

The Alzheimer's Podcast

Episode 137: “*What criteria makes a person valuable?*”

Christy Turner: Based on our recent history here, it seems to me that yes, there will be fewer people in nursing homes. Because there will be fewer people alive to be in nursing homes.

I don't want to be cynical. I am not seeing evidence, or enough evidence, that each of our 50 plus healthcare systems within the United States are giving a rip about people who live in nursing homes.

Phil Gutis: Right.

Christy: And when that is the case, and there is a pandemic, it's very problematic. And it's extraordinarily likely that people who live in nursing homes are going to—you know, their death is going to be hastened.

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You're listening to *The Alzheimer's Podcast* with Christy Turner of Dementia Sherpa, where we're all about bringing the Good Stuff—that's respect, kindness, love, empathy, and compassion—for people living with dementia, their families, and the professionals who support them.

I'm Christy Turner, AKA The Dementia Sherpa. I've enjoyed the privilege of working with over 1,500 people living with dementia and their families so far, including multiple experiences in my own family. In the course of my career, I've transformed from *total* train wreck on my first day as a professional to local go-to expert, speaker, trainer, and consultant. And if *I* can go from scared spitless to confident care partner, I promise *you* can, too.

This episode was recorded April 27, 2020. Just like last week's episode, we again talk about the value of a human life. It's a recurring theme on *The Alzheimer's Podcast*, because we believe that when others don't see people living with a dementia diagnosis as having value simply because they're our fellow humans, then every human life can be devalued. And when that happens, inhumane treatment can be justified based on any criteria those in power come up with in the moment.

Obviously, we had no idea when we recorded this episode that it would be released during a time of global protests demanding the perfectly reasonable acknowledgement that Black lives matter. We are in no way looking to co-opt a movement or diminish the message that Black lives matter. Rather, we stand in solidarity.

Phil: Did you see....

Christy: The President of the United States telling all of us to mainline Clorox? I did.

Phil: Yeah. No, not that. There was, I thought, a piece in *The Washington Post* from a lady in assisted living or a nursing home.

Christy: She's in a nursing home. I have it bookmarked. I haven't read it yet.

Phil: *We wait in our nursing homes helpless, scared, knowing the virus is coming.*

Christy: Yeah.

Phil: And there's something I was reading, *Will pandemic end 'warehousing' the elderly?* I think I'm going to write my next journal piece about nursing homes, memory care, and what's been going on.

I mean this stuff about nursing homes, I mean, do you think nursing homes will—will this change the experience of nursing homes and memory care?

Christy: In what sense?

Phil: I don't know.

Christy: I think, to me, it just all keeps coming back down to, *Who do we elect to represent us?* Because that is such a determinant of how much money various programs receive, which then determines who gets help and who doesn't. And so, nursing homes across the United States—the pay source for most is Medicaid.

Phil: Right.

Christy: So, that's one piece. Medicaid is perpetually on the chopping block for people who have less need than to live in a nursing home. So, the more you eliminate community-based services, the likelier it is that people do end up in a nursing home.

So, that being the case—and then just very recently has CMS said, *Oh, you know, you probably should count Covid-19 deaths in nursing homes*, it—being in a position, and I think that this has been true for it feels like perpetuity: people who live in nursing homes are so often forgotten; considered less than; and their personhood not necessarily recognized, validated, valued.

So, just one little subplot is the PPE. The focus has been on hospitals. And I'm not taking anything away from that. Absolutely first responders, hospital workers should have PPE. As should nursing homes and assisted livings and memory cares and adult care homes. Any healthcare worker should have PPE, and it should not need to be rationed.

Phil: Right.

Christy: That has not been the reality. So, in a reality-based way, based on our recent history here, it seems to me that yes, there will be fewer people in nursing homes. Because there will be fewer people alive to be in nursing homes.

I don't want to be cynical.

Phil: But you can't help it because you were born that way.

Christy: Well, you know, I am not seeing evidence, or enough evidence, that each of our 50 plus healthcare systems within the United States are giving a rip about people who live in nursing homes.

Phil: Right.

Christy: And when that is the case, and there is a pandemic, it's very problematic. And it's extraordinarily likely that people who live in nursing homes are going to—you know, their death is going to be hastened. And I think a very cynical attitude would be, *Well, so many people who live in nursing homes have complex medical needs, have underlying conditions. So, *shoulder shrug.**

Phil: Yeah. And have lived their lives.

Christy: Yes. Yes.

Phil: They're just there waiting to die anyway.

Christy: Exactly. So, it goes back to this idea of where is their value, in a person? Like, what is the criteria that makes a person valuable? And throughout this, I have seen it linked far too often to the ability to generate some sort of economic value to the larger society.

