

**Dana: Welcome to I Swear on My Mother's Grave. My name is Dana Black, and in 2016, I lost my mom. And now I'm talking to other people who have also lost their moms. And I don't just mean in death, because there are so many ways you can lose a mother. And we're going to get into it. So let's talk about our moms.**

**So this the first episode that is featuring a living mother. Yay! I think most of you know that when I started this thing, I wanted to talk to people who had lost their mothers in death like I had, but I also wanted to talk to people who had lost their mothers while they were still living, which is also something I feel like I experienced with my mom, that she was sort of leaving this earth while she was still here, and that I was mourning her death before she passed.**

**So I reached out to this guest via email this summer, and I said, "Hey, I've started this podcast, and I'm exploring the many ways we can lose our mothers, sometimes in death, sometimes with her leaving. And I feel like you'd be a great person to talk to, because I'm assuming you're experiencing some loss with your mother's dementia." And this guest wrote back and said, "I would absolutely be willing to talk to you. But I just want to be clear: I'm not experiencing loss in the typical sense of the word." She said that her mom had become more distilled down to the person that she really was, and that her mom was still there: her same sense of humor, her love of dogs.**

**In this episode, we're going to talk about Hartwell Memory Care. It's a memory facility located in Andersonville, in Chicago. It's about five minutes from my house, walking. My guest invited me there this summer to sing outside in the courtyard at six feet in our masks for the residents, but really for her mom, because music is helpful. And we're going to talk briefly about the song Yankee Doodle Dandy and the problematic lyrics inside it, such as, "And with the girls be handy," which we sang at full volume for those residents. We're going to talk about the saying "below the frostline." We're going to talk about her mom's love of watching people work. We're going to talk about a beautiful, sunny summer day in Chicago, and an adventure that she went on with her mom many years ago. And we're going to talk about dementia.**

**My guest's mom's dream was to live in the same place as most of her family. And she got to do just that, when she purchased a two-flat building in Chicago, and got to live there for a few years, with her daughter on the top floor and one of her sons and his family on the bottom floor. Oh, and with Bob Barker, the dog. Remember that name.**

**And my guest says that things went pretty well living together. Her mom is more even-keeled, temperament-wise, and my guest is more sharp around the edges—she gets it from her father—but they made it work. And things were going good, until her mom's dementia got to the point where the anxiety kicked in, and she wasn't sleeping through**

**the night, and she would get up and lose sense of what time it was. And I guess that is sometimes the start of Alzheimer's, which can feel like more than just the regular aging dementia her mom had been experiencing. There was a sense of restlessness in her mother, and that meant that she needed more care that my guest wasn't able to give.**

**This is Ann James. [end intro]**

Ann: Before that was just a question of, she was forgetful, sometimes the logic was odd. And she couldn't walk around the neighborhood on her own anymore; she'd get lost. But when the restlessness started in, then it was, "I can't do this, 'cause I can't be here. I'm not sleeping." So that was when we first moved her to an assisted living place, where the meals would be provided, but she had a nice little fairly large room. She kind of adjusted pretty well, and was always eager to do things and stuff. But the restlessness was still there.

The apartments are around a big atrium. And she'd go out, when she'd get anxious—she was on the third floor—and she'd just go out to the atrium and say, "Help! I don't know what to do!" So after that happened a few times, they were like, "She can't stay here, because it's very unnerving to the other residents." So that's when she moved to Hartwell, which was perfect. It's just the amount of structure—she never had to make a decision, and that's what the anxiety was from. She was so afraid she was going to do the wrong thing.

**Dana: What does that mean? In terms of get in trouble again, like what happened at the atrium?**

Ann: No, that she would be, "Oh, I'm not sure what I should do now. [05:00] Should I read? Should I watch TV? Is that okay? Is it okay if I'm watching TV?" She would call to me when we were living together, like every 20 minutes. "Is this what I'm supposed to be doing right now?" I'd be like, "Yeah, you can watch TV. That's fine." (laughs)

**Dana: Is that the restlessness?**

Ann: Yeah. She's clockwork, would get up and walk every 20 or 40 minutes. So I think that's probably really hard on her right now, 'cause they're quarantined to their rooms.

**Dana: And Hartwell is a place, just so that we're clear, it's a memory care facility up here in Andersonville. It's about five minutes from my house. I just walk over. And you invited me a couple months ago, and a bunch of people, to come over and sing six feet outside the building in the courtyard, because singing to them is something that helps them. It helps with memory. It helps with... what?**

Ann: Music, any music, really has been shown to be incredibly therapeutic. And they can remember songs that, when they can't remember people or events, they will remember songs. And there's a lot of research now that in fact, if they sing, that people who don't speak actually sometimes will speak after they've sung, and then go back.

There was, ages ago when I was working for a religious news magazine—the headline was great. It was "Hymns Below the Frost Line. And this was a good 30 years ago, so Alzheimer's was just—people were becoming aware of it. And she talked about going to visit her mother, and her mother didn't recognize her. Her mother wouldn't speak or anything like that. And she just one time started singing some old hymn, and her mom chimed right in. So that's what they did. Every visit, they sang together for like 20 minutes, and her mom was back to who she remembered, and then would slip back again, like she said, "below the frost line." But the music brought her out.

