

Forgotten Pieces of a Jigsaw puzzle

By Mick Kendig

Dementia is not a disease. It refers to a set of symptoms brought on by other medical conditions. Dementia is a generalized term for memory loss and cognitive deterioration that impacts daily living. The most common cause, Alzheimer's Disease, accounts for 60-80 percent of dementia cases. Most forms of dementia like Alzheimer's progressively get worse.

There are 7 stages:

1. No impairment. Your loved one will show no symptoms, but tests may reveal a problem.
2. Very mild decline. Your loved one will remain independent, but you may notice slight changes in behavior.
3. Mild decline. You'll notice more changes in their thinking and reasoning. They may have trouble making plans, repeat themselves a lot, and have a hard time remembering recent events.
4. Moderate decline. They'll have more problems with making plans and remembering recent events. They may have a hard time with traveling and handling money.
5. Moderately severe decline. They may not remember their phone number or their grandchildren's names. They may be confused about the time of day or date. They'll need assistance with some basic day-to-day functions, such as picking out clothes to wear.
6. Severe decline. They'll forget the name of their spouse. They'll need help going to the restroom and eating. You may also see changes in their personality and emotions.
7. Very severe decline. They can no longer speak their thoughts. They can't walk and will spend most of their time in bed.

My grandmother has always been a mystery to my family. There are very few moments in her life we know about, let alone know in detail. Even my Mom knows very little about my Grandmother's personal life. Though to be fair they've never been super close. Too much distance and resentment I think. Not enough open communication. Now my grandmother is around stage 5 or 6 with symptoms of stage 7. There's no hope for open communication now. Not when her brain is like knotted yarn. Not when she can no longer recognize my mom but is constantly looking for her precious little girl.

Beginnings: Two Are Better Than One

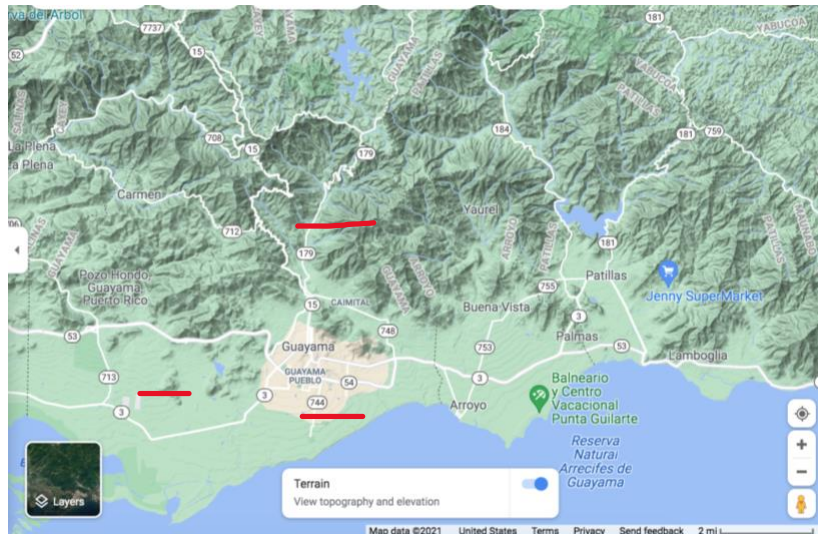
Puerto Rico

Yaurel, Arroyo – May 6th, 1926

A baby girl is born to Francisco Perez and Amelia Velazquez. She disobeyed her father's wishes and arrived 2 weeks earlier than discussed. This would be the only time she disobeyed her father.

She takes her first breath of air. Her lungs hadn't known what they were for until this moment and react poorly to this first gulp of air forcing their inflation. That wasn't what they were for was it? The rush of oxygen is sharp in her **previously submerged** lungs and she lets loose a wet cry that shakes the room with **her** discomfort. Francisco takes the small bundle in his arms and whispers admonishments at her early arrival. His brow creases, "What are you doing little one? I told you to be on time, not early, not late." He slowly sways the baby in his arms. "Shhh, your mother is tired". Francisco nods to his wife asleep in their bed and sweat drenched after a long and strenuous labor. "Shhh you must behave yourself sweet girl". She peeps half a

glance at her father as he speaks. Her breaths get easier and easier until she's quiet. Her lungs stretch and settle into an easy rise and fall. She hardly makes a sound after that.