Paul Ryan talked about the takers. Going back—this is pre-pandemic, obviously, when Paul Ryan was Speaker of the House—I think it may have even been before he was Speaker of the House, his life's dream has been to make sure that people who don't “deserve” insurance don't get it. His worldview is you have to have some type of a financial benefit. Almost like you have to be an income-generating business. You have to have some economic value in order to be a worthwhile human being. That is the only thing that counts.

What is your economic value? Is it positive or negative? So, if you're generating income, if you're generating wealth, then you're worthy of life. And if not, you are not. And there are too many—I mean, blessedly he's no longer around, but there are far too many people in positions of power who do have that worldview.

Now, let me go back again to the Lieutenant Governor of Texas. I cannot even begin to wrap my head around how to understand, how to comprehend that world view.

Phil: It's not just Republicans. I mean, obviously this crisis—the crisis of nursing homes—predates our current political situation. In *The Sacramento Bee* piece, it talked about how—it's really, it's a very comprehensive piece—they talked about the history of nursing homes, and how they've existed:

Institutions that house the elderly have existed in some form in America since colonial times. English colonialists imported the idea of alms houses for the elderly,

mentally ill, and orphans. They continued to operate in some form until the Great Depression when ghastly reports of overwhelmed and unsafe conditions led to reforms....Current system began to take shape after World War II.

Christy: Dr Tia Powell talks about this pretty extensively in her book [*Dementia Reimagined*]. I had her on the show. She did a lot of research into the hows and whys and the historical context of people with dementia symptoms or people with some type of what we classically think of as a mental health problem or a mental health diagnosis and how they have historically been treated. Which is, by and large, abysmal—

Phil: Right. I guess that's what I'm trying to say.

Christy: —until the Quakers. The Quakers tried something different in the UK and some of that was imported to the United States, before there was such a thing as the United States. But yeah, to your point, I didn't—other than Paul Ryan, and I'm not even sure I used the word Republican in relation to that.

Phil: You said it's a question of who we choose to elect.

Christy: It is. It is. And so that doesn't mean what somebody has after their name, what initial they have after their name. That means, Is this person an advocate for people with disabilities? An advocate for older adults? For people living with a dementia diagnosis, or whatever the case may be?

Is this person an advocate for vulnerable populations? Or does this person have a track record or public statements indicating otherwise?

Phil: Right.

Christy: In my line of work, it can be all dementia all the time. But that has broader implications. For example, I just did an interview with Donna Thomson, who is amazing. She's an advocate, and a lot of it [her advocacy work] has centered around the fact that she has an adult child with cerebral palsy who has had very complex medical needs throughout his life. But she also became a care partner for her mom, who lived with the diagnosis of dementia for over 10 years.

And so I think we need to look at what the applicability is across various sections of the population. What is a person's thinking on any of this? And it comes down to, *What is the value [of a person]? What indicates value?*

And where we put our money, where we put our time, that indicates what we think has value. That's a pretty sure indicator. So, when you keep cutting programs, you keep cutting safety nets, you underfund research because we need another [military] jet.

Phil: Right.

Christy: I mean, could we please think this through? These are actual humans. And I really appreciate the fact that, you know, *The New York Times*, *The Washington Post*, Nicolle

Wallace on her show [*Deadline: White House*], people have really talked and taken the time and the care to say these are real human beings attached to these Covid-19 deaths. But the same is true for people who live in any type of a care home. These are real, actual people.

Phil: Right, right. And I guess the question is, is it going—I mean, under our current system, where we are—where people don't feel that they can support their older parents or people with dementia, that they can't keep them at home because they may not have the resources available to do the home care, or they have jobs and you know, just two people and you know, mom would be home alone all the time. You know, for a lot of reasons, as long as that is the case—well, I guess with better home care, I guess that would change things. Well, with the caregiving.

Christy: Sure. And it goes back to, again, money. There are some home care agencies who accept Medicaid.

Phil: Right.

Christy: So, you can get that in-home care. I think there's a combination of reasons why—and let's use, for example, people living with an Alzheimer's diagnosis—ultimately live in memory care, versus living at home with their families. Often it is financial. That's the reason, because they live in a state or in a situation where Medicaid will pay for a communal setting such as a nursing home or a memory care or assisted living or an adult care home, but will not pay for community-based service, like in-home care.

So, that's one thing. Another thing—and I think this is typically too often overlooked—is what support are we giving to families along the way?

Because typically it is a couple of years [after diagnosis] before a person qualifies for being admitted into a memory care community or to a nursing home. The care partner's already just crispy. Stick a fork in them; they're done. Because they haven't got the support.

You know, a lot of times people are diagnosed and at the time of diagnosis, the family isn't even told, *I'm terribly sorry. I understand this is extraordinarily difficult news on a number of fronts, but I do also need you to understand that it is a chronic, progressive, incurable, fatal condition.*

Right? Most families aren't even told that at the time of diagnosis, let alone given so much as a photocopied fact sheet or list of resources. I mean, we could just do so much better in supporting care partners.

