



**A QUESTION OF  
CARE**  
WITH ROBERT ESPINOZA

SEASON 1 TRANSCRIPTS: A RAPIDLY AGING AMERICA

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A Question of Care™ is dedicated in loving memory of Robert Eloy Espinoza and Aurora Lopez de Espinoza.





A society that does not value its  
older people denies its roots and  
endangers its future.

NELSON MANDELA

# ABOUT THE PODCAST

How did one of the wealthiest countries in the world get to a point where it can't support more than 54 million older adults and nearly twice as many by 2040? *A Question of Care™* explores the many answers to this question with expert insights into our caregiving system and how to solve the growing crisis in care.

Hosted by Robert Espinoza, a national expert and frequent speaker on aging and the long-term care workforce, *A Question of Care* explores several pressing topics related to our country's caregiving system through interviews with leading experts, reporting, and editorial commentary.

The first season of *A Question of Care*, which premiered in September 2023, focused on the primary challenges facing older people. Future seasons will examine other aspects of caregiving. The podcast was produced in partnership with Modry Media.



*A Question of Care* is available on all major podcast platforms and at [aquestionofcare.us](http://aquestionofcare.us).

The transcripts that follow have been lightly edited from the original episodes to improve readability and accessibility —while preserving the guests' authentic voice and conversational style.

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EPISODE 1

# WHAT HAS HAPPENED TO OUR COUNTRY'S CAREGIVING SYSTEM?

**High-quality long-term care remains out of reach for millions of older adults in the U.S. Given this challenge, what should we know about our country's caregiving system to fix it once and for all?**

**In the first episode of *A Question of Care*, Robert Espinoza spoke with expert guest Howard Gleckman, Senior Fellow at The Urban Institute and a columnist at *Forbes.com*. They discussed the profound challenges facing older adults and why the U.S. caregiving system needs a complete transformation.**



Howard Gleckman, Senior Fellow at The Urban Institute and a columnist at *Forbes.com*

**Robert Espinoza: How did the wealthiest country in the world get to a point where it can't support the health and long-term care needs of more than 54 million older adults? Welcome to *A Question of Care*, a podcast that explores the many answers to this question through different viewpoints and topics. I'm your host, Robert Espinoza, a national expert and frequent speaker on aging, long-term care, and the workforce.**

**Throughout this season, we'll examine various aspects of the long-term care system for older adults in this country. Our discussions will shed light on critical topics like ageism, systemic racism, the difficulties in home care work and nursing homes, and so much more. To kick things off and provide an insightful overview of the issues ahead, we're joined by Howard Gleckman, a**

seasoned expert and writer who has extensively covered topics such as Medicare, Social Security, and the unique challenges facing older people in the United States.

**Howard Gleckman:** I'm Howard Gleckman. I'm a Senior Fellow at the Urban Institute, which is a policy research organization in Washington, DC. I wrote a book called *Caring for Our Parents*, and I spend a lot of my time writing and thinking about how we care for older adults, particularly older adults with chronic conditions in this country.

**Robert Espinoza:** The caregiving system in the United States is a complex web of services and support mechanisms aimed at assisting individuals who require long-term care, in particular, older adults and those with disabilities. It encompasses a wide range of settings, from private homes to congregate care settings like nursing homes and assisted living environments.

However, the system is often characterized by a myriad of challenges, including rising healthcare costs, limited access to quality care, workforce shortages, and a lack of comprehensive coverage for long-term care under traditional programs. These issues have given rise to a pressing need for reforms and innovative solutions that ensure that older people receive the compassionate and dignified care they deserve while easing the burden on paid caregivers and family members who, too often, are shouldering significant responsibilities.

So, to begin our conversation, I asked Howard a simple question: What has happened to our caregiving system?

**Howard Gleckman:** It's almost inappropriate to call it a system. It is so disorganized, siloed, and dysfunctional that it isn't a system. It's a group of options for care that works very poorly together and leaves people who need this care, people living with chronic conditions, and their family members in a terrible state of stress and confusion.

Doctors don't talk to home health agencies, who don't talk to nursing homes, who don't talk to social workers. So, it's really not even a system. As far as what's happened to it, I wrote *Caring for Our Parents* more than 10 years ago, and

it's only gotten worse. And for a couple of reasons. I mean, the first reason is that more and more people need this care. The number of older adults, of course, is increasing rapidly as the baby boomers age. And the number of younger people with disabilities also is increasing, people particularly with intellectual and developmental disabilities. So, the need is growing. And the ability of the system to keep up with it is just declining.

**Robert Espinoza:** For many people who need long-term care, they soon discover that it's quite expensive. Research shows that the national monthly median cost for long-term care can range from \$4,000 to \$8,000, depending on what you need, what you want, and what's available. Why is long-term care so expensive, and what do people do when they can't afford it?

**Howard Gleckman:** So much of the cost of long-term care is labor costs. It's the cost of aides, home care workers, CNAs, and nursing homes. It's a paradox. We don't pay direct care workers nearly enough. Many of them are on Medicaid themselves. On the other hand, the cost is beyond the reach of many families. If you hire a home care aide through an agency post-COVID, it probably costs \$30 or \$35 an hour in many places.

The aide gets half of that. The agency gets the other half, which it uses to pay benefits and taxes and all the rest and make a profit if it's a profit-making agency. But for the family, \$35 an hour is a lot of money. If you need to hire an aide for at least four hours a day, it's \$150 or \$140 a day. That's way beyond the capacity of most families. So, it is this paradox. It's too expensive for people, and it's not enough to produce a living wage for the people who do the work.

**Robert Espinoza:** And why haven't government leaders addressed this paradox? Why haven't they fixed this problem of affordability?

**Howard Gleckman:** We've gone through this. You and I, of course, have served on a number of groups together to try to think about this. We know what the solutions are. This [issue] is not one of these, you know, rocket-science things where somebody has to think out of the box to figure out what to do. We know what to do. The problem is the political system doesn't have the will to do it. The



# AGING ON THE EDGE

## The Hidden Financial Struggle of Older Adults

**80.8  
million**

Projected number of people age 65 and older in the U.S. in 2040—up from 54.1 million in 2019



Percentage of people age 65 and older who will need long-term care in their lifetimes

**\$53k-\$105k**

Median annual costs for long-term care in 2020, such as home care, assisted living, and a private room in a nursing home

**80%**



Percentage of households with older adults—or 47 million—are struggling financially or at risk of becoming economically insecure as they age



Housing Insecurity



Widespread Ageism



Bias & Discrimination



Long-Term Care Workforce Shortages



Health Challenges



Social Isolation & Loneliness

main reason for that is most of the solutions require getting more money in the system, and getting more money in the system requires raising taxes, and politicians don't want to raise taxes.

So my experience has been, and I'm sure yours is, that when I talk to politicians about this, and I talk about some of the solutions that you and I have come up with, the politicians say, "Great idea, but we're not going to raise taxes to do it. I can't pay for it." And it dies, at least on the federal level. There are some solutions, and we can talk about them. There are some solutions on the state level that are certainly worth watching. But at the federal level, we're going nowhere, at least for the next couple of years.