Population in 1920:

Yaurel-1,666; Arroyo-3,025; Guayama 8,924



The town of Yaurel

Arroyo, Arroyo – September 2nd, 1926

Francisco Perez is a farmer in Yaurel, a small mountain town in Puerto Rico. To be honest, it was more of a village than a town. It didn't even have a hospital, any government

buildings or a high school. It's just a few buildings owned by the farmers and a small church. Francisco is a hard worker and has little extra time if he wants to support his ever-growing family (which would eventually total 11 people). Therefore, it should be quite understandable that it is not until September that he makes the trip down the mountain to the next biggest town in the area, Arroyo, to officially document the birth of his daughter Esmeralda Perez Velazquez.

Of course, later on this BOGO birthday situation makes life a bit complicated but for now little Mery does not care. She is all too happy to have two birthdays to celebrate. Who wouldn't be? She is more concerned with the absence of the strong arms which rock her.

There's a phenomenon common to dementia patients called sundowning. As the sun sets patients become increasingly confused, anxious, and aggressive. It persists well into the night. The cause is unknown, but it is believed that sundowning may occur with the changing light because patients' biological clocks are messed up and cause confused circadian rhythms. To me that theory makes sense because in my experience, half of sundowning issues are made up by my grandmother. They are like a dream or hallucination carried into waking hours. She becomes aggressive and confused. Most nights the air in our home is strangled by her curses and sobs. She becomes a lost child, belligerent and scared, desperate to find her parents. She often tries to walk along the unlit road at night because she believes it will take her to her parents' house but they've been dead 30 years. Our front door alarm is armed 24/7 now and the key to the backdoor is hidden.

Guayama, Guayama – circa 1940

Mery and three of her sisters walk dutifully along a narrow mountain pass lined by ferns slick with the drops left from the last rain shower. The thrum of insects accompanies the squelching of the girl's footsteps. Despite the mist and mud that frequently makes up the Puerto Rican mountains though, the girls are unfazed. They don't need to watch their steps along this path. They know it as intimately as they know each other's faces. They know where the ruts are too deep because Carmen rolled her ankle seven months ago. Those jagged rocks waiting to rip a hole in your knee? Consuelo mapped them last year after a mud slick tripped her and turned her stockings red.

The sisters make the same eight-mile trek to the city of Guayama twice a week. Every Sunday afternoon and Friday night. Why you may ask? Because Guayama has the only high school nearby and they needed an education. I bet that if you had to do the same you wouldn't watch where you were going either. Now this was obviously not a walk they could make to and from school every day, so the girls stayed in a boarding house during the week in order to attend school. Not all of them think an education is totally worth the grueling walk up and down the mountain, but Francisco and Amelia do. None of the girls will risk their parent's judgement so they walk this path twice a week. To be fair though, the journey always starts out with laughter and plans for when they arrive before it shifts into a mud lined silence broken only by the occasional grumble from someone's downturned lips or a Coqui's whistling call.

Dementia patients often mix up or forget the names of loved ones, they may even forget how old they are or who is in their life. My grandmother doesn't know who I am. "Pia! Abuelita!" I say as I hold her face in my hands. She laughs. Her eyes half glazed. She doesn't know me, not as her granddaughter at least. Does she know she forgot? Or does she think I'm joking, that I'm insane, when I tell her I'm her granddaughter? A few times

she's tried to call the police on me or other family members because she thought we were intruders. She often thinks my mom, her only daughter, is one of her sisters. Or she believes her daughter is a cleaning lady or tenant of an imaginary upstairs apartment.

We are strangers to her.

I find her much stranger.

