'A race to the bottom?' How U.S. nursing homes are failing us

“I have examples of good nursing homes and residents receiving phenomenal care. But it's way too few and too far between. And the vast majority, vast, vast majority of the calls and the emails I get are from people having anywhere from a bad experience to a disastrous experience.” – *Tony Chicotel*

911. What's your emergency?

America's healthcare system is broken and people are dying.

Welcome to **Code WACK!,** where we shine a light on America's callous healthcare system, how it hurts us and what we can do about it. I'm your host, **Brenda Gazzar.**

(music)

This time on **Code WACK!** The COVID pandemic devastated nursing homes and other long-term care facilities highlighting the need for major reforms. So how are these facilities faring today in 2024? What changes have been made so far and why are nursing home residents still so vulnerable? To find out, we spoke to **Tony Chicotel,** senior staff attorney at **California Advocates for Nursing Home Reform, or CANHR,** where he promotes the rights of residents in long-term care facilities through litigation, legislation, regulatory policy, and consumer education.

Welcome to Code WACK!, Tony!

Chicotel: Thank you. Thank you for having me. I have a question.

Yes.

Chicotel: Where does the word “wack” come from?

Q: Yeah, so wack is a slang word for messed up because we believe our healthcare system is so messed up.

Chicotel: Oh yeah. Okay. That's what I thought. Yeah. So when I was a kid, I was a breakdancer and we used to say, ‘oh, that move was wack,’ meaning not very good.

Oh, I love that you were a break dancer! That's awesome.

Chicotel: An early B-boy.

Q: Yeah. So where did you grow up?

Chicotel: I grew up in Ohio near Cleveland.

Q: Nice. Tell us a bit more about yourself. How did you become interested in nursing home reform?

Chicotel: I'll try to make this long story kind of short. I knew from a pretty early age that I wanted to be a lawyer. I initially wanted to be a high powered, highly paid rich lawyer. That was my initial thought when I was a kid. I got to college and realized that there wasn't really a super close connection between having a lot of money and having fun and having a good life 'cause I was never more poor than I was in college and had a blast. So I started to focus on things other than money and I was really interested in policy and politics and I just thought maybe I could do something a little more productive for society, a little more helpful for society with a law degree and I discovered legal services, ended up as a legal services attorney for older adults, which is a program throughout the country, funded primarily by federal dollars under the Older Americans Act.

And I started working with a legal services program in San Diego County, taking care of seniors, older adults and their legal issues, all sorts of different legal issues. AndI was really interested in long-term care issues 'cause as part of my job, I had to

do a lot of home visits 'cause a lot of my clients didn't have transportation to get to come and see me. So one of the interesting parts of our projects was we would go to the clients where they were sometimes in their homes and sometimes in long-term care facilities. And I was just really struck by the problems I saw there. And it was a big contrast from my first job, which had been as a disability rights attorney working in mental health facilities and I saw an enormous contrast between the rights' protections in mental health facilities and in nursing homes in particular. And there's a huge disparity here, and I think I would like to focus on that and try to bring more rights protections into nursing homes. So I started focusing my practice more and more on nursing homes. My boss and I got a grant to do nursing home work in San Diego, which started my relationship with California Advocates for Nursing Home Reform and then I moved to the Bay Area to get a policy degree and started working for CANHR part-time then and just stayed on when I finished school.

Q: Oh, that's great. So some 1.4 million residents live in nursing homes in the U.S. and nearly half of people turning 65 will need some type of paid long-term care services in their lifetime. How would you characterize the state of nursing homes today in terms of both safety and quality of care?

Chicotel: The first word I think of is wanting. The second thing I think of is we can do far better. For the amount of money that we spend collectively on nursing home care, I think we can do far better from a safety perspective and from a quality of care perspective. Much better, honestly. I think overall we have pretty good federal regulatory standards and statutory standards. I think overall in California we have really good regulatory and statutory standards. The problem is that just those promises have not been realized in the average consumer experience.

And I think the big piece of that is enforcement, and I also think that another piece of that is that the incentives don't really align – that pretty much our worst nursing home care providers get paid about the same as the best. And when you don't have incentives to really differentiate yourself by quality in a for-profit industry, then you're gonna have a lot of times a race to the bottom. That's not to say that there's not good providers out there because there certainly are. I have examples of good nursing homes and residents receiving phenomenal care. But it's way too few and

too far between and the vast majority – vast, vast majority of the calls in the emails I get are from people having anywhere from a bad experience to a disastrous experience.

Q: Wow. So in 2022, the National Academy of Sciences Engineering and Medicine's Committee on the Quality of Care nursing homes released a 600-plus page report that called for moral courage to implement a wide ranging set of recommendations in light of failed promises for better nursing home care. What impact has this report had so far?

