

A FAMILY IN FRESNO

an excerpt from *Standard of Care*

a novel by

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The needle-nosed turboprop, one of those bend-over-and-walk-down-the-aisle commuter jobs, was the only non-stop from Oakland to Fresno. Doctor Daniel Fazen used the time on board, all of it, to read through Kerry's case summary. Left alone by the overwhelmed Olympia-Fresno nurses, she had bled nearly to death following a tonsillectomy. The icy prose of the medical narratives did nothing to diminish the horror of it.

After a brief misadventure in his Avis sedan, Dan found the Jameson house, a stucco one-story in the southeast part of the city. The driveways in both directions were packed, house to curb, with SUV's and pick-ups.

"Well, thanks for letting me come down to talk with you," he said. "You must be tired of going over this again and again."

They were in the living room, Dan in a flowered armchair and Ed and Paula Jameson across on a matching sofa. She had just placed a basket of warm muffins on the table between. Nine-year-old Kerry was propped in a wheelchair to Dan's right. He was certain that she comprehended nothing.

"That's okay," Paula said. "Anything we can do for the medical team, we will do." Dan thought that she sounded Oklahoma or West Texas. He would learn later that she had spent her whole life in Bakersfield and Fresno.

"Well, I came down here basically to meet you," he said, "and to learn more about Kerry. As much about her life now as about what happened four years ago. Mrs.

Jameson, you're with Kerry most of the time?"

"Please call me Paula, okay?."

Dan smiled a half smile and nodded. He was there to cast new eyes on an old case, to formulate one more opinion, to tilt against hopelessness.

"Yeah, I'm with her most of the time," she said. "But I get some breaks. Ed'll take over for a while on the weekends. Gives me a chance to get out. Kerry's aunt, my baby sister, she'll watch her so we can go out to dinner, go to a movie. We've got a routine. But no question, I'm the main child care worker 'round here."

He repositioned himself so that he was facing Kerry. "Can you tell me a little bit about the daily routine?"

As they spoke, he dissected the details of Kerry's appearance. At nine, she looked five. To stabilize her in the chair, there were pillows stuffed at both flanks, and cloth straps, like seatbelts, across her chest and thighs. Her stocking feet were pigeon-toed on the metal foot plates. She was in a dark blue jogging suit, similar to the one her mother was wearing. A thick tube snaked from the bottom edge of her jacket to a plastic bag hung from the left armrest. It was one-third filled with dark yellow urine.

"Well bless her, she sleeps a lot. We put her down about eight. She'll fuss some during the night but usually sleeps 'til about seven or so. She'll be more fussy if she gets stuffed up or somethin'."

As Paula began, Dan was pierced by an essential part of this tragedy. She was describing her daughter in the specific language of mothers and their infants. Their schoolage Kerry had died. Their new Kerry was an oversized, disabled infant, developmentally frozen.

"We do give her little tastes of baby food and pudding and sips of water by mouth," she said. "But most everything, her supplements and drugs and water, she gets by the G-Tube. She can't swallow too good."

"What medications is she getting now?"

"She's down to the Macrodantin, the Valium and the Dilantin."

If Dan had never seen or heard of Kerry Jameson, one look would have told him she was on the anti-convulsant Dilantin, and had been for years. It was her thick, protuberant gums which had overgrown her teeth, covering nearly half their surface. She held her mouth partially open, exposing her tongue and those huge gums. As he watched, her head was in constant random motion. Her eyes, open and moving in unison, did not seem to fix on any particular thing.

"What's happening with her seizures?"

"Well, she gets the little ones all the time. On the right side. She hasn't had a big one, you know a grand mal, for maybe three weeks." Paula pronounced it as though it were the name of a shopping complex. "And that one lasted only about two minutes. Hell, I hate the way the damn Dilantin makes her look, but it works better than all that other stuff. Excuse my language."

The photograph had been in Dan's peripheral vision, on the end table next to Ed. As Paula spoke, he realized it was Kerry. She was thigh-deep in a round inflatable swimming pool, smiling and waving at the photographer. He thought she looked four or five, and wondered how close in time this had been to her hospitalization. Her first hospitalization, the one that led to all this.

"What do you do when she has a grand mal?" Dan adopted Paula's pronunciation.

"Not much. We hold the padded blade between her teeth." As she said it she pointed to a metal jar on a bookshelf behind her daughter. In it was a cluster of wooden tongue blades, the kind used for routine throat exams, each wrapped with white gauze at one end. "If it keeps goin', you know five minutes or more, we'll call 911. Usually doesn't though."

"Do you keep those in more than one place?"

"Here and her bedroom."

