

Family caregivers find support on #dementia TikTok

October 27 2022, by Kate Wells



Credit: Unsplash/CC0 Public Domain

It all changed on a Saturday night in New York City in 2016. Jacquelyn Revere was 29 and headed out to attend a friend's comedy show. She was on the subway when her phone rang. It was a friend of her mom's,

back in Los Angeles. That's weird, Revere thought. She never calls.

"And while I was on the subway, my mom's friend said, 'Something is wrong with your mom,'" Revere said. "'We don't know what's going on, but your mom got lost driving home. What should have been a 15-minute drive ended up taking two hours.'"

Revere flew to L.A. At her mom's home in Inglewood, she found foreclosure notices, untreated termite damage on the porch, and expired food in the kitchen. Her mother, Lynn Hindmon, was a devout evangelical who worked for her church. A slim, regal self-declared "health nut," Hindmon was now forgetting to pay bills and couldn't remember whom she was talking to on the phone.

Revere did not know it then, but that tough time would lead her to find—and help build—a community of caregivers who support one another on social media. TikTok has been an especially helpful platform. Content with the hashtag "dementia" has racked up more than 4 billion views on TikTok, as younger generations, already accustomed to sharing their lives online, now find themselves caring for aging loved ones—often with little preparation and no idea how to do it. Over the past few years, Revere's account, @MomofMyMom, has become wildly popular, with more than 650,000 followers. Ardent fans have told her they feel like they personally know her and her mom.

It would take nearly a year to get the diagnosis that confirmed what Revere already suspected: Her mother—still in her 50s—had Alzheimer's disease. Barely 10 years since Revere left home, she found herself moving back in to become a full-time caregiver for her mom and her grandmother, diagnosed with Alzheimer's years earlier.

"That first year and a half, I was just filled with fear: What if I lose the house?" Revere said.

Because of the stress, she said, "I went through bouts of migraines. My hair, right in the middle, fell out completely."

"I had to figure out how to get control of all the banking, figure out the passwords, make sure the bills are paid, make sure everything's taken care of."

In 2017, her grandmother died. Revere's grief and isolation felt overpowering. Her friends in their 20s either couldn't relate or thought she was "wallowing in pity," Revere said.

Trying to make them understand what her daily life was like now seemed impossible. "I just wanted to find people I didn't have to explain everything to," she said.

Revere tried a support group for caregivers, an hour's drive away. But the other attendees were decades older and had more financial resources. "[They] would say, 'And now I have to take equity out of our house,' or 'I'm thinking of reaching into our 401(k).' And then I would tell my story, and people would be looking at me like ... a charity case, or like my problem is unsolvable. ... I just felt worse."

These days Revere no longer feels so alone. She's a celebrity of sorts on TikTok, at least among the hundreds of thousands of people who post about the difficulties of caring for a loved one with dementia.

Daughters are often dementia caregivers

Alzheimer's is the most common form of dementia. Others include vascular, Lewy body, frontotemporal, and mixed dementia, says the Centers for Disease Control and Prevention. Nearly all forms worsen over time, and there is no cure, although there are some treatments.

The task of caring for people with dementia usually falls on [family members](#). Every year, an estimated 16 million Americans provide more than 17 billion hours of unpaid care for relatives or friends suffering from Alzheimer's disease or other dementias, according to the CDC. About 60% of these caregivers are women.

"Unfortunately, there is not a very strong system of paid support for people with dementia," said Elena Portacolone, an associate professor who studies aging and cognitive impairment at UCSF's Institute for Health & Aging. "And so the most common way of supporting persons with dementia is the daughter."

Like Revere, many of the women who become caregivers end up quitting their jobs. They often find themselves financially vulnerable and "extremely isolated," said Portacolone.

Another expert, Teepa Snow, said too many caregivers are struggling. Snow, an occupational therapist in North Carolina, runs a company that trains caregivers of people with dementia. Her own how-to videos about practical, compassionate caregiving rack up millions of views. "TikTok is where people are expressing an unmet need," she said.

Because there's no cure for dementia, the medical community often treats it the way previous generations of practitioners treated cancer—like "a big black box," Snow said. Decades ago, when people got cancer, "we didn't say anything; we didn't talk about it. We said, 'Oh, gosh, that's horrible.' And people were like, 'How long have they got?'"

What family members need from the medical system, Snow said, is more understanding of symptoms and how to handle them, more help setting up long-term support systems, and knowledge about how patients can be helped by changes to their dietary, sleep, and exercise habits.

All too often, however, caregivers are left to muddle through the complex tasks of keeping a patient safe. "That's pretty lonely," Snow said.

The COVID pandemic disrupted or closed down much in-person support for caregivers, including the adult day care center Revere's mom had been attending five days a week. Desperate to find social connection, Revere did what so many others did as the pandemic stretched on: She got on TikTok. The short video format has attracted caregivers, who find they can document and share the vivid moments of their worlds at home in ways that would be less visceral on text- or photo-centric platforms.

You can watch a woman's "day in the life" video of caring for her husband with early-onset Alzheimer's or one of Revere's @MomofMyMom posts from 2020, which walks viewers through their bath routine.

