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**HARD CANDY**

**caregiving, mourning, and stage light**

**GUERNICA WORLD EDITIONS 1**

chapter excerpts

**Sloan-Kettering Downton Abbey**

Mom's in 519. I'm in 721. This has never happened before. Our doctors and respiratory therapists and friends go up and down to each of us. We needed it. We were taking care of each other but in a mucous factory for weeks—putting the pillows out the windows to air out and get sterilized by the sun, cooking chicken soup. The laundry stayed piled in the hallway. The food shopping never got done. I took us in, like surrendering at the station house. The bacteria rose in my throat, a tidal wave, pushed me under, not breathing, while others waved to me from shore. Can't tell you when it started. I'd have to back-up and back-up again. I forgive myself for getting sick again though again I can point to—like my father before me—a shared food or handshake that augmented what he called “the battle with my phlegm.” I woke up with a closed neck baked with mucous. I panicked. I went to a local doc who gave me a loading dose of Prednisone. Mom and I have been doing hospital / hospice care for each other for months—weeks—years—decades. We were both sick as kids. Mom was a cripple and I was a chronic asthmatic. Now we both need to be home on oxygen. My oxygen

saturation numbers don't match this claim but I feel better on oxygen. In the hospital, oxygen is a lullaby and I am peaceful.

I'm in quarantine. Isolation. Great way to get a "room of one's own." I love the privacy. I love there's no smells from other people or other's beeps. The high pitched beeping of monitors drives me nuts. I love the 'room of one's own.' I love the yellow masks and gowns. I love the hierarchy and gravitas. I love being shielded and I love being dangerous. The sign on my door reads: Droplet Precautions. My droplets, my sneeze, contaminate—droplet bullets shoot out my mouth.

There's an intimacy in illness that Mom and I share. A slowed down-ness. A tender care. A need for simple food, bright entertainment, plenty of water. To have my Mom in Sloan-Kettering at the same time as me feels special; it is the first time in my life that I know all our needs are met. We are safe, cherished, watched over, in two beds—which has never happened! It's always been one bed one couch, one of us on the couch. We are visited by people, wonderful nurses and friends to talk with, friends bring our favorite things and the food is the best in the world. Mom looks so happy having her little room; bed, table, snacks, TV, phone, tissues, oxygen, nurse call button. She needs this. And for once, I can get some rest. I am so calm here tonight knowing Mom is calm and safe and has Nurse Melissa to watch over her and someone to watch over me. I have Nurse Fallon on duty. So, me and Mom are both okay. Safe. Well fed. Oxygenated. Hydrated. Medicated. Rested. Visited. Electrolytes balanced. Remembered. Communicated with. We need this on a more regular basis—community—tribe—healing residence—a place where we are not all alone making every decision about our care.

Basic needs met. Clean. And the relief of retreat, of quiet, and not having too much clutter and accumulation to deal with.

Marco is the waiter for the floor. Marco caters to me. Brings me my meals. Brings me extra muffins and tea. Asks me if I want anything extra. Sloan-Kettering is our Downton Abbey. The short ribs and roasted potatoes are the best in town. The music therapist can sing *The Sound of Music*. The arts & craft room sends us paints, sewing projects, beads, anything we want, even Mom's #11 size knitting needles. The visiting dogs, bedside massages, good company walking around the halls, some of the cleaning staff put down their mops and pray with me and sing gospel. We have a jam session with the music therapist. I call our band, "The Metastatics." My friends come and are focused. They put away their cell phones. In a way, I'm having the best time of my life. Pampered and served, and a comfortable bed, a bed at all. Being in the hospital is luxury, a whole bed for myself, and constantly clean sheets. Anything I drop on the floor, they remove and replace, oxygen cannula, cup, pillow. The "environmental specialist" comes with her mop, sings gospel, and over me, prays.

Mom is going to a special cosmetics class for cancer patients. She is thrilled. They wheel her in. She gets free samples of expensive products and a make-up bag. I go down and see her in her hospital bed, fully made up like she's going out dancing. She says she had to take off the lipstick they put on that "puffed" the lips. She got regular lipstick, the kind she likes. I rarely see her this happy, as our two-week stay in Sloan-Kettering. She's glowing.

