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FIERCE BLESSING

**A Journey Into Alzheimer's,
Compassion, and the Joy of Being**

Wayne and Terry Baltz

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Red Feather Lakes, Colorado**

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— *Prologue* —

The call comes in the middle of the night. Every cell in my body knows I cannot answer. I wrestle the phone off the night stand.

“Wayne,” I say, and pass it to him beside me in the bed. He fumbles with the headset, hoists it clumsily to his cheek.

“Hello?” His voice is aged and deepened by sleep.

My fingers trace the cord that stretches across my chest in the silent dark.

It’s Lilith. I know that.

*The world is but a bridge, build no house upon it.
Life is but an hour, spend it in devotion.
All the rest is the unseen.*

—Akbar

August 1, Year One Shortly before noon my mother-in-law, Helen, arrives at the airport in Denver, Colorado from her home in California. Her daughter Terry and I are here to meet her as she strides down the enclosed tube connecting the plane to the terminal. She is all smiles and so are we. We find her luggage, make our way out to the car, and begin our journey. For twenty minutes the conversation is so relaxed, so normal, that I begin to doubt our plan, to question what we have set in motion. And why.

“I want to take you kids out to dinner tonight,” Mom offers as we rumble down the rough ribbon of asphalt.

My gut tightens a notch. With these few, utterly prosaic words, normalcy evaporates. From the back, Terry answers, her tone level, matter-of-fact.

“We can’t, Mom. You’ll be at the hospital.”

“At the hospital?”

“Yeah, you remember. That’s why we asked you to come out here.”

“What?” Mom’s voice rings with incredulity.

“That’s why we asked you to come out here.”

“Why?”

“To find out what’s wrong. Why you’re forgetting so much.”

“Forgetting what?”

Yikes! A tough one. *“Forgetting what?” “You know.” “Know what?” “Well, about those things.” “What things?” “Those ones you don’t remember.”* My grip tightens on the steering wheel. I focus even harder on the road ahead and leave the answering to Terry.

“Well, you were forgetting pots on the stove. Burning things. And you were getting lost while you were driving. Remember?”

“Hmmp,” Mom snorts, crossing verbal arms over her chest. “If you can remember things as good as I do when you’re my age, you’ll be lucky.”

Two miles later, Mom points out the window toward the west. “I remember that,” she says, indicating an outlet mall that did not exist when she last visited us.

We arrive at the sleek new hospital, get the tour, then head for lunch. The three of us work our way through the selections in the cafeteria, filling our trays with familiar, soothing foods. Mom half turns, facing me between the mashed potatoes and the green beans.

“Wayne, I need for you to tell me something. Do you have the keys to my suitcase?” I assure her that I do. We head for the desserts. Terry and I help Mom with the choices.

The dining area is filled with natural light but otherwise is nearly empty. We select a table near one of the many large windows. An antiseptic, weed-free expanse of lawn and a far off backdrop of mountain ranges look in on us.

“Wayne, now, you have the keys to my suitcase, don’t you?” Mom asks.

“Yep, I’ve got ’em,” I tell her, smiling and patting my front pants pocket as I come round to help her with her chair.

The Admissions Coordinator joins us. Soon we are all seated, starting on our meal, making small talk. Trying to put Mom, and ourselves, at ease.

“I just have one question,” Mom announces with some urgency, interrupting an exchange of weather commentaries. “Wayne, do you know where my keys are?”

“Absolutely. I’ve got them right here.” I fish the keys from my pocket and display them briefly. “Don’t worry. I’m taking good care

of them,” I say, then tuck them away again, as though they belong here in her son-in-law’s pocket. Mom seems satisfied. She goes back to eating, eyes down, responding only when directly addressed.

But, stabbing with her spoon at a cube of preternaturally green gelatin a few minutes later, it is obvious from the look on her face that an important question has suddenly come to mind: “I just want to know one thing, Wayne. Where are my keys?”

After lunch, Mom claws her way through the mental status exam, suffers the plunder of her purse, endures our explanations and reassurances. In the end, we leave and she remains, with nothing to cling to but her gutted handbag and our promise that we will visit tomorrow. Her plaintive wail—“Terry!”—thuds against our backs as we flee.

Evening. We call Mom at the hospital, hoping she has settled in a little, hoping she is doing well. She speaks in a furtive whisper, her voice leaking urgency and despair.

