Ms. S was a Broadway dancer. “Just the chorus,” she says, but even that very fact amazes me, especially as I see her now, frail and wheelchair bound. The idea of this woman as young and spry, prancing around a Broadway stage, seems almost irreconcilable with her current state, an entirely different life that can’t be gleamed from first impressions. Yet acute ironies like hers are a common occurrence at TCC.

I’ll ask Ms. S if she likes thinking about those days and any friends she made while in shows. But she laughs in my face, “I wouldn’t call them friends.” Talking with Ms. S is much different than talking with many of the other patients at TCC. Small-talk conversations are quickly challenged, and half-thought-out comments are turned in your face, so that you have to really rise to her level. Yet the next day I can come back and she will not remember a thing she said, much less who I am. Because in another twist of irony, this sharp and vibrant woman has Alzheimer’s.

I came into my first meeting with Ms. S knowing that she had Alzheimer’s, expecting a slow-talking, disoriented elderly woman, which made her sharp demeanor all the more startling. Her memory of her past was impeccable, and she told me stories of traveling around the country with her theater group. Even her short-term memory was better than I expected, as she bemoaned the fact that she was stuck in a nursing home and enthusiastically greeted an RN who popped in the room. Yet when I asked her who he was, she stared at me blankly: “I don’t remember. I think he’s some type of helper.”

I came to realize that this sort of response was typical. I would ask her what she did earlier in the day or what activities she did for fun at TCC, and I was greeted with the same confused expression and strained response: “I.. I just can’t remember.” In moments like this she seems to drift into the recesses of her mind, aware that something is amiss. I’ve never gotten up the courage to outright ask her about her disease, partly because I avoid
sensitive topics if a patient doesn’t bring it up, but also because I don’t know how much she remembers about her diagnosis and I don’t want to have to tell her.

One day I visited Ms. S, determined to bring her out to the rest of the facility. I told of her of all the activities TCC offered, from BINGO to horticulture classes and offered to take her to them. She lit up, in disbelief that all of these activities were available, and I left that day feeling that I could at least improve her daily life in a small way. It was not until I peeked into the dining room the next day and saw her participating in a BINGO game that I realized that these activities were not new to her. She spends so much time in the main dining room that she inevitably participates in all of them. She just didn’t know it.

Every time I leave her, I know I’ll have to restart the next time I see her. I’d sometimes struggle with understanding the point of my visits, as I only seem to provide temporary comfort that cannot leave a lasting impact. But this all leads back to the question of dying with dignity. No one wants to die lonely, and the loneliness in TCC is heartbreakingly present. Even if I am a stranger every time I greet her, at least some of the dignity in treating her as someone worthy of basic human needs, such as socialization, can be maintained.

So today I will visit her again. We will have the same conversations and do the same activities. She will open my eyes wider and teach me about life and death, all without knowing who I am. And on Monday we will start from scratch.
As soon as I walked into Rachel’s* room, I knew what had happened. All I needed to see was the bed holding a bare mattress.

Yesterday, I spent many hours sitting at Rachel’s bedside. She was lethargic, shaky, and cold. I would hum to her on the same beat as her labored breathing. When I get tired, I would open YouTube on my phone and play Ave Marie on a loop for her. I watched Father J perform a beautiful Sacrament of the Sick ritual. I observed Chaplain C, with one of the most determined expressions I have ever seen, go on a hunt around TCC to get Rachel the pain medication that she so desperately needed. I spoke with her daughter, who was working hard to make sure all of her mother’s arrangements were taken care of.

Everyone knew Rachel was dying. Yet, her room was filled with life. Life trying to ensure a good death. She wasn’t a burden, but rather a force of life. That, to me, is a death with dignity. And that is everything.

*Patient name has been changed to respect privacy
It was 1955. The Brooklyn Dodgers just won their first (of five in nine years) World Series against the Yankees. They were done “waiting;” their “next year” had finally come. It was a big year for the Dodgers, and it was a big year for Dodgers second baseman Jackie Robinson, the first black player in the major leagues.

Number 42, don’t forget. That’s what Ms. M told me. She was the Dodgers’ biggest fan.