Chicotel: I would say so far, very little in terms of actual accomplishments. It has inspired some movement, at least some talk about reform. There's the Moving Forward Coalition as a group of stakeholders that have tried to move forward on implementing the recommendations in the National Academy of Sciences report but I don't think there's been a whole lot of actual progress. And of course, we were really enthusiastic that shortly after the report came out, President Biden launched a nursing home initiative, a nursing home reform initiative in a State of the Union speech, and then released a memo. This was January of 2022, I believe, so about two years ago, and made some pretty bold promises but very few of them have been realized now. We're in the middle of perhaps the boldest initiative, which is to create a minimum staffing requirement in nursing homes nationally for the first time ever and the regulations have been proposed. They were drafted and proposed. There was a public comment period, and now we're waiting for the adoption of the final rule. We don't know whether it's gonna be a great rule or a terrible, you know, a poor rule. So there's still a lot up in the air here. So I would say as of right now, very little has changed, but we're hopeful that a year from now that will no longer be the case.

Q: So according to the Kaiser Family Foundation, one out of five COVID-19 deaths were residents and staff of long-term care facilities, which includes assisted living and nursing homes. What happened? Could we have avoided this high death rate?

Chicotel: We could write a book about this. I mean, honestly, what happened is it was a perfect storm. We had a long track record, decades of infection control failures in nursing homes and in long-term care facilities. For years, the No. 1 sighted deficiency nationally in nursing homes was infection control failures. So we

had sort of that as our background and then you introduce a highly infectious, very lethal disease for people who are older and frail health, and it's like fire through dry grass. That's one of the documentaries that came out about the experience in nursing homes and I think that's a good way to explain it. And I think that's a quote from Governor Cuomo in New York about, you know, COVID as we saw it in March of 2020 and that's what happened. It was like fire through dry grass. It just blew in and was devastating. So the facilities were very poorly prepared to fight an infection like this that was this contagious and this lethal. They didn't have the PPE, they didn't have the training. They didn't have the traditions and the culture of highly regarding infection control. So we had many, many deaths. Could it have been avoided? Absolutely. It could have been had we focused more on infection control prior to 2020, had we made the regulatory standards stick, I think the COVID rates and the death rates would've been far lower.

I think one of the biggest pieces that's hasn't been talked about a whole lot related to the number of deaths in nursing homes during the pandemic was that a lot of them were not COVID-19 related. A lot of them were because of the isolation and the poor care and neglect that occurred when we locked all of the outsiders out of nursing homes, the people who supplemented the care of the staff, and this is mainly family members and friends, what we call essential caregivers, who had routinely come into the facility before 2020 and provided lots of direct hands-on care, including feeding, activities and a lot of psychological support, as well as advocacy to get the care that the residents needed. And when we lock those people out there was a lot of suffering, malnutrition and deaths, you know, attributable to the isolation and depression that naturally occurred.

In retrospect, I mean, it was really hard to know at the time what the right policy was, but it was pretty clear within a month or two that the residents were really, really suffering, not just from COVID but from all of this imposed isolation and policy makers were really slow to recognize all the deprivation that they had caused by prohibiting access to the facilities and they were slow to get people back into the buildings under the same safety protocols as the staff. I think that was a major mistake and I think it led to a lot of suffering, unnecessary suffering and death.

Q: That's horrible. I imagine there's no way to measure that or is there?

Chicotel: So we know from an Associated Press report eight months into the pandemic, that there were about 40,000 excess deaths in nursing homes that were not attributable to COVID-19. I think the vast, vast majority of those were probably directly related to the policies to prevent the spread of COVID-19 as opposed to actual COVID-19 itself. So that was one study I can think of. And then there was subsequent studies that came out that showed how much care outside essential caregivers were providing prior to 2020. And it was significant. And I gotta tell you, even I didn't understand the breadth and the depth of the care that was being provided by outsiders. I had seen it with my own eyes. It just never really sunk in that this was, this was typical that family members would come in and perform care in a nursing home.

You think your facility's getting thousands and thousands of dollars a month. They would take care of everything, but that's not the case in a lot of situations. And the families would just do it. They didn't brag about it and they didn't ask for compensation. They just did it. And we didn't find out really, I think collectively as a society until 2020 how vital and important that care was.

Q: So you're assuming that it was largely because of the lack of contact they had with their loved ones and the care that they got from their loved ones. Is that right?

Chicotel: Right. Yeah. I mean, a prime example is the data on malnutrition in nursing homes. So every nursing home reports a series of data points for each resident throughout the course of the year. And if you look at the rates of malnutrition in nursing homes in 2019, it's about 5%. By 2022, it's something like 24%. So we had this enormous increase in malnutrition, which seems impossible in the land of plenty where there's lots of food in America. How could this happen?

Well, we found out there's two vital services that outside caregivers provide as it relates to nutrition. One is they feed their loved ones in nursing homes, a lot of times the staff are too hurried. Eating can take a long time. We have to do it patiently and to make sure that they're getting a full meal. The other thing is they bring in food from outside sources that's more pasty and nutritious, more

appetizing to the residents. So bringing in food and then actually taking the time to feed them. When we cut those services out, people lost a ton of weight. And I always talk about weight being a pretty good proxy for health for older adults. And when they lost weight, they are more prone to bed sores, become more frail, less active physically and suffer and in some cases die before they otherwise would have.