**Dana: We've been going—I go when I can—on Saturdays around 3:30, and we sing. And you hand us these pieces of paper, and some of the songs are curated by you. Yesterday was the Fourth of July, so there was some patriotic...**

Ann: (laughs)

**Dana: ...and some troubling lyrics from "Yankee Doodle. "The girls get handy." Getting handy with the girls. It's a little problematic. But you pick these songs that they might remember, Doggie in the Window. So do you ask your mother some of her favorites? Or do the residents, have any of them chimed in to say, "This is a certain song we love"?**

Ann: No, she's the highest functioning of the people. Even when she went it, she was. I never would have any more of a conversation, because Bob can come visit.

**Dana: Who is that?**

Ann: The dog Bob. Bob is her dog, Bob Barker.

**Dana: (laughs) How could I forget.**

Ann: So when she moved in, I would come with Bob, so all the other residents' relationship is with the dog. That's who they would talk to, not me. So I never really developed much of a relationship. (laughs)

**Dana: He was a celebrity.**

Ann: "Oh, here's the dog!" Except for the one poor woman who's like, "Ah, there's a dog! Get the dog away from me!" So we had to avoid her.

But anyway. I would sometimes arrive when they were doing their group music thing. So initially the curating was songs I knew they had sung in their own music therapy before all this stopped. And then the guy that came late yesterday had given me a huge packet of old folk songs, 'cause he came to the first one. And he's big on folk music jamming. So we started on Mother's Day weekend. We're just doing it. At this point we're not necessarily getting as many people. The staff, this is not a priority for them, in some respects, 'cause they're so overworked now that they have to go among and open all the windows. But they're better. I just have to kind of remind, call. And we'll get at least these windows open for listening.

**Dana: And you had to get your mother, yesterday. We had to say, "Can we bring her to the window? Is she sitting down?"**

Ann: (laughs)

**Dana: "Where is she? We're singing out here."**

Ann: And I keep thinking, "I'm sure, if I could only go in and fix the problem." But her TV set is in front of the window. She's not watching TV. They could move that and put a chair by the window. But they're not thinking of those things.

**Dana: It is extremely—as a controller and a doer—[10:00] this time is really hard for me too, with my grandma, and wanting to get into that room and declutter, or wanting to help her with this downsizing of her old apartment. Like, "I could move that. I could do that. I could give you this." Or, "Why can't they just do this thing?" Well, because they're taking their temperature every 20 minutes, giving them COVID tests, taking their blood pressure. There's just many things that the staff has to do. But you're right: if you can't be there in person, it's just so difficult, not only to touch them and love them, but just to help them out. That must be hard. And it must be hard that you can't even see. At least my grandma's on the first floor right now, so that's nice. But yours is on the third.**

Ann: Well, yeah. It winds up being like the third, 'cause it's sort of just a garden level. But they say it's the second floor, but it's 2½ stories up. So she can see pretty well, and you can talk there. (laughs) But there's all these air conditionings.

**Dana: She knows like what's going on? She knows what COVID is? She understands the virus, or what is happening?**

Ann: Yeah, she refers to it as "this virus thing." That that's why we have to do this, is because of this virus thing. But then she is always asking, "When are you going to come

up here?" It's like, "I don't know, Mom. I don't know." But, now at least she can come downstairs into the courtyard.

**Dana: And do a six feet.**

Ann: So we're doing two of those visits, among the family. We're doing that twice a week.

**Dana: My grandma's best friend is 85. They've been friends for 50 years. And she just the other day called her and said, "Can you go for a drive?" God bless her. My grandma was like, "Absolutely not. Maybe in 2021." It was like, "No, I can't go for a drive. If I leave this facility, I can never come back." (laughs)**

Ann: (laughs)

**Dana: We laugh about it. It's true though. She cannot leave. Legally, she could say, "Yeah, I want to go for a drive," and then she'd sign her rights away and take off. (laughs) She has to live somewhere. But there's this hope of "When can I see you again? When can I go on a drive? When can I get my hair done?" It's like, "Not until there's a vaccine, probably."**

**When I reached out to you, you were one of the first people that I was reaching out to whose mother was still alive. And I wanted to talk about loss and how my mom was sort of leaving this earth mentally, emotionally, physically, 'cause she was just depressed and addicted to opioids and dealing with depression. And I thought, "Well, I want to talk to people who are also losing their mothers through maybe incarceration or memory loss." And I was like, "Well dementia," I said. "That must feel like a sense of loss to you. And I'd love to talk about your mother." And you said, I'll quote, "I'd be happy to participate, but I just want you to know that I haven't been feeling loss in the way that it usually works in these cases. I think my mom does feel loss at times, but I don't want to speak for her. It's been a long process, but while I have seen changes in her, and felt changes in our relationship, I've never really characterized it as loss, the way others do."**

**"I had a great-aunt who used to say," this is what you said, "People distilled as they age. They just got more themselves.' And that's sort of what we've seen with my mom. Her charm is still there, her good humor, her love of dogs, her general sense of having been lucky in life, even though I can see a lot of that luck is out of her own effort and adjustments. She's still very much who she was, just distilled." That was just such a beautiful way of talking about it, which I had never heard. And I wanted to know if you wanted to talk a little bit more about that with me?**

Ann: Yeah, and actually it winds up—that was at the start of the quarantine—it feels more like there's more loss felt, because we can't be with her. And the weakening has accelerated, I think.

