

The Banishment of Carrots: A Collection of Works About Dementia

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Chapters

1. Methodology	Page 3
2. The Banishment of Carrots	Page 11
3. Benjamin and Mary	Page 18
4. Being Human	Page 45
5. Homo Bubo	Page 60
6. Regretfully They Tell Us, But Firmly They Compel Us	Page 72
7. Bibliography	Page 74

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Methodology

Prior to settling on my thesis topic, I considered focusing on the formation of the United States Africa Command (AFRICOM). It could have happened — a fellow student who had worked at the State Department offered me her connections. I thought too about drone warfare and former Nicaraguan Contra commanders living in the United States. The thesis, I thought, should further my interest in anti-imperialist organizing and activism.

So why dementia? When picturing the future, I saw myself campaigning against extrajudicial CIA killings, not doing anything health related. What could be compelling — i.e., what could be radical — about this topic?

Enter narrative medicine. The class *Illness Narratives* with Marsha Hurst fundamentally altered my understanding of the world. It gave me a theoretically rigorous introduction to disability studies, leading me to examine norms of appearance, the power (both liberating and oppressive) of narrative, and the very idea of health. More remarkably, it helped me to link the personal to the political in a way that no class had before. Every week, we had to write our own illness and/or disability narratives. Instead of appropriating a disability for myself, I wrote caregiver narratives. These represented my closest proximity to disability, as far as I was then willing to acknowledge.

For a while, I wasn't public about my caregiver status. There's a certain feeling that comes with holding something in, totally unlike my other feelings of fall 2012: exhilaration at moving forward with oral history; disbelief at having spent \$40,000 to do so; desperation due to my partner's endless job search; shame upon telling the cashier "EBT." This feeling was preferable, at least for a semester, to my quickening heartbeat whenever family came up in conversation. Chatting about family felt like swallowing something too big which slides slowly and painfully down your throat.

My choice of thesis topic came down to the fact that I was always thinking about it anyway.

So why not write a paper on it? But to do that, I had to say its name out loud.

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Final Thesis Proposal

Three years ago, my family and I acknowledged that my father was suffering from memory loss. He repeated himself over and over without knowing it, he had trouble learning new things, and he had become a startlingly bad driver. An auto accident forced him to stop teaching. He degenerated quickly, and a year later we moved him to an assisted living facility. I resettled in Iowa, where I could see him more frequently. After combing his hair and changing his clothes, I often took my dad out for French fries and ice cream. Sometimes we stayed in and watched Johnny Carson reruns. When the weather was nice, we went for short walks. During these occasions I prompted my dad to retell stories from his past which I had heard since childhood. He would usually remember only fragments, so I would journey back there with him: to the farm in Atlantic, to basic training at Fort Leonard Wood. These were stories my dad used to love telling, and with Alzheimer's disease ravaging his more recent memory, they were some of the few memories still accessible to him. But those were not the only reasons I brought them up. I focused on these stories because they are fundamental to my own identity.

Finally it was out there, public knowledge, freeing me up to talk about it. Every time I discussed my dad's dementia, there was the hope it would *not* feel like a fresh disclosure.

For my thesis, I would like to investigate what happens to the stories of people who suffer from Alzheimer's disease. Where do they go? To whom are they important, if anyone? What are different people's stakes in the telling and retelling of these stories? How do people close to Alzheimer's sufferers relate to these stories? What stories do caretakers and Alzheimer's sufferers decide to remember, and why? How is the past constructed by people with memory loss, and how do those close to them interact with that construction? How do we talk about silences in the context of memory loss? What significance does storytelling have in the context of memory loss?

One of the wonderful things oral history has taught me is that everyone's life is partly shitty. For some, it's all shit. Conversely, one of the things narrative medicine has taught me is not to assume people experience their lives as shitty. Applying this to my thesis, "Alzheimer's sufferers" have become "very forgetful people."

A more fundamental change has been in my focus on often-repeated stories. When prompted, the caregivers I interviewed could not recall stories their loved ones with dementia used to tell. Perhaps I failed to ask the right questions; perhaps it was difficult to remember something like that in the interview setting; or perhaps my assumption that people carry around a healthy stock of stories was off the mark. My interviewees did, however, detail their changing communication with their loved ones in vivid, moving, and surprising ways. Timothy Samberg, a retired social worker, described this transformation in his stepfather:

