‘No Way to Live’: The Cost of Nursing Home Isolation

"The first time I heard him say, in a very weak voice, 'This is no way to live,' and hearing him cry—that's the one moment that particularly was and still is heartbreaking.” **Melody Taylor Stark**

That's Melody Taylor Stark, recalling one of the darkest moments of the pandemic.

Before COVID, Melody spent nearly every day with her husband Bill, a retired dentist living in a Los Angeles County nursing home because of post-polio syndrome. They read horoscopes, shared meals and treasured their time together.

But when nursing homes shut their doors to visitors, Melody was suddenly separated from the man she'd seen almost daily for years. As weeks turned into months, she watched from afar as the upbeat husband she loved became increasingly depressed and withdrawn.

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.

Today, we're revisiting one woman’s devastating loss and the push to make sure nursing home residents are never again separated from the loved ones they depend on most. Although the bipartisan

Essential Caregivers Act has been introduced in Congress several times since 2021, it has yet to become law.

How did one woman's grief lead her to become an advocate for change? And what can Bill Stark's story teach us about the healing power of human connection?

To find out, we spoke with Melody Taylor Stark, who has spent the past several years fighting to make sure no one else has to hear the words that still haunt her:

Melody: "This is no way to live."

Host: I first spoke to Melody Taylor Stark in the fall of 2020. I was a freelance journalist in Southern California doing a series of articles on COVID and its devastating toll on nursing home residents and staff.

When the pandemic began, Melody was no longer allowed to see her husband Bill at his nursing home. Bill was a retired dentist who suffered from post-polio syndrome and had lived at the LA County facility for 5 years. Previously, she went to see him twice a day on weekdays and spent weekends with him. For Melody, home was where Bill lived.

Melody: "I would stop by on my way to work. It was a hug and a kiss, and reading the horoscopes, and off to work. And then I would come back so we could spend the evenings together and just try to incorporate whatever we could to make things as normal as possible in this very not normal setting."

During the pandemic, it became clear the total ban on visitation – day after day of isolation – began taking a toll on Bill.

Melody: "Seeing him become somber, and uncharacteristically for him."

Host: He was also moved to a smaller room, where he could no longer maneuver his wheelchair. That was when, according to Melody, Bill lost much of his independence. He had to rely more on nursing home staff to do things like getting the TV remote control.

Meanwhile, chronic nursing home staffing shortages were getting worse during the pandemic. Facilities brought in on-call staff who were not always familiar with the residents' needs. Nursing homes were also given permission to bring in nursing assistants who weren't fully licensed to alleviate the shortages.

Melody:

"So I started, you know, hearing more from him. He wasn't just being taken care of, they weren't responding to calls, the assistance wasn't there. And then that upped the frustration of him not having the mobility."

On one occasion, Bill became exasperated after a nursing assistant couldn't transfer him from the wheelchair to his bed.

Melody:

"One night he called me, and he was crying, and he said, 'The CNA doesn't know how to use the Hoyer lift.'"

Host: That's a mechanical patient-lifting device used to safely transfer people who have limited mobility

When Melody asked the nurse supervisor on duty that night if he could go and teach the nurse assistant how to do that, he said that wasn't possible.

Melody: "Now remember this is the person in charge of the entire facility and he said, I can't. I said, 'How come?' And he said, 'I don't know how to use those.'...

Host: After Melody said she was about to call adult protective services, the facility asked a CNA who was trained in using the lift to help Bill.

Melody: "It was through a lot of those things that I'm like, 'okay, this care is not happening here,' and I'm not there, you know, directly to help him with his voice."

Host: When Melody was visiting her husband before the shutdown, she wasn't just a visitor. She was an essential caregiver, providing

physical, emotional, psychological and social support integral to her husband’s care and quality of life. Suddenly for Bill, all of that support was gone.

The neglect became evident in other ways, too.

While on a video call in June, Melody noticed something about Bill that concerned her

Melody: “He was on a medication that caused skin irritation, and not realizing it, he was scratching his arms, and he put his hands up to his face, and his nails were dangerously long.

“First of all, it was something he used to take care of himself, so that was an indication he wasn't just wasn't doing that, for whatever reason, and there was also dried blood under his nails. Multiple phone calls to the administrator, the director of nursing had no results. And after three weeks, I reported it to the Department of Public Health, and you know, they came in, they were cited for it, and the administrator was just furious with me for reporting this, like this is an issue.”

After Bill’s cellphone stopped working, and Melody spoke with him on a landline, she sensed that something was not right.

Since he had faced multiple bouts of pneumonia, she asked a nurse supervisor, whom she liked, to check his oxygen saturation. Melody knew that a healthy level would be in the high 90s.