**Dana: Physically.**

Ann: It's still not a final loss, because there is a sense of like, "There'll be a recovery." And I hope—she's incredibly resilient. Physically, she's had ovarian cancer, breast cancer, a pneumonia that put her in the hospital for a week and then rehab for three weeks, and that was all after she was 65.

**Dana: She had ovarian after 65, and recovered?**

Ann: Yeah.

**Dana: I'm in shock.**

Ann: And then like ten years later got breast cancer, and then had this pneumonia, and there was one other thing in there. (laughs) And now she's got something wrong with her valve. A year ago, they wanted to operate, and we're like, "No." She didn't want to go through any of that anymore. 'Cause she'll be 94 in October. And she's had a hip replaced and a knee replaced. [15:00] The breast cancer happened after my dad died, so that was at 80, in her eighties.

So she's incredibly resilient. So my sense is she's going to last through this. But it's just being afraid that the diminishment will be such that when we can see her again, I don't know how much will come back as it was before with her. But she can still make jokes and things like that. But it's a little hard, 'cause the conversation can be like five minutes long, and her frustration sometimes. But I think it was on Monday. I told her I had come across some photographs that I'd sent to her sister, who lives in Virginia. And she said, "Oh can I see them?" And I said, "No, I sent them to Charlotte." And she said, "Well, I'd like to see some photos. I'd like to see the photographs from when I was whole and could do things." And I thought that somehow subjectively and cognitively she's very aware of what her situation is. So that part of her is still very active. And I thought it was great—it was the same thing as that she has given herself the best diagnosis of anybody from the beginning, "My shrinking brain."

**Dana: You said that as well.**

Ann: And that's exactly it. When you look at the X-rays, that's what it is. The brain is sort of...

**Dana: Smaller.**

Ann: ...shrinking. You get these holes. And that's what she's feeling, is "I'm not whole."

**Dana: So to her, the picture of when she was whole again is when, seventies? Is there a certain age, a certain moment, a certain time, where she would say, "That's...?"**

Ann: I think it would be any time before the last three or four years. I think it was even in the moment then, where she's feeling—I think the key was—and can do things. Both she and my dad were do stuff all the time. They never went on a beach vacation where you sit on the beach. (laughs) They're going to lectures. We spent the bulk of every summer building a cabin, building various buildings. And then they built the house. They had a local contractor, but they did all the finish work on the house and stuff. And then always had a big garden and everything like that. So that the not being able to do stuff...

**Dana: And she remembers doing things?**

Ann: Yeah.

**Dana: That's how I felt with my mom. She was sick and in bed and couldn't move and couldn't walk a lot of the time. But she remembered everything. Her memory was so intact. So then you're trapped in this nostalgia or the thing you used to be able to do, and now you can barely walk. I almost wish she had lost her memory of that, that she couldn't then be in pain about what she was losing. But if your mom is still able to do a little bit of both, she can slightly remember doing things. Is she specific about it? Does she talk about specific memories still?**

Ann: No, 'cause in fact—so then the next time, I brought her some photographs. It was a perfect day. I think it was about 20 years ago. I think she'd come down to help me move to a new apartment. But it was a perfect June day. And we just took the day off, and went downtown, and we went on a Wendella boat cruise, which, they're not educational, but they're much funnier, 'cause they make stuff up. (laughs) And you still get to see the buildings and the river, and so it was great. And it's shorter and all that. And then we went to—they were just starting the Seadogs—so we did that, which she loved.

**Dana: Those are fun.**

Ann: And I'm like, "I hate." I don't like to go fast, and stuff like that. But we did that. We also walked out onto Navy Pier, and they were in the midst of remodeling the ballroom, the far part. So we kind of just walked into this construction zone. And there was nobody else around, so we go ahead and walk around the edge to the northern part of the pier, and we see an open door. And my mom's like, "I wonder what that

is?" (laughs) I said, "I don't know." So we went in, and it's just stairs to climb to the tower. And all the way up we're making up this story, if anybody stops us. "Well, we're just visiting from Wisconsin."

**Dana: (laughs)**

Ann: "We were trying to find where to go, and it just kept going up." (laughs)

**Dana: Play dumb.**

Ann: Total dumb. [20:00] And we got all the way to the top, so we had this incredible view of the city, and then came back down. It was great. But it was her deciding, "Well yeah, let's go do this."

And then we went to the Billy Goat for lunch, which—that was one of the things I wanted to mention about, 'cause her writing stuff. When she was a kid and for the first two years—the college she went to was just a two-year college to start with, and then after the war it went to four years—she finished her associate's degree, and then came and worked. She wanted to be a journalist. That's what she wanted to do. So she came back, lived at home but commuted in, and worked at the *Chicago Sun*, so it was before it became the *Sun-Times*. So she would talk about: she was the copyboy for Irv Kupcinet and Roman Pucinski, 'cause he was working for the paper at the time. And she loved it.

But then—I'm not sure exactly all the reasons—but she wound up going back, and then her junior year, that's when she met my dad. He was at that point a sophomore. So he'd started the year she was away, and then they met. And then it changed, so that she just went into figuring that she'd teach, because she wanted to have a family and stuff. And I think a sense she couldn't really be—she graduated in like '48, so just not a big sense of. If she were still single, she would have gone and become a journalist, I'm sure.