On an impulse, unexpected and unwelcome, Dan began to construct an image of Carly, his own daughter's arching back and jerking extremities. He wrenched himself from the hideous vision. The thought, even the beginning of the thought, could not be held. Like swallowing broken glass. And here were these people, working their child's seizures into their daily routine.

So far, Kerry's father had been a spectator. In his late thirties, Ed Jameson looked like a man who had begun losing his hair at about the time he got his high school diploma. He was dressed for work. Solid black tie, gray cotton slacks and a white shirt with a red, white and blue "All-Star Hardware" patch over one pocket.

"Mr. Jameson, uh Ed. May I call you Ed?" He consented, bemused, as though this was not the sort of thing that people asked him. "Ed, can you tell me a little about Kerry's abilities?"

"Her abilities? Like whaddaya mean?"

"Well, vision, hearing, recognition of things, pain responses, likes and dislikes, everyday things. Whatever you observe."

Ed hesitated, resting the side of his face against a calloused hand. Then he answered without looking up, "Paula, I think maybe you could tell him better than me."

She stared at her husband, expressionless. Then she turned, not just her head, toward Dan. "Well, she can tell a real bright light. She'll turn away from it. Maybe a year ago her doctor, her rehab doctor, was checkin' her eyes with the, uh, whatchamacallit"

"Ophthalmoscope?"

"Right. And she sorta thrashed at it. She could see that light."

"Uh huh. Do you think she ever fixes, you know focuses, on anything?"

Paula smiled. "Well, I like to think that sometimes she sees my face. Her eyes'll line up with me for a few seconds. But I know she can't."

“How about her hearing? I mean I understand that she can hear, but can you tell me how she responds to sounds?”

“Well, she’ll turn toward a loud noise. Sometimes she’ll act like startled. And she likes music, I think it soothes her. There’s times when she’s like real agitated and I’ll put on a CD—we’ve got a little stereo in her room—and she’ll just calm right down.”

Ed spoke up. “Yeah, she especially likes this one Vince Gill album Paula likes to play.”

She looked at him and then turned back to Dan, as though she had something to say and reconsidered.

He wanted to acknowledge Ed, but came up short. The three of them sat there in the awkwardness for a few seconds, though it seemed longer. Dan pushed ahead, “Do you think Kerry recognizes your voice?”

“I do,” Paula said. “If there’s company over, you know a bunch of people talkin’, she’ll stop or slow down when it’s me doing the talkin’. I can just tell. Or when I put her to bed and read to her, she’ll just settle down. She knows me.”

Dan wondered how this little girl could “know” anything. He had read the description of her resuscitation three times and yes, it was by the book and it had worked. The problem was that Kerry had been choking on her own blood clots for as long as nearly a half an hour. Unobserved and unmonitored. Putting himself in the place of the physicians on the scene, he would have made the same choices. The actual period of asphyxiation was unknown. Children can be resilient. This was a previously well child. If you can, you save the kid’s life. Ethical ruminations are for the terminally ill and the ancient. And before or after the action.

He looked at the bag hanging from her wheelchair. “Tell me what’s going on with her kidneys, and her infections.”

“Oh, she’s doin’ good there. Since they put the catheter through her belly, the neurologic bladder hasn’t been a problem.” He knew she meant *neurogenic*, but left it alone. “There’s no new infections and they say her kidney function is stable.”

“That’s great. How about her bowel movements. Any problems there?” He knew there were.

“Well, yeah. She gets constipated real bad.” She hesitated. “I hate it. Nothin’ works. We’ve tried everything. All the stool softeners and all the special enemas. She gets like a rock, seems no matter what.”

Dan had suffered more experience than he ever wanted with his constipated geriatric patients. “How often does she go?”

“She’ll go two, even three weeks without a BM. Her belly swells up and you can feel it through her skin.”

“So what happens when she just can’t go?”

“I used to take her to the ER. She’d be there for hours. The nurses hated it. They’d give her the enemas and then dig her out with their gloved hands. Now I just do it

myself. It ain't no fancy skill."

The matter-of-fact acceptance of particularly this task embedded itself into Dan's comprehension of Paula Jameson, of her dreary adaptation to her losses.

"Well, I'm afraid I've got to get to work." Ed was on his feet, extending his hand across the coffee table. "It was nice to meet you, Doctor Fazen."

Dan was surprised. There had been no prelude to the departure. He rose and met his grip. "It was nice to meet you too, Ed. I'm sure I'll see you again." He remained standing as Ed went out the front door, then sat and waited for Paula.

She stood, walked over to Kerry, and pivoted toward Dan, her hand on her daughter's shoulder. She was looking at the carpet. "He's a good man, you know."