Q: Malnourishment. That's shocking and so sad because it's totally preventable.

Chicotel: Yeah, totally preventable, right? I mean, we have, during 2022, we had an absolute crisis in malnutrition. One of every four nursing home residents was listed as undernourished. It's incredible when you think about it.

Q: So, Tony, talk about the staffing issues that nursing homes have faced long before the Covid pandemic even started.

Chicotel: Oh, yeah. So nursing homes as a general industry are widely understaffed. We have almost all the complaints we receive at some level have an understaffing component to them. And this has been going on for decades. And the primary reason why is because staff is the number one cost of doing business in a nursing home. So if you want to make profit or you know, higher profit, the one way, the easiest way to do that is to cut staffing and to try to get by with as little as possible. And when we have an enforcement system that tolerates to some extent poor care and understaffing is sort of par for the course, and you get a situation where the providers really have very little incentive to staff up. So it's been a pretty consistent problem for many decades that nursing homes don't have the staff necessary to meet the needs of all the residents. And that's why the federal initiative is so important. This would be the first time ever we have the federal government saying what, and, you know, actually using mathematics to determine the amount of staff that need to be in the building to take care of the residents at a minimum of the number might be. If you have residents who have more needs than average, you might need to go well beyond that number, but at least we would finally have a number nationally to hold nursing homes accountable to.

Q: We're several years into the pandemic, and these problems have existed for so long. So it's kind of shocking to me that it's taken this long to even have a

proposal on this issue unless there have been previous proposals that have not been passed for some reason?

Chicotel: No, this is, you know, a whole new direction for the federal government. There's never been anything like this proposal. I mean, advocates have agitated for a minimum staffing requirement for a long time unsuccessfully and as recently as 2016, the federal government did a wholesale review of all the nursing home regulations and said, 'well, you know, we considered a minimum staffing requirement, but decided against it.' And they had their list of reasons. So, you know, as little as seven years ago, the federal government had taken a look at it and this was under the Obama administration and decided against it. But now that's changed. And I think the main reason for that is all the suffering during COVID. Now states, I should mention that a lot of states have had minimum staffing requirements for a long time, including California. But I'll tell you, as nice as it is to have a standard, it only means so much, you need enforcement.

And I'll tell you, California's had a minimum nursing home staffing requirement since 1997. And we are just now having conversations with our enforcement agency, this is 26 years later, how to enforce that mathematical standard when you file a complaint for understaffing. California has an audit system set up to audit compliance with the rules, but it's got a lot of problems with it. But if you as a consumer, as a resident or a loved one of a resident call in a complaint and say, 'Hey, this facility doesn't have the right numbers of staff as required by state law,' they still don't know how to handle that. So they've been sending it to their audits unit, but the audits unit doesn't do complaint investigations.

So right now we're trying to figure out how to align these two functions – complaints and audits – so that if someone argues or complains that a facility has inadequate staffing, they can actually check the numbers and check compliance with the state law. This is 26 years after we've had this state law. So the idea of having a federal minimum standard is great, but it's gonna have to be accompanied by a real implementation plan, an enforcement plan, otherwise it's not gonna do much good.

Q: Wow. So are you saying that if a resident or staff member complains about the amount of staffing, that there's no systematic way to investigate that?

Chicotel: That's what I'm saying. Yeah. So right now the staffing data is publicly available. You can see there's some reasons to doubt the accuracy, and I think a lot of it's overinflated, but you can still see a number that every nursing home has to produce and it's available publicly. And in California you have to have 3.5 hours of direct care staff per resident, per day, the number is 3.5 but you can identify through publicly available data facilities that on their average day are well below 3.5. If you file a complaint and say, this facility is below the 3.5 standard, the (state) Department of Public Health still doesn't really know what to do with that, the investigators will say, well, we check all light response time will wander through the building and see if residents are getting their care needs met. But we don't do the math. That's the audits unit. And then the audits unit says we don't do complaints, we do audits, and we're not set up to do complaint investigations.

Q: That's so insane. What do you think can be done about this?

Chicotel: Well, we can get the state investigators trained up on how to do the math. I think that's the short answer, but I think probably what's happening is the state's kind of waiting and dragging their heels a little bit because they wanna see what the federal standard ends up being. So I don't think they're willing to invest a lot of time and resources into getting the state enforcement right when we think that there might be a chance that it all becomes moot if we end up with a federal standard that has higher standards or is more exacting.

Q: Right. And we know that the higher the staffing is, the better patients fared during the pandemic. Right?

Chicotel: I believe there is a lot of research on that, that facilities with better star ratings, you know, better historical regulatory records and with higher staffing levels had fewer deaths than nursing homes with poor track records and with less staffing.

Thank you, Tony Chicotel of California Advocates for Nursing Home Reform. Stay tuned for next time when we continue our discussion with Tony about the state of nursing homes today.

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