**Dana: What did she teach, again?**

Ann: She taught all kinds of stuff. She taught kindergarten for a while. She taught music. She had sixth grade for a while when she was first teaching. And then she wound up taking the part-time job as a librarian at the elementary school that we went to, and loved that. So then she went back in the '70s—so at that point I was in high school—she was teaching part-time; she had three kids; my dad was a teacher as well—and she goes back and gets her MFA part-time. And she manages to do that. She gets her master's in library science, right when libraries were becoming information centers, so computers were starting to be introduced, and this whole revolution and how libraries were going to operate. So she was sort of in the forefront of that and figuring out how to do that at the elementary level, as a children's librarian.



**Dana: For how many years?**

Ann: So between the part-time and the full-time, she probably did it about 15 years. That's what she retired from.

**Dana: And were some of the writings that you found, are some of them from the Sunday, the journalist job?**

Ann: No. She was copyboy. I don't think she wrote. She was copyboy. She just took copy. (laughs) She doesn't even edit or anything like that. She was waiting for people to yell, "Vera!"

**Dana: "Get over here!" And I love that it's copyboy, not copygirl.**

Ann: No, it's copyboy. I haven't come across anything. The first, the earliest stuff I had—and then I couldn't find it—were these letters she was writing. She and my dad moved to Long Island after they got married. They decided that they probably needed to not be so close to their families, 'cause both families were very close. Both sets of grandparents were great. But my dad—I think they both thought—"I think we need to be a little bit independent as we start our married life." So he wound up getting a job out in Long Island.

So actually one of the things—it didn't come across—is her account of driving a Airstream trailer out to Long Island, timing it so that they were driving through New York City at 4:00 in the morning, so they could not deal with as much traffic.

**Dana: An Airstream, though. An Airstream through New York City.**

Ann: And they still wound up pulling into the wrong thing, and wound up by the river somewhere, and then having to back up.

They did two years out on Long Island, living in an Airstream in a trailer park with the baby and the toddler. And then I think they decided, "Okay, we need to go back, so that he knows his grandparents and the family and everything." So they moved back.

**Dana: But what was some of the writing then? It was mainly letters that you found, or did she write novels? Did she write poems?**

Ann: I found some letters that she sent back [25:00] to tell the grandparents what were going on with the grandson. And then she didn't write at all when we were growing up. Well, she didn't have time with all the stuff she was juggling. I remember her talking once about her dad saying—when she had gone back to school, they had the house in Northbrook, that she was working part-time time, she had David and I, she was always

the choir director at the church and such, she was maybe teaching piano too, I think—and her dad saying, "You're going to kill yourself. You're doing too much." And this is when she's in her mid-thirties, juggling. So she didn't have time to do any writing then. But then she started back up again after they retired. And so every trip they took, she was doing journals and then writing up accounts of the trip afterward.

That was one of the other things I did think about when we were younger. We became closer the older I get. When I was in elementary school, we didn't have a real, Mom-and-we-would-bake-cookies. She'd do some of that. But there wasn't a lot of that, 'cause she was very busy since she was working and stuff. And she wasn't that kind of a domestic person anyway. The family story was that I was maybe two, and she called my dad out of frustration or something, and he was going to be coming home. And he came in the door, and he said, "You need to go back to work. You need to talk to somebody over three feet tall." (laughs)

**Dana: (laughs)**

Ann: That it wasn't necessary—of course, the income was good and all that—but it was him saying, "You're not a housewife. You need to get out there and work." And then it was she was very happy. She always was happy. Even with the juggling, it was. She took in what our dad said, but it was like, "Yeah, but trapped in a house all day. That's what would kill me."

**Dana: When my mom retired from teaching high school, I think was the beginning of the end. I feel like there was something about giving up that identity, and then on top of whatever else was coming in her life, she just couldn't get past losing that part of her.**

Ann: The work existence.

**Dana: And then she had to sell her house, and they moved to Arizona. And then they got a divorce, and lots of things came—but losing that identity. But she didn't want to be resentful. She didn't want to become a teacher who was bitter. She knew it was time to go. She knew it was kind of time to retire, for her, even though that gave her purpose. And she's not a housewife. She was a good housewife—she could play the role—and a corporate wife. But she needed to be working. So I think it was like, "Ugh."**

Ann: And that was the thing my mom had discovered. Well, between their traveling and then it was—my mom picked up, "I'm going to write again." So she did that for quite a while, and was a pretty good correspondent too, with friends and stuff. She'd always do a first draft of a letter (laughs) and edit in stuff, and then do the letter.

**Dana: Did she have personalized stationery?**

Ann: No.

**Dana: Oh my gosh, my grandma has ten sets of Donna stationery, either her initials or just her name.**

Ann: (laughs)

**Dana: Long sheets, short sheets, colored sheets. The envelopes have your address on the back.**

Ann: I thought that was the coolest thing in the world, so I would order those things as soon I could.

