

Nay Nay's Rebirth

By Sara Lynne Wright

My mother reaches out to me almost every night. Sometimes she offers me *bulalo*, her favorite dish, the one I used to make for Zia and Joshua when they were small. For the first year after we became U.S. citizens - back when I could stand long enough to cook - I made only Filipino dishes, to remind my children where we came from. I taught them to call me Nay Nay, the same nickname I use for my own mother.

Sometimes, when she visits these days, Nay Nay cradles me in her arms and tells me she's so glad to have me back with her. When she can tell I'm anxious, she sings songs in Tagalog. My favorites are *kundiman*, classic love songs, most of all one called "Minimahal Kita" that she used to sing with my father. Whatever she does, it's always comforting.

Tonight, she beckons me to bathe: "You're my little piglet again!" I follow her unquestioningly to the shower.

I don't remember which knob is for hot water and which is for cold, so I pick one and turn it. The icy water shocks my skin. I rock back on my heels and lose my balance. Being ninety-four isn't all it's cracked up to be - terrible pun intended - because I fall onto my back, and then I hear bone cracking.

It feels as though a burning iron rod is piercing repeatedly through the center of my ribcage. I wail in an octave so deep I don't recognize my own voice - then slap my hand over my mouth. My nighttime awakenings are my guilty little secret, my waking dreams an escape from the suffering I feel the rest of the time, and I don't want my children to tell me they're not real. I miss my Nay Nay. I'm everyone else's Nay Nay now. There's no one to be mine - except when I see her in my mind's eye.

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Zia and my caregiver Lili rush to my side. "Nay Nay, what are you doing?" Zia's deep brown eyes are sunken and exhausted most of the time - she works too much - but right now they're horrified. She turns to Lili, "Should we take her to the hospital?"

"How bad is the pain, dear?" Lili is strong and sturdy. She reminds me of myself in my thirties, so long ago. Lili can tell when I'm lying, so I always tell her the truth.

"It's very bad. But I don't want to go to the hospital."

Zia looks at me like I know nothing, though I've been on this earth more than twice as long as she has. She's always been overly cautious. She turns again to Lili, wearing the same expression

she had when she was a child who didn't want to go to her first day of school. "Can we get her in the bed?"

Lili maneuvers her strong, sturdy arms beneath my armpits while Zia grabs my legs. The second they lift me, I feel the iron rod burning red hot like a blacksmith's handiwork again, penetrating the entire height of my body. I wail again, that unfamiliar guttural sound. "Don't drop her!" Zia cries out. She must be talking to herself when she says this, because we both know Lili would never drop me.

They get me into the bed. I curl into my usual fetal position, hands and legs contracted as though submerged in a bucket of ice. I wish they were, but there's nothing to cool the hellish blaze through every part of my body. Still, the fetal position comforts me, reminding me of Nay Nay.

"We should go to the hospital," Zia says, "Tomorrow is Sunday. Clinic isn't open until Monday, and Joshua's out of town until then."

I don't want to go anywhere. I want to be home. I want to see Nay Nay again. So I say, "I don't want to go. I'm fine."

Zia looks at Lili again. Lili shrugs. "If she doesn't want to go, she doesn't want to go."

Zia sighs. "Maybe she'll feel better in the morning," she says, again speaking to herself more than to Lili.

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Joshua shows up on Monday morning. "She probably broke her back, and you're not taking her to the ER?!"

My son is a yeller. "Old Yeller!" I say in a sing-song voice as a joke, but he doesn't laugh. He thinks I'm the one about to be put out of my misery. Maybe he's right; he is a nurse, after all. I hope he's calmer under pressure when he's at work. He's always had the fiercest temper in the family.

"Mom, why did you get in the shower by yourself? You know you're not strong enough for that."

"She saw Grandma again," Zia says, like I'm not lying right there.

"We need to do something about these hallucinations. Do you think it's the oxy?"

"I'm not stopping it now, when she's in this much pain."

I speak up, "I like seeing her."

Joshua sighs. I can't tell if he's exasperated or only exhausted. "It's not healthy, Nay Nay. It's not real."

"I'm ninety-four. I decide what's healthy for me."

I can tell Joshua wants to argue with me, but instead he turns to Zia. "I can't believe you let her stay like this for a full day. She needs to go to the hospital."

"She doesn't want to go."

Joshua's large hands envelop my shoulders entirely. I can't see where my arms begin. I feel armless. "Nay Nay, you have to go."

"Why?"

"You probably have a spinal fracture. It's the only way we can get you better."

"I'm fine."

"No, you're not. Do you want to fight to get better or not?"

