Phone interview transcript with Sabrina

Facility #1

Well, right before the pandemic, my mom decided, and thankfully, she was very open and frank with her abilities and with us about what her abilities were, she felt that she was no longer able to live independently. My parents are divorced; they have been for quite some time. So she had been living on her own at least 15, probably 20 plus years.

We moved her into assisted living first, and that was in February of 2020, so right before everything shut down, and everything was marching along quite well. You know, we would have periodic visits with her when we were in town. And at some point, she started having more frequent falls where, staff would find her on the ground, or she wouldn't necessarily report that she fell, I guess that was also what we were told which, I do believe might be the case. Once she had several falls like that, and those were happening more frequently, and she was requiring more care. As a result, she wound up hospitalized, and this is where it kind of gets interesting, because having some background (in the medical field), I didn't really see exactly medically, what was putting her in the hospital. But anyway, she was hospitalized, and I already saw it coming from afar. I knew that she was not going to be able to go back to assisted living, like I could just feel it, and that, again, is from some of my previous experience working in hospitals. I mean, I knew, I knew what was going to happen. I knew that the reason why they wanted to hospitalize her, or what I felt was the reason was, that they could transition her to long-term care and no longer have her in assisted living.

And it's true, she really was probably ready to be in long-term care. She was certainly becoming more dependent, less mobile, and so forth. Fast forward, I get a call, "she's going home on this Wednesday, and you need to figure out where she's going to go, because she can't come back here (to the assisted living facility)". I mean, it was, it was rather abrupt. It was, if I did not have the knowledge that I had, I would have been completely taken off guard. Like, "Wait, what are you talking about?" You didn't leave this conversation in a way that would let me feel that we were getting to this point. Like there were a couple of allusions to that, but nothing that I felt, in my eyes, was a direct type of communication, like, "hey, you know that the hospitalization was going to be the trigger to transition". That was very stressful, especially living afar, I quickly flew in and I wound up selecting the nursing home that I did for a couple of reasons. A, she is, she was already in the "system" (of facility #1), and so that sort of limited us. While I did feel that my mom did a lot to prepare financially for this time and taking out long term care insurance when she was probably my age. I'm 53 so she maybe even started paying for it earlier. She was definitely ready to be able to finance long-term care. I selected (facility #1) because I loved that it was smaller. That was one of my big things. When I toured it, the staff, they were quite receptive

to talking to me and the folks who were in charge then and are no longer in charge now. I mean that I don't even know how many times the leadership has changed in that regard, but I think it's been quite a few times, and the nurses who were there are not nurses that are necessarily there now. There's at least one I know of who is still there. There's at least one I know of who is still there. So that's pretty much how we arrived at (facility #1). And I guess that was, I think in 2022 or 2023.

Q: Has the staff changed since your mother arrived in facility #1?

Yeah, except to say maybe one or two CNAs. I mean, this may be not completely accurate, because I should attach it is hard for me to regularly visit living far away. I mean, if I had it my way, I would be going over there daily, probably, or, you know, at least every other day, or something like that. But I do try to visit every other month. And it does seem to me that the staff just, it's this constant turnover, really, and that goes for administration too, like, I don't know who's on first (shift) at any given point in time. It really feels challenging sometimes to find out who I'm supposed to talk to and so forth.

Gosh, it feels like it's all motivated by money, I don't know. Make it make sense. Not people's lives, I feel like the humanity is missing, and for so much of the care and how it's delivered.

Q: How has your mother's care changed since entering facility #1?

Yeah, I would say in the beginning, I felt like the care was very attentive. I was overall, very happy with the care that she was receiving, and she was also very happy with the care she was receiving. I did not hear anything from her, she was 100% cognitively intact, and is really only a little bit less so now than when she first moved in. So, this is a person who knows all of her medications. She knows what they're for. She knows when they're supposed to be given to her. She asks a lot of questions, you know, and at first, I felt like all of that was really well received. They loved her. It was tolerated by maybe at least one person on staff that I knew for a fact. There were, you know, occasional head butts with but overall, I felt that nursing and everyone else, they were very, very receptive to caring for her, you know, and being fairly prompt with answering call lights and things like that. If there were any issues, I didn't hear about it from my mom. As we've been marching along, you know, when I've gone for visits and my sister goes to visits, my mom has revealed multiple issues regarding care.

Her primary complaints are around kind of being shamed, sometimes when she's asked certain questions or when she's made certain requests at specific times, versus just as well as like, very long waits for basic care. And I don't know if that was happening in the beginning or not again, like I said, if it was happening, I didn't hear about it. So I would say,

overall, just kind of the sequela of events that we've experienced really seemed to start to when one specific nurse that we loved, she wound up retiring, which was very challenging, I think, for us, because she really took amazing care of our mom and the nurses who remain, I feel like they are also attentive, but they are taxed. They are only one person, and sometimes it feels to me that there is quite a disconnect between nursing communication and like CNA or nurse assistant communication, like maybe they're not very cohesive as a team, and then perhaps a little infighting between the nurse assistants themselves. I don't know. It's just like some body language and action and so forth or inaction that I have observed when I've made visits that sort of peaked my interest, that there may be more going on here. And that impacts care, I don't see how that couldn't impact care.