“I can’t get better here,” she says.

. . . our approach, our ‘evaluations,’ are ridiculously inadequate. They only show us deficits, they do not show us powers; they only show us puzzles and schemata, when we need to see music, narrative, play, a being conducting itself spontaneously in its own natural way.

—Oliver Sacks, M.D.

“It’s deja vu all over again.”

—Yogi Berra

August 2, Year One The Geriatric Ward representative at the hospital tells us—informally, and prior to the completion of the battery of physical, psychological, and cognitive tests Mom is undergoing—that it looks like she has dementia, depression, and delirium.

August 6 Wayne and I take Mom out of the hospital on a day pass and have dinner at The Salad Bowl. “I’ve been here before,” Mom declares, although she has not.

She wants to go home.

August 9 Staff tell us today that my mother “will go downhill.” They enumerate a long list of horrible things that will happen and say that now, at this moment, she needs 24-hour care. They offer no hope, no way out.

How can this be? Ten days ago Mom was living entirely on her own in her mobile home in California. She moved there when she

was 61 years old, and has lived there for sixteen years. And for five years before that she lived alone in St. Louis, ever since my dad's—her husband, Russ's—cerebral hemorrhage. Despite the trauma of his sudden and unexpected death she did what needed doing. She made arrangements for her financial future. Within a year she sold the house she'd lived in for thirty years. She found a small rental in the neighborhood. Two years later she went through a double mastectomy and survived both the cancer and the chemo. When she was ready, she moved again, to be near my sister, Sharon, and her family. Yes, she made the move with Sharon's encouragement and with Sharon's husband, Denny, to pack the trailer and drive—but it was *she* who pulled up stakes and relocated two thousand miles across the country to San Diego County.

My mother is a person who knows her own mind. She does what she wants. She goes where she wants, when she wants. For twenty-one years she has lived life on her own terms.

And now she can't be left alone for ten minutes? What's she going to do? Burn the place down? Get lost on the way to the bathroom?

Okay, some things about her are different. She used to be an extrovert. Loved people of all ages. Talked to everyone, everywhere. When Wayne and I would meet her at the airport after a flight to visit us she always had stories to tell about her seatmates. She knew their life stories, and they, probably, hers. She was the one in the neighborhood who helped those who needed a visit, a pot of homemade soup, a driver to get to the doctor or grocery store, a companion. But somewhere along the line that began to change. Six, maybe seven years ago, she started pulling away from her neighbors at the mobile home park.

When I thought about it at all in those days, I attributed this withdrawal to her mastectomies. One day, three years after my dad's death, she found a lump in her breast. She went in for a biopsy, ended up with a mastectomy, and then a second one two days later. I never heard her complain, but on some level, I think, the loss of her breasts shook her confidence. She had a collection of

prostheses, her “boobs” as she laughingly called them but, to my knowledge, she never developed or even considered an intimate relationship after her surgeries.

Slowly, my mother’s social circle grew smaller. More and more she relied on Sharon, the grandkids and eventually great-grandkids, and Wayne and me, to be the people in her life.

There were other oddities, too. I remember visiting her about five years ago and noticing the calendar on her desk. The little square for every date was filled with neat but cramped writing. Not just “Dr.’s appt.” or “Leona’s birthday” but an accounting of the details of each day: who called, what she purchased at the store, not only whose birthday but their year of birth, their computed age, and where they live. Doubtless, this was an early storm warning, but I did not see it for what it was. My eyes saw only my neat and thorough—and perhaps a bit compulsive—mother, keeping her life in order.

One day three years ago Sharon called, upset about Mom. She was getting at least four phone calls a day from her. “But what’s worse,” she said, “is that she doesn’t seem to know that she’s already called.” At Sharon’s urging, Wayne and I invited Mom to visit us. She was a little eccentric, but we thought she did pretty well. We didn’t see, or maybe didn’t recognize, the worrisome behaviors that Sharon had described. I just figured that her sitting in front of the TV so much and not participating very actively in conversation was due to her getting old. She was in good spirits. I was satisfied that everything was all right with her.