I see fire burning in his eyes, my dear *anak*, my oldest, the protector. I know he's well-intended, but I can't stomach the thought of that cold hospital room, nurses hooking all those machines to me again. I want to yell back at him.

Then I see Nay Nay in my corner, the edges of her billowy linen skirt floating in the breeze from the window. She's smiling at me gently, moving her hands slowly up and down with her palms facing the earth, a gesture she used to tell me to simmer down as a child. I think Joshua got his temper from me.

"Okay." My agreement makes the fire in his eyes die down. But I feel a much worse fire now, searing my whole body from top to bottom.

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"Am I crazy?" I ask the doctor. I've been here three days. The doctor's asked me all about what I see that other people don't see. I've told her the truth: how it's comforting when Nay Nay appears to me, how I don't want it to stop. The hospital team members speak to me with either wonder or pity, never harsh but also never direct. That's why I've asked, directly, the question I've been asking myself since I fell. I hope she'll answer honestly. If you have wits enough to ask if you're crazy, doesn't that make you not crazy?

"No," the doctor says, placing a gentle hand on my shoulder. I can't feel my arms much at all now. Again, I feel armless, and that makes me feel powerless. Still, I can tell she means this gesture to be comforting. "You're going through a hard time, but you're not crazy."

Then she turns to Joshua and tells him I probably have Lewy Body Dementia. This lady is saying I'm demented right in front of me, right after telling me I'm not crazy. With that kind of behavior, who's the crazy one?

Joshua asks the doctor, "Couldn't it be the oxycodone? Is she taking too much?"

The doctor tells him I've been on oxycodone for chronic pain for a long time and seem to be tolerating it well. Joshua covers every organ system: What about her liver, her kidneys, her heart?

He pummels the doctor with questions, like I'll die if he forgets to ask one: *Can we add or take away any medications to make her hallucinations better? Why do you think she dreamed someone tied her to the bed and wouldn't let her go? Why does she always wake up in the middle of the night? Why wasn't she on a drug to prevent dementia? Why can't she be on the new one that was just approved to treat it?*

The doctor says she's doing her best to balance the effects of my medications while controlling my pain. She says we're juggling preserving my heart with preserving my kidneys. I imagine her juggling my heart and my kidneys, and that makes me laugh. My laugh makes the doctor look at me with pity. That look makes me wonder if I'm crazy again. I stop laughing.

The doctor says sleep disturbance and hallucinations are common in Lewy Body. She says a drug to prevent dementia wouldn't be worth the side effects now that I'm this far along in the illness. She says the drug to treat dementia was rushed through FDA approval, that she doesn't recommend it for anyone, that for me she recommends symptomatic relief only. She asks Joshua if we're interested in hospice. Why isn't she asking me?

"We're not ready for hospice," Joshua says, "We're not giving up on her."

"I wouldn't view it that way--"

"She deserves to be given the option of the dementia medication," Joshua interrupts the doctor. I thought I raised him better than that.

"Do you want to try the medication for your brain?" he asks me. I can tell he wants me to say yes. For a moment I want to, for his sake, but instead I close my eyes.

I see myself in a fetal position in Nay Nay's arms again. She would want me to tell the truth. "No, please. All I want is to take the pain away."

The doctor speaks with caution, like her words could land in a minefield: "Hospice can help with that."

Joshua's fierce eyes fall. I hate disappointing him, but at this point I'd hate disappointing myself more. I may be delusional, but I'm seeing more clearly than I ever have.

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Even in bed all day, muscles frozen, waiting for someone - to change my diaper, to bring me food, to watch over me like a child - I'm grateful. I've spent most of my life caring for others; now it's my turn to be cared for. I'm lucky I have children who want to do that for me.

We each have our own reality. I've always known that, and I don't mind that they can't see mine. My physical frailty frustrates me, but it's temporary. I know my suffering will pass, and that knowledge helps me get through it. The hardest part of being alive now is watching my family grieve while I'm still here. I recognize the process, having lost so many people over the years. But empathy doesn't make it easier to see my loved ones losing me. I'm afraid for them. I see Nay Nay by the door of my hospital room. She holds her arms out to me. Her eyes take me in with the same warmth they had when I would come to her crying after a nightmare as a child. I slowly stand and shuffle over. I hear the bed alarm beeping its discordant, repetitive notes. I tune it out.

Nay Nay enfolds my body into hers, and all the pain leaves my body. Suddenly, for the first time in years, I don't feel lost. I'm filled with faith that my life has been what it was supposed to be.

She releases my body but holds my gaze with those soothing eyes of my childhood. She takes my hand and leads me out of the hospital room. I follow her without question, the two of us singing "Minimahal Kita" together.

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