**Robert Espinoza: You alluded to this earlier, but one of the central challenges in this long-term care world is that employers are desperate to find and keep direct care workers. They anticipate about 7.9 million job openings in direct care by 2030. Likewise, those workers are desperate for jobs that pay enough and offer good benefits and a career path. How are you seeing these workforce issues play out?**

**Howard Gleckman:** So, workforce issues are an enormous challenge on a number of levels. One of the things that happened even before COVID was the looming shortage of care workers.

Yet, a lot of it goes back to the demand: more older adults with chronic conditions and more younger people with disabilities. So, there's just a need for more workers. The supply of workers is constrained in several ways. One of them is the pay. You can get paid as much or more working in a warehouse as you can being a direct care worker.

One of them is the dangers of doing this work. I often remind people that being a direct care worker is one of the most dangerous occupations in America. It's more dangerous than being a coal miner in terms of injuries on the job. Most of those injuries are back injuries where you're trying to transfer somebody, and you blow out your back. But also depression is a significant problem for many care workers.

It becomes more of a problem because you're often doing a job with no benefits, including no sick leave. And that means if you do hurt your back, you keep going to work, and you're hurting your back even more until you can't work anymore. So, and people know about this: this [recruiting] is the kind of work that's the sort of word of mouth often... So, again, you get a job that pays more and is less dangerous doing something else.

Another issue for supply is immigration. We are competing with the rest of the world. Remember, we're not the only country that's aging. We're competing with the rest of the world for care workers. And many other countries are enthusiastically letting care workers into their country. And we're not. And whether that's nurses or home health aides, some people want to come here and do this work, and we won't let them in. And if we let them in, we don't give them a work visa. They can't work even if they're here. So, you know, we've brought this on ourselves.

**Robert Espinoza: The research shows that most of us want to age in place, wherever we are. And we want to live independently as long as possible. And we also want person-centered care that respects our preferences, values, and dignity. How close are we to this ideal?**

**Howard Gleckman:** Not even remotely close. I mean, we are so far away from that care ideal it scares me. Yes, you're right. Most people want to age in place, and most people do, you know, it's interesting. We focus so much on the nursing home problem, and it clearly is a problem, but the vast majority of people get long-term care in settings other than nursing homes. Probably 80 percent of people get care either in their own homes or in a senior living community or something like that, but not in a nursing home.

Nursing homes provide 5 or 10 percent of the total care we get. So we are getting it at home, but getting care at home is not so simple. Delivering care in a nursing home has its problems, or an assisted living facility has its problems, but it's relatively efficient. You have a large number of people who are in a confined space. And you need relatively few



workers to care for them because they can go from one to the other relatively rapidly. If you have people who are living in suburban cul-de-sacs, just getting to them is a huge challenge. You spend time sitting in traffic, going from client to client. Or, of course, many aides don't even have cars, so they have to go by bus, which is, you know, an even less efficient way to get around. So, it's inefficient.

It's also very lonely. Imagine you're somebody again who lives in that suburban cul-de-sac. You grew up. You raised your kids there. You've lived there for 40 years, but your neighbors have now all moved. So you now have a whole new generation of neighbors who are families with kids, and you don't know them, and they don't know you. Maybe you can't drive anymore. So, getting even to the grocery store becomes difficult. This is just a huge challenge in terms of person-centered care. I wish the healthcare system thought about this more than it does.

So, imagine a typical kind of situation: an 85-year-old widow falls at home and fractures her hip. She goes to the hospital, the hip fracture is repaired, and the discharge planner at the hospital says, "So here's a list of skilled nursing facilities where you're going to go for rehab. I can't tell you which is better than another, but here it is. Good luck." They go to a skilled nursing facility, and maybe they never leave, or maybe the rehab goes well, and now they're discharged from there, and they're sent home, and they have no idea what to do.

Nobody even knows, in many cases, whether the home they're going to has stairs. Or whether there's an adult child living somewhere in the area who can help care for them. Or whether it is a neighbor or somebody in their church who can help care for them. No one has any idea. So, how can you set up a person-centered care system when you don't know anything about the person? They're just a fractured hip that we repaired, and we sent on their way.

**Robert Espinoza: Anyone who has gone through the healthcare or the long-term care systems, whether coming home from a hospital, managing a serious illness, or needing to see multiple doctors and specialists—knows that these experiences are often disconnected. It seems that**

**professionals and other people are not talking to each other. The information isn't being shared, and it's not being coordinated. Why are these systems so siloed? And why haven't holistic, integrated approaches been widely adopted?**

**Howard Gleckman:** So, much of this goes back to 1965 and the creation of Medicare and Medicaid. In 1965, we created the Medicare system that provides health care for older adults and some people with disabilities. And then, we created the Medicaid system that provides personal care for older adults with chronic conditions who are also very poor. But these two systems have completely different payment structures, and they have completely different languages and completely different metrics for success. So we've created these two parallel systems that never really connect.

Another problem is you think about physicians who don't know about long-term care and don't get paid to give their patients advice about long-term care. There was a research study, a survey, done about five years ago by Levitt Associates. They surveyed physicians and asked them about a series of social determinants of health that could be important to their patients. [They] asked them two questions. One is, "Do you think these are important?" And the second question is, "Do you think you have any responsibility for helping your patients navigate these systems?"

What it found was nearly no physician who answered those surveys felt they had any responsibility for doing this. One striking example was that 75 percent of the doctors they surveyed said, yes, it was important that their patients had information about transportation to the doctor. Because one of the big issues we have in this country is people don't go to the doctor because they can't get there. So 75 percent of doctors said, yes, this is very important. Two percent said they thought they had some responsibility for telling their patients what to do about it. So, what we need to do is find some kind of a system that can integrate the healthcare world on one side of this wall with the supportive services world on the other side.

We do it in a few places. There are PACE programs, which are very interesting.

There are about 130 of them around the country, very interesting programs that provide care for people who are mostly "dually eligible," people eligible both for Medicare and Medicaid. There may be an adult day program. There's also a medical clinic associated with it, and they provide additional services that help people stay at home.

Certain kinds of managed care plans are called "special needs plans" for people with a high level of need. And some of these work quite well. There was a lot of variability in them. There's Medicare Advantage—about 52 percent of Medicare recipients are now in Medicare Advantage plans. Those Medicare Advantage plans for the last few years have begun to provide a little bit of personal assistance and other supports for people living at home, but it's very small. The way that the plans are compensated for doing this limits the amount of money they're willing to spend. So, while they may provide some personal care, home renovations, or meal deliveries, the value of the Medicare Advantage, which they call "supplemental benefits," is \$30 to \$50 a month. So, it's very, very small, but it's a toe in the water. It's the little beginning of this.

The last place we do it a little bit is with Medicaid long-term care. Most states have turned that over to managed care organizations, and they are supposed to provide fully integrated long-term care with health care. The idea, the theory, is that if you provide good long-term care, you'll reduce the health care costs. These plans are paid a fixed amount of money every month for their patients. The more they can do to reduce hospital utilization, the more money they can make.

So, the theory is we can align the incentive. Patients don't want to go to the hospital. The managed care plans don't want them to go to the hospital. The plans could do what they need to keep them safe at home. That's the theory. We don't know whether it's working or not. But that's the idea. And conceptually, it makes sense. Fully integrated within a plan like this should work. We just don't know if it does.