Two years later, during an eight month period that Wayne and I lived in San Diego County, I saw things a little differently. I noticed that Mom couldn’t bear to watch TV dramas anymore. She only liked the silliest, broadest comedies. She’d also apparently forgotten how to prepare her famed turkey chili. And now she called *us* four times a day, and was frequently confused about when we were coming to her home for dinner. I began to share my observations with a gerontologist friend, who helped me realize that maybe Mom wasn’t just “getting old.”

The next and final time we were in the area, this past May, I went to the doctor with her. Mom had always been a confident driver but now she seemed to have moved significantly along the continuum toward aggressive. She drove fast. She braked hard. I wished I were driving.

During the exam her doctor asked me to leave the room. When I returned, Mom confided to me somewhat uneasily that she hadn't been able to tell him the name of the president, "even though I voted for him." In the hallway later, the doctor told me my mother was "having memory problems" and that we should move her closer to us. I asked about a medication she was taking at the time, Halcion, whether it might be the cause of the problem or some part of it. He wondered where she got that, and told me to take it out of her house that very day. A weight descended on me. I was suddenly being put in charge of something not my own, and that was a responsibility for which I had no desire. My mother was no longer in complete control of her life.

I think she knew that she couldn't be, although she had no intention of carrying the idea to an extreme—like giving up her Halcion. She was furious that we were even discussing the subject with her, and it was embarrassing and heartbreaking to have to search out the drug, Wayne or I distracting her while the other plundered her privacy. And it was odd and angering to discover from the labels that the medication had been prescribed by the very doctor who had questioned its presence in her house. Because Mom had purchased them in blister-packs Wayne was able to exchange all of the unopened ones at the pharmacy for a refund. When he returned without the medication to face Mom's anger he led off with the handful of cash. Mom was very pleased to get the money and, to our surprise and relief, never mentioned the Halcion at all.

Wayne and I were hoping that it was medications that were causing her mental fog, and that she would soon improve now that one had been eliminated and her doctor had reduced another, Valium, to a maximum of one tablet each evening before bed.

Soon after, Wayne and I left for home in Colorado. A month ago, in July, Sharon called to say that Mom had taken a rather sudden turn for the worse. We knew of a hospital here in Colorado we thought might be able to help.

Our hope when we invited Mom here for a diagnostic work-up was that she would recover her health, go back home, and live her life.

It is still our hope.

August 11 At the Planning Conference today my mother is told that her diagnosis is “Probable Alzheimer’s-type Dementia.” Irreversible. No driving. No drinking. No living alone.

“My father lived to be ninety-five and didn’t have this,” she says, squeezing my hand as she peers across the table at these people who are directing her life. “Where would I live?” she asks of no one in particular. “Would I sell my mobile home?”

After the meeting Wayne and I decide to find a place for the three of us to live together. The problem is that two years ago we committed ourselves to working full-time to start our new writing/publishing business. To cut expenses we sold many of our belongings and household furnishings and have lived since in a dozen places, including our cabin in the mountains, the homes of friends, a travel trailer in my sister’s yard, a nature preserve in California, and a high rise apartment building in Colorado.

We actually consider moving the three of us up to our cabin, but as it is located at 8,000 feet elevation, has only one room, inadequate heat, a limited amount of solar-generated electricity, and no bathroom or running water, we quickly abandon the idea and enter upon a panic search for rental housing in town.

August 14 Mid-August: the absolute worst time to find a place to rent. But somehow, in three short days we’ve done just that—found a two-bedroom unfurnished house on a quiet street, not too far from the business district, stores, and doctors. The price with utilities is \$800+, way beyond any personal budget we have or can

imagine. But it is available, and the owner is willing to let us have it on a month-to-month basis, a real plus and virtually unheard of here, where 12-month leases are the norm. We have no idea how things will turn out—whether Mom will recover and return home, whether her health will worsen in short order and she will require nursing or hospital care, whether she might die suddenly or live many years at home with need of assistance.

August 15 At the attorney's office Mom is calm and patient and cooperative. We're here to receive Power-of-Attorney from her. We need it so that we can speak for her legally in all matters. It's what we have to do. All the books and all the experts say so. Still, it's our idea, not hers. We don't know if she really understands what is taking place, but we know she understands that something important is happening. "Your dad would be sad if he knew what we were doing," she says. "He'd want to be here."