He was living alone in Manhasset. We had to wait out his inability to do checks and bills where he was paying four thousand dollars instead of forty dollars. We'd take him to the diner and he would sort of socialize with people there, but later on he couldn't become part of it. He was mumbling his words. He was getting confused more and more, and this fueled his rage. Finally, we kidnapped him. We put him in the car and took him to an assisted living facility in Manhattan where he raised a lot [of hell], but then settled down and transformed himself into the sweetest guy you've ever known. It was the best period in his life. He socialized with people, he would socialize with the staff, and he was conversant without anger. We would talk long hours a lot of times during the week. I learned about his brother, I learned about his childhood, I learned about maybe why he had such a temper, his frustrations in life. And then talking became a little bit more difficult, and more difficult, and then finally we didn't talk at all but we just sat together and that was okay.¹

Timothy's account resonated with me – not because my father was a tyrant (thankfully), but because my experience of his Alzheimer's disease rubbed against the usual story of Alzheimer's as tragedy. This was a revelation. My recollections of taking walks with my dad, gently guiding him along the line where the grass met the sidewalk; of going to Dairy Queen and flipping his Dilly Bars once he had eaten everything on one side of the stick. Positive emotions, previously shunted aside, could now be acknowledged and incorporated. The personal was about to meet the political.

¹ Timothy Samberg, interview with the author, May 4, 2013.

Why Oral History?

The theories underlying the field of oral history apply especially well when working with people with memory loss. Alessandro Portelli writes that “[oral history] tells us less about events than about their meaning.”²

Although the narratives of people with dementia can impart valuable information about their life history, due to the nature of the disease, not all of this information is available for recall. But as an oral historian, what is important to me is not simply the facts of the past, but the meanings attributed to the past and the process of telling. My questions for people with dementia were therefore more focused on emotions and opinions than facts. This helped to prevent situations where interviewees felt uncomfortable because they could not remember specific facts about the past.

The use of oral history in this project entailed extended, one-on-one interviews with four people with dementia, two spouses of people with dementia, and one person whose father and sister had dementia. Four of my interviewees made it into my thesis: two individuals with memory loss, one spouse, and one family member. I located interviewees through the assistance of Wendy Panken, a social worker employed by the New York City Chapter of the Alzheimer's Association. Wendy was incredibly helpful during the course of this project, not just in locating interviewees, but also in leading a support group I joined for young people whose parents have dementia.

² Alessandro Portelli, *The Death of Luigi Trastulli: Form and Meaning in Oral History* (Albany: State University of New York Press, 2001), 50.

Ethical Concerns

People in different stages of memory loss are variously able to consent to the interview process.

While people experiencing mild cognitive impairment may be quite able to understand the interview project and the implications of participation, people with moderate dementia will often be unable to give informed consent for participation in a project such as this. No matter how the details of the project are communicated, some people with dementia will not be able to understand it and weigh the risks and potential benefits of participation. Additionally, people with dementia often do not fully comprehend that they have dementia. Explaining that this oral history project is about dementia, and that I would like to interview them because they have dementia, could potentially have caused them immense psychological distress. Therefore, I did not seek informed consent solely from my interviewees with dementia, as identified by social worker Wendy Panken. Instead, I obtained surrogate consent from their legal representatives. Going through Columbia University's Institutional Review Board approval process helped me hash these matters out and develop a framework for conducting my project in the safest possible way.

Unlike in most oral histories, due to the personal medical information collected through the interviews, interviewees had the option of maintaining anonymity. Interviewees had the chance to review, edit, and redact sections of the transcripts before they were made publicly available. This allowed for a high degree of confidentiality should the interviewee and/or legal representative prefer to hide personally identifiable information in the interviews. Of my interviewees, Mary Rykov-Samberg, Timothy Samberg, Julie Graham, and Henry Mencken opted for anonymity. These names are pseudonyms. Written transcripts of the interviews will be archived at the Columbia Center for Oral History.

From Oral History to Literary Narrative

Making real people the subjects of literary stories is profoundly discomforting to me. Stories have characters whose personality traits are exaggerated, ignored, and misrepresented, characters who are inevitably flatter than real people. Turning someone into a character involves slicing away layers of depth and grafting on layers that don't exist. No matter how a story is collected, be it oral history, journalism, the piecing together of written diaries – writing about people is the ultimate privileging of one's conception of another human being over their own self-conception. Turning people into characters is the most violent act I can think of – except for perhaps shooting someone.

With this attitude going into the project, it is strange that I ended up with several short stories, a memoir, and two plays. I ask myself: did I write these materials regardless of the damage they may cause my narrators? I don't think so. I came to believe something new and transformative in the course of writing this thesis: that characters may be based on real people, but they are entirely separate beings. To aid me in giving characters their own space to exist, I changed the names of narrators who did not prefer the use of pseudonyms. It was incredibly helpful. It felt like finally realizing something deceptively simple that Gerry Albarelli talked about in Day One of his class, *From Oral History to Literary Narrative*. It felt like freedom.