**Robert Espinoza: I've often found myself taken aback when stepping into a pharmacy and seeing all those anti-aging products. This serves as a**

**reminder of the prevailing cultural perspective on aging that it's something we should hide or fix. So, what exactly are these attitudes that society holds about aging? And how do they influence our experiences as we journey into our latter years?**

**Howard Gleckman:** So, the United States is interesting. We think about families. And so if you play word association with people, you say, "families," and they think about parents and children, you know, young children. And older adults are somehow separate from that world. When Congress has debated family leave, for example, often what they talk about is leave you can take for a newborn or a newly adopted child, not leave you can take to care for a parent. So, you get old, you're on your own in this country.

We also think that just because you're older, you are a taker of services from this country. We don't think older adults have something to give, which older adults often do. Of course, many work well past age 65 or 70—many volunteer. I'm on the board of a local community-based organization called the Jewish Council for the Aging, and one of the things we do there is provide volunteer opportunities. And we provide training programs to help people do resumes. And we don't operate on the predisposition that older people are useless and only stay home and wait to die.

But that is often the culture in the United States. I don't mean to beat up on physicians again, but this happens all the time when older people go to a doctor. A person goes to the physician and says, "You know, doc, I'm a little depressed." And the doctor often says, "What do you expect? You know, you're old, your friends are all dying. Of course, you're depressed. Go home."

And the medical system doesn't know how to talk to older adults. Many employers don't know what to do with older adults. They immediately look at them and say, well, they'll never get the technology. And, you know, some of us do, and some of us don't, but you can't just make a general supposition.

And, of course, we all remember what happened recently when Nikki Haley, one of the Republican candidates for president, looked at Joe Biden and said these old politicians ought to all have a



dementia test so we can realize whether they're competent or not. Frankly, I heard that and said every politician ought to have a test to determine whether they're competent, no matter their age. But that's not how we think in this country.

**Robert Espinoza: Howard, we've officially entered the presidential election season with several leaders declaring their candidacy. How would you describe the political climate surrounding older adults and aging?**

**Howard Gleckman:** I think, for the most part, politicians are ignoring it. And frankly, I fear that this discussion of Biden's age, and frankly, if Trump is a Republican nominee, Trump's age, is going to make people even more reluctant to talk about getting old and what that means, but we don't talk about it.

I'll give Biden credit. When he ran for president, he did include some very ambitious proposals. Remember, he was going to increase Medicaid spending for home- and community-based care by \$400 billion over 10 years. That wasn't going to solve the problem, but it was going to go a long way. And Congress wasn't interested in doing anything about it. But Biden has given it some thought. He's talked about family leave. He's talked about some of these other things.

Pete Buttigieg, when he ran for president for the Democratic nomination for president, didn't make it, of course. He had a fairly full-blown plan for long-term care. Hillary Clinton talked about it a little bit in her campaign years ago. So, it's surfacing a little on the federal level, but not very much.

There is interest in the states, and that's where we ought to be looking for the next few years. Washington State has adopted a public long-term care insurance program. They will begin collecting the taxes and the premiums for that next month in July [2023]. And they'll begin paying benefits in a couple of years. California is thinking about doing the same thing. Minnesota is looking at a number of different options for financing long-term care, some public and some enhanced private solutions. And many states are looking at delivery enhancements and better ways to provide home- and community-based services,

for example.

One of the things about the Medicaid program is that it's run by states, even though the federal government contributes much of the money. It's run by the state, so you get lots of variation in the states. And some of that's good. Some states are very creative about what to do, but some are really bad because some states are very reluctant to provide the kind of resources that people need to stay home if they need long-term care.

**Robert Espinoza: We saw the state variance during the COVID-19 pandemic. And I want to ask you a question about this crisis. It ravaged nursing homes, and it brought to light the challenges that are facing, specifically low-income older adults and people with disabilities who need 24-hour skilled care. What lessons have you drawn from this healthcare crisis?**

**Howard Gleckman:** So, the first thing to keep in mind is the magnitude of this for older adults. Nine hundred thousand people died of COVID during the pandemic [between March 2020 and May 2021]. And we're beginning to learn that even more people died of loneliness and social isolation. It wasn't COVID that got them, but it was the consequences of COVID. About 200,000 nursing home residents died during the pandemic of COVID [as of February 2022]. I think the pandemic was an inflection point for the nursing home industry. It also was challenged before. But it's had huge challenges since. Its occupancy declined dramatically. It's ticked back up but still not gotten close to what it was.

Remember that nursing homes mostly do two different kinds of work, which goes back to this Medicare-Medicaid problem we discussed. There are skilled nursing facilities that mostly do rehab for people who have been discharged from the hospital. Then there is the long-stay part of nursing homes, which are often patients with dementia, other people who are living in the nursing home, and they'll probably be living there for the rest of their lives.

Both of these were happening in the same buildings. And they were happening in the same buildings because Medicaid does not pay enough for nursing homes to make money or break even. Medicare tends to pay more than it costs to care

for its patients. So, what nursing homes did was use the Medicare dollars to subsidize the long-stay beds.

That system does not work very well anymore. For example, somebody has a hip surgery or a knee surgery in the hospital. Much of that rehab now is happening at home because the technology makes it easier to do it. The surgery is less invasive. The rehab technology is much more flexible. So, a lot of that rehab is happening at home.

Another thing that's happening is these managed care plans are paying the nursing homes 20 percent less than traditional Medicare did or does. So that's reducing the amount of money these nursing homes make on the Medicare post-acute, post-hospitalization side. But they're still not making enough money on the Medicaid side.

So, what's been happening is a lot of particularly not-for-profit nursing homes are going out of business. They cannot afford the labor costs, which are going up because of COVID. Many of them have to be recapitalized. They need a lot of renovations. Some of that includes better air conditioning and air handling systems because of COVID. They're probably going to lose the ability to have quad rooms; some of these Medicaid nursing homes often have four people in a room. We learned from COVID that it's a really bad idea. So that's going to change the economics.

So what's happening is a lot of the not-for-profits that were running on very narrow or no margins at all are going out of business. They're being acquired by not-big, huge chains. But they're being acquired by the small chains that may have 30 or 40 nursing homes in a particular geographical area. Some of those operators are pretty good. They're doing a pretty creative, good job with this. Some of them, frankly, are terrible.

This is a real challenge for government regulators. On the one hand, you need to impose sufficient regulations to make sure that residents are safe and healthy. On the other hand, you don't want to overregulate, so you make it impossible for operators of nursing homes or

assisted living facilities to be creative and think differently about how they provide their care. So, finding that balance is a real challenge for the regulators, and I don't think we're there.

**Robert Espinoza: In 2010, I entered the aging services field, starting with a focus on the policy barriers facing LGBTQ older adults and then transitioning to my current role, which focuses on improving jobs for our country's direct care workforce.**

**When I first joined this critical field, I was motivated by the reality that my parents, like many older Americans, were reaching an age when they would soon need professional long-term care support.**

**And yet, when I looked into what was available, I was stunned to discover the support system that was supposed to be in place was, in actuality, fractured, thin, and unaffordable. Like many family members, I panicked. What would our family be forced to do to ensure my parents could continue to age with dignity?**

**A Question of Care targets people like us, caught in these situations, struggling with an inadequate caregiving system and unsure where to turn. In our first season, we'll explore nine critical topics from different perspectives, shedding light on how older adults are affected.**

**Join me on this journey as we explore the questions we must answer to start repairing our caregiving system.**

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EPISODE 2

# WHY DO WE TOLERATE AGEISM?

Ageism affects all of us, and yet it is one of the least discussed issues of our time. It's also expensive—one study found that ageism resulted in roughly 17 million cases of common health conditions, totaling \$63 billion in one year.