August 16 Wayne and I bring Mom to look at the house we're thinking of renting. She says she likes it. "This is a lot of trouble for you," she says. "I'd like to help out."

In fact, it is her funds which will pay the bills here. We want to tell her, to reassure her that she *is* helping out, but we don't know a way to do it that she can understand, that won't frighten and upset her. So we sign the contract in her name, pay the deposit and first month's rent from her checkbook, and prepare to care for her in a house that she believes is ours.

August 21 We drag a few things down from the cabin: a double bed for Mom, a small dining table, two molded-plastic chairs, an ancient washing machine that has been threatening to fall apart for a decade, and some basic cooking utensils. Friends—and even our new neighbors and our landlord—have loaned or given us a medley of needed household items and furnishings.

A house-filling, and a house-warming, too.

August 23 Mom sits in the middle of the living room on one of the plastic chairs. Terry rubs her shoulders and upper back, the chair swaying slightly under the rhythmic pressure.

“You’re awfully cute,” Mom tells her daughter’s reflection in the vacant TV screen.

“I was thinking the same thing about you,” Terry says.

August 25 My mother talks about going back to her mobile home. Often. She has totally forgotten that she was told she has Alzheimer’s, that two weeks ago she herself talked about selling her mobile home. Now she expects to find it around every corner. She searches for it on foot. She begs us to drive her there, offers to pay us. Wayne and I take turns explaining to her that it’s very far away—“more than a thousand miles” we tell her honestly—that it would take two or three long days of driving to get there.

She doesn’t believe us.

August 26 This evening, a night out with Mom to celebrate our new living arrangement. Wayne and I have chosen a small café which, even though located at a bit of a distance, has a distinct attraction for us: Mom and I ate lunch there during her visit three years ago. It seems that nearly every place she has been these few weeks since her arrival in Colorado she has proclaimed, “I’ve been here before,” despite the fact that in almost every instance she has not. Tonight she’ll be right.

“I’ve never been here before,” Mom announces happily as the three of us approach the door.

And what might be the name of this restaurant she claims never to have seen before? *Deja Vu*.

All over again.

August 28 Today is Mom’s 78th birthday. I get up with her at 5 a.m. She loves it and lauds me with her new version of a compliment: “For a younger daughter you are really terrific,” she exclaims. “I can’t get over it.”

During a phone call later, Sharon tells Mom that she is welcome to stay for a while in the camper trailer parked in their back yard if she'd like.

After the call I find that Mom has misinterpreted my sister's offer. "Sharon doesn't want me in her house now that I'm ill," she tells me. "She's afraid I'm contagious. Afraid I'll hurt the kids."

August 31 Although my mother-in-law's communications are often muddled, confusing, and sometimes unintelligible to us despite our best efforts, this is not always the case. For the most part, in fact, we all understand one another quite well and with little or no difficulty. At times, her statements are even exquisitely concise and expressive. By turns humorous, poignant, poetic; lush with metaphor and powerful imagery.

As we prepare to run some errands Mom searches her purse, finally extracting from it a piece of clear vinyl. With curious anticipation she unfolds it. It is a raincap, but a series of splits in the aged plastic render it useless now.

Mom studies the article a moment, her long fingers nimbly reading the damage. "This is what happens when you don't use things," she says, methodically refolding the hat. "This is what is going to happen to me."

September 10 Mom gets up this morning at 6 a.m., cold. I coax her back to bed and tuck her in.

"I was lying awake," she confides, "wondering if my brother Steve is alive." I reassure her that he is and hug her. "My little mother," she says. "You're my mother. I'm not your mother. I used to be your mother, but . . . other things took precedence."

September 11 Over a simple meal of soup and sandwiches Mom shares something unfathomable about the workings of her brain. Gazing out the window to the street and indicating our car parked at the curb she announces, "I think that when I bite this potato chip that car is going to move."

September 14 “How long does it take for the plane to get me to Sharon’s?” my mother asks as we eat lunch and discuss her upcoming weekend trip to California for granddaughter Mimi’s wedding.

“About 2½ hours,” I say.

“I don’t like to eat anything when I fly.”

“Good, because they aren’t feeding you anything.”

“That’s good, because it makes me sick.”

“Well, you won’t have to worry about that this time.”

“I had food on the way out here.”