With the exception of “Regretfully They Tell Us,” initial drafts of the short stories were written in Marsha Hurst's Spring 2013 Narrative Medicine course at Columbia University entitled *Illness Narratives*. Drafts were edited with the input of Gerry, Mary Marshall Clark, and classmates.

Originally, I intended each of my narrators to claim their own chapter in a book. But as I worked with Gerry, I realized that the narratives could be compared much more vividly if the narrators were allowed to talk with each other. The process of re-creating each interview as a book chapter was useful, however, in removing redundant and/or irrelevant text and ordering the stories to create broader movements.

The play “Timothy and Mary” (now entitled “Benjamin and Mary”) started out as a “realistic” portrayal of my interviews with Tim and Mary, but Gerry suggested I make it more absurd. I did, and the play came to life in a new way. The work consisted of developing salient themes, reinterpreting and inventing some dialogue, building mutable relationships between the characters, and writing stage directions to add new layers of meaning. My initial concern with accurately representing my interviewees prevented me from taking any of these actions. Once I decided to respect the characters as characters, however, the work became almost joyful.

“Being Human” is the only piece that remains in the form of a book chapter. Julie Graham gave me two 1.5-hour interviews, and her memoir draws from both of them. While I could have grouped her stories by character or by theme, ordering them more-or-less chronologically created greater heterogeneity in the memoir and allowed me to build new connections. Julie’s words transformed from a stream-of-consciousness non-narrative to a Ferris wheel of characters revolving around an axis of family pathology. In this narrative re-creation, the various insanities of Julie’s family – her sister Lucy’s paranoia, her father’s brain cancer, her sister Debbie’s dementia – scream at each other in a cacophony of confusion and pain. At any rate, that’s what I was going for.

The last piece I wrote for the thesis was “Homo Bubo.” Lots of different unresolved questions and tensions gained expression in the piece – which is not to say that they were answered or resolved. The piece contains a healthy dose of self-satire. I originally conceived of Bubo as an exact copy of my interviewee Marty Schwartz in eagle-owl form, and *The Outdoorsman* quickly became me. But I felt uncomfortable making only one of us an owl, and in the process of writing the play, the characters gained their own agency. I identified with both characters at different times, and both received dialogue adapted from Marty’s oral history. The result is that the characters are each a mixture of Marty, myself, and Chemical X.

I conducted several interviews that I did not incorporate explicitly into the thesis. Two narrators did not make it in: Suzy Schwartz, the wife of Marty, and Henry Mencken. I initially tried to write a play including Marty, Suzy, and myself, similar to how I wrote about Mary and Timothy Samberg. But I found that Suzy's interview, while great, contained too much of my own strain of thinking regarding dementia. Suzy believes it is often harmful to pull people with dementia from their world into "reality," and I have much the same sentiment. Marty's interview, on the other hand, remained inscrutable. By including only Marty, I dealt with his interview more directly while avoiding any kind of conclusion. In the case of Henry Mencken, I lost communication with his spouse and was unable to get a legal release signed. In addition to these, several interviews with my father did not make it into the thesis. This is directly related to his death on August 4, 2013. While I did not directly use any of these interviews, their content greatly influenced my thinking. Suzy and Henry are as much co-authors of this thesis as anyone else.

Fortunately, the work of this thesis will continue. Although I would like to march out of the cave like the Outdoorsman in "Homo Bubo," this can of worms has been opened – the little guys are squirming around, waiting to be impaled and tossed in the lake.

The Banishment of Carrots

Traffic

“Hey Dad, can I have that ride to the DMV now?”

“Sure. Why do you need to go there?”

“I lost my luggage in Nicaragua, remember? My driver’s license was in there.”

“Oh. You didn’t lose any credit cards, did you?”

“No Dad, just the license.”

“That’s a relief. That would have been a big mess.”

“Yeah, but that didn’t happen, so it’s OK. I just need a new license.”

“OK. Let’s saddle up.”

After years of use, the button that opened our garage door had faded from pearly white to scratchy brown, and you needed to press it hard several times to make it work. When the door finally jolted upward, my dad and I turned toward the street and gazed at our neighborhood. The noon sun shined brightly on the ranch-style houses, on the white oak trees, on our lawn, once carefully manicured and now a bit overgrown. Screams and laughter permeated the air as children a couple houses down chased each other in mini electric Hummers and Big Wheels. The garage door finished its ascent, and we got in the car, backed out the driveway, and started off down Maxwell Avenue.