We talk on our cell phones from room to room. On my phone, the digital voice assistant never understands my Bronx accent, so I switched it from English to Italian.

Instead of saying, “Call MSKCC” for Memorial Sloan-Kettering Cancer Center, I say, “*Chiama Em Essa Kappa Ci Ci*,” and not only does the phone *capishe* me now, but I bring a smile to my own face every time. And believe me, I call “*Em Essa Kappa Ci Ci*” more times than I want to count in life.

Mom and I go over the renowned menu, curious about what the other will order for dinner, what sides—roasted zucchini and snap peas? What dessert. Pie? Pudding? Pound cake? Ice-cream? Peaches in the can? I coach her how to navigate the complicated TV channel system. When *Downton Abbey* comes on tonight we will both watch, and talk about it after. Usually we identify with the servant staff; the cooks, the servants, but not tonight, tonight both our feet will be up and our arms won’t hang off the side of the couch into the air.

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## **Gum Is Not Food**

*340 days out*

A knock at the door. I'm used to people coming and going by now; visiting nurses, social worker, case manager, psych consult, physical therapist, oxygen tank supplier, long-term care supervisor, spring water deliverer. This one came without notice. Just appeared at the door. Dressed all in white.

“Are you the nurse?”

“Yes,” she nodded sweetly, popping gum.

“C'mon in. I'm Annie. The daughter. My Mom, Rachel is in the living room. What's your name?”

“Darnell.” She puts her bag on a chair, takes her jacket off. I mechanically tell her to wash her hands, that we have paper towels, liquid soap dispenser and hand sanitizer in the bathroom. My mother and I say this almost simultaneously:

“Make sure she washes her hands.” Marching orders to anyone who enters the apartment. My mother listens for how long people have the bathroom water on. Enough to thoroughly wash hands? She'll comment later. Was there a paper towel in the bathroom trash? Proof she washed her hands? I have a box of yellow flu masks and gloves out on the snack table. I quickly surmise how the nurse is breathing. No sinus congestion. She asks if we have a blood pressure cuff, and I hand it to her, and she proceeds to wrap it around Mom's arm. She pumps the cuff and looks at her watch and repeats this until it is clear to my mother she has no idea what she is doing. My mother tells her, “You are not a nurse.”

“No, I'm the aide,” she says slowly and sweetly, gum popping.

Darnell's hours are two to six. One night we offer her a bowl of chicken soup. It's time for my mother's dinner. We are not comfortable eating in front of someone without offering them some too. We share what we have. We know by now that Darnell has three school age children down south, and that she is here to get training so she can earn more money when she goes home. So, we're sitting at the table together, the three of us, while she chews her gum while she eats our healing chicken soup. My mother and I are stunned and nauseated. Since she's up north for training, we take it upon ourselves to teach her how to eat.

"You gotta spit your gum out," I tell her.

"I'm cheeking it."

"Hah?"

"It's on the side of my mouth, in my cheek."

"What?" She's breaking our cardinal rules of eating. My mother and I have a whole silent conversation with our eyes, but we both preach out loud to Darnell. "No," I say, "you can't eat like that."

"What's a matter wit' you?" Mom chimes in, "you can't eat chicken soup with gum in your mouth."

"Okay," she says, "if you say so Miss Rachel."

After a coupla more spoonfuls of soup, I hand her a napkin. "Spit it out."

"I swallowed it."

"You what?"

"It's food."

“Gum is not food,” Mom says, “look it up on that fancy phone of yours.”

“You taught your kids to swallow their gum?” I am amazed.

“Yeah. It’s food.”

“Gum is not food.”

“Where do you think gum goes?”

“I don’t know. The stomach takes care of it.”

“It’s not digestible,” I tell her, “it’s not food. You gotta spit it out. Gum is not biodegradable.”

She giggles. “We swallow gum all the time.”

“You let your kids swallow gum?”

“Yes, it’s food.”

“Google it,” Mom tells her, “gum is not food.”

I love when my mother is adamant.

“I guess it’s made from trees, but there’s no way you can eat it,” I start reasoning. It’s impossible to continue eating our soup. Darnell’s shift is over and as she leaves we make her promise to look into what happens when you routinely swallow gum. When she’s out the door Mom says to me:

“How do people survive? It’s common sense, gum is not food.”

