

The Washington Post
October 26, 2017

Even as her lungs were failing, she kept singing

Deadly illnesses haven't stilled the voice of this opera singer

by [Tara Bahrapour](#)



Opera singer Charity Tillemann-Dickhas received two double lung transplants and has battled skin cancer. (Photo: Ricky Carioti/The Washington Post)

Charity Tillemann-Dick was a promising 20-year-old opera singer when a voice coach in Budapest told her that to be truly great three things needed to happen: “You must get very sick, you must fall in love, and you must work, work, work.”

As it turned out, those instructions would form the arc of her life. A month after that encounter, she learned she had stage 4 pulmonary hypertension. The right side of her heart had enlarged to three and a half times its normal size. Though she had been experiencing fainting spells, she had no idea she was so ill. Without a lung transplant, 70 percent of PH patients die within five years of diagnosis. A leading expert on the disease ordered her to stop singing immediately.

Instead, she switched doctors.

Tillemann-Dick, 34, is accustomed to taking bad news and incorporating it into her own dramatic narrative. For years after her diagnosis, she walked around with a pump that constantly injected vasodilator medication into her veins, and continued to perform until she could no longer stand.

Sitting this week in her grandmother’s townhouse steps from the Supreme Court, a few blocks from where she lives with her husband, she nibbled on cherry-infused prunes and talked about the waves of terrible and wonderful luck that have buffeted her and that form the basis of her new memoir, [“The Encore: A Memoir in Three Acts,”](#) published this month by Atria Books, an imprint of Simon and Schuster.

Like nearly everything else she’s done, it was hard to write. “I did not know how challenging reliving all of the most challenging experiences of my life would be,” she said. “For me it was complicated to piece together the emotional arc.”

It was also difficult to incorporate the large cast of family members, doctors, and teachers. Tillemann-Dick, who grew up the fifth of 11 children in a Mormon-Jewish family in Denver, is a granddaughter, on her mother’s side, of the late U.S. Congressman and Holocaust survivor Tom Lantos. Her paternal grandmother, Nancy Dick, was the first woman to serve as lieutenant governor of Colorado, and her brother Levi is running for Congress in Aurora.



Charity Tillemann-Dick, 34, sings as she receives an opera lesson from her coach Justina Lee at the University of Maryland in College Park (Photo: Ricky Carioti/The Washington Post)

In a high, bubbly speaking voice accompanied by expansive hand gestures, Tillemann-Dick described how she held out for five years before getting her first transplant.

Two other young women she knew who had had the operation had died. Even if hers was successful she knew it could damage her vocal cords. When she finally underwent the procedure, her surgeon had to also perform an impromptu open-heart surgery. After a month-long medically-induced coma, she awoke unable to speak. She was terrified her singing career was over.

It wasn't; her vocal cords were intact and after months of grueling physical therapy she was back onstage, performing and giving TED talks about her experience.

It is hard now to watch some of that old footage of her singing an aria, sparkling with optimism, unaware that two years after the initial operation those donated lungs would fail.

As she awaited another transplant, doctors told her family she was unlikely to survive. She recovered from the second transplant and started singing again, making an album with members of the Cleveland Orchestra that reached the top of the Billboard classical chart.

Though Tillemann-Dick had in the past worked in journalism and written a blog, the idea of writing a memoir was daunting. "It sounded really emotionally perilous," she said. But her

brother Levi, who had also written a book, encouraged her. “I knew that if I didn’t tell my story either someone else would or no-one would, and I thought that was a waste of all these experiences.”

It turned out they weren’t over. In 2015, as she was working on the book, she noticed a new freckle on her forehead; within three and a half weeks it was kumquat-size. She was diagnosed with a rare and aggressive skin cancer, likely a result of the immunosuppressant drugs that prevent rejection of the donated lungs. One tumor on her face grew to be baseball-size, and the cancer spread to a salivary gland ; surgery to remove it required cutting a nerve and affected muscle movement on the right side of her mouth.



Charity Tillemann-Dick, an opera singer who has received two lung transplants, found her voice was unexpectedly improved by surgery for skin cancer. (Photo: Ricky Carioti/The Washington Post)

The cancer was eliminated. But the damage it caused to her cherubic face was in a way more emotionally traumatic than the PH had been. At parties, people she had known for decades did not recognize her, and she was rattled by how quickly her physical appearance changed.

“I think everyone’s face is their identity – for me it was something I had relied on in my darkest hours. This is going to sound vain, but when I would look in the mirror, I would say, well, at least I still have my face. When this crutch was taken away, I went through the aging process in a matter of a few months instead of a few decades, as most women do.”