It was August 24th, 2009.

* * *

Five years have passed. I live in Manhattan now, where I recently finished studying how to sit quietly. Every week I organize the overflowing bookshelves of a sweet, thoughtful, retired *New York Times* art journalist. Every other day I jog a block to Planet Fitness, which allows No Lunks. Twice a day I take vitamins for my everlasting health. Every other moment, I do what I was taught.

Superman floated in the air, his chin balanced on top of the Daily Planet. Dad always pointed him southwest, toward the old farm by Atlantic.

* * *

It was on that stretch of downhill road by Brookside Park where it's easy to fly above the speed limit. A skate park filled with high schoolers to our left; gravel parking to our right. I was thinking about everything I had lost in Managua when I forgot my luggage on the bus. My KRLX T-shirt was in there, my audio recorder, photocopies from the Bluefields historical archive. It would be a lot harder to write my comps now. I replayed it in my head, imagining stepping off the bus and gliding straight to the taxis. I had been coasting on my ego after giving my bottled water to the thirsty woman next to me. If I had just paused for a second, everything would have been different.

Approaching the railroad overpass, a CyRide bus emerged from the shadow. It felt like my dad had drifted too far to the left. For a half-second a warning raced into my mouth, but I clamped my teeth shut. Our car smashed into the bus at the left headlight, unleashing an impossibly loud shriek of disintegrating metal. We spun backwards, then forwards, the world visible only in streaks. Tightness gripped my body. Wheels ground into pavement, and we slowed to a stop on the other side of the overpass. In front of our car was a field of dandelions and crabgrass.

Ears ringing, I looked over at my dad through the smoke. Blood trickled from his forehead, and his glasses lay shattered in his lap. He stared into his deflated airbag. The look in his eyes was hurt, afraid, and mostly confused. I wanted that look to go away. Instead it pressed itself into the muscles of his face, establishing a permanent place for the years to come.

Mule Story

March 2010

Dad: My name is Richard Robson, and I just want to talk a little bit about my dad. He was a great guy, but he was also fun to be with and sometimes he would do things that were especially fun. One of the things that I remember from being on the farm was we had a couple of mules. In those days we didn't have any electricity or running water, it was pretty primitive. In terms of how we worked the farm and the land, we had a couple of mules and we had a couple of horses. So the first thing I'll make some comments on will be picking corn over on the – woulda been the east side of our farm. Essentially what happened that day was, my mom was also picking corn with us. And turned out that we had a couple of mules that were pulling the wagon. My dad had a certain amount of patience, but it only went so far. Those darn mules decided that they were just tired, so they sat down. It made my dad rather upset, to say the least. My dad walked back to the farmstead and came back and had some gasoline. Not a lot, just a little bit of gasoline with him. First he unhitched the wagon, course I was in it at the time and he wanted to make sure that I would be okay. And then my dad stood behind the mules not too far, threw some of that gas underneath their butts, and lit a match. Those mules took off like a by-god rocket ship. I've never seen an animal could move that fast before. That was something I've remembered my whole life and just showed how interesting my father was.

August 2012

Dad: My dad decided those mules were really – it was so hard to get them to move. So he. Told you that time before, he got ahold of those mules and it made him so mad he got up and just made those mules go like crazy.

Sam: Didn't he get some kerosene or something and –

Dad: Yeah, he probably could have.

Sam: And he lit a fire under their butts.

Dad: Yeah.

Sam: You used to tell me that they took off like a rocket ship.

Dad: Yeah.

On Crafting Meaning from Disability

In *The Diving Bell and the Butterfly*, Jean-Dominique Bauby describes the letters he receives from people who barely knew him before the stroke that left him almost completely paralyzed. Unlike the letters of close friends, which are filled with the mundane details of life, the letters of these people abound with musings on the nature of life. Bauby is generous toward these people: “Their small talk had masked hidden depths.”³

I am less generous. For many people without disabilities, the minds and bodies of disabled people serve as jumping-off points for contemplating death and what makes life worth living. To accost disabled people with these thoughts is presumptuous, and to think this way risks transforming disabled people into symbols, stripping away their humanity. Applying this logic to my own situation, I wrote myself a reminder not to look at my father and see a *memento mori*.

And yet, in the case of my father, I can’t help myself. There will never be someone as close to me in the same way as my father, and now he is gone. Or he’s on his way out. It’s hard to tell. I want my oral history project to contribute to the argument set forth by people like Anne Basting and John Zeisel: that people who forget things are still people, and as with all people, the way we communicate has to be accessible to all parties. I want people with memory loss to be able to be heard.⁴ But I also have my own story to tell. And by doing so, I hope to discern some shapes in the darkness.

