

What's So Funny?

Caregiving with a Smile

BY NICOLE SAVINI

For The Association for Frontotemporal Dementias

It's an ordinary day and my mom and I are engaged in the "new normal" struggle to get her dressed. She is having a hard time today. She just can't seem to convince her brain to put on the pants. And I'm losing my patience. I've tried negotiating, I've tried explaining, heck, I've even tried some bribing ("If you put on your pants, we can get ice cream!"), but it seems like she will never get in those pants. I reach for the last tool in my bag of tricks: The Hokey Pokey.

"Okay, mom, here goes," I belt it out. "*You put your right leg in....*"

She stares at me. I try again.

"*You put your right leg in....*"

Nothing. If you have a loved one with FTD, you know this look. She's just not there.

"Mom!" I plead, "*You put your right leg in... and you shake it all about.*" I jump around like fool, shaking my leg awkwardly and singing, "*you do the hokey pokey....*" The truth is, I'm desperate. And then it happens:

My mom cracks a smile and starts to laugh. I see her wake up, it's almost like I can see the neuro-whatever-you-call-them firing in her brain. She's back and she's with me. Mom tells me I look silly, and (hallelujah!) picks up her right leg, even shakes it all about, and shoves it in to her pants.

Victory! Okay, well, not exactly. There's still the left leg. Mini victory!

I'll be honest; the Hokey Pokey doesn't always work. And I am certainly not always dancing and singing through every task with my mom. But having that light moment erases the frustration I felt just a few minutes before. It gives me a burst of positive energy, which helps me to face the next challenge (in this case, the left leg). And, for a moment, I am with my old mom, the one with a sharp wit, who can clearly see that, frankly, I look ridiculous. When you're dealing with a disease like FTD, and you've been told again and again that you can do nothing, that is definitely something.

We've all heard the old adage "laughter is the best medicine." There are countless studies analyzing the health benefits of laughter. Researchers have found that laughter boosts levels of endorphins, the body's natural painkillers, and suppresses levels of epinephrine, the stress hormone. Some research even claims that laughter can be as good for your heart as exercise (yes, you *can* skip the gym to watch *Seinfeld!*) But, truthfully, if you're a caregiver, or family member or friend of someone with FTD, it can be really difficult to see what's so funny.

But you have to try.

Laura Federico, MSW, is a care consultant for the NYC chapter of the Alzheimer's Association and an FTD support group leader. She says it can be helpful to separate yourself

from the “nuts and bolts of the disease” and “if you see an opportunity when you can laugh,” she says, “please do. It’s important to be good to yourself in every way you can.”

Melissa G.’s father began showing signs of FTD around 2003. He now lives in a facility and requires total care. “Humor keeps me sane,” she says. “When I brush my dad’s teeth, brush his hair, clip his nose and ear hairs... I often make myself and my dad laugh when I sing the song from “The Wizard of Oz” when they are all getting primped. *“Snip, snip here, snip, snip there and a couple of tra la las...”*”

FTD is not funny. But that doesn’t mean there’s nothing to laugh about.

Federico says, caregivers should allow themselves to recognize that “some things are just funny. And the person with dementia recognizes that it is funny as well.”

Case in point, my mom has recently become convinced that my sister and I are the most beautiful and coveted women on earth. No matter where we go, no matter how single, married, or old a man may be, she commands his attention and declares, “She’s beautiful isn’t she? I made her.” While excruciatingly embarrassing, we have to admit, it’s also hilarious. Oddly enough, though, I haven’t met my match this way.

On a recent trip, my mother told my father that she was looking out for dead animals on the side of the road. Rather than worry about why my mom said something so out of character, my dad quickly responded, “Oh, hon, I didn’t realize you were so hungry.” She thought that was very funny.

As Michele C. says, “You’re not laughing at the illness. You’re laughing at the actions.” Michele’s mom was diagnosed with FTD over a year ago, and while she no longer speaks, she often wears a smile. Sometimes, Michele says, “I think my mom remembers what irritates me and she still does it.” And rather than get angry, Michele takes it as a positive sign. “I have to laugh...and it’s kind of nice to see her come out. That’s my mother. That’s not this other woman that’s in my mother’s body.”

And that’s an important moment, says Federico. “Sometimes something funny can be a moment to share with a person with dementia as well as a way to get through.”

While seeing her father’s FTD progress quickly has been difficult, Melissa G. is still able to use humor as a way to connect with her father. “As my dad declines, it becomes more challenging to reach him... making him laugh has been my way of “reaching” him.” And just recently Melissa realized she’s not just entertaining her father: “...the other day when I was doing my 70’s “Saturday Night Fever” John Travolta dance with a shower cap on my head, one of the nurse’s aides came in my dad’s room. I didn’t hear her knock. She now thinks I’m insane. Oh well.”

When it comes to FTD, there is a real loss of control and it’s terrifying. But sometimes you have to say “oh well.” One thing we can control is how we view a situation.

As a final word Federico reminds caregivers that, just as laughing can have health benefits, failing to see the humor can be harmful to your health. “People who have difficulty seeing the lighter side can become entrenched in the duties and burdened by the implications of the

disease,” she says. She has seen this lead to serious health problems in caregivers. As Michele C. says, “It such a long disease, you’re never going to get through it if you don’t have a smile or if you can’t laugh about it.”

When my mom was diagnosed with FTD, my father told her, “We’ve laughed every day up to this point, so why don’t we just laugh our way through the rest of the way.” She agreed. And he’s kept good on that promise. After a recent run-in with Canadian law that involved dairy theft, my dad remarked, “Yeah, she stole an ice cream but it’s not like she poked a kid in the eye with the end of a Nutty Buddy!” In my family, we’ve all followed his lead and I think we are healthier and happier because of it.

So here is my humble advice: When faced with a moment where FTD is winning the war on your wits, take a moment and follow me (singing, please!). You put your *whole* self in and you shake it all about. You do the hokey pokey and you turn yourself around, and you put on a smile. Finding your smile will help you cope, it will push you forward, and it will make you a better caregiver.

And that’s what it’s all about. (clap, clap)

Nicole Savini is field producer for the Peabody and Emmy Award-winning series “The Colbert Report” on Comedy Central. Her mother, Kathy, has FTD.