But in the awful way of a fire, letting go of the physical touchstone she’d depended on turned out to be cleansing. “I realized that if I’d lost that, then I didn’t have anything to worry about

anymore. I still have my life. I cherish my life. It allowed me to move on, in a way.” (It also, as she notes, gives her an excuse to swan around in a glamorous oversized white hat).

Each section of her book is headed with an excerpt from an opera in which the heroine is undergoing a challenge (for the audio version of the book she sang the arias) – though as she acknowledges in the book, “No opera could hope to capture the messy, grotesque, gorgeous truth of life.”

The book also sparked the publisher to partner with Donate Life America to create the Donate Life America #MyEncore Challenge, which invites people to submit their own stories of second chances and then nominate five friends to do the same. “Everyone wants a chance to have a second shot in life – obviously with organ donors, but also in academics, in school, in work,” Tillemann-Dick said.

To her mother, Annette, a tiny, energetic woman replenishing a tray of cheese and glasses of apple cider, Tillemann-Dick’s embrace of second and third chances is fitting. “Charity said, ‘This could make me miserable. I’m not going to let it make me miserable; I’m going to enjoy my life.’”

She was referring to the cancer, but the sentiment could have applied to most of the past 15 years: the diagnoses, the near-death experiences, and losses such as Lantos’ death in 2008 from esophageal cancer, and the death of Tilleman-Dick’s father after a car accident, the same year.

Tillemann-Dick’s other rock is her husband, Yoni Doron, an education technology innovator whom she married just before the second transplant – despite her initial insistence that he deserved to spend his life with someone healthy.

Those doubts returned after her cancer surgery. Looking in the mirror, she wondered, *How’s my husband ever going to love me if I’m changing like this?*

“He said, ‘Honey, you know I really don’t care about this, to me you’re just as beautiful as you always were,’” she said. “Of course it’s great to have a wife who looks like a pageant queen, but that’s not why he was with me. There’s this deep bond that comes with having experienced so much together, and that bond can’t be tarnished by age or scars or transplants.”



Since being diagnosed with aggressive skin cancer, Charity Tillemann-Dick wears a large-brimmed hat when she goes out. (Photo: Ricky Carioti/The Washington Post)

Like the operas with which she identifies so viscerally, Tillemann-Dick's own plot twists continue. She is clear-eyed about the fact that her ending is still uncertain. The second transplant, which she received in 2012, is technically in chronic rejection, though this time around the rejection is slow and stable, and as long as she stays generally healthy it should last a while. She could live into her 80s like her grandmother (also a Holocaust survivor), but she may not.

"Yoni and I talk about death all the time, literally at least three times a week," she said. "I often give him instructions on who he's to marry and how he's to marry when I die...I've already beat the odds because I'm alive, but people die who are healthy and who are sick. Death is as much a part of life as birth, we're all going to die, and I don't think anyone benefits from that conversation being awkward or delayed."

For now, she travels frequently for singing or speaking engagements, flying with a "big, fat mask" to protect her compromised immune system. Last weekend she debuted (Oct 15) at Boston's Symphony Hall, singing songs by Ilse Weber, a nurse in the Terezin concentration camp who wrote the music in hopes of keeping up the children inmates' spirits; she was killed before the end of the war.

Cancer surgery added one more unexpected twist to Tillemann-Dick's story: it left her singing better than she had originally. With a voice that is unusual in that it is both very big and very high, she is adept at coloratura – the fast, agile singing typical of Rossini repertoire. But “I was never happy with the way my lower voice sounded. My teachers were frustrated, they told me, ‘There’s too much tension in your jaw.’”

Now, “My low voice is totally there,” she said. “I don’t know if it’s because of the surgery or despite it, but it’s allowed me to sing all these roles I’ve always wanted to sing, and come into my own.”

At a coaching session at the University of Maryland, College Park this week, Tillemann-Dick took a deep inhale. The words (translated from the Italian here) of the heroine from *Adriana Lecouvreur* by Francesco Cilea flooded the practice room.

Look here; I’m scarcely breathing...

*I’m but the humble servant of the brilliant creator;
He offers me the words that I impart to the heart...
I’m the verse’s music, the echo of human drama,
the fragile instrument, the lowly hand-maiden...
Timid, joyous, terrible, I’m called Faithfulness.
My voice is just a whisper, which, with the new day, will die.*

Her voice was rich and fulgent, and she clasped her hands as if in supplication.

Or it could have been gratitude.

Tara Bahrapour, a staff writer based in Washington, D.C., writes about aging and generations.