**Dana: I have them. I have Dana on them. My parents got me them. I'm all about personalized stationery. My mom didn't have personalized. But my grandma, she's all about it.**

**How did your mom talk about her mom to you? I'm really curious about that.**

Ann: That was kind of interesting too, 'cause her mom worked. Again, I think Nana was needed to work, personally, but then for the income, 'cause that was during the Depression. So Nana's mother lived with them from fairly early on, at least from the time when my mom was entering kindergarten. My mom's sister is ten years younger than her. So as a young kid, she was an only child then with three adults in the household. And Nannie was the one who really was the caregiver, 'cause my Nana was working, and was working downtown. So that was from Downers Grove, taking the train downtown and then coming back.

**Dana: What did she do?**

Ann: She worked for Rotary. She was primarily a bookkeeper, I think. And then Daddio was working downtown. He was a draftsman. When he could find work, he was a draftsman and was working at architectural firms, and also downtown. So they were gone. [30:00] So she had a close relationship with Nannie, and loved her mother. But they didn't have the same time of daily closeness, I don't think, and sort of felt that. Because then, when things kind of—and her mother was always supportive of all the stuff that she did, and was very proud of her, and such—but at one point, actually I think I was giving a sermon, and I was talking about Nana, and saying, "We were very close," and how much I felt from her I could do no wrong in Nana's eyes, and she just thought I was the bee's knees or whatever, from early on had that. And afterwards my mom saying how glad she was to hear that, that I had that relationship with Nana, 'cause she

didn't think she had had it. Not blaming Nana at all, but just the circumstances. And that how glad she was that I had that with Nana. 'Cause Nana was terrific, very much a people person, an extrovert, doing all this. So I think, temperamentally, they might not have meshed real great. Daddio was also kind of more reserved, like my mom.

**Dana: But your mom wasn't jealous of this feeling of my daughter?**

Ann: No, not at all. She was so happy that I had it with Nana.

**Dana: That's wonderful.**

Ann: After Nana wound up moving and living with my aunt, her first husband was a professional opera singer—is a professional opera singer. He got a contract at the Met, so they moved out to the East Coast. So Nana went with to be the caretaker of the kids and stuff. And I would go out every summer to visit. So that's why Nana and I could be so close, 'cause I had this two weeks of being with Nana every summer. My brothers didn't do that, so they have the same. As again, there's a certain extent, you just need the day-to-day now and then with somebody, to really feel like you get a closeness. And that's what I feel like now. I'm not getting the day-to-day.

**Dana: Do you talk every day to your mom, at least, on the phone?**

Ann: Actually, I go every day, and we talk through the window.

**Dana: Oh, that's where you do it. You don't do phone. That's harder.**

Ann: The phone, with her hearing aids and everything like that—we tried FaceTime before the weather got warm, and those were so frustrating for her. She couldn't hear things. And a lot of it is, I go every day so she can see Bob. We walk there. And that's her anchor, is being able to see, 'cause she always had a dog. Nannie raised dogs before she moved in with them, so Nannie made sure they always had a dog. I think the two years in Long Island were the only time my mom didn't have a dog.

**Dana: Will she be able to touch the dog, when you guys do six feet? Or will she not be able?**

Ann: Yeah, 'cause the dogs aren't transmitters. So unfortunately the chairs aren't quite big enough. The dog wants to get up in the chair with her, but there's not enough room. But he goes and sits right underneath her. They pet, and then he goes and sits. So he recognizes her. He knew I was the alpha dog when we were living together. But he would always go be with her.

**Dana: Animals are therapeutic. Dogs can be helpful. And I know there's that one woman in the building who clearly doesn't want that dog around. Maybe they've been bit. Maybe they have trauma. But is there something about animals in dementia? Do they say anything about pets?**

Ann: I don't know. It doesn't take any brainpower to relate to a dog. They can pet. They can have that sensation, the sensory stuff. And they do bring dogs in regularly. There is some therapy program that comes in. Before they allowed the outside visits, they were going to have Fox News, I think, come. This was back in the end of May. So they were out there working, and I had told—'cause I don't have a garden anymore, 'cause I'm in an apartment—anyway, they were out working, and I said, "I'll be happy to do some of this." And they were like, "Oh, great," 'cause they were trying to get stuff ready for Fox News filming in the courtyard. So I came the next day, and they wound up bringing my mom down. So this was before the official policy, but they thought, okay, as long as I'm here [35:00] and I stay away from her, she can come down and be in the garden while I'm working. So she loves it, and I had the dog and stuff. And then she says, just like she used to, "Oh, I love watching people work." (laughs)

**Dana: (laughs)**

Ann: Which was not really true. She always was the worker, but now she can pretend. "I just love being able to watch other people work." (laughs)

**Dana: And if she can't do the work...**

Ann: "So I'll watch it."

**Dana: "Boy, are you really working hard." That's nice.**

Ann: She used to bring a lawn chair out, and she'd sit by the front door while I'd be working in the front area.

**Dana: My grandma's nursing home, there's rooms that face the outdoors, and there's rooms that face the garden and these trees. She doesn't want those. She wants to face the street. So her room faces the street, the parking lot, which is like Manchester Road.**

Ann: (laughs)

**Dana: Nothing glamorous out here. She wants that, to see the comings and goings. So then she feels less, "Oh, I'm just stuck. I just stare at trees all day." She still wants to see who's going to places, who's coming, what aides are showing up, when is my**

**granddaughter coming. I don't know. I think she wants to see the world, still, and still is like seeing action, activity, movement.**

**What was the thing that gave your mom the most joy? Do you remember, growing up, was there something that just lit her up?**

Ann: They had a group of friends that all the time they were growing up. They called themselves the Dirty Dozen. It was six couples. So they would get together once a month. And she liked those friendships. And the couple they were closest to lived next door to us, George and Millie. And she loved being friends with them, and such.