In this episode of *A Question of Care*, Robert Espinoza was joined by Ashton Applewhite, author of *This Chair Rocks: A Manifesto Against Ageism* and co-founder of the Old School Anti-Ageism Clearinghouse. They delved into the definition of ageism, the ways in which it manifests in our culture, and how to combat it.



Ashton Applewhite, author of *This Chair Rocks: A Manifesto Against Ageism* and co-founder of the Old School Anti-Ageism Clearinghouse

**Robert Espinoza:** Many of us are familiar with the terms "racism" and "sexism," as we see them day after day in headlines, news clips, and social media posts. But the word "ageism" is one that we don't hear or see as often, even though it's an issue that deserves equal importance. To help contextualize our conversation, Ashton defined what ageism means.

**Ashton Applewhite:** The dictionary definition is stereotyping and prejudice on the basis of age. The World Health Organization has a wonderful anti-ageism campaign. And just a little footnote I'd like to point out: it's not the "World Old People Organization." If there's one reason to wake up to ageism, it's because it's bad for our health. Take it from the World Health Organization. And they frame it as how we think, feel, and act about age and aging, our emotions, and how we act on them. We create structures and systems that reinforce inequity. So, it's a whole system of beliefs



and practices.

**Robert Espinoza: To open our conversation, I told Ashton about a time several years ago when I was meeting with various high-level professionals in the aging sector. The facilitator of this meeting asked us to introduce ourselves and, as part of our introductions, to state our ages. People were troubled by the question, and many refused to reveal their ages. I was stunned that these people were leading the discussion on aging in their professions, yet they were scared to share their own ages.**

**Ashton Applewhite:** I wish I could say, "Oh, I'm shocked. I can't believe that happened." You know, when I started thinking about all this, which was about 15 years ago, one of the many things I was astonished by was the fact that older people often are the most ageist of all. Because we have had a lifetime of being barraged by messages about how awful it is to grow old and how tragic it is to encounter any impairment unless you stop and question those messages and look at where they come from. Most of us haven't done that, you know. That's the work I do, asking people to take that tough step. They become part of your identity. And people in aging services are no exception.

I can't tell you how many rooms I have been in full of people, you know, working in what I refer to as "Ageland," not an official term. Many of them have more road behind them than ahead, obviously, and are talking about older people, their clients, their patients, their constituents, and even their friends and families as "them," not as "us." And all prejudice relies on othering, right? Seeing a group of people as other than ourselves in some way. Other sports teams, other skin color, other political whatever. The weird thing about ageism is that the "other" is us. It's our own future older selves. It's a form of self-loathing, and people are reluctant to do it because we live in an ageist world that worships youth.

**Robert Espinoza: In your book, you talk about how ageism operates at various levels, similar to other forms of oppression. It operates at the individual level, at the interpersonal, institutional, and systemic or structural levels. Can you help us understand some examples of ageism at a few of these levels?**

**Ashton Applewhite:** Well, you just gave a terrific example of internalized ageism, right? That is unexamined bias. And let me be very clear that we are all ageist. We are all, I think, racist as well. We all harbor bias. Kids, we come into the world free of bias, but kids start to adopt attitudes from the culture around them and the people around them very early, right? Attitudes towards race, gender, age, etc. So when someone doesn't want to say how old they are, that is a good indicator that they haven't done the work to see age as just another component of who they are.

In my ideal world, it would not be a negative. It wouldn't be a positive either. We don't deserve, you know, special privileges for being older or clapping for someone who's 103. We all deserve to be respected.

How it manifests in the world, you know, look around you. Ageism is a huge obstacle in the workplace. It's a gendered issue because women are penalized for, god forbid, getting some wrinkles and ceasing to look young in, you know, representation. You know, DEI [diversity, equity, and inclusion]. There are a million wonderful conversations happening around diversity and inclusion. If you ask people, and I urge you to do this, "What are your criteria for diversity?" People come through the usual suspects, which are important, especially race, gender, sexual orientation, and perhaps ability. Age is not typically part of that conversation. So next time that happens, say, "What about age?" You know, just put it out there. If everyone in this room is the same, you know, age, how come? You know, there's seldom a good reason.

**Robert Espinoza: What are some of the ways that ageism impacts our caregiving sector?**

**Ashton Applewhite:** Well, that is a huge question. I don't want to equate aging and needing care. Most of the care provided to older people is provided for free by other older people, right? And, of course, younger people do a ton of caregiving, too. It's a problem to put a big magic marker around any circle.

There are only two inevitable bad things about aging: you're gonna lose people you've known all your life, and some part of your body will work less well. But we all need help lifelong, right? We all give

and receive care practically from birth. Infants don't give a lot, but they give a sense of joy and purpose.

So, let's be wary of categories. Physical and cognitive decline are not inevitable, but we will need more help with things. I mean, I've had a shoulder replacement. I don't even try anymore to lift my suitcase into the rack. I can do it, you know, wibbly, but the people behind me in the airplane are at risk. And why should I, right, ask for help? So, when you live in a culture that valorizes "independence," and I put those quotes around it because no one is independent ever. But when you live in a society that celebrates this myth of independence and self-reliance, asking for help is a source of shame.

And if you live in a world that doesn't value its older members, it doesn't value the people who care for older people either, or younger people, right? There are tons of younger people. We don't have paid childcare here in the United States, which is disgusting, and P.S., another form of ageism. Kids don't vote. Kids don't spend money. So, they do not have a good lobby. I mean, I think that's crude.

Another reason that affects the landscape of care is that most care is done by women. There are beautiful exceptions, but it is part of a larger color where women's work is less well paid and less well valued, and within that sector, a tremendous amount of it is done by women of color. We saw this tragically highlighted during the COVID epidemic because so many caregivers were going from facility to facility because they had to work more than one job to pay their bills, were exposed, and died in far greater numbers.

Many of them are immigrants, some of whom are undocumented, so they are experiencing a fourth level of discrimination. So, all these patterns are at play in a heartless, for-profit, capitalist economy. Let's zoom out and look at the pressures squeezing healthcare, in general, to become profitable at the expense of not only the good people who need care but the good people who provide care who often wear both hats.

**Robert Espinoza: I want to discuss the relationship between ageism and .**

**ableism. In your book, you write, "Americans' can-do ethic can be almost as problematic as the ageism script of learned helplessness. People with disabilities have a term for uplifting pictures of disabled people doing the things the rest of us might not expect them to be doing." They call it "inspiration porn." And the media loves these stories. How are ageism and ableism entwined, and how are they different?**

**Ashton Applewhite:** The shortest answer is to think about the reasons we may be apprehensive about growing older. And let me be very clear that there are real and legitimate reasons. I am not one who says if you eat enough kale or have the right attitude, it's all gonna be great. Money helps. Attitude helps. But luck, privilege, you know, none of us is in control of all the things that affect how we age, which links back to this idea of independence, right? If you get all your ducks in a row, you can be the boss of everything. And you can't, right?

