



Why Nursing Home Residents Need the Essential Caregivers Act

INTRO

Imagine not being able to see your aging mother for months.

She's living in a nursing home, but you can't bring her favorite foods. Or help feed her. Or dress her. Or make sure she's taking all her medicines.

You can't help her get in and out of bed.

You can't hug her.

Or hold her hand.

Or give her shoulders a reassuring squeeze.

She's essentially cut off from you — and from everyone she loves — during an unprecedented public health crisis.

For thousands of families during the COVID-19 pandemic, this became a heartbreaking reality. And without new laws, advocates say, it could very well happen again.

Today, we'll look at why families and advocates are fighting to ensure that loved ones are never again separated from those they depend on most in nursing homes and other long-term care settings.

Welcome to Code WACK!, where we break down how our healthcare system really works, what it means for you, and how we can make it better for everyone. I'm your host, Brenda Gazzar.

When nursing homes and other long-term care facilities shut their doors in March of 2020, the goal was to protect vulnerable residents from a deadly and highly contagious virus that swept around the globe. But for many families, the resulting separation came at a devastating cost.

That's because many visiting family members weren't just visitors.

They were actually filling the gaps in care that existed long before the pandemic erupted.

Today we're speaking with Tony Chicotel, senior staff attorney with California Advocates for Nursing Home Reform, or CANHR. For decades, Tony has fought to protect the rights of nursing home residents. And he says the isolation and neglect that families experienced during COVID was one of the most painful chapters of his career.

Chicotel: "We had call after call from family members of long-term care facility residents who were completely crestfallen at their inability to provide support directly to their loved ones who were going through such horrific circumstances in their facilities."

Tony knows firsthand how much families do for loved ones in nursing homes.

Not because anyone asks them to.

Or because anyone praises them for it.

They simply do what needs to be done. And that was the case before the pandemic, too.

Chicotel: “Despite the fact that the facilities are supposed to cover all the needs of the residents, they often don't. And the family members just filled that role without glorifying it, without rubbing it in anybody's faces. They just did it. And so I had observed that but it really hadn't made much of an impact on me.”

Then suddenly, they couldn't.

All in-person contact with loved ones stopped – for weeks, then months. The results were often gradual yet devastating. And for Tony, it felt almost unimaginable.

Chicotel: “And then COVID happens, and now suddenly, it's Armageddon like the, the, the unthinkable has happened where the family members are completely cut off or almost completely cut off, but certainly directly cut off from seeing their loved ones or being in the facilities. And many cases that they had visited daily to provide direct support to these residents and now could no longer get into the building. They were super concerned.”

He recalls trying to convince policymakers to find a way to safely allow these caregivers back inside.

But despite all his efforts, his pleas were rebuffed. Elderly and disabled nursing home residents not only had to deal with this terrifying pandemic, they had to do it without their loved ones by their side.

Chicotel: “I remember feeling a low in my career for being power, for feeling powerless. Um, one of the things I love about my job and my work is I've always felt like if I put enough time and energy into something, I can make a difference. It might not be everything that I hope to get, but at least some favorable outcome that will help some people in our state or in our country in long-term care. And on this issue, I felt like I was up against the wall and I just couldn't get through. And I was communicating with family members who I just couldn't help.”

One issue came up again and again during the nursing home lockdown.

Food.

Chicotel: “There was so much concern about my mom, my dad, my grandmother will not eat the facility food. I bring them food so that I can be assured that they're gonna eat, or, um, when the food is delivered, no one, they need help. And the staff typically don't help them. So I'm very concerned about them losing weight.”

Some residents refused to eat the meals provided by the facility.

Others needed encouragement or help eating.

And many families had quietly taken on that responsibility years earlier.

Without that extra care and attention, people worried.

Would Mom lose weight?

Would Dad simply stop eating or drinking?

Unfortunately, those fears weren't unfounded.

Even before COVID, severe weight loss affected around 8 to 10 percent of nursing home residents. During the pandemic, the problem appears to have grown worse. While comparable national data for nursing homes are limited, one study found that nearly one in five residents in assisted living and memory care communities experienced severe weight loss during periods of quarantine and isolation.

For Tony, such numbers reveal everything we need to know about the plight of long-term care residents during COVID.

Because food isn't just about consuming calories.

It's also about their health and wellbeing.

It's about human attention.

Someone sitting beside a resident.

Talking to them.

Encouraging them.

Helping them.

Making sure their basic needs are being met.

And food was only one piece of it.

Some family members helped with grooming.

Others monitored their medications.

Some provided remarkably skilled care, like clearing mucus from breathing tubes.

Chicotel: I had family members who did, you know, tracheostomy suctioning for their loved ones so the level of care can vary from, you know, quite skilled to just general assistance with activities of daily living, but some consistent provision of that care. That's the expectation the visitor had, that I would provide care.

And then there were things most of us rarely think about.

Like helping residents with limited mobility change positions.

Because many nursing home residents are unable to move themselves.

Without regular movement, pressure injuries, like painful bedsores, can develop.

Family members often helped with that too because they knew their loved one needed it.

Meanwhile, nursing homes – who were already chronically understaffed before the pandemic– were dealing with a crisis of their own.

Chicotel: “The ban on visitation and essential caregiver access didn't occur in a vacuum. There was also this horrible infection raging in the community.”

Workers were getting sick.

Others fled the profession entirely.