“You know, you don’t have to eat it when they offer you food. You can just say ‘No, thanks’ and they’ll pass you by.”

“Why would I do that?”

“If you don’t want to eat on the plane.”

“Honey, I’d get hungry!”

“Well, then you could eat.”

“Good.” Mom takes a bite of sandwich, then surveys Wayne and me with a serious gaze. “I don’t know how I’m going to be able to thank you kids for all you’ve done for me,” she says.

Wayne and I are speechless. What have we done to deserve this sudden accolade?

“And all you’ve undone,” Mom adds. The two of us burst out laughing. Mom joins in. “I had to make that funny, didn’t I?”

September 16 On the Interstate, heading to the airport:

Mom: So, in other words, she’ll meet us at the airport.

Wayne: Yes. Sharon will meet you at the San Diego Airport.

M: What?

W: Sharon will meet you at the airport. In San Diego.

M: She’s not going to be here to pick me up?

W: No, she’s going to meet you in *San Diego*, when you get off the plane.

M: Oh, shit. I don’t want to go to San Diego. I want to go to Sharon’s.

W: I know. And you *are* going to Sharon's. But first you have to get to California. Then Sharon will pick you up at the airport and take you to her house.

M: I thought you said she was going to meet us here.

W: She can't. We're too far away. See, we're in Colorado. Sharon lives in California. It would take her three days to drive here.

M: (perplexed) What?

W: That's why you're taking a plane. It will get you to California in just a couple of hours.

M: I don't understand how a plane can land at Sharon's.

W: It won't. It will land in San Diego. Sharon will drive down from her house to the airport and pick you up. Then she'll take you to her house.

M: Sharon won't be here at the airport?

W: No.

M: You said she was going to meet us.

W: She'll meet you in San Diego. See, first I take you to this airport in Colorado. Then the plane goes up in the air and flies to California and lands in San Diego. Sharon will be there. Just like *I'm* taking you *to* this airport, *she'll* meet you *at* the San Diego airport and take you to her house. You'll stay in David's room.

M: How does the plane know how to get to my mobile home in California?

W: Not to your mobile home. To California.

M: How does the plane know how to get to California?

W: There's a pilot. He knows how to get there.

M: How does he know? I don't know how to get there.

W: That's his job. He does it all the time.

M: Honey, he does not. You can't land a plane at my mobile home park.

W: He won't land at your park. He'll land in San Diego. Sharon will pick you up.

M: Do you know where you're going?

W: Yep.

M: That's good. Because I don't know where in the hell I am.

W: That's okay. Stick with me. I'll get you there.

M: And Sharon will pick me up in San Diego.

W: Exactly.

M: She knows where the airport is?

W: She sure does. She'll be waiting for you when you get off the plane.

M: In other words, she's not going to meet us.

W: Not here. She'll meet you when you get off the plane.

M: I'm going to *fly*?

September 19 On the way home from the airport after her return from California Mom is in a particularly good mood. "Wayne," she says, "you know how you always tell me it's 3,000 miles to my mobile home?"

"One thousand miles. Mmmhmm."

"Denny didn't think so. He found it right away."

September 21 Deterioration of language skills and abstract thinking ability are well known symptoms of dementia. Even so, we take oral communication—especially simple, everyday interactions—so for granted that problems in this area provide unending surprise and puzzlement. They can be dangerous, they can be funny, and they can be extremely frustrating.

For some years prior to our current understanding of the scope and cause of the cognitive problems that Terry's mother is having, I found her becoming ever more obtuse and offensive in her verbal interactions. It became common for her to respond to almost any introductory sentence in a conversation with an emphatic, irritated (and irritating) "*What?*" By her response one might think that asking her if she wanted anything from the store was akin to asking if she wanted anything from the moon. Or that telling her that Sharon was on the phone—"*Who?*"—was for a moment like introducing her to a daughter she somehow didn't even know she had.

Early on, my thought was that she was becoming hard of hearing. But this theory seemed not to hold up to other observations in

which her hearing appeared average to acute. More and more I came to assume that her “What?” was an intentional, lazy manipulation of those around her, although what purpose this served I could never understand.