Most of what we fear about aging is how our minds and bodies might change over time. That's not actually about age. Plenty of younger people live with a disability or cognitive impairment as well. Plenty of older people escape severe disability, even incapacity of any kind, if they're lucky, you know, and if they're very healthy. That is not ageism. Now, as I just said, as we age, more things about our body function less well, so we are likely to encounter higher levels of impairment.

It's tricky because a lot of progressive people in Ageland push back very fiercely and legitimately and importantly against the equation, the depiction of older people, you know, on those road signs as hunched over or, you know, "I've fallen, and I can't get up." And those images are ageist and ableist. They are stereotypes, right? We have this image of, like, all these bad things are going to happen. One day, we're going to wake up old and not get out of bed. That's not how it happens. But there are overlaps between age and ability.

Most of the big disability advocates out there are younger, and they talk about "inspiration porn." They talk about "supercrips." That's their word. It's not a community with which I identify, although I'm learning to, depending on



my circumstance. I'm happy to talk about that because I am almost completely deaf in one ear. And as mentioned, my shoulder ain't what it used to be. So supercrips are the people providing the inspiration porn.

There is a very powerful equivalent in Ageland, which is the proverbial octogenarian jumping out of airplanes or doing the limbo, performing some, you know, physical feat, which is fine. They inspire people, but they are outliers. And it's important to contextualize them like that.

I don't ever want to jump out of an airplane. You know, I can't do the limbo. I couldn't do the limbo when I was 20, right? So, it's really important to tell the more complicated, messy story of the messy middle and where most of us, by definition, will end up, but that's not a sexy headline. Most of us will muddle through okay, encountering difficulties and learning how to cope. And I'm already yawning by the time I get to the end of the sentence. You know, the story of the, you know, the 53-year-old struck down by early onset Alzheimer's or the 90-year-old who climbs Mount Everest. That's a story, but it is a misleading story.

**Robert Espinoza: Ashton, what are the most common misconceptions about older people?**

**Ashton Applewhite:** I mean, all prejudices rely on stereotypes, right? The assumption is that all members of a group are alike or share a whole bunch of traits. They're always wrong. But they are especially fact-free and erroneous when it comes to age because the longer we live, the more different from one another we become, right? Every newborn is unique, but every 15-year-old, you know... 15-year-olds have far more in common physically, developmentally, and socially than 45-year-olds who are way more alike than 77-year-olds and so on out, right? So, any generalization about older or younger people can never be true. But we age at different rates, physically, socially, cognitively. So, the older the person, the less their age reveals about them.

So, you know, it's one of the reasons I dislike the term "the elderly" so much. Elderly wouldn't be a bad word in a non-ageist world, but it does smack of frailty,

so it reinforces that old equals frail thing. But my real problem with "the elderly" is the "the" in front of it because it implies that very old people belong to some homogenous group when nothing could be further from the truth.

**Robert Espinoza: One of the concepts I love in your book is that you draw the connection between ageism and capitalism. And these are big concepts. I want to focus on two areas. One is the role of ageism in the workplace and how it affects older adults, especially women. The other is in relation to the billions of dollars generated by the anti-aging industry, these skincare products, and even the phrase "anti-aging." Can you help us understand how capitalism creates and reinforces ageism?**

**Ashton Applewhite:** Capitalism requires companies to grow, grow, and grow. And they do that by employing people and ultimately exploiting people, exploiting the planet. Prejudice is fantastic for capitalism. It requires it to grow because all prejudice pits people against each other. As long, for example, if women are arguing about who's a better mom—a stay-at-home mom or someone who works outside the home—they are not joining forces to close the gender wage gap so that women can choose whether or not to stay home. Ageism in the workplace: it's not just an old-person problem. It is why people may look askance at a younger person in a job.

I mean, I was in the hospital overnight for an emergency room visit, and I remember looking around and thinking, "Wow, all these doctors look about 12," and, you know, which was an ageist thought. Honestly, my next thought was, "No, you're old. I'm old. That's why they look so young relative to me," which is real. That is not a factual observation. They know what they're doing, as indeed they did, right? But ageism in employment. Ageism is any judgment on the basis of age, including you're too young, you know, to know what you're doing around my bedside. And it enables employers to take advantage of workers at both ends of the spectrum by getting rid of older workers on the premise that they're too expensive. They may be paid more, but they bring additional value in terms of experience and additional knowledge, and they may wish to transition gradually out of the workplace, right?



# BREAKING DOWN AGEISM

## Understanding Its Impact on Society and Older Adults

**93.4%**

of people age 50 to 80 report regularly experiencing at least 1 of 10 forms of everyday ageism.

**What is ageism?** "Ageism refers to the stereotypes (how we think), prejudice (how we feel), and discrimination (how we act) towards others or oneself based on age.

Ageism is everywhere: from our institutions and relationships to ourselves. For example, ageism is in policies that support healthcare rationing by age, practices that limit younger people's opportunities to contribute to decision-making in the workplace, patronizing behavior used in interactions with older and younger people, and in self-limiting behavior, which can stem from internalized stereotypes about what a person of a given age can be or do." ~ **World Health Organization**

### EXAMPLES OF AGEISM

#### In the Workplace

- "Refusing to hire people over or under a certain age
- Asking for someone's age at a job interview when it is not relevant to the work
- Enacting policies that unfairly privilege one age group over another
- Viewing older people as out of touch, less productive, or stuck in their ways
- Viewing younger people as unskilled, irresponsible, or untrustworthy
- Bullying or harassment"

#### In Personal Relationships

- "Treating family members as though they are invisible, unintelligent, or expendable based on their age
- Making ageist jokes that imply someone is less valuable or less worthy of respect, based on their age
- Making offensive generalizations about a specific generation, e.g., that millennials are entitled
- Disregarding someone's concerns or wishes due to their age"

Young people have a hard time getting started because people look at them and say, "What could you know at your age?" A lot. But it benefits capitalism because workers can't pit young against old, ambitious woman A against ambitious woman B. It is a system that prioritizes profit over people. I know I'm the millionth person to say that, and I feel really, really sorry for all the good-hearted people trying to deliver care whose hands are tied by for-profit companies trying to pinch pennies.

**Robert Espinoza: I want to shift to solutions and what it means to reimagine aging and to challenge ageism. In your book, you write that aging experts are "either invested in a deficit model of aging, in other words, helping the frail and needy age, or its misleading opposite, successful aging." You write, "I hope to set an example of radical aging." What does radical aging mean for you, and how can we incorporate it into our long-term care system?**

**Ashton Applewhite:** Well, I wonder if I would say that today because it seems a little immodest. You know, my radical age may be different from someone else's, and I now have a clearer understanding of how many factors are at play that are out of our control in how we age. Although I hope to enlarge people's vision of what aging involves and the enormous possibilities. So, if that's radical, then I hope to be radical.

The deficit model of aging is the idea that aging equals decline. The successful aging model is the opposite, bringing up another way in which... the role of capitalism. No one makes money off satisfaction. If women looked in the mirror and said, it is starting to get a little saggy here, which I did just the other day in the back of an Uber. I'm not going to spend any money buying, you know, creams or plastic surgeries to "fix that," right? So the problematizing of wrinkles and the appearance of aging, and the pathologizing of age-related physical changes in your body, some of which may indeed involve a disease process, right? I'm not saying you should never take hormones or never do. I'm not a physician. But look hard at who is selling what.