Melody: “And she called me back a little while later, not too long, but she said it was 82 and the doctors coming in, and we started him on some, on some oxygen, and so forth, and so I'm thinking I discovered that over a bad landline there's professional staff licensed, some not fully, but licensed. Did anyone notice there was a change of condition, you know? And he ended up being in the hospital for a couple of days as a result. “

Host: Family members acting as essential caregivers are often experts in their relatives’ care. They recognize when something isn’t normal for their loved one, and know their past medical history.

In the early days of the pandemic, the federal Center for Medicare and Medicaid Services told nursing homes to close their doors to most visitors. For many residents, that meant months without seeing the family and friends they depended on, except in limited "compassionate care" situations — often interpreted as end-of-life visits.

Then as the human toll of isolation became impossible to ignore, CMS gradually changed course. By the fall of 2020, the agency had begun encouraging nursing homes to allow indoor and outdoor visits under certain conditions.

But that message didn't always make it to the front door. Even as CMS relaxed its guidance, some nursing homes continued to impose strict visitation limits, prompting repeated reminders from federal officials that residents have a right to see their loved ones.

It was the isolation during the pandemic, and not being able to see his wife Melody, that affected Bill the most.

Host: “The first time that I heard him, probably toward the beginning of July, that I heard just a very weak voice saying ‘this is no way to live,’ and hearing him cry, and that's kind of the one moment among many, but that's the one that was particularly, and still is heartbreaking for me to see the crushing, destructive effects of isolation, and here was a system that was not responding, and when I say system, it wasn't just the facility he was in, but it was the facility, it was the corporation that oversees that facility, it was public health, it was all the way up on the line, not giving acknowledgement to the person.”

Host: After about five months of completely banning visitors, the LA County nursing home began allowing Melody and other family members 15-minute visits once a month.

I interviewed Dr Bill. Stark by phone in October of 2020 for the Los Angeles Daily News and the Southern California News group. His words still affect me to this day.

The coronavirus, he said, was "nothing to fool around with." But that didn't make briefly seeing his wife once a month or the social isolation any easier. "I'm in essence in a cell," he said. "I've got TV and the newspapers but that's it. ... I am not happy."

When Bill was actively dying, Melody was allowed a compassionate care visit.

As soon as she walked in, she saw Bill's face transform.

Melody: "He was all of a sudden himself. He was smiling. … The conversation was there, the interaction was there, and just from being present and noticing that, that his wife was there, that I was there, I know that you know there was some element of failure to thrive when he passed."

Melody was using the same Personal Protective Equipment or PPE and safety precautions as staff.

Melody: "When I had that compassionate care visit, I was using the same PPE, the same safety precautions as staff. I had to stay six feet away from my husband. As I was leaving, two nurse assistants were coming in, who were on-call nurse assistants, never seen them before, he didn't know them, I didn't know them. They were very close to him and providing some very up close and personal support, and it's like I'm over here using the same PPE as you guys are using, but I can't even go hug my husband."

Host: Melody was able to see Bill only a couple times in person since the pandemic started before he passed away from a bacterial infection, pneumonia and COVID on Nov. 22, 2020 just days before Thanksgiving. He was 84 years old.

Melody says that Bill could have had a longer and significantly better quality of life had she been allowed to continue her daily visits during the pandemic.

Melody: "So to have someone going from this upbeat, optimistic play the cards to I don't want to say it was giving up, because he always said he would never give up, but it's like can't do this anymore."

Since her husband’s death, Melody has been advocating for the passage of the Essential Caregivers Act.

The federal bipartisan bill would prevent nursing homes from completely separating residents from their chosen caregivers during future public health and other emergencies.

It recognizes that loved ones who provide essential care are not just visitors — they are an essential part of a resident’s care team.

Although the Act has been introduced several times in Congress since 2021, it has yet to pass. Similar state bills in California have also failed to pass.

But Melody Taylor Stark and other advocates continue to raise awareness around this issue and are pressing lawmakers to act.

Melody recently joined me and other supporters of the Essential Caregivers Act when we had a Zoom call with a staff member of Rep. Mike Levin, my congressman in South Orange County California, about the importance of the bill.

Melody keeps fighting because she doesn’t want another resident or family to suffer like her husband Bill did.

Melody: “So many people during lockdown died of failure to thrive as a result of the isolation. We can’t let this happen again. We can’t let the damage that happened during COVID happen for another public health emergency or another type of emergency.”

That was Melody Taylor Stark, wife of the late Dr. Bill Stark and advocate of the Essential Caregivers Act.

Stay tuned for next time when we dive deeper into the role essential caregivers play for nursing home residents and how the Essential Caregivers Act would help.

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.