Phil: So that when the time comes—

Christy: So that when somebody really needs even more hands-on care, it's not coinciding with when a care partner is cooked.

Phil: Right, right.

Christy: A lot of care partners don't even know the basic mechanics of how do you care for another adult.

Phil: Right.

Christy: How does that even work? They don't know.

Phil: They're making it up as they go along.

Christy: Yeah.

Phil: Yup, yup. Like we do with many things in our world.

Christy: Right.

Phil: Yeah. This is going to be interesting piece. There's so many—I'm glad I went to that memory care facility, though, or that memory care home.

Yeah. It's so hard. I mean, just aging alone in this youth obsessed society of ours is so hard too, you know. We're just so, we don't respect the wisdom of our elders anymore, you know.

Christy: Yeah. Or just the value of life, I would say. The value of a human being, whether they're 90, or 58 with young onset Alzheimer's diagnosis, or a child who's born with complex medical needs.

Phil: Yup. Yup, yup. I mean, like my cousin who I don't think ever—they basically thought he would be institutionalized for his entire life. And here he is at NIH on a fellowship after graduating from Harvard, London School of Economics, Stanford.

Christy: Yeah, and that's a really inspiring story and one of those things that makes you feel good when you read about it. My point is even more expansive than that, because even had he not done any of those things, would he not still have value just because he is?

And that's a question that a lot of people don't really want to look at.

Phil: Yeah, no, it's hard.

Christy: Because then it comes down to the lowest common denominator is, are you pro-life or are you pro-choice?

Phil: Pro-life until birth.

Christy: I started to say to me, what feels like a more accurate descriptor would be pro-birth.

And you know, if, and I don't doubt that there are people who are quite sincere, with their, you know, their religious beliefs.

So that's what I mean about what are we actually valuing, because whether you're pro-life or pro-choice, it doesn't matter in the sense that, tell me what a three-year-old is contributing to the economy.

Nothing! Zero. Nada. It's a hopeful situation. We as a society—our hopes is what we pin on any random three-year-old: *Well, you're going to grow up to contribute. You're going to grow up to do great things.*

Maybe, maybe not. We don't know, but we're all collectively making that gamble. Right?

But that three-year-old in actuality has no more financial ability to give than a 97-year-old who lives in a nursing home.

Phil: Right. Except for them, we've said, *Your time has come and now it's gone.*

Christy: Yeah. And there are quite a few people, or at least the ones who are speaking the most loudly right now, who seem quite comfortable with playing God.

Phil: Yeah. Yeah. And in old times, that 97-year-old would have been as valued or possibly even more valued than the three-year-old. Because the wisdom of the elders, the elders, the place of the elder in society.

Christy: True. But what if the 97-year-old was nonverbal? Are they still valued, or do they have to be able to impart their wisdom to us verbally?

Phil: I think there are some cultures where they're still valued, right?

Christy: I hope so.

Phil: Asian cultures, Latino cultures.

Christy: In my experience, that has been true although I'm not a native part of either of those cultures.

Phil: Yes, yes, exactly. Me either.

Christy: When I'm talking about the collective 'we,' I'm talking about Americans. And we're kind of sucking at this.

Phil: Yeah, indeed we do. We do. Lots for me to think about.

Christy: Yeah. I'm looking forward to reading your piece.

Phil: So am I!

Christy: Hey, care partners. Now is a really scary time to have your person in a nursing home, assisted living, or memory care. Accurate, up-to-date information is hard to come by. Although the Centers for Medicare and Medicaid Services, or CMS for short, has finally required Covid-19 related data, that doesn't apply to every community. Of those it does apply to, 20% aren't reporting. At least 30,000 nursing home residents nationwide have died

during this pandemic, and that is almost certainly a gross undercount. As if all that isn't enough, 21 states have enacted shield laws protecting long-term care companies from legal liability and keeping you from accessing details about your person's care.

If your person is living outside your home—whether that's in a nursing home, assisted living, or memory care—and you're trying to figure out if you should bring them home with you, please [join our next live Masterclass Training](#) on Saturday, June 27th at 9 am Pacific.

I'll help you figure out if a move is even viable in your situation; what supports and equipment you'll need in place for a successful transition; assist you in developing a realistic timeline for making it happen; tell it to you straight about what to expect once the move happens; and show you how to make it successful for both your person and you.

Go to DementiaSherpa.com/masterclass for [details on joining our next live Masterclass Training](#) on Saturday, June 27th at 9 am Pacific. That's DementiaSherpa.com/masterclass for details. DementiaSherpa.com/masterclass.

And that's our show. Thank you so very much for listening. Head on over to the [show notes at DementiaSherpa.com](#). You've been listening to *The Alzheimer's Podcast* with Christy Turner, wishing a blessed and easy week ahead.