Yaurel, Arroyo - 1944 (probably)

Mery stands in the kitchen doorway. Her head leans against the wall smushing her walnut curls against the doorframe. Her mother wipes her hands across her apron so that no trace of the green plantain she just sliced remains on her fingertips. "Mother?" Mery's eyebrows upturn a bit at their inside edges and her eyes narrow a smidge. Amelia rocks her cast iron pan and the oil inside lazily spills to each side in waves. She nods nearly imperceptibly as she places the slices in the pool of oil.

"Well, what do you think?"

"Child, you know I support your desire to leave and study as a teacher"

"Really? Are you sure it's okay for me to leave?"

"Why are you looking for reasons to stay?"

Esmerelda takes a step forward and her hair falls forward obscuring her face. "What about you and father?"

"We are fine"

"The sugar cane harvest though.."

"Mery..."

"And Chefi and Noris are just starting highschool"

“We are fine, child”

The plantains are golden now and ready to be flipped. Amelia obliges. “Go. Craft the gifts God blessed you with. We will be fine. Your brothers and the hired hands will handle the harvest.”

“But mother..” Amelia turns to Mery and grips her chin. She pulls it up. Mery’s hair falls away from her face. Her mouth is set.

“Your father already made boarding arrangements for you. Do you want to tell him you will not be using them?” Mery’s eyes widen and she inhales sharply before her eyes find the floor.

“I will make you and Father proud Mother.”

Amelia’s attention returns to the tostones she has been making. “Now go remind your father we are leaving tomorrow for Guayama. He can’t miss your graduation.”

Mery leans in and kisses her mother on the cheek “Yes Mother”.

“And Mery? Tell him and your siblings that dinner is in half an hour as well.”

“Of Course”



The Middle: What We Know (not much)

Arroyo, Aroyyo – 1946

Mery stands in front of a class of small children. A boy with tightly curled hair and large brown eyes is tugging at the dress of the girl in front of him. Mery is writing in curling letters the day’s lesson, multiplication tables ,when she hears a sharp “AH” and a muffled tumble. She turns to find the young girl half falling out of her seat. “Josefina? What happened?”. The girl’s eyes lead Mery to those of the boy. “Enrique! Come here.” she says. The boy turns haughtily towards his teacher. He doesn’t move from his seat. He sits draped like an iguana sure no one will disturb it. Mery lightly begins tapping her ruler in her palm. He shuffles a little in his seat but doesn’t back down.

“You have until the count of three before I demonstrate in front of your classmates what such behavior deserves 1...2...3”

Enrique leans over to the boy next to him and whispers something in his ear. The other boy laughs while looking at Mery. THWACK. Enrique's eyes shoot up and begin watering but he grits his teeth. His hand rises from the desk where it rested and curls against his chest. An angry red streak crosses the back of it. A stinging lesson from Mery's ruler.

"Now who can tell me what 7x6 is?"

Viejo San Jaun, PR – 1958

Mery stands on a wrought iron balcony overlooking a side street from her second story apartment. She's waiting to see if that mainland gringo with the cerulean eyes is at the café across the street again. He is. His head's tilted towards her as if in invitation. A voice calls out to the stranger and a slim hand with manicured fingers wave him over. It's not Mery. Her younger sister is sick of Mery's patience (shyness) and invites the young man, Dick, up for a coffee. Less than a year later Mery and Dick are married.

Berkley, California – 1963

Mery and Dick have settled in California for the minute as the search for a child to call their own continues. Mery desperately searches for a baby in Cali before she and Dick set off again for his next assignment. Dick, a military contractor, never set down roots for very long and Mery already had her eyes on a little girl with big brown eyes and little curling wisps of brunette hair. Her own little angel.



There are two main things people don't always realize about dementia patients. One, most people end up caring for their loved ones at home because nursing homes are very, very expensive in the U.S. The second is that nursing homes are impractical since dementia doesn't have a set timeline. No one can tell you how long you will be dealing with it. There are 7 stages but each stage progresses differently. It can take a few weeks or a few years for a stage to progress. You may go through 1 of the stages within a handful of months or many years and then the next stage could take,

1 month,

2 years,

5 years,

8

They're Just. Estimates.