Great quote from a scholar named Amos Wilson: If you want to understand any

problem in America, don't look at who suffers from it—look at who profits from it. The successful model and, giant air quotes, hope you can hear the wind going around the mic, around "successful," because how could you fail at aging, right? If you wake up in the morning, you are aging successfully. Congratulations. We don't fail at childhood. We don't fail at midlife, but right away, you have a goal.

And then you're looking around and seeing: how are the other people doing? And to age successfully in this model. You may not need to jump out of airplanes, but which, P.S., costs a lot of money, as do all those skin creams, right? So, a lot of these "remedies" for these "problems" involved spending money. You age successfully if you are a woman by appearing to not age. And you age successfully as a man by moving like your younger self. A woman has to look like her younger self, and a man has to move like it. That's highly gendered, of course, and there's crossover, thank god, and more crossover all the time.

You know, I'm 70. I started the book when I was 55, the project. And when I turned 70, that's a big number. And I am starting to think about how much time I have left. And how I want to spend it.

I hope to do what I can to forestall disability to stay as active as I can. I have a lot of privilege. I can afford a good doctor. I have a stable housing situation. I have a partner who is, knock on wood, in good health. But, you know, everything could change tomorrow. So, I tell people it is impossible to read my book without feeling better about the years ahead. Partly, that's just because we know most of us think it will all be awful. Just look around you at the older people instead of past us or instead of with fear.

If you're afraid, think about what you're afraid of, right? Look at these fears because once you look at fear, it automatically becomes less fearsome once it has a shape. Once it's tangible and doesn't embody all our darkest imaginings. Right? And when we do that, we open the door to a more nuanced and accurate version of what might lie ahead for us and safeguard our health.

The World Health Organization launched a global campaign to combat ageism in 2021 because they acknowledge that the

biggest barrier to living not just longer lives, which await us all, but healthier, spending more of those lives healthier, is ageism. Not clean water, not going to the gym. Ageism, between our ears and in the world around us. Learning all this has made me a more active participant in my aging, less afraid, and more open to learning from how people around me are doing it, which is everybody. Behaviors that I think are great that I want to emulate. Behaviors that I think are not great that I want to avoid, right? Open, you know, come out of your foxhole and look around,

**Robert Espinoza: I spoke with Ashton in April of this year [2023], about a month before the Society for Human Resource Management released a study showing that nearly one in three U.S. workers report feeling unfairly treated because of their age at some point in their careers. And among these workers, 72 percent said it made them feel like quitting their jobs.**

Ageism is shaping the political discourse, as well. The widespread use of terms like "gerontocracy" to describe how certain politicians are "too old to be in office," as if age alone dictates the kinds of attributes that are needed for these roles, like relationship-building skills, emotional maturity, policy knowledge, critical thinking capacity, and ethical standards, to name a few.

While it's true that cognitive decline comes with aging, that decline does not correspond with any specific age, nor can we assume to know someone's true cognitive skills or their physical and mental health profiles simply by the number of years they have been on this planet. Any doctor will confirm this point.

What I appreciate about the ageism discourse is that it begs us to consider how every single one of us has internalized problematic messages about aging and how we can inadvertently spread them throughout our daily lives, workplaces, and society. All these ideas profoundly harm older people, yet, ironically, that describes most of us, now or not too far in the future.

The next time an ageist idea crosses our minds or comes out of our mouths, we

**should ask ourselves, "Where did I learn that concept? And will that notion make it easier for me to age with dignity?"**



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EPISODE 3

# WHY DID THE COVID-19 CRISIS RAVAGE NURSING HOMES?

Since its onset, COVID-19 has disproportionately impacted nursing home residents, primarily because they live with the types of medical conditions that put them at risk of severe complications. But there are other important reasons that the nursing home sector remains vulnerable to health crises.

In this episode of *A Question of Care*, Robert Espinoza spoke with David Grabowski, a professor at the Department of Health Care Policy at Harvard Medical School. They touched on the history of nursing homes, what COVID-19 has revealed about this sector, and how it should move forward from this crisis.



**David C. Grabowski, PhD,**  
Professor, Department of  
Health Care Policy at  
Harvard Medical School

**Robert Espinoza:** Before diving into today's topic, it's important to understand who the average nursing home resident is. During the height of the pandemic, we got used to seeing news stories about nursing home residents dying in droves, making it easy to forget sometimes that these residents are also individuals. They are our parents, grandparents, aunts and uncles, and our friends. To help contextualize our conversation, David described for us who makes up the average nursing home resident.

**David Grabowski:** Nursing home residents have a pretty broad range of backgrounds and care needs. But your typical nursing home resident... it's usually a she, but he or she is in their 80s. They have, oftentimes, both limitations in terms of cognitive functioning and physical functioning, high rates of Alzheimer's and related

dementia, need for assistance with activities of daily living, such as bathing and dressing and toileting and walking. And they also have quite a high level of medical complexity. And that means that there's a real onus on coordinating both their long-term care needs, but also their medical needs as well.

And I should add one more point: that there are, within nursing homes, two very distinct types of residents. So the resident that I just described is a long-stay resident. He or she would be receiving long-term care services. They would expect to be there for the rest of their lives. Their care would typically be financed by the Medicaid program, with some out-of-pocket private payment.

There's a second type of nursing home resident, and that's a short-stay individual, post-acute, who has come from the hospital, would typically spend 4-to-5 weeks in a nursing home before transitioning back to the community.

The final point is that there is some blurriness with these groups in that sometimes an individual comes to a nursing home as a "short-stayer" and transitions into a "long-stayer." And then sometimes you have long-stayers that will need to go to the hospital and then come back for rehab and therapy and for a short period of time be post-acute patients. But the post-acute patients tend to be younger. They tend to have higher cognitive and physical functioning, but they have really sort of short-term needs around therapy and rehab.

**Robert Espinoza: In 2020, Professor Grabowski was appointed by the National Academies of Sciences, Engineering, and Medicine to its Committee on the Quality of Care in Nursing Homes, which examined how the U.S. delivers, finances, regulates, and measures the quality of nursing home care. The committee released its final report in 2022 and offered a brief history of nursing homes, which helps partially explain why they are the way they are today. It notes how families were historically responsible for delivering care to older adults and people with disabilities. However, due to various federal policy developments in the 20th century and medical advances, nursing homes began mirroring, "an**

**acute care model with a medical focus." So what has this medical setting model meant for both nursing home residents and the sector overall?**

**David Grabowski:** You'd be hard-pressed to find anyone that wants to live in a hospital, yet many of the nursing homes around the country look like a hospital and have the same setup. You know, the nurse's station at the end of the hallway, the long linoleum flooring with rooms on either side, and two-to-four residents per room.

This might work in a hospital. And I stress the word "might." This does not work for a nursing home, whereas I just described, these are individuals, the long-stayers that are going to be there for the rest of their lives, months and years in this setting. This is not very home-like. It's over-medicalized.