Now we have a new story to tell. Having all these strangers in the house is useful that way; we get the perk of having a common source of aggravation to unite us and make us laugh, and the bonus of taking our mind completely off our mutual breathing problems. The gum conversation continues. I tell Mom what I remember about Primo Levi’s writing about gum removal in my favorite book, *The Periodic Table*:

“You know all those black circular spots on sidewalks all over? That’s gum, old pieces of discarded gum that never go away. Primo Levi was a chemist. Once he had to figure out a chemical way to remove the black spots of gum from the sidewalk. Gum is not biodegradable.”

“Of course,” she agrees. I look on my phone and Google: “Is gum food?” “Can you swallow gum?” “Is gum biodegradable?” And there it is; facts. Gum, as it turns out, is now made from plastics and rubber, and can cause intestinal blockages, and no, is not biodegradable. Darnell never believes us though. She comes back popping gum, and laughs if we bring up the topic.

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## **The Rackets**

I drove steadily, continually checking the tank valve so that we wouldn't leak any oxygen. We needed every minute. Mom survived the bilateral pulmonary emboli attack in Connecticut. Now we had to drive home to New York. The problem was, oxygen cannot be delivered across state lines. No one could authorize giving us two tanks of oxygen for the trip. Not the doctor, not the Patient Advocate, not the social worker, not the Discharge Coordinator, not the Charge Nurse, no one could get Mom more than one green tank, a two hour supply. Enter the quagmire of Medicare contracts with 'durable medical equipment' suppliers.

Sitting in a car for hours and not drinking enough water increased Mom's chance of blood clots, now she was being sent home without enough oxygen to take a pit-stop. I coached her to move her legs and ankles up and down in the car to circulate blood. I sped. I lowered the level of oxygen for a while to buy minutes. We prayed the oxygen tank didn't leak, or the nozzle washer break, or the pin housing loosen, like they routinely did. We prayed we didn't hit traffic. My plan was this: if we ran too low on oxygen, I would find the nearest Fire Department for help. Firemen are much more helpful than anyone. They deal with high alert. So many years of our lives have been on constant high alert. I always had a contingency plan my whole life.

The next six months I worked hard to get Mom a portable oxygen concentrator on wheels. This is like carrying a vacuum around everywhere you go that makes oxygen out of air; now you only have to worry about running out of batteries, again every two hours. You don't have to worry about oxygen leaks or explosions. After six months of continual

battle, a concentrator was delivered to our door by a durable medical equipment supplier. I examined it and realized it only “pulsed” oxygen. It was not capable of “continual” oxygen. The pulse of oxygen was dependent on the patient’s rhythmic inhalation / exhalation. Mom needed continual oxygen. With heart failure, her ‘air hunger’ caused anxiety, panic and terror—she was not able to regiment her inhalations and exhalations. The oxygen company said they had no such “continual flow” machines. After weeks of phone calls, my sister succeeded in identifying who at Medicare evaluates the performance of the suppliers who win the contract bids. “Medicare’s Competitive Acquisition Ombudsman; the C.A.O.” Now we had someone specific to call when we needed intercession. Mom called the C.A.O. to report the oxygen company as an inept vendor. The C.A.O. immediately called the oxygen company while Mom was on the line, and said a complaint had been filed against them. Mom said, “You should lose your contract with Medicare, the way you treat people with one foot in the grave!”

The oxygen company man replied, “A continuous flow concentrator was just delivered to our warehouse! I was *just* about to call you Mrs. Lanzillotto!”

It was at our house the very next day.

“Jackasses!” Mom said.

The oxygen company workers routinely lied. What was the racket with durable medical equipment? Once we got the portable oxygen concentrator, I called for extra batteries so that when we hit New York City traffic getting to Sloan-Kettering, I could change the battery and Mom would have uninterrupted oxygen—and wouldn’t die in the car. I also called for a car plug. When I say “called” I mean spending three hours a day on the phone trying to achieve these goals, navigating the obstacles and lies of the oxygen

company. First they said, “You can’t have both an oxygen tank and a concentrator in the house. You don’t qualify.”

