

Dear Me,

*You have to live.*

Rest is important. You want to live a long time. But on the days that you're not drunk with fatigue or quaking with feverish chills or suffocating from dyspnea, you have to get out. And live. Live more on each of those days than others live in a week.

Over time, you've grown afraid – afraid to plan, afraid to adventure, afraid to think ahead. You've let the disease overtake your desires, letting fantasies go unfulfilled, choosing to forget them rather than fuel them. Do not forget about them; they are who you are, just as much as your brain and bones and muscle and mutated CFTR genes.

Time has been cruel to you. Others get to accrue their dreams, and then, as they grow up and gain independence, check those dreams off their bucket list. Friends can save up, take their vacation days and go to Thailand. They can pack a backpack and head to Tahoe for the weekend with friends. They can spend their lives outdoors, in the world, interacting with people; they can keep their finger on the pulse of their communities, staying connected by staying involved, the simple act of stepping out the door aligning them with their peers.

But for you, time goes on, and your abilities are stripped away. That love of the ocean, those long ocean swims in Maui and Santa Monica, that desire to be a marine biologist, to do a dolphin research trip in Belize – you cannot indulge those, for now. But you have to replace one love with another. You cannot replace a love of something with nothing, or there will be a void, and you will feel an anger and a resentment that will separate you even further from those around you.

So, while abilities are stripped away, you must think of ways to replace what you are losing with other things that fulfill you in different but equal ways. You must first and foremost stay connected, because community is at the core of your being. The heart is to the body what community is to your soul; it is what circulates the substance that keeps you alive, keeps you vital. You must find ways to nourish the intellectual curiosity that buoyed you through school and that differentiated you in the eyes of your mentors. You must continue to step outside, even if just to get coffee and go home, even when visible medical equipment attracts the stares of strangers. You must get over your aversion to being stared at for your medical equipment.

Time will be kind to you again, I believe. If 2016 was a year of decay, 2017 could be a year of revival. The crux of the matter is that you must get worse in order to burst forth with new lungs and a new life. You are going through hell, and that is the path you must bravely walk, for now. Your life cannot be compared to any other person's. While for others, these years are for exploration, for you, these years are for survival, for keeping your body strong enough for transplant, and for keeping your mind strong enough to stay hopeful even on the darkest possible day.

Your friend died in 2015, in Pittsburgh, and her death felt close to home, as she was farther along on the same path you knew you would walk. In 2016, you watched another friend get dangerously close to the end, live for a month on life-support; you watched her get transplanted with the perfect pair of lungs, then die two days later. You watched the hope swell like a perfectly formed wave, and then crash, the destructive whitewash engulfing everyone who knew her in grief until, ironically, no one felt like they could breathe.

But these are not the only stories. 2015 also showed you two friends getting new lungs and using the ensuing years to live fully, beautifully, admirably, madly – to get married and to move apartments and to travel and to surf again and to take long walks, miracles of muscles and lungs and hearts that for so long had not been possible.

So for now, you have to have the strength to believe that you can be a success story, the resilience to not shatter if you ever reach that critical point of being on life-support while awaiting lungs.

In time you will be on the other side of this nightmare, and you will wonder what you can do to honor your donor. What you can do to embrace every minute of a life unfettered by limitations, a life with the chains unbound. You will never forget those old chains; the scars on your body will serve as physical reminders of how far you've come. The options for your new life will be endless. It will be dizzying. It will be incredible.

But for now, you must live – not simply exist, but *live*. You must do so by deliberately choosing the light of intention, gratitude, vitality, and curiosity over darkness. You owe it to the little girl who dreamed of researching dolphins in Belize, who devoured books with a hunger, eager for a glimpse outside her sheltered world. And you owe it to the woman you will become, one day, with new lungs and a second chance.

Love,  
Me