People talk to doctors. Not just to their doctor, but to doctors. Informal second opinions, settling arguments, scouting forbidden territory, just getting freebies. Throughout his career, Dan had been dumbfounded at the things that people, all but strangers, had said to him. An auto mechanic once asked him a question about his (the auto mechanic's!) testicles. The woman behind the counter at the dry cleaners wanted to know what he recommended for excessive farting. This in response to his asking if he could get his shirts by five o'clock. And they ask about deadly serious diseases in themselves and loved ones. Scary questions, too frightening to confront with their "real" doctors. And unsolicited they talk about the most private things in their lives.

She looked up, directly at him. "He really is. He helps out in every way he can. Besides the SSI from the state, he provides all the money. I went back to work with the IRS when Kerry was four months, but since this happened I haven't worked a day. Ed does it all. He does all the shoppin'. He helps with the household chores, the cleanin', even fixes supper. He keeps the yard."

Dan watched her return to the sofa.

"Like I told you, he'll look after her so I can get out. Maybe once a week, but then he'll want me back soon. Like no more than say two hours. I know he hates it. He even doesn't want to look at her. Like watchin' TV, he'll angle his chair so he doesn't have to see her. He does it subtle, but I can tell."

She was speaking in her strong cowgirl voice without emotional hitches.

"This broke his heart. He was so close to her, she just lit him up. We used to talk about havin' two or three more. Now he won't hear of it. Says that with Kerry I wouldn't have time for a baby. That it wouldn't be fair. He'd never say it, but he's scared to death."

Though it wasn't something Dan had intended, Paula's plain-spoken defenseless soliloquy transformed the Jameson living room into a psychotherapy space. They were directly opposite, each with their legs crossed, she in her jogging outfit and he in his business suit.

"You know, we were high school sweethearts. Ed's the only man I've ever been with.

You couldn't tell it now, but he was the happiest guy around. He loved to be with people and everybody just loved him. We were invited to everything. After we got the house, he'd always want to have a crowd over on Sundays. He'd invite everybody, his high school buddies and their wives and kids. Grill steaks and burgers and hot dogs. Buy a couple of cases of beer."

Dan kept quiet as she hesitated and then started again, more slowly and sadly.

"When Kerry got sick, it's like his light went out. He actually started workin' more, doin' overtime. He said it was for the money since I wasn't workin'. And that's true, but I also think he just didn't want to be here. Seein' her the way she was. He'd be real responsible about chores and stuff, but most of the time he'd just sit in front of the TV. He never wants to have company any more. Just lost his spark." She emitted a one syllable laugh, a nasal exhalation. "Lost his spark for me, I'll tell ya."

Dan was no shrink, but he knew when to talk and when to shut up. There was nothing that he could say that was going to improve this woman's life. What he could do was get in her way. For all he knew, he was the first person, stranger enough and by credentials trustworthy, that she could open up to. He gave her soft eye contact and she went a little further before retreating to the safety of Kerry's problems.

"He loves me, I know he does. But we haven't made love in over two years. And we don't talk about it. It's not the kinda thing we talk about. Never did." She was quiet, eyes averted, for several seconds. "I don't think he's doin' anything. You know, with somebody else. That's not his way. I think he's just lost his desire." She looked up and lightened. "Hey, I'm sorry. You don't need to hear this. You didn't come all the way down here to listen to me cryin' in my beer."

"It's okay, really."

She turned toward Kerry. "One thing that I think helps her is the physical therapy. Twice a day I do the range of motion on her arms and legs. Keeps her from tightenin' up too much. And it seems like she likes it."

They talked for another twenty-five minutes. About the passive range-of-motion treatments, the care of the suprapubic catheter, the gastrostomy feedings, the intranasal medication. As he was leaving, she offered him the muffins. "Here, for your family."

He knew it was risky to go there in March. About its weather, a local wrote that Fresno was more hospitable than, say, the moon. In the summer it's the relentless three-figure heat. In the winter it isn't the cold or the wind or the rain, it's the fog. Named after reeds that grow in the marshes of the Central Valley, they call it Tule fog. And when conditions are just so, it closes the airports and, for anyone with a scrap of sense, the roads.

It would take him almost four and a half hours to get home on the *San Joaquin*,

Amtrak's clackety antidote to zero visibility. At the window there was no distinguishing night from fog except when they passed something bright and close, headlights or a street lamp. Then the energy diffused in the vapor, luminous, like isinglass.

After a few minutes of the ghostly show, Dan closed his eyes and listened to the wheels muffling along the railbed. He thought about Kerry and about his daughter Carly at Kerry's age, and about what life was supposed to be like when you're nine years old.