ethical one. The point of accommodations is that, as the saying goes, tests should measure abilities, not disabilities. In many realms, processing speed is hardly relevant (there's no great advantage to the speedy sonneteer); in other realms, it's obviously critical (a truck driver can't ask for extra time in deciding whether to brake). And in your field? Your view is that developed talent may involve being able to work at a certain rate, not

just getting the right answer in the end. Someone who solves a lot of problems in an hour is, in one obvious respect, better at problem-solving than someone who takes much longer. In many jobs, I'll grant, intellectual productivity matters; and productivity is a matter not just of what you do but how soon you get it done.

Inevitably, there are debates over whether accommodations make things fairer or less fair. Since the major testing companies announced, at the beginning of this century, that they would no longer flag test scores obtained with special accommodations, the number of students receiving those accommodations increased significantly. Accommodations are, of course, easier to get if you're well-off and can afford to find and pay a psychologist who will diagnose a condition that entitles you to special treatment. (A College Board study suggests that nearly all students, not just disabled ones, do better on their SATs with extended time, especially in math.) In a California study from 2013, researchers concluded, "Higher rates of A.D.H.D. observed in affluent, white families likely represent an effort by these highly educated parents to seek help for their children who may not be fulfilling their expectations for school-work." In short, the system can be exploited.

But these concerns must take their place among others. As an ethical matter, we ought to treat everyone with such a diagnosis as if it's real. Anything less would be unfair to all of those with genuine disabilities. And let's remember the upside of the new regime as well. Thousands and thousands of young people who would have failed in college or been denied places altogether are now getting educations that allow them to contribute more to the economy and to make more meaningful lives as well.

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