

# One More Thing

*Cecilia Petricone*

I have always volunteered for one more thing than I can handle. If a course load is five classes, I took six... and worked as a TA... and held down two jobs... and wrote one chapter of a book I'll never finish... and.. and...and...

I was this way before my transplant, but since then, now that there are *no excuses*, the little voice in my brain that says

“s l o w d o w n”

is fainter and fainter. The jenga tower of my life was as wobbly as ever as I boarded a 9pm flight from Boston to Fort Lauderdale that cool May evening in 2019. I sat the whole flight, foot tapping, anxiously typing on the notes app of my phone. I knew I was delivering this speech for months. Answered a half dozen check-in emails with calm reassurance of the “great progress I had made” on my remarks. But if the weak airplane coffee and gentle glow of the screen I was furiously typing on proved anything... it was that I hadn't written a single word.

I turned off airplane mode.

*\*buzz\* \*buzzzzzzz\* \*buzzzzz\**

“You are going to do amazi'ng tomorrow, I am so proud of you!” -Mom

“I'm in the car by your gate, come quick, we have 11pm reservations” -Dad

“Is your speech done? Email me your draft ASAP. We will have your credentials ready at the entrance, let me know as soon as you arrive. Can't wait to see you!” -Sokphal

I looked down at my cluttered screen, cautiously typed in the same 4-digit pin I've had since I was 13 and opened my notes. There it was, the speech I knew I had to deliver in front of a room of medical professionals later that day.

*First of all I would like to thank Patrick for that great introduction and the NPF for inviting me to speak to you all today. I would also like to thank all of you, both for taking the time to listen to my story...<sup>1</sup>*

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<sup>1</sup> This excerpt, and all excerpts to follow, were taken directly from the note in my phone titled “NPF Fellowship Conference Speech”, written on May 3, 2019 at 10:04pm.

Why had it taken me so long to start?

This is my life's story they want to hear. After years of fighting, screaming, kicking, pulling out IV's, being refused care, being called a drug addict, probed about "childhood drinking", cursing the names of a dozen doctors, refusing consent for feeding tubes. You'd think that the opportunity to look at a room full of medical professionals, some the best in the world, others at the start of their career, and tell them about my suffering, would be an opportunity that I would have abundantly prepared for. But I hadn't. Not even a little bit.

This was one more block in the jenga pile of a life I had created. But this wasn't a stable piece, not a safe move for just anyone to grab at any minute. This piece needed precision, it needed intention, it needed care. I knew it wasn't just my story that I had to tell... I had to speak for Adam and Rose and Luke and Cece and dozens of other young people who have also had to suffer like me. It was the instability that comes with responsibility like this that had prevented me from just grabbing this block earlier.

Three hours and four cups of weak plane coffee later though, I had done it.

I explained my pain-

*...a few months into school my biggest fear came true, and I found myself in tears outside of my freshman dorm at 5am ordering an Uber to the hospital because I was in pain so excruciating I could barely talk.... For someone who loves to plan, there's nothing quite as devastating as having no control. I couldn't attend my classes, couldn't plan with my friends, I couldn't even look at my phone some days. I would practice my mandarin and try to read my political theory books in the sweet spots of my day, after the pain medicine mellowed enough that I was able to focus on something, but before it wore off enough that I couldn't stand the pain.*

I did everything I could to put not just my identity, but our identities, into my remarks. I talked about how my life was molded by this-

*Sometimes I think back to my years of illness and it almost doesn't feel real anymore. But pancreatitis has been a huge part of my life. There are plenty of horror stories I could tell you of scary days and traumatic events, but it wasn't all that, a lot happened in those hospital rooms. I planned my sweet 16, started a relationship with my first boyfriend, celebrated holidays, enjoyed the company of my friends and family, met some remarkable people, and ultimately learned how resilient I am.*

I knew I had to tell our stories, I needed to go beyond the pain. Our lives have been molded and guided and flipped upside down in every way. I needed them to know. It's not always easy to get the attention of a doctor. Let alone 200 doctors.

So when the time came, early that next morning, I walked into the hotel, my dad by my side. I had a name tag that made me feel a little important pinned to my pastel floral dress, and when I saw my cue given from across the room... I got to the podium.

I cried writing the speech, I cried reading it to my dad in the car that morning, I cried when my friends responded to my proofreads, I cried sharing it with my fellow sufferers. I was confident I was going to cry.

But I didn't. I never cried.

Instead I spoke calmly. My voice was steady, I addressed my audience with reverence as their prestige called for. But I also got a chance to challenge, to push them. They were there to hear me. Thousands of times I sat in front of people like them, on paper covered tables, on scratchy hospital sheets, looking up to them for hope... almost always to end up disappointed. But now it was my time, our time, to assert how we felt. I did it for us.

The close of my remarks-

*But really, if it weren't for my medical teams in Connecticut, Boston, and Minnesota, I wouldn't have any of this. So thank you all for the work you do, may you continue to learn, remain passionate about healing, and always remember the impact your work has on the lives of those you care for.*

-gave me an opportunity to express everything I felt. Gratitude for those who saved me, but importantly, a reminder that what they do every day impacts us.

To tell my story is difficult, to tell the collective story of us... nearly impossible. I put off writing my speech because it wasn't just ONE more thing. It was hundreds more. Hundreds more people, hundreds more stories. It was an incredible privilege but also a remarkable burden to speak for us. My one more thing mentality should be stopped sometimes (oftentimes), but one of the few burdens I take on again and again... that I never live to regret, is taking on one more thing to speak for us.

*Cecilia Petricone is a senior at Boston College earning a degree in Sociology and Political Science with a minor in Medical Humanities.*