“We have frequent power outages,” I explained. “We need a tank in the house in case the power goes out.”

“If the power ever goes out, call us and we’ll deliver a tank.”

“She’ll be dead by then.”

“That’s the system.”

Then: “You can’t have extra batteries for your portable concentrator. You only get two. Then you plug in wherever you go.”

“Two hours is not enough time to get to the doctor. We get stuck in Manhattan traffic.”

“Don’t get stuck in traffic. You only have two batteries.”

Finally I learned their language—lies. Lies to survive by: “One of the batteries is not working. Please deliver another one.” When the delivery guy came, I lied again: “Another delivery guy picked up the bad battery already. No I don’t remember his name.” And that’s how I got an extra battery. I needed more and I still needed the car plug. I pulled the same routine, but when the delivery guy came, he lied first:

“I have no batteries, just the car plug.” And he handed me the wire.

I screamed at him, “We needed batteries! They promised us batteries!” but Mom, sharper and calmer than me, noticed pink bubble wrap sticking out from the delivery man’s armpit. In the pink bubble wrap, as she surmised, were the new batteries. He was lying to us. Why? How could he profit? Mom pulled me aside, pointed out the pink bubble wrap and hushed me with her time honored wisdom:

“Never argue with a jackass.”

Phil was his name. He looked at the concentrator and tried to pull one battery out, the one I said didn’t work. He couldn’t get it out. The rubber handle was awkward. Phil used force, then gave up. “I am afraid to break it,” he said.

I lost my cool. I telephoned the oxygen company and yelled, “Phil is afraid! Phil is afraid! Where are our batteries?”

“I gotta go look in the truck,” Phil said, but he lied again. He only walked out of the apartment and into the hallway. I followed him. There they were—the pink bubble wrapped batteries tucked under his armpit—just as Mom had eagle-eyed.

I went back into the apartment, removed the batteries from the concentrator and hid them. A few minutes later, Phil walked back into the apartment with the batteries in his hand, saying, “I found these in the truck, they are for someone else but I can do *you* the favor.” He lied again and again. What could be his racket? I had always tipped these delivery guys good.

“Yeah you’re doing us a big favor,” I said, and grabbed the batteries from him.

“Where are the old batteries?” Phil asked.

“I already gave them to you. You brought them out to your truck.” And that is how we got the batteries we needed to go to the doctor, enough to swap out so Mom could breathe in peace, her last year of breaths on earth.

Bottom line. I found these batteries selling on eBay for \$500 each. Therein lies the racket. Mom figured it out: Phil could sell the batteries online and report to the company that he had given them to us. He’d pocket a thousand bucks. There’s always a racket. Durable medical equipment, as it turns out, is the biggest one of all.

## Holy Cards

*9 days left*

After funerals I open  
my mother's replica antique wooden box phone  
and add the next Holy Card to the deck she keeps there.  
Here are the ancestors, a card for each one  
like their rookie baseball card, now rookie angel card.  
The cards have pictures of saints and angels  
and on the back, prayers. The only individual details  
are the person's name and birthdate dash deathdate.  
It's wild seeing who died within weeks of one another  
strange groupings that never would have happened  
while they lived.

Very few of my friends are represented in this deck.  
My dead friends didn't have lavish funerals  
with Holy Card expenses, coffins, plots, the whole nine yards.  
"Put me out with the trash," Tony told me.  
I make them by hand now, a Holy Card for each soul  
missing in this deck. I don't wonder anymore  
why my mother keeps these cards and all together  
in her old antique telephone, this wooden box  
hanging on the paneled living room wall  
with a black pear-shape beaker  
on a cord to hold up to your ear  
and one to talk into, and two round brass bells  
set into the wooden face of the telephone like big owl eyes.  
Two round brass bells that never ring.  
Her "telephone to the dead" I call it.  
I flip through the deck, read the names,  
examine the dates, look at the saints,  
see who has the best pictures with gold trim,  
wonder who's next.

My mother and I sit on the porch through sun downs.  
We wait for death to swoop  
down on us like a bird of prey  
an owl with silent vast wings.  
The telephone's brass hook and catch are bent.  
At night as we relax on the couch  
the door of the phone  
swings open