Untitled

By Lisa Johnson*

In the past few months, my sister has stopped talking. She'll want to say something, realize she can't, throw up her arms and roar.

A year ago, she would sigh and say "I lost the genetic lottery." That was after doctors diagnosed frontotemporal dementia, which strikes the planning, self-regulating part of the brain. Months later, they realized she also has bulbar palsy, which is disabling muscles from her neck on up.

Today, my Ivy League college-educated sister—a journalist and book author—grunts or roars if she makes any sound at all. Her tongue slides around in her mouth like a snake; we have to remind her to chew as she stuffs food greedily into her mouth.

That's disinhibition, a symptom of this poorly understood type of dementia.

Note to self: cut her food into small pieces. Don't put too much on the plate. Wait until she's done before offering seconds. Keep serving dishes out of sight.

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"You sound like a beast of the forest," I joked with my sister the last time I saw her and she roared in agitation, a week before Christmas. "Or maybe the jungle."

She caught my tone of amusement and knew she wasn't being judged. Her eyes held mine. I opened my mouth wide and scrunched up my face. "Roar!!!!," I yelled.

As I expected, she smiled. I'd distracted her. It was a game we were playing together.

"Roar!!!," I repeated, hopping from one foot to another.

It was silly but it wasn't at her expense. Her serious sister was playing the part of a clown and she appreciated it.

There's nothing like humor, if you can get the tone right. Sometimes it works; sometimes it doesn't and my sister's glare will register offense.

You can't know how to reach her without trying and watching how she reacts. If she throws up her arms she's probably not happy. If she walks away and sits in another room with her back

turned, she's probably overstimulated. If she wanders around, she's probably looking for something like her e-cigarettes.

Note to self: good to ask, then, if she wants help. And have a pad of paper at hand; writing sometimes seems to center her.

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For more than a month, my sister has been railing against Allie, her in-home caregiver, a gentle 31-year-old who never raises her voice or demonstrates any sign of impatience.

"Allie is a spy," she has written on the pads she uses to communicate.

"I don't like Allie."

"Allie must go."

It's very clear: my sister doesn't want a stranger in her house, keeping an eye on her, intruding on her privacy. It galls her to no end.

Before Allie became her mortal enemy, there was Christine, who left. Before Christine it was someone else whose name I no longer remember. To my sister, these women represent everything that is wrong in her life. Her compromised autonomy. Her diminished capacity. Her loss of independence.

They're the figures on whom she projects feelings she can no longer name or control. Fury at being left all day without the people to whom she's most attached. Irritation at having nothing to do. Terror at the prospect of abandonment.

Allie seems to understand this. You'd think my sister's negativity would antagonize her. But each morning she returns, with quiet determination.

Query to self: What happens if Allie decides enough is enough? Ask my sister's husband the next time we talk. What can we do to make sure that doesn't happen?

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Yesterday, my sister tried to attack Allie twice. It was a long, tense day following a week-long vacation that gave them both a much-needed break. Eventually, Allie texted my sister-in-law, who came over as soon as she could.

My sister-in-law is one of the warmest people I know and an oft-called crisis-manager when things get rough. “Allie is here to help your husband make sure things are taken care of,” she said firmly, standing in front of my sister.

(My brother-in-law—a sweet, devoted man—lost his job when my sister’s behavior became erratic; yes, his work suffered. Though we’re grateful he found another one, that’s when paid caregivers came in and these current troubles began.)

My sister had worked herself into a scalding rage; she wouldn’t listen. She clenched a nail file in her fist and charged at my sister-in-law, who covered her head to prevent a blow from falling. Allie looked on, her eyes dark with distress.

I wasn’t there, but I heard about it later when my brother (the oldest sibling, whose judgment we all defer to) called to tell me what had happened.

Another note to self: transitions are hard for people with dementia. Next time, maybe Allie can stop by for a few hours the day before she returns to work full-time? It might defuse some tension.

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None of us know what my sister thinks or is capable of understanding. If you ask her what’s wrong with her she’ll write “frontal lobe disorder,” which suggests a degree of self-knowledge. But then she’ll scribble “I don’t have Alzheimer’s” and smile as if that were good news.

The day after her outburst, she told her husband she would behave. “Allie irks me because she watches TV all day,” she wrote.

That word “irk” hits the mark, a reminder of my sister’s prodigious verbal skills. What words inhabit her mind, unexpressed? Does a reservoir brimming with language remain intact, with a lifetime of associations attached?

Her prognosis is dreadful: two to three years left, at best, websites tell us, because of her dual diagnosis. Asked for his opinion, her doctor declined to speculate.

Is there an image that conveys the horror? An innocent, uncomprehending child encased in a body of stone? No, she's not a child, she's an adult who is undergoing a series of unfathomable losses before our eyes. However helpless she seems, she's not a child.

Another mental note: Do not talk down to her. Be matter of fact. As normal as possible. And kind.

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The physical burdens are relatively easy to bear, at least at the moment, but the anguish is overwhelming.

No one talks about this. Not the doctor, who limits his engagement to ritualistic six-month checkups, nor the social worker, who has too many commitments and a flustered air that doesn't inspire confidence.

Several members of my sister's family are seeing psychologists, a tremendous financial burden on top of the caregiving expenses. Only a few friends make a point of coming around. Most people don't know what to say or do and stay away.

For days on end, Allie is the only person my sister will see other than her husband, bleary-eyed after work, or another close family member.

Note to self: remind Allie how much we appreciate everything she does. Next time you come by, make sure to ask how she's getting along. Be around as much as you can to relieve the stress. Treasure this time, however hard. It won't come again.

**A pseudonym. The author's real name has been withheld to protect the people written about here.*