But there does seem to be this sense all through my childhood that she was working and doing. It was either stuff around the house. It was work. They did remodeling at our house in Northbrook, or then working up at the river, and stuff. And there was always—and I can feel myself get in those modes sometime, where you're kind of on overdrive. You're not really experiencing what you're doing.

**Dana: You're not really present.**

Ann: You're not as present. And now we're much more aware of that than it was when I was growing up. But lots of people were in that, that happiness or joy were not things that were a priority in the same way. Not that she was unhappy. And loved these momentary things, but not as sustained, until they retired. They still stayed very busy, but it was always things of a sense of "my choice." That "We want to go to Australia. And we're going to go to Australia and visit New Zealand, and we're going to love this." Or, "We're going to go to," whatever it was, "that John Campbell Folk School for a week. We're going to learn these things. And we're never going to use that stuff." She took a basket-weaving course. (laughs) Never finished. The undone basket and supplies were still there in Glenhaven, 20 years later. Or going back to doing the writing. But the moments of joy were occasional as I was growing up, but much more sustained when they retired.

**Dana: I know we talked about my assumptions around dementia and how you feel about it now. But when people say to you, "I'm so sorry," when they learn, what do you say back to them? You sent me a long email about what she was going through, but you can't do that in small talk or in quick conversations. How do you describe how you feel about your mom going through this? "Don't feel sorry for me. Don't feel sorry for her. She's doing okay." How do you talk about it?**

Ann: It's one of those things where it is of the stuff that actually—I'll say that she [40:00] generally remains happy. It's fortunate because she's at a place where the anxiety and restlessness was able to be dealt with, which her neurologist said. "If you

can change the living situation to deal with it, that's so much better than having to go on meds to deal with the anxiety." So win-win all around. The last time she went to the neurologist, there was no change in her cognitive, when they give you the test. She was stable. So it was like, "Well, we don't have to change any of her meds." She's got some anti-anxiety things she takes, and something to help her sleep, and something that supposed to, maybe, slow the progress of the Alzheimer's itself. But otherwise she's not on much medication.

**Dana: It's just the facility. That's incredible.**

Ann: The facility is the best medicine. And she's happy there. We've been spared, because sometimes Alzheimer's can start affecting the parts of the brain where people are angry and aggressive. There's a guy there—it's hard for me to tell if this is the Alzheimer's—that he gets so pissed off things and yells at, or was he always somebody who yells. And I watched an interaction between what I think was his wife once, early on, and I thought, "Oh, I think they yell at each other all the time. She seems to be having the same thing." So they found each other, and that was their dynamic all the time. So we have been spared that.

So my mom, as I said, she was very happy there. It's frustrating now. And it flits through my head sometimes about a lot of the decision to sell the building was 'cause I couldn't deal with her care and trying to do a career. And so the selling of the building and getting free of all that stuff, right at the time when all my plans for what my career was going to do, are now—I don't know how soon I ever can do. It's going to be a year and half, two years before I can do anything theater. So how do I figure out—I don't have a career right now. So then I do think, "Geez, maybe the thing of, she's somewhere so that I'm free, and what are those final years for her going to be like, there, if we can't?" She's still happy there, I think. But if it gets to the point of, she's not, then maybe I change my living situation again. I'm now old enough, we can both move into an assisted living place. (laughs) And for the amount that we're paying there...

**Dana: Are you thinking that?**

Ann: It just went through my mind, because it was sort of like, "I can't afford to do that on my own." But if it's a case of we both go move into some place, then she can have her daily contact with family again.

**Dana: That complicated feeling of, "That could extend her life, having contact. And yet right now we're trying to sustain, keep her living."**

Ann: Her life is being sustained...

**Dana: ...if she's not getting the virus.**

Ann: If it starts to feel like her—we've had lots of discussions. My dad was wonderful about, "We need to talk about this stuff." The first to have a living will, the first to have to have all the do-not-resuscitate, all those kind of things in place. And the case with her as well, and the decision not to have the heart surgery. Her, "I'm not going back into a hospital. I don't want to go to a hospital. That's the worst. If it's just an extension, I'm 94. I don't need an extension of my life." But if it got to the point where just a sense that she's unhappy where she is, then the best thing in the world would be if she got to die in her own bed, with the dog laying on the bed with her. That's the best end. But it's all speculation, 'cause we still are just in the throes of...

**Dana: Right. [45:00] I go, "Is this better for her?" Your mother or my grandmother being alone? And yet, what if I had COVID and didn't know it, and go in and give her a hug. And I kill my grandma. I don't want that. But people say that by visiting her every week the way I've been doing—and the things you're doing: singing, seeing her—will help get her through it. That's what they say, so I try to believe it, even if she's not getting enough activity, even if she's not moving around enough, even if she is lonely.**

Ann: And that's it. This is like a make-shift thing. So if this can keep her stable, good.

**Dana: For maybe the spring.**

Ann: But if it feels like she's not stable, if there seems to be a decline, then we need to think about the quality of the life she has right now.