"It's bath day," Revere says at the start of the post, while still lying in bed. "I try my best not to make this an emotionally draining experience," she sighs. "So let's begin."

Bathing someone with dementia can be difficult, even dangerous. They can get disoriented, or feel threatened when someone takes off their clothes or maneuvers them into a wet tub. They may slip and fall, or try to fight their caregiver. Revere has created a soothing, predictable routine for her mother. At the time of this video, Hindmon is 63, and it's about five years after her Alzheimer's diagnosis. She's not speaking much. Lynn Hindmon is tall, with great cheekbones. This day she's wearing neon-blue leggings and a purple beanie.

Revere starts off by promising her mom a present—which she'll get after the bath.

Revere walks her audience through the process, sharing what works for them. She turns on some soul music, plugs in the space heater, puts the dog outside, and lays out all her mom's clothes. "Lure her into my cave," she says, as her mom enters the bathroom.

The video then cuts to after the bath is over: Mother and daughter are celebrating with a bathroom dance party.

The video got more than 20,000 views. Hundreds of people left comments, saying how they can relate. One comment read: "My mother-in-law passed a year ago this week. This was the most frustrating part of caring for her. Devoted a whole day to getting this done." Another commenter told Revere, "God Bless you! I know it's hard. I see you and send so much love your way."

Revere posted a follow-up right away:

"How many of us are on here?" she said into the camera. "I've been, like, looking for people my age that I can relate to, who have the same experience."

Revere's following soared from just a couple of thousand followers to more than 650,000. Many people used the comments to talk about their own caregiving struggles. They wanted to see the little victories, like Revere's gentle, joyful tricks for getting through bath time. They also listen to Revere's candid confessions.

"Y'all, I have never been so emotionally drained in my life," she shared in one video. "Caregiving eats your soul. It kills your spirit. It's constant mourning for years. ... And it's beautiful."

Content creators weigh ethics of going public

The intimate, unvarnished depictions of dementia on TikTok have raised ethical issues surrounding privacy, dignity, and consent. There are videos on the internet of adults who haven't consented to their most vulnerable moments being shared with millions of strangers.

In one TikTok, a woman chronicles her grandmother's aggression, filming as the elderly woman chases her through the house, fists swinging wildly. Other content creators film the verbal abuse that caregivers can experience.

Beth Kallmyer, vice president for care and support for the Alzheimer's Association, doesn't think the people posting these videos intend to be exploitative. "You could tell that the caregivers just felt isolated and frustrated and at their wits' end, with no resources," she said.

"If I were talking to a family member ... considering doing this," Kallmyer said, "those are the questions I would pose to them: Would they [the person with dementia] be comfortable with this? Is there a way for you to film something that gets the idea across but maintains their dignity?"

"Should we have a video of somebody that isn't fully clothed? Or maybe [before Alzheimer's] they only went outside when they were dressed to the nines or really put together, and you've got them in pajamas or sweatpants or whatever, and they don't have makeup on. I'm not sure that's the best way to go about using TikTok."

Revere has a video that, in retrospect, she now feels ambivalent about posting. It's the most-watched video on her channel, with 27 million views. In it, her mother is walking around the living room with an open bottle of mouthwash. She somehow got past the locks on the bathroom cabinets.

Lynn Hindmon thinks the mouthwash is a drink, like juice or milk. She looks frustrated and dazed as Revere tries to explain why she can't drink mouthwash.

With some negotiation, Revere gets her mom to hand it over in exchange for an ice pop.

Some comments on that post call her mom an alcoholic, or say she looked scary. The experience made Revere feel protective—like she needed to be more careful, as she didn't want to post anything that might put her mom in a bad light. Still, after much consideration, she decided to keep the mouthwash video up. She said it's a good example of "redirecting" away from a risk—something other caregivers would understand.

On March 9, Jacquelyn Revere posted another video on TikTok, letting her followers know her mother had died. She was 65.

On TikTok, the messages of surprise and condolence poured in.

Revere, an only child, had always assumed that when her mom died she'd mourn her alone. Instead, people were checking in on her, sending her gifts, sharing memories of their favorite videos of Hindmon.

"It's been the least lonely I've ever been throughout this experience, actually," she said.

Revere has continued to post on @MomofMyMom, talking about what it feels like to miss her mom, and to mourn the life she didn't live while she was caring for her.

Now she has time to go on dates, get a pedicure, or drive by the ocean.

After six years of caring for her mom, starting when she was just 29, Revere is now trying to figure out who she is now—and what she wants. She knows she wants to stay connected with dementia caregivers.

"I just want them to know that they're being thought about," Revere says. "Because that's what I needed most. Just to know that life isn't passing me by, and I'm not seen.

"I just want to make sure that they feel seen."

2022 Kaiser Health News.

Distributed by Tribune Content Agency, LLC.

Citation: Family caregivers find support on #dementia TikTok (2022, October 27) retrieved 3 May 2024 from <https://medicalxpress.com/news/2022-10-family-caregivers-dementia-tiktok.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.