That's not to say we don't need clinical care. I said earlier, there's incredible medical complexity, but we need to balance the nursing part of the nursing home with the home side. And this history sort of growing out of hospitals that, you know, these large institutional buildings that have a real medical feel hasn't served our residents well in the sense that it is their home and the quality of life has really suffered in these buildings. And unfortunately, many times they haven't done either the nursing, the medical side of it, or the quality-of-life and home-like aspect of nursing home care very well either. But by over-medicalizing the delivery of services, it's created a setting where it's very institutional and not really about the needs of the residents. It's much more about the sort of need of the nursing home itself. And that hasn't, once again, served nursing home residents very well.

**Robert Espinoza: David, under what conditions would you live in a nursing home?**

**David Grabowski:** So, like everybody else, I would prefer to receive my long-term care in the community. But I would move to a nursing home if I believed my quality of life would be better there. And there are points for all of us where nursing home care may offer the set of services that I would need. And so, I think there's often been this zero-sum way of looking at nursing home care vis-à-vis home- and



community-based services.

I'm a huge supporter of home- and community-based services. Everybody who can receive services in the home and the community should receive services in the home and the community. But it's not realistic to think that all of us are going to be able to do that. Sometimes quality of life and quality of caregivers' lives are going to be higher if a family member receives services in a nursing home.

I'd have some pretty strong feelings, as you can imagine, Robert, on what kind of nursing home I would want to enter into. But I think I would do it if I felt my quality of life in the community was at a point where it was no longer manageable, and I could have a higher quality of life in a nursing home.

**Robert Espinoza: If someone you loved needed to reside in a nursing home, what would you advise them?**

**David Grabowski:** I would really want them to seek out a place where both the nursing and the home are strong. And so let's start with the nursing. Nursing is all about staff. Staff are the backbone of any nursing home in the U.S. One of the things I like to say is that a nursing home is only as good as its staff, and that's really true. You need a place with a strong nursing model. We can talk more about this point, but I really believe you want a place where, one, it's well-staffed, the staff are retained and want to be there for the long term. The staff are valued and empowered.

And then the home side of it. I want to find a place that doesn't feel like that big institution we described earlier. I want to find a place where it really feels like my home. It's my room. I can wake up when I want. I can go into my room and spend time doing the things that I want to do or spend time with others. If you come into my room as a staff member, you knock on the door. That's my space. I'm empowered the same way the staff in the building are empowered. If we treat residents and staff with the dignity that both deserve, that's the kind of nursing home I want my family member to choose.

Unfortunately, there aren't many of those out there, and that's the real struggle. And that's why we set out for that National Academies report for you

described—to really transform nursing homes. Because most nursing homes in the U.S. today don't have strong nursing and don't have strong home-like models. That needs to change.

**Robert Espinoza: In the nursing home report we're discussing, the committee lays out various factors that influence the quality of care in nursing homes, and I want to review a few of them for your thoughts. Since the beginning of COVID-19, nursing home residents and staff have been disproportionately impacted by this pandemic. And we know that one of the reasons nursing home residents are vulnerable to this virus is that they often have the medical conditions that put them at risk of severe complications.**

**But there are other reasons, as well. Why has the nursing home sector been so ravaged by this pandemic?**

**David Grabowski:** We termed it in one of the papers we wrote, "a perfect storm." If you wanted to design a sector that would be most impacted by COVID, you would design the U.S. nursing home sector. And unfortunately, it was that perfect storm.

So, one, this is somebody's home. So it's very different than a hospital. And because it's a home, it has a very different feel in terms of personal protective equipment and the ways in which social distancing might occur.

The second part of this: you have staff members kind of coming in and out every day. Some of these staff live in areas that had huge outbreaks in the community. Those staff are moving room to room. Sometimes these staff are working across different buildings because we're not paying them a living wage. And so they're having to work across multiple settings.

Third, we have these residents packed into a very small space here, oftentimes sharing rooms, two, three, four residents in a room together. If one of them gets COVID, how do we keep the other roommates from ultimately getting COVID?

And then, four, you do have older, frailer individuals. Once they have COVID... This is not like, you know, high-school-age kids getting COVID. This is our frailest and most vulnerable individuals in the country getting COVID.



And so, what could have been just maybe needing to be in bed for a few days if you were in the community—for them meant hospitalization and death. And so that's why we saw the numbers that we did see in this setting. It was just really hard to keep [COVID-19] out. And then once in nursing homes, it was really hard to keep from spreading.

We did a study with a Massachusetts nursing home where we looked at them back in April 2020. I was involved in an effort here in Massachusetts to try to identify nursing homes with no COVID where we might create, you know, an environment where we can move other residents into the building. We were trying to think about COVID and non-COVID environments.

And we went into this building. Not a single resident was reporting any COVID symptoms in early April. We tested every resident. It turned out nearly half of the residents in the building had COVID without even knowing in early April. By the end of the month, roughly two-thirds of the residents by that point had COVID. Thirty of them had died by the end of April 2020.

That's how quickly we would go from no symptoms to two weeks later, having 30 residents having died from COVID. Things move very quickly. And the challenge was, at least back in 2020, was really, how do we keep it out and then how do we contain it? And this was not a setting well-equipped to either keep it out or contain it.

**Robert Espinoza: The report notes that about 1.2 million people help provide care and maintain nursing homes, including nurses, nursing assistants, administrators, and many others. And yet most direct care in nursing homes is provided by nursing assistants. And nursing homes have struggled to recruit and retain these workers to the point that many say it's now a crisis.**

**What are the workforce challenges facing nursing homes, and what would it take to convince a nursing assistant to take and stay in this occupation?**

**David Grabowski:** Yeah, it's a really interesting workforce, and I try to explain this to colleagues that study other parts of the healthcare system. Nursing homes have, you know,

physicians and registered nurses and licensed practical nurses. But the bulk of the workforce are these certified nurse aides.

They're doing most of the direct caregiving. So, most of those tasks we've been discussing—bathing, dressing, toileting, walking, feeding the residents—that's the certified nurse aides or CNAs.

How do we recruit these individuals? The first thing is pay—pay and benefits. I always start by saying that's necessary but not sufficient. And let me explain what I mean by that. Nobody wants to take these jobs if they're not well-compensated and well-supported. But that's not going to be enough to bring a lot of new individuals into these jobs and then keep them in these jobs.

Nursing homes compete with a lot of other parts of the economy. It's not just other healthcare settings. An RN might move from a nursing home to a hospital or physician's office. A CNA might move from working in a nursing home to Amazon or Walmart or McDonald's. There's other jobs, and if those other jobs are paying more, and by the way, in some ways, may be easier and [have] better working conditions. Then it's not just about pay. So pay has to be a big part of this. We need to support the caregivers in nursing homes but that's just the first step.

The second step is really making these jobs worth having. And there have been some nursing home operators that have really changed the working conditions in nursing homes, empowering workers. A typical nursing home... You know, we have 16,000 nursing homes in the U.S. We have more nursing homes in the U.S. than Starbucks or McDonald's, and they need lots of workers. It's been hard to recruit individuals given these aren't great jobs.