Ms. M studied Classics at a college here in the City and lead a small, but productive student organization after classes. A debate was in the works, comparing sports in Ancient Greece with those of the modern 1950s. They needed speakers. A Classics professor, who specialized in Ancient Greece, would speak for the former side, but the latter spot was still vacant. Jackie Robinson would be a perfect, but completely unattainable candidate. Ms. M knew that. She knew he’d just won the World Series. She knew he was very busy. But she also was the Dodgers’ biggest fan, and Mom always taught her to live without reservations, and she always took what Mom said to heart. The decision was easy. Ms. M wrote Robinson a letter, short and brief, and made sure to include that “we don’t have much money, so we won’t be able to reimburse you.” She didn’t want any misunderstandings or conflict. So candid and so unapologetically her.

And against all odds, Robinson replied. He came to Hunter College, and he debated. The room was packed; students spilled out the doors. Athens vs. Sparta became the Dodgers vs. the Yankees. Past became present.

I think Ms. M’s fearlessness is a core part of her identity. She acts according to what she believes to be right, with a blind eye to all the artificial walls that society has constructed. She grabs life by the horns, and just lives. She is a college graduate; an archeologist; a lover of canned dinners; a beloved sister, best friend, and soulmate to R. Her personality is just slightly off-kilter, just enough to catch your attention, but still remains perfectly relatable and imperfectly human. She makes me feel human.
She makes me question myself. If put in her position, would I have the guts to casually email Steph Curry or Lebron asking them to visit my tiny organization at my tiny school with no compensation? I know they get thousands of emails a day that someone else probably checks for them, but would I do it anyway because why not? Or would I laugh at the suggestion, call it a waste of time, and write it off as a senseless product of ignorance and naïveté?

One day, I will be in Ms. M’s chair. And I can only hope that I will have had a rich life, one full of self-reflection and depth and risks taken, full of decisions made according to what I believe is right. I hope I can say I did what made me happy and fulfilled.

When I talk with Ms. M, I sometimes forget that this is all she has. This room, this chair, these few house dresses, that stack of books are her entire life. She used to go to her church in East Village. She used to take the bus to her dentist. 135th and 5th Ave. She’d pass a bookstore and read that sign in its window display: “If you don’t know, learn. If you do know, teach.” She’d think about it for weeks and weeks. Now, she spends her days sitting outside her door, reading in the hospital hallway. Now, she can only tell me about all the things she used to do.

My experiences with Ms. M offer just a small look into the lives into which I’ve had the privilege to walk so far.

Ms. W is a pediatrician who now has severe Huntington’s disease, a doctor turned patient. When we met her, we asked her, “What sort of things would you enjoy hearing us read to you?” A response clearly formed in her head, but came out her mouth jumbled and muffled. Anguish spread across her face as she fought to answer this simple question, a question that she probably could have answered without a problem just a few years ago.

I imagine that Ms. W used to walk into a sports-decorated exam room, like the ones at my old pediatrician’s office, to see a little boy who had strep throat. I imagine that she used to smile and ask him about his day and how school was going, as she listened to him breathe. I imagine sometimes she’d go home after a hard day, questioning how and why she worked so hard to be a doctor, and after a great day, reminding herself that she wouldn’t
be happy doing anything else. I imagine she cooked herself dinner and caught up on the latest pediatrics journals, watched The Bachelor and went out for drinks with friends.

I imagine that, one day, she noticed that her hands moved a little strangely, twitching, as she wrote notes on her clipboard—the first sign of Huntington’s fated onset. Maybe she denied it at first, or maybe she knew right away what was happening. I imagine, one day, as her Huntington’s progressed, she couldn’t see her patients anymore and had to retire.

I imagine she did all those things, but that’s all I can do—imagine. Because now, she sits in her wheelchair in her room and struggles to answer “What sort of things would you enjoy hearing us read to you?” even though, inside, she’s probably blurtling out the answer. I can’t help but to feel that this disease has slowly stripped her of her identity and forcibly replaced it with a new one as she fights to maintain who she really is. I know she was once a doctor, but only because that’s what her doctors told me; all I know personally is Ms. W, the patient, and that makes me sad.

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There’s Mr. H, an Emory University graduate, a practicing lawyer in New York, and, now, a resident with dementia so severe that he just yells the same statements each time you pass by.

And Mr. M, who is so incredibly skinny that we were absolutely floored to learned that he is only 56 years old. That’s younger than my mom. Mr. M showed us the photo that was taken when he graduated from the Police Academy in Puerto Rico. The bulky, muscular man in uniform was an entirely different person from the skinny, wasting man in hospital gown in front of me.