I dreamed I was standing outside my childhood home at night. The lights in the living room glowed orange, and the silhouette of my father appeared in the window. This was strange because the house had been abandoned, my father relocated to an assisted living facility 140 miles away. Who was the man in the window?

³ Jean-Dominique Bauby, *The Diving Bell and the Butterfly* (New York: Knopf, 1997), 83.

⁴ The change has to be in the rest of society, not in the people with memory loss.

When I Take His Personhood Away

One leg lumbers ahead, then the other. The movement is automatic. There is no machinery at work in the arms, no swaying: they just hang there, occasionally jiggling to incidental movement. Around and around and around my zombie goes, searching for nothing.

My zombie walks past the greeting area occasionally, where other residents of the complex sit in various stages of decay. When he passes the kitchen, a human woman sometimes walks out to him and attempts to initiate dialogue. Sometimes the shadow of a smile seems to cross his face, or at least that's what she tells the other guards.

My zombie prefers ice cream to brains, although I've never actually conducted that experiment. He can talk, too. "Dilly bars," he says, lips quivering. He has an insatiable appetite for those things. Arriving back from an institution-approved trip to Dairy Queen, he'll mutter in a low, raspy voice, "Let's go get those Dilly Bars."

It's not always ice cream, though. The cooks in the complex make all sorts of things to appease the zombies' appetites – burgers, chicken fingers, fries – the kinds of things the zombies liked before they were infected. Sometimes, however, an item slips into the menu that does not align with the finger-food code, established when scientists reported that zombies have difficulty operating utensils. Spaghetti and meatballs, for instance. On these occasions, my zombie's clothing tells me what he had for lunch far better than he can.

When I walk my zombie back to his cell, sometimes I pause at the display outside his door. There, inside a glass frame, are pictures of him pre-infection. What strikes me is how similar he looks. I know he's rotting, the evidence is there, but it's somewhere below the skin.

Body Thoughts

The food was best when I was young. I rolled in potatoes still fragrant with the sweet scent of earth, bathed in milk still warm from the cow, wrapped myself in bacon whose ancestors I knew. They were heavy meals to sate a hefty appetite, grown while baling hay and driving the John Deere on humid summer days.

During the marriages, the food was decent: tuna casserole, spaghetti with garlic bread, smoked cocktail weenies in grape jelly sauce. Following the divorces, I ate ice cream. Then the kids left, the freezer ran out of food, and I shrunk. For a while, I forgot how to taste.

Then the parade started! Everything was back on the menu. French fries, Yoo-hoo, chicken tenders, fingernails, hamburger buns, chopped hot dogs, Dilly Bars, tin foil.

I took it to go.

The Banishment of Carrots

I returned home for Spring Break to discover a new ritual. Every day at 4:00pm, my dad fetched a bag of baby carrots from the refrigerator. He sprinkled 10-15 of them onto a cutting board, slid a knife out of the knife block, and methodically chopped them into little circles. Then he scraped the carrots into a cereal bowl and retired to the living room, where he sat on the couch and quickly shoveled them into his mouth with his fingers. If I were reading or watching TV on the opposite couch, he looked up at me after a few mouthfuls and asked with a self-conscious, creased brow, “Am I crunching too loudly? Anya says I make too much noise.”

For years, my dad’s snack items, and some nights even his dinners, consisted entirely of food from the top of the nutrition pyramid. That was his normal abnormality. But somehow, my little

sister had convinced him that he needed to eat better. When we went to Cub Foods, Dad picked up a couple bags of carrots regardless of how many we had stocked in the fridge.

After his knife slipped one day, Dad told me he was worried the carrots were too round and therefore too dangerous to cut. “Have you ever seen crinkle-cut carrots?” I asked him. When we went grocery shopping and I held up a bag of the ridged, checker-size carrots, his face widened into a grin so big I could see the chipped tooth he usually kept hidden.

After his car accident, Dad relied on his at-home caretaker Mary to provide his carrots. On Mary’s day off, my older sister Kristi sometimes drove from Iowa City to give him his meals. One day she arrived and found my dad in a panic. “We’re out of carrots! We need to go to the store.” Dad muttered the whole drive to Cub Foods. When they stopped in the parking lot, Kristi glanced at him and asked, “What would you do if there were no carrots here?” He stared down at the glove compartment and whispered, “I don’t know what I’d do.”

Then one day it ended. When Mary brought Dad his tray with a sandwich, lemonade, and requisite bowl of carrots, he pushed the bowl aside and declared, “Carrots are banished.”

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