My grandmother was diagnosed when I was 15. I'm 22 with no end in sight. She's the picture of health outside of her dementia. But how can you be healthy when you don't know who you are where you are, or when? When you can't recognize your loved ones? People are their history and how its shaped them. For my grandmother, I'll always be guessing, estimating, struggling to put together the pieces of who she was.

Laurel, Maryland – 1977

Dick is gone. His daughter Wanda remembers very little of him. The one time she does recall is when he tried to teach her to drive. She was twelve.

Its just Wanda and Mery now. To Mery, Dick's dead. She can't acknowledge the other woman, the other child. Wanda will follow suit in her mother's denial though she goes a bit farther. She does more than just swearing off grieving the man. To her, he no longer existed that false, treacherous, not-father.

Endings: They Are Ever Nearing

Columbia, Maryland – 1999

Wanda and her husband give birth to their 3rd and 4th children. Two twin girls weighing 3.1 lbs and 4.4lbs respectively. Mery cradles them both in her arms as her precious daughter dozes from the painkillers and exertion. The father is checking on child 1 and 2: older brothers. Mery slowly rocks the twins as their lungs settle into easy rises and falls. They squirm and mewl but when she speaks to them, they quiet, soothed by her rolling and lisping English.

The thing with dementia patients is that when they can no longer remember most things, One thing still matters: feelings. Dementia suffers like my grandmother live by emotional association. This has been hard for me and my family. When she's mean to you or upset, if you brush her off, condescend, or argue with her she remembers that. She remembers she doesn't like you and she can't mask it. She is blunt and unfiltered and will make life hell. Yet, my dad and brothers live with her now and they won't give allowances for her circumstances. They argue with her, yell at her, upset her. They berate my mom for coddling her and not reasoning with her. My mom, my sister and I do our best to de-

escalate at all times. We use other ways to handle her. We distract, hide, engage, and overall avoid her triggers so she is less agitated and easier to work with.

We know the truth.

Reason is DEAD.

It died with her diagnosis.

They don't get up with her 4 times a night to comfort her crying, change her Depends diapers, etc. My dad wants time with his wife but ignores her mother's needs and her own wishes. He hasn't been sleeping, like his wife, on the floor outside my grandmother's door for nearly two years. My brother, the eldest son yells at a 96 year old toddler for irritating him but he can leave the house for more than an hour at a time. My mom can't. In fact he could move out. He is 26 and employed. Instead he reverts to his terrible two's. Does he not hear Mom on her makeshift bed in the front room stifling sobs at 2am? Does he not care?

Severn , MD – 2020

I sit next to my grandmother, doing a jigsaw puzzle. Her daily ritual. She'll do them for hours sometimes. as if to say, "look come over, the wrong. Blank They don't fit and

She glances over at me what I did" . But when I pieces are jammed in cardboard is facing up. she doesn't realize it.



What makes a person?

Relationships? Emotions? Memories?

There's an ancient riddle that goes,

Which creature walks on four legs in the morning two legs in the afternoon
and three legs in the evening?

The answer is Man, as they go from a crawling babe to walking as an adult and then walking with a cane as a senior. Yet there is another layer to this riddle to me. People don't just lose their mobility with age but their personhood. What makes them the person you knew disappear. Dementia makes people unrecognizable. They become foreign and the only way to deal with it is to become familiar with this stranger in your loved ones body. You become a Caregiver, willingly or not, you are a steward for this person in

honor of the memory of who they were. And in my case I will do my best to honor her while she's struggling with dementia even though person I knew, barely, is already long gone. I'll continue to mourn each lost and blank puzzle piece that made up my grandmother's life rather than try jam them in one by one. Maybe along the way I'll stumble upon those forgotten puzzle pieces.