Q: Has your mother had long wait times with call lights?

So, my sister has timed when she has been there, visiting, and I have too, 45 minutes waiting for a call light. In my observation, when I've visited and that's happened, someone has come in and said "they're waiting" or "they have to get a lift" or "they need a second person" because my mom is total care, like she is a total lift. She can't assist in any way. So, I understand that too and understand that they have other folks they need to tend to as well. It seems like everyone needs that assistance at the same time, everyone has needs at the same time. So, that is challenging, my mom has timed, for example, how long it takes to get her pills sometimes and how overdue they are. Or, that somebody is going to come back and bathe her at 7 (o'clock) and they don't come back.

There is not necessarily communication about that delay in between. There have been other long waits for the bed pan, for sure, and was told to just "pee in her diaper" and I promptly did discuss that with staff, the director of nursing, and they said it was resolved, I'm not even sure if that staff member is working at (facility #1) anymore."

Q: How have the staff and administration at facility #1 been receptive to your concerns?

I have mixed feelings about how I've been received. I do feel to some, I am viewed as the enemy, because they do know I do have a healthcare background. That doesn't mean I know about caring for folks in a nursing home. That shouldn't have any bearing on how they interact with me. The Director of Nursing has been good with telling me how a situation has been resolved. There have been a few things left open, for example, (staff) recommended that my mom see a neurologist because she's had some cognitive changes, and we aren't there every day, and can't say "yea" or "nay", and I'm not a diagnostician in that regard, so I don't know if she has some type of dementia or not. It was recommended, along with

speech therapy with some cognitive retesting, that she see a neurologist. I agreed if my mom was on board with it.

I was told that an appointment would be made and I would be notified. This was a couple months ago, and I've heard nothing. That's just one example.

Q: Have staff been communicative in regard to your mother's health changes?

Yes, I think so, for the most part. I felt like when I arrive (to the facility), there aren't any surprises. When she was scooted up in bed and wound up getting a skin tear in her arm, I was called immediately, which I appreciated. I was glad they called. I do think they do generally update me. I call and I ask for updates and the information I receive isn't as in depth or detailed as I'd like. I feel like (staff) are rushed and taxed to get off the phone and get to the next thing.

There is not as much interest in talking to me. I don't think anyone has been rude and if they have, it's been addressed.

Q: Would you say there is not enough staff working at facility #1?

100%. My sister asked why can't the facility get more nurse assistants and the response was "we've submitted a request for staffing and it will be at least a year before we get more". I don't believe the staff member who stated this is in a position of authority but that was the answer she received. What does that even mean? If three people quit, then you don't get any more staff for another year? Who is not willing to invest more in care? Who is getting paid loads of money and capitalizing on the care, or lack thereof, of these human beings in this facility? They are not willing to sacrifice one iota of that for better care. It's capitalism. Bottom line is, we don't value elderly folks in our county like they need to be, or human beings for that matter. We don't humanize people. ... I think until you live it yourself or have exposure to it, as a nurse I was exposed to some horrific cases from folks who came (in from nursing homes), and this was in Virginia is where I saw some of the worst cases of case that had not been giving, it was bad, really bad. Going about this with my mom, I thought I made a good decision. My dad was in another facility (facility A) and passed away a couple years ago. That facility he was in was supposedly supposed to be amazing but one rehab facility he was at before he transitioned to long-term care, he fell and broke his hip at- in a rehab facility, he fell and broke his hip! He was found after quite some time on the floor. This isn't just my mom's experience this is what my dad went through. The care he got during his end of life was quite good. I did not want him to suffer. I felt like the folks during that time were very responsive. The couple of times I did visit him, while crowded, the staff seemed very responsive and adequately staffed but looked very stressed. There seemed to be more residents in a smaller space.

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They brought him hospice, they were very attentive. Pleased with what happened there. I liked the way the staff at (facility A) interacted with me, more so than (facility #1).

It's really not that difficult to care for someone like they are someone you love or care for. And to keep in mind that other people care for that person even though you don't know them or connected to them in that way, that is part of why you're in the position you are. You were deemed as someone who could care for others. I don't feel like a little more concern, or showing more concern and pausing a beat, listening to families, and recognizing, the humanity of these folks you take care of. My mom is a very, very bright, inquisitive, person, more intelligent person I know, book smart wise and common sense, and I don't feel like she's always heard, or recognized that she knows things and remembers things, she wants to be informed. If you hand her a pill, you need to tell her

what it is and what it is for, she may be forgetting that now, she needs reinforcements, she needs to know that her voice is heard and that she is cared for.