**Dana: I like to end all of these calls with a question: I ask everybody their mother's name and how you feel about your mom in this moment, today, this morning, talking to me.**

Ann: Well, (laughs) not to do another tangent, but it's one of the funny things about her name. It's Vera Jeanne James. Her dad loved the name Vera.

**Dana: It's beautiful.**

Ann: And was always adamant then it was Jeanne: J-e-a-n-n-e, the French spelling of it. So it's Jeanne. But through high school, she was Vera to everybody. She didn't really like Vera, so when she got to college, she changed to Jeanne.

**Dana: With the spelling, the French spelling.**

Ann: With the spelling, and then with sort of cringe when people would start calling her Jeanie.



**Dana: (laughs)**

Ann: And was just like, "No," and then explain to them, "No, this is the French spelling. It's Jeanne." And so then from college up until like eight years ago—it started that we were doing all the medical stuff, and all that was happening more—she becomes Vera again. Because when you're filling out the medical forms, they're all going to call her Vera. So then people who've met her since she was 88, like at the home, they call her Vera. (laughs) All her doctors call her Vera. And the people at church where she goes, where we were going, she's Vera now.

**Dana: So she went back.**

Ann: So she has these names, and depending on what they call her, we know when she met them. So the Jeanne portion of her life is kind of gone, 'cause all the people that she knew from college till she was 88, they're not in her life. So now she's pretty much Vera most of the time. That's what her sister calls her. (laughs) And then that's what all the doctors and the staff call her: Vera. And she doesn't mind Vera anymore, like she did before. I think it was just strange. But then they went to Russia, and their guide was named Vera, because Vera is a very popular Russian name. And ever since then, the Russian trip, she's like, "Oh, Vera is a very good name. I like Vera." (laughs)

**Dana: (laughs) I love it.**

Ann: "Yeah, I like Vera."

**Dana: My mom's name is Shirley Jo. So Shirley she hated. Started going by Jo, but then kind of went back to the full Shirley Jo. She just started becoming Jo Black, Jo Black, Jo Black, Jo Black. So the same feeling of, some people know her as Shirley Jo, some people know her as Shirley.**

Ann: (laughs)

**Dana: Most people know her as Jo, Jo Mama.**

Ann: (laughs)

**Dana: Pick a name, go with it. But I love that she picked the masculine name, if you will. Shirley's really feminine, in a way. And Jo feels very...**

Ann: Well, Jo, that's *Little Women*.

**Dana: There weren't a lot of them, anyway.**

Ann: As to the question of how do I feel now. I feel a such a sense of how precious she is, and wanting to make sure she's cared for in the best possible way. This is my mothering phase. I consciously and unconsciously and subconsciously and all kinds of things never wanted to marry, never wanted to have kids, did not see myself as a mother. [50:00] I was fine as a nurturer in other capacities. But I did not want that. It always felt constraining.

I would think the same aunt that had the, "People just distill." She was a very high-powered woman, got her PhD in the '50s, had quite a career with Akron public schools, and in retirement moved back to the family home. She was one of the unmarried siblings, so moves back to Batavia to take care of her three older siblings. And she would talk about, "I had to learn how to be a whole different person, 'cause I had to become a nurse. And I was never a nurse." And I feel like that, in a way, caring for my mom. It's that, find in myself the capacity to care for her because she's so precious, knowing it's not to help somebody grow, in the same way, to nurture. It's to make sure that the life they have is sustained as goes.

**Dana: I send you and your mom all my love. And maybe I'll see you on another Saturday.**

Ann: At some point I'd love to meet your grandmother.

**Dana: Maybe at her window, someday, or at six feet.**

Ann: (laughs)

**Dana: [start outro] I want to go sing at Hartwell right now, but it's 42° outside, so probably not. But that was so joyful to do this summer. It was just so wonderful to leave my house, and gather with others at six feet, and wear a mask, and sing for residents that I didn't even know. It was so communal and wonderful, and I'm so grateful for it, Ann. So thank you for letting me sing, and thanks to Vera for having us.**

**If you want to see pictures of that courtyard and us singing, pictures of my grandma and her nursing facility, pictures of Bob Barker the dog, pictures of Ann's mom, you can go to our website. It's mothersgravepod.com. And also on that website, you can learn about The Night Ministry, which is an organization that's been around since 1979, providing housing, health care, outreach, spiritual care, and social services to adults and youth who struggle with homelessness, poverty, and loneliness. Ann's mom has been supporting The Night Ministry for years, with the gift designated for veterinary care, because it's estimated that about 5–10% of Americans experiencing homelessness have an animal companion. So there's a vet who goes along on the Health Bus, and that vet donates their time and supplies towards those four-legged**

companions. So if you want to give money to The Night Ministry, you can find their information on our website, [mothersgravepod.com](http://mothersgravepod.com).

I want to thank Ann for talking with me. I also want to thank Suzi Pond, one of my oldest friends, with Redbird Media Group for editing and producing this podcast; Alice Anderson for sound mixing; Na'Toria Marketing and Design for the website; Meredith Montgomery for the logo and individual episode designs; and Matt Chapman for his theme music. And special thanks to Jill Wolf, who is my therapist; Heather Bodie; Lora Nicole; Danny Bravman; Jonathan Baude; and all of my friends for your love and support. And for all of you who listen and share and rate and subscribe and tell everybody you know, it means a lot to me. So thanks for supporting. And if you're on Instagram, you can follow us. We are @mothersgravepodcast. So come see more behind-the-scenes images and some of my general musings about moms.