And those who remained were spread thin and pushed to the brink.

Chicotel: So at the same time that we cut off this vital resource for residents, we were also suffering from, you know, unparalleled understaffing in nursing homes. And the staff who were there were just overwhelmed with infection control protocols that they previously hadn't had to adhere to.

Care suffered in ways both large and small.

Chicotel: “So pretty much in every way that you could imagine, perhaps with the exception of infection control protocols, care had never been worse.”

And one of the most important sources of support, essential caregivers, had now disappeared.

Families also served another role.

They were advocates.

They noticed things.

When Mom seemed unusually sleepy.

When Dad's medications looked different.

When something just didn't seem right with the way the residents talked or acted.

And they spoke up.

Those extra eyes and ears mattered.

Especially when nursing homes became overwhelmed with the pandemic, and the number of infected patients swelled.

Eventually, some facilities began allowing window visits.

Sometimes, even cracking the window open so they could talk to one another.

For families who hadn't seen loved ones in months, even that felt like progress.

Tony remembers receiving photographs from those visits.

Families were grateful.

But the overwhelming emotion, he says, was still sorrow.

Chicotel: "The mixed emotions. They can finally see them in person and maybe even speak some words to them that weren't over the phone or through a device, an electronic device but then there was also the overwhelming feeling of just sadness that they couldn't touch, they couldn't hug."

And for residents living with dementia, the experience could be especially painful.

Many didn't understand why their loved one was standing outside.

Chicotel: "In a lot of cases, these residents had cognitive impairment and didn't understand 'why are you out there? Come in.'"

Instead of providing comfort, the visits sometimes caused confusion and distress.

Chicotel: "And it put the essential caregivers through just misery thinking like, 'oh no, I've upset them when I was really just trying to comfort them.'"

Tony remembers looking at those photographs and thinking:

Chicotel: "This is just terrible. This is not enough. And yet we had thought that was a breakthrough to be able to get window visits. It was a really tough time."

Meanwhile, many residents with dementia didn't recognize the staff members or understand what they were doing in their rooms.

Chicotel: "For people with cognitive impairment, those staff were strangers. They don't have any long-term memory of them being surrounded by strangers, feeling at some level you have to feel abandoned by your loved ones. You don't know where you are. Just beyond awful."

Today, Tony and other advocates are trying to make sure families never experience that kind of separation again.

So they're pushing Congress to pass the Essential Caregivers Act.

The bill would give nursing home and other long-term care residents the right to designate an essential caregiver during future public health and other emergencies.

The idea, supporters say, is simple.

If staff members are allowed inside, essential caregivers should be allowed inside too, provided they follow the same safety protocols.

The legislation does allow for temporary restrictions. Federal authorities could limit access to such caregivers for seven days and, under certain circumstances, extend that for another week.

But supporters say that's a far cry from the prolonged separations families experienced during COVID.

Some states have already enacted protections.

Texas even amended its constitution to protect caregiver access, with overwhelming support from voters.

California, however, has twice failed to pass similar legislation. Public health officials had argued they should be able to exclude caregivers during future emergencies.

But Tony and other advocates see it differently.

They contend that essential caregivers aren't optional.

They're a critical part of a resident's care team.

For many families, this isn't just about visitation. It's about protecting both the care and human connection nursing home residents depend on. It's about avoiding the unnecessary isolation we saw during the pandemic, which negatively affects people's mental and physical health.

Chicotel: "Massive amounts of depression from the isolation of not being able to see people from the community and families and friends is, um, horrible, horrible amounts of isolation and depression."

For Tony, the issue is deeply personal.

The years between 2020 and 2022 were the most challenging of his professional life.

And because of that, he made a promise to himself.

Chicotel: "That whatever I could do to prevent that from ever happening again, I'll do, and here's our opportunity, the Essential Caregivers Act, I think it would, it would be amazing."

Today, he supports the federal Essential Caregivers Act and is urging Congress to act.

Because one lesson from the pandemic stands above all the others.

Chicotel: "I think for me, the biggest lesson learned from COVID is how vital caregivers are, how vital these family members are to the support and the outcomes of these residents. And this is one way that we can acknowledge how important they are to protect that access no matter what happens."

These loved ones were never just visitors.

They fed people.

Helped them move their bodies.

Watched over the administration of medications.

Spoke up when something seemed wrong.

And they ensured residents weren't alone. They reminded them that they mattered and their needs mattered. And perhaps most importantly, that someone who truly cared for them was paying attention.

Tony says the passage of the Essential Caregivers Act would ensure that such direct care remains constant.

Chicotel: "I would feel just so much better about what happened during that time period that we did learn from it and improved our policy as a result."

That was Tony Chicotel, senior staff attorney with California Advocates for Nursing Home Reform, or CANHR.

Listeners who agree that nursing home residents should never be separated from their loved ones can contact their senators and representatives and urge them to support the Essential Caregivers Act. Stories from families who experienced these separations can be especially powerful.

If you're not sure who represents you, call the U.S. Capitol switchboard and they'll connect you to your member of Congress. That number is at 202-224-3121.

If you enjoyed this episode and would like to support Code WACK, subscribe, leave a review and share this episode with a friend.

This episode was powered by HEAL California, uplifting the voices of those fighting for healthcare reform around the country. Thanks for listening. I'm Brenda Gazzar and until next time, stay healthy.