“I don't trust anyone who doesn't laugh.”
— Maya Angelou
CAREGIVERS DON’T TRUST ANYONE WHO DOESN’T HAVE A SENSE OF HUMOR

– THAT’S WHY IT CAN BE HARD TO WORK WITH BUREAUCRATS 😊
The first sentence in the well-known book "The Road Less Traveled," written by the late M. Scott Peck, is this:

Life is difficult. Indeed it is. If not for our human ability to often find humor in difficult situations, life could be very dreary for many of us.
But as caregivers, it is no wonder that our sense of humor is often the first thing to go even though we know that

HUMOR IS HELPFUL
AND
LAUGHING IS HEALTHY
For 50 years, my parents were the primary caregivers for my brother – a person born with physical and cognitive disabilities. Amazing & the source of a lot of my difficulties 😊

When my dad passed away in 2011, the “stability” of their lives and so, too, mine, also disappeared.

That is when I became both my mom and brother’s primary caregiver. No one else wanted the job 😊
WITH ALL DUE RESPECT...

We sold my parent’s house, rented out our own home, bought another house that needed a major renovation in order for it to be possible for my brother to move in, and along the way found temporary housing for my brother. All in a period of six months.
The circumstance of caring for her adult brother is fairly unique amongst white middle class 21\textsuperscript{st} century Americans. Poor people on every continent do it. Families, living under one roof, sometimes in one room, generally include grandparents and cousins and nieces and nephews. The notion of parents and their children being the only members of a household uncommon. And generations before now took in extended family as a matter of course. But in the company of her peers, she stands alone. Her household configuration, unusual and somehow disquieting to those now having to consider choices they’ve made that would not allow for such a situation to befall them.
MOM - OUR “LITTLE GIFT”

My 85 year old mother passed away in February of this year, but I am still taking care of my brother.
MY BROTHER PAUL

He attends a day program, but he uses a wheelchair and is for the most part in need of 24/7 oversight given his cognitive limitations.
Nothing in my entire life prepared me for this kind of work.

Even though caregiving is a job that many people, and most women, are required to do as a matter of course, many times with no monetary reward.
(UNPAID) DOMESTIC LABOR
I ask him if he took his medicine and he says, “I did. Just now. A little while ago.” My daughter, who is in the kitchen with us says, “That is absolutely, almost the best oxymoron I’ve ever heard.”
Unlike many 24/7 services that employ complex schemes to ensure resistance to potential disruption, we are incapable of preparing entirely redundant and parallel infrastructures in the care that we are asked to provide for those people in our life who are entirely dependent on us to care for them.
A lot of the recommendations for experiencing more laughter, tell you to go outside your experience rather than look w/in. I get it. America’s Funniest Videos is good for that.

But there are many funny things happening in front of you, EVEN OR ESPECIALLY, in the serious things that are happening all the time.

1. YOU DO NOT NEED TO BE FUNNY IN ORDER TO SEE FUNNY.
IN THE PLEASURE OF DRESSING UP
“What have I done to make you think I’m impaired?” My mom asks me, without making eye contact.

“Well, yesterday you put both your legs into one pant leg and almost fell over. Last night, you couldn’t use the spoon to put food into your mouth.” I pause. She still isn’t looking at me. “All week, You kept thinking the tv remote was your phone. And you keep putting dirty dishes into the dish washer before removing the clean ones.”

“Says you,” she tells me.

In the conversations that you have with the people you are caring for...
IN CREATING ADL CARDS TO TEACH YOUR BROTHER THE STEPS TO SHOWERING ONESELF

WASH YOUR BALLS

WASH YOUR ASS
2. SOMETIMES YOU JUST NEED TO CHUCKLE

Like when you are trying to help your mother relocate from her bed to the wheelchair so she can have a bowel movement on the toilet, and she is moving at a snail’s pace and digging her fingernails into your arm, and you think that you can lift her – she is only 100 pounds after all– but 100 pounds is 50 pounds more than a sack of potatoes, and you don’t want your back to go out, so you holler for the assistance of your respite worker, a small but strong Tibetan man who is kind, but doesn’t speak good English, and he comes in, sees what is going on and he says, “TAKE YOUR TIME, ROSE, TAKE YOUR TIME.”
Or growing up with a brother who is a person with disabilities, and how everyone in your family would use any opportunity to scare one another. After the initial fear, every person would laugh – the one who did the scaring, the person scared and anyone who happened to be watching. You’ve been made to wonder (for years now) why your do this as often as they did. Not every family does. In fact, in some families, it would not be ok. But you realize and remember that desire for relief, the relief that only laughter can provide sometimes. It’s like crying. And sometimes you need to do something to induce the tears so that they flow.
Or sending your mother at her 85th birthday party to the door at 11 pm at night because two cops are standing on the front steps. Neighbors called and complained about the noise of fireworks that you set off and you know that the police are not expecting to see a little old lady at this hour of the night.
3. Realize that when we have lost our ability to find the funny, we are probably stressed out. In that sense, not being able to laugh is informative.

Many times, the urgency & intensity of caregiving makes it difficult to experience levity even though that is what we probably need.

That is when we need to feel compassion – for ourselves and for the people we are caring for.
MY MOM AND BROTHER
Remember that laughter adds life to your years!
I’m here because I want to share some of what I’ve learned.

But I also want to learn, and connect with others like myself (isolation is a big part of what we do), and I feel obligated to be an agent of social change.
THE END...IT NEVER ENDS