HEALING ARTS

Materia Medica

Tale of a Tape

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Mr. Jones was the last surviving member of his family, a family who had lived off the Carolina soil for four generations. He was losing his memory and he lived alone, making do with help from church members, neighbors, and Meals on Wheels volunteers who sat with him while he ate.

Each time he came to see me, I coaxed him to accept assistance from home care or hospice.

“I don’t want no strangers in my house,” he’d say.

“But strangers already come to your house.”

“Do not.”

“Do too.”

Then we’d both laugh. It was always a friendly stalemate. A colleague noted we were like an aging father and son.

There was always one thing he tried to tell me, but he could never quite express what it was. All he remembered was “tape.”

“Duct tape?” I’d ask.

“No.”

“Scotch tape?”

“No.”

“Cassette tape?”

“No.”

“What kind of tape?”

“I don’t know.”

Sometimes he’d grimace, repeating “tape, tape, tape;” other times he’d sit there staring vacantly.

“Don’t worry, bring it next time,” I’d say. But he never did. And so it went, visit after visit.

Mr. Jones’ long-time neighbor Gladys sometimes attended the appointments to advise me of her concerns. Mr. Jones had designated her as his surrogate decision maker. As months passed and his disease progressed, I became increasingly worried about his well-being, as did Gladys, and I encouraged home care with growing urgency. He continued to refuse. One day after a long visit of wheedling and cajoling, and a cookie and a Coke, he agreed to let a home care nurse visit his apartment.

The next time I saw him in clinic, he hurried excitedly down the hall, climbed onto the examining table, and started talking in an animated frenzy.

“I love my nurse doctor. She’s so smart. She really knows what she’s doing. Her name is...um...” He pulled a piece of paper from his pocket. “Her name is Debra. She’s from...” He searched the paper. “Connecticut. That’s up near Maine I think. And can you believe it, she comes whenever I need her, and doctor...she even brought me a pie once. A pie!”

“That’s wonderful Mr. Jones, I’m so happy for you,” I said.

He paused and looked at the paper. “843-111-1111. What’s that?”

“I think that’s your nurse’s phone number.”

“Oh yeah.” He looked at the paper again. “Doctor, here’s a list of medicines...she says they need to be refilled.”

Debra’s updates offered the same assessment—she and Mr. Jones had developed a wonderful relationship. I felt relieved, as did Gladys, to have another pair of eyes watching Mr. Jones.

Several weeks later, Debra called to say Mr. Jones was refusing to eat, drink, or get out of bed. Could I make a home visit? That evening on my way home, I stopped by the apartment. Gladys met me at the door.

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"I know his place don't look like much, but he's comfortable and we take good care of him. Besides, with his confusion, we try to keep things as simple as possible." She paused and wiped her lips with a cloth. "We do what we can with his monthly check...and what little money we can give him."

"You all are doing a wonderful job," I said, and I meant it. Caring for a demented person is one of the hardest jobs there is. It's physical, it's emotional, and it's never-ending.

My eyes were drawn to a large piece of duct tape holding the back of a kitchen chair together. I paused. Could that be the tape? Was he simply asking for a new chair? Then I noticed another piece of duct tape holding a note to the refrigerator door: *Bible study every Wednesday night*. Could that be the tape? Was he trying to invite me to Bible study?

Gladys motioned for me to come and see Mr. Jones. As we entered his bedroom, she pulled me close and whispered, "He's acting crazy...he don't know where he is, he don't even know me." She hesitated, wiped a tear from her eye, and then said, "Be careful doctor, he hit me twice...but he didn't mean no harm. It's his sickness."

Indeed, Mr. Jones was mumbling and grabbing at the air. Clearly, he was delirious, likely from dehydration, an infection, or one of the myriad causes of delirium in the elderly. Gladys agreed to have him hospitalized for evaluation and possibly transferred to inpatient hospice.

As I was calling the hospital, I noticed something attached to the middle of his bedroom door. There, scribbled in pencil on an 8 by 11 in. piece of yellow legal paper and carefully secured by worn and frayed duct tape, were six faded words: *Do Not Resuscitate. Check the refrigerator*. There it was—the 'tape.' I gently traced the outline of the paper with my finger as I thought of the labored moments in clinic when Mr. Jones desperately tried to recall this misplaced piece of memory. In the refrigerator, amid several food-filled Tupperware containers and an unopened bottle of Coke, was Mr. Jones' laminated one-page living will: no resuscitation, no tube feedings, no ventilator, and 'no machines of any kind.' Exactly what we had in his chart at the clinic. But penciled in at the bottom of the page were six additional words: *Just let me go. I'm ready*. Remarkably, in the cloud of dementia, he knew there might be a time when Gladys might not be there and when he would be unable to make learned and informed decisions. He also knew that his words would need to be printed and public.

And now, as I stood far from the din and commotion of the clinic, the struggle to decipher Mr. Jones' solitary word was over. 'Tape' now had clarity, import, and meaning. Here, in the comfort of a stark yet loving apartment, was a note that longed to be seen and a message that begged to be heard—all held together by a ragged piece of tape.

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