There’s also Ms. B, whose memory has deteriorated at Alzheimer’s hands. Memories stolen away. Memories that were filled with experiences that, again, I can only imagine. Maybe there was a silly boyfriend who always made her laugh, especially at night when she was exhausted from the too-long days of work. Maybe there was a surprise birthday party that she said she’d never forget. If only. So many memories gone, and with them, again, so much of who she is and the life she lived. The only glimpses into her life that I have come
from the few memories that remain. Memories of nights spent dancing mambo, and others spent sleeping peacefully as her cat diligently watched over her.

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So many lives that once were.

That’s what I can’t stop thinking. Maybe that implies a poor attitude, a poor way of looking at things, but I don’t mean wrong. I know these patients are still able to feel joy and to laugh, to have rich and fulfilling lives. It’s just a matter of making that a reality.

These ramblings may be incoherent, incomplete, and drawn out, but so far, that’s all I have: a growing collection of thoughts and concerns and ethical dilemmas, through which I’m struggling to sort. I’m trying to identify where and how I can be useful here and to answer all these questions—practical, personal, ethical. I feel restless. Restless and inspired.
The domains of quality-of-life, as defined by Dr. Rosalie Kane are “security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being, and functional competence” (The Gerontologist (2001) 41 (3): 293-304 doi:10.1093/geront/41.3.293). I asked a patient with Huntington’s Disease what he likes to do for fun. He responded that he likes to be independent. A veteran and a former railroad worker, he enjoys walking around and spending time outdoors. His reality at TCC, however, is that he is dependent on clinicians and he can only spend a limited time outdoors. His independence has been subordinated to his health.

What I have noticed is the ongoing difficulty of balancing a patient’s independence, freedom of choice, and ability to function with a patient’s wellbeing, especially when contradictions arise. The difficulty of this question has explained the need for such an interdisciplinary staff. Holistic care requires a diverse staff that includes physician, nurses, physical therapists, occupational therapists, recreational therapists, nutrition therapists, social workers, maintenance staff, and administrators. The big question seems to be: how can a caregiver optimize quality-of-life with health and safety?
“Caring for the Forgotten” – by Sophie McAllister, June 13, 2016

Whenever someone asks me where I’m working during the summer and I tell them that I’m working at a nursing home that deals with end-of-life care, I usually receive a sort of wince as a reaction, or sometimes a remark along the lines of, “wow that’s gonna be tough, do you think you’re up for it?”

I suppose this sort of reaction comes from the perceived emotional strain that comes with having to accept that you cannot “save” your patients and from losing people you have grown attached to. Yet if we are to view success in this field in this manner, then the end-of-life caregiver will always fail. An entirely different mindset should be adopted in which the metric for success is quality of a patients’ final days rather than purely quantity.

Of course when I actually came to TCC I realized that the reality of end-of-life care isn’t what I, or most people, had imagined. Having mostly observed the geriatrics unit and the HIV/AIDS unit, or discrete unit, most of the patients I encountered have years left to their life. What I found striking was that in my hometown, many of these patients would have been living an incredibly independent life in their own house, perhaps with the care of a private nurse. The only thing keeping some of these geriatrics and HIV/AIDS patients there seemed to be financial barriers or the lack of family support. In fact, if it weren’t for TCC or similar facilities, many of these HIV/AIDS patients would be left to the streets. In that way, TCC serves those whose lives are easily ignored, by both alienated family members and the community as a whole.

Towards the end of the week, we visited a geriatrics patient who was on hospice care, meaning she was expected to live less than six months. As we searched for her room, one of the other patients who we had gotten to know told us she wasn’t doing well and had been taken of dialysis and other life-sustaining measures. She was asleep when we entered and had been asleep for a couple of days according to her aide. We left after a short while because there was little we could provide, yet in the following days I continued thinking about the aide. Her entire job consists of going bedside to bedside of people who are on their last weeks of life; she has the job that every person who winced at my job description dreads. I wonder if she finds her work emotionally heavy, if she looks on it with a negative or positive light. Indeed, she might mark a sort of final step for a patient, a sign that the
hospital has determined the end. But she is also a sign that they weren’t forgotten, up to the very end.