There were other odd behaviors that crept in over the years: a compulsion to note and comment on the right- or left-handedness of those around her; a tendency to interrupt and distort conversations by turning the focus to herself; a tiring repetition of quips and jingles—“Have you driven a Ford lately? I have *never* driven a Ford!”; an endless attention to tedious details of her immediate environment while losing the thread of the conversation; the placement of periods at the ends of lines of address on envelopes.

Although in hindsight such behaviors seem like connected and glaringly obvious symptoms, at the time they seemed like nothing so much as an accumulation of old-age eccentricities and bad manners. For the most part, I was outwardly patient and forgiving. But privately, and to Terry, I wondered why her mother—so unlike the woman I had known for the previous quarter of a century—insisted on being so testy, self-centered, and mean-spirited.

When we made arrangements a month ago to live under the same roof, the frequency with which I experienced these behaviors intensified dramatically, along with my feelings of resentment. It is unflattering testimony to my own self-centeredness that her diagnosis did little to soften my judgments.

In recent days I have made a conscious effort to view her behavior differently. I do not dismiss entirely the notion that at least some portion of the communication problems we have is under her control, but I recognize, and struggle to accept, that much of it is not. It may well be also that the difficulties she experiences are so angering and frustrating to her, that she is so tired of correcting herself, so ashamed of misunderstanding and being misunderstood, that she *does* occasionally succumb to the temptation to make life a little difficult for those, like myself, who have at times been less than generous with her. Occasionally she tells me as much: “I’m just giving you a hard time.” But even that may be a cover—defining her

behavior as intentional, a joke, rather than having it recognized as yet one more mistake.

To the extent that I succeed in taking on this more compassionate perspective, rather than taking things personally, I find it is easier to be patient and tolerant. An unexpected discovery: patience and tolerance are not only easier on Mom, they are easier on me! Assuming good intentions rather than ill leaves me with more time and energy. I am much more alert now to catching the confusions as they come, anticipating them even, interpolating and editing for her as she speaks. I am less likely to correct her—because I see her less as “wrong”—and when I do, it is more likely to be with a gentle rephrasing, demonstrating (and checking) that I understand her meaning.

Recently I taped some colorful leaves to the wall in the living room, “They’re all crisp and dry and fall-like,” Terry said. “Well, of course!” Mom replied. “They’re right under the heat!”

A forced-air heat register was nearby below the leaves. The leaves were not right under the heat, they were right *over* the heat. I have heard her make numerous other errors of a similar pattern—using the opposite of the word intended; getting the right words but putting them in the wrong order; transposing subject and object.

Terry and I both caught her error in this instance and responded as though she had not misstated herself. In this case it was not an important mistake. But it gives me pause. Are these merely verbal missteps, or are they part of some broader range of perceptual and processing errors? What if she is driving down the road in her 1973 Dart Swinger, as she was doing less than two months ago and as she longs to still? Might she mistake left for right, stop for go, accelerator for brake?

It is my habit to take another’s words at face value. It is difficult, indeed impossible, always to catch another’s mistakes, to read between misspoken and unspoken lines, to ferret out intended meaning.

And it is tiring. Might it not one day prove altogether exhausting?

September 24 Mom tells Wayne and me today, “It’s a darn shame I can’t live in my mobile home where I so desperately want to be.”

September 26 Mom has watched *Guiding Light* for as long as I can remember. And she has carried her habit into her new home with us, where it has provided a welcome link to all those yesterdays.

Today, in the midst of the program she exclaims, “I’ve been watching my soap opera so long now I almost know what’s going on!”

September 28 With purple dusk still tinting the windows, my mother readies herself for bed. It is just past 7:30 p.m., her usual hour now, though when she lived alone she was always a late-nighter. She always had a small array of medications by her bed then. Now, she turns to me for such things.

Tonight she asks me for a Tylenol. “So that I can go to sleep,” she says. Wayne and I have substituted Tylenol for Valium, which she took for many years prior to coming to us. Mom doesn’t seem to mind, and sleeps better now than I’ve ever known her to. This night I suggest prayer, knowing that she always enjoyed praying at bedtime.

“I can’t remember any,” she says.

“Make them up,” I encourage. “That’s the best kind.”

I tuck her in—another role-reversal ritual, one that we both enjoy—kiss her forehead, tell her that I love her.

“I love *you*,” she says. “More than you know.” She says it with a beautiful, sparkling smile. “You’re a good kid,” she adds suddenly.

Like a mom.

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