Since we just talked a lot about her, it feels fitting to end this episode with my Nana. You're going to hear her voice as well as my boyfriend's voice and my voice. Since March, her nursing home, which is about an hour outside Chicago, has been shut down to outside visitors, like every nursing home all over the world. So my boyfriend and I decided we would go and visit her about once a week at her first-floor window, and call her on her cell phone.

And it's been great. We talk about everything. We talk about the social justice movement. We talk about politics. We talk about COVID. We talk about the President. We talk about Jeopardy!. We talk about the Mariah Carey memoir she wants to read, about bobby pins she needs at Target, how much she misses the hair salon. We talk about my dog. We talk about the weather. Sometimes, if she's up for it, we talk about my mom. A lot of the time though, her thumb is in the way, so we have to say, "Please, move your thumb. It's in front of the microphone on the cell phone." Or her mouth is weirdly not close to the phone. It's like, "What are you doing, Grandma? We're trying to record you (for a podcast)," which I eventually told her.

[55:00] A friend told me at the top of this pandemic that being able to see my grandma at her window every week is going to be the thing that gets us both through this. It's going to be the thing that saves us. And they were right. It's been wonderful, and I'm so grateful to have it.

And in this clip, you're going to hear us being really positive. You're going to hear a couple pithy comments. You're going to hear some laughter. And you're going to go, "Oh, isn't that wonderful." Well, I hope that's what you're going to say. "What a cute Nana." But I want to be honest with myself and all of you, as I sit in this closet by myself, about how hard it is too. I know I'm not alone in feeling that way. I know it, and

that's why I'm sharing it. It's so hard not to be in that room with her. She wants me to brush her hair. She's lonely. She finally agreed to start talking to a social worker. She is sad.

I recently asked her a question about my mom, and she said, "I'll answer that next time you're sitting across from me." And so we wait. We wait to be together again. That's all I can do. I can pull her out of there, and take her to my house, and take care of her. What? Sometimes I don't even put on underwear. Like how am I going to take care of my grandma? But I dream of taking her out of there. I dream of living with her. But I know I can't. And I know that's the best place for her, even when I'm frustrated with the facility. So all I can do is show up, make a couple jokes about Mariah Carey, tell her she looks good even if her hair isn't brushed, and tell her I love her, and leave. That's the best I can do, and that has to be enough.

**This is my Nana, Donna. [end outro]**

**Dana: Hi, hello!**

Nana: Hello, hello, hello.

**Dana: How are you?**

Nana: I am fine.

**Dana: Do they ever open your window? Do you ever get any fresh air?**

Nana: No, not on the first floor.

**Dana: Oh, why?**

Nana: I suppose because of burglars or something.

**Dana: There's no burglars here. Your room looks tidy, like you tidied up, or someone.**

Nana: It does, doesn't it. How are you?

**Dana: We're good! It's a gorgeous weekend, so it is nice out.**

Nana: It was supposed to be rainy.

**Dana: Have you gone out yet? Have they taken you to the back patio?**

Nana: No, they always say they're going to, but they always run out of time.

**Dana: Well, maybe you can get your wine again, and get out there. It's nice. You should ask them.**

Jonathan: It's like 72°, 73°. Perfect world, you get to have a glass of wine and a book, and read outside. That would be amazing.

Nana: That's nice.

**Dana: Aw, I wish we could take you and do that, and give you some shrimp or something nice.**

Jonathan: (laughs)

**Dana: If you could do one thing right now out in the world, what would you want to do? Besides your hair salon appointment. But if you could do anything right now, what would you do?**

Nana: That I really could have, not something I wish would happen?

**Dana: Whatever you want it to be. Do you want to be on a boat right now? Do you want to be shopping? What do you want, if you could do anything?**

Nana: I wish that I can walk through—even if it was just through Target. That would be fine.

**Dana: To walk through Target, without a walker, without any issues, just stroll around.**

Nana: Oh god, that would be wonderful.

**Dana: (laughs) You've made Target seem very glamorous. We're going to go there, and we'll think about you.**

Nana: (laughs)

**Dana: Did you ever think of that memory of Mother?**

Nana: What?

**Dana: Remember, last time we were here, you had a memory of Mom?**

Nana: Yeah.

**Dana:** But you couldn't remember it. I was just curious. Remember, we thought it was a dream?

Nana: Oh, no.

**Dana:** No, okay.

Nana: It's nothing completely.

**Dana:** It wasn't meant to be.

Nana: Wasn't meant to be.

**Dana:** That's right.

Nana: That's right, ah well.

**Dana:** Alright, well, we're going to see our friend and then shower. Look at us. We're a mess. I wish we could come inside. It's so, so sad that we can't come inside. But hey, we've gotten this far.

Nana: That's right.

**Dana:** That's right.

Nana: I love you.

**Dana:** I love you.

Nana: Bye-bye.

Jonathan: Love you too.

Nana: What?

Jonathan: Love you too.

Nana: Okay, thank you.

**Dana:** She really can't hear you. (laughs)

Jonathan: (laughs)

Nana: Bye-bye.

**Dana: Bye. We'll see you. I'll email you. [end 1:00:07]**