And guess what? This only got harder during the pandemic. We've never valued this workforce. But during the pandemic, we wrote an op-ed for *The Washington Post*. We ran some quick calculations and discovered nursing home worker was the most dangerous job in America during the pandemic. So, on top of the low pay, the challenges, the difficulty of the work, it's also really rewarding work, so I'm not trying to say that no one should take these jobs. It's the opposite. We should

# BEHIND THE MASKS

## A Visual Overview of Nursing Homes & COVID-19

More than 15,000 nursing homes around the country house over 1.3 million residents, primarily older adults and people with disabilities. They also employ more than 448,000 nursing assistants, among other staff. Yet the COVID-19 pandemic underscored and worsened the immense challenges facing this sector. **Below are some key points.**



### Nursing Homes

15,600	Number of Nursing Homes
1.7 million	Number of Licensed Beds
\$146.9 billion	Size of Nursing Home Industry in Dollars

### Nursing Home Residents

1.3 million	Number of Nursing Home Residents
83%	Age 65 or Older
49%	Alzheimer's Disease or Other Forms of Dementia
2.2 years	Average Life Span

### Nursing Home Staff

448,000	Number of Nursing Assistants in Nursing Homes
\$17.06	Median Wage
39%	Percentage Living in or near Poverty
99%	Turnover Rate

# 167,000

nursing home residents have died from COVID-19 since the start of the pandemic



COVID-related deaths in the U.S. is a nursing home resident

# 26%

percent of nursing home staff are up to date with COVID-19 vaccines per facility

In 2022, the National Academies of Sciences, Engineering, and Medicine issued a report, *The National Imperative to Improve Nursing Home Quality*, which stated "the way that the United States, finances, delivers, and regulates care in nursing homes is ineffective, inefficient, fragmented, and unsustainable." This report examined offered various recommendations to improve this sector, organized across these areas:

**Deliver comprehensive, person-centered, equitable care that ensures residents' health, quality of life, and safety; promotes autonomy; and manages risks**

**Ensure a well-prepared, empowered, and appropriately compensated workforce**

**Increase transparency and accountability of finances, operations, and ownership**

**Create a more rational and robust financing system**

**Design a more effective and responsive system of quality assurance**

**Expand and enhance quality measurement and continuous quality improvement**

**Adopt health information technology in all nursing homes**

value the important work that's being done in these settings.

But on top of everything else—the challenges of the pandemic, the fear that a lot of residents had of getting COVID themselves and bringing it home. We lost a lot of caregivers in nursing homes. And that's something that I think we really need to revisit here as we think about nursing home policy going forward. How do we support this workforce both in terms of pay and benefits, but also working conditions that really support the important work that's occurring in these settings?

**Robert Espinoza: What I appreciate about the report is that it also looks to the future. It imagines the kinds of recommendations and policy changes that need to happen to really transform the nursing home sector. The first overarching conclusion from the report states, “The way that the U.S. finances, delivers, and regulates care in nursing homes is ineffective, inefficient, fragmented, and unsustainable.” What stands out for you from this conclusion?**

**David Grabowski:** I love that conclusion. And the part that stands out is the “unsustainable” part.

And that doesn't mean... When I say it's unsustainable, that doesn't mean it's suddenly going to get effective, efficient, and coordinated. What I mean by that, what we meant by that, was it's going to get worse. We have aging baby boomers. We need to change this now or else we're not going to have a nursing home model that's sustainable for all of us.

And I often ask that question to colleagues and friends, and when I'm speaking to different audiences. Where do you think you're getting your long term care? Where do you think you're getting your nursing home care? These are the options out there. We're not, for the most part... We have a very, I'll repeat the quote, “an ineffective, inefficient, fragmented model.” And if all of us receive our care there, we're going to have the same outcomes that older adults do today.

So, if we want better options, we need to go about creating those better options today, such as they're there for all of us. Because otherwise, it's even going to look worse in 20, 25 years after the baby

boomers have really kind of gone through their long-term care years. If we don't fix this now. We're not going to have the options for all of us going forward.

**Robert Espinoza: David, are there any developments, either in policy or practice, that give you hope regarding the nursing home sector?**

**David Grabowski:** Yeah, there's a few. So, I'm part of a group called Moving Forward. We're a coalition. I co-chair a working group on nursing, on payment and financing. But there's working groups for health information technologies, workforce staffing. There's quality of care, there's regulation. So we're trying to change all of the issues that were brought up in the National Academies report.

It's hard. This is not easy, but it's trying to take the 600 pages that we wrote and the recommendations that we made for the nursing home industry and trying to work with them and put these recommendations into practice. So, I hope listeners will want to get involved in this effort. It's a broad coalition of workers and operators and advocates and ombudsmen, and you name the role... medical directors. If there's a role in nursing homes, we have them represented in our coalition. But I'm optimistic or hopeful as you asked about. Because a lot of us want to roll up our sleeves and change things.

One of the things that's always struck me about nursing homes. I don't know that the current payment models, regulatory models, quality of care, staffing are working very well for any of the stakeholders involved. They're not working well for residents or family members. They're not working well for staff in these buildings, operators, and on and on and on. It needs to change. And so I think everyone's kind of come to the table looking to change things. It's not going to be easy.

I worry that nursing homes, although they were front-and-center during 2020 and 2021, kind of faded a little bit, and they're not still in the headlines. Maybe that's a good thing because that means that we're not seeing the case rates and the death rates.

But a lot of the factors, as we've been discussing, that led to those high case



rates, that led to those high death rates, are still present. And so I almost think, all the causal factors are still there, and this sector isn't, unfortunately, in a better position today than it was in 2019, early 2020, to withstand the next pandemic.

We really need to invest in this sector and not just for the next pandemic. But because it's in need of huge improvements. That needs to start today. I think the Moving Forward Coalition is an effort to try to do that slowly, to try to make change.

**Robert Espinoza: If you could do anything to transform the nursing home sector, what would you do?**

**David Grabowski:** I'm a big fan of the Greenhouse Model. So, let me quickly explain Greenhouse. I'm certain many of your listeners are already aware of this model. But it's basically a small-house model where 8 to 12 older adults live in a home together. Each has their own room. The residents, it's really their home. They get up when they want. You knock to go into their room. They spend their days the way they want to spend it, not the way the nursing home wants them to spend it. If they want to go outside and garden during the summer months or during the spring, that's their prerogative. It's really about living a meaningful life.

The staff—it's not the hierarchical model that we see at a traditional nursing home. The staff are empowered, valued, well-paid. They take on a universal worker model there where they're cooking and doing some cleaning as well in the home. The meals are cooked right there. The elders eat around a table together.

So, you have these three components: an empowered staff, a resident-centered model, and a small home. That's the kind of transformation. In order for that model to happen, however, we need to change the kind of payment models, regulatory models. Everything around it needs to change. That's the kind of nursing home that if I was out there looking for a loved one, that's the kind of place that we would all want our loved ones to receive care. Life still has, you know, meaning in that type of environment. However, there are just so few of them, and that's the real policy failure.

**Robert Espinoza:** Both of my parents passed away in nursing homes located about 15 miles away from each other in northern Colorado. My mother died in December 2020 after having lived in the home for nearly seven years, and my father, in February of this year, passed away quietly in a hospice unit after only a few days.

The nursing homes where they spent their final moments embody both the offerings and the challenges David described in this episode—a duality that leaves many of us conflicted about the future of this sector.

On the one hand, moving into a nursing home was the only affordable option for both of my parents, given their needs, and that's a reality shared by many people who enter these settings. Despite the lack of choice, my mother raved about several of the home's staff members, from her physical therapist to the CNAs and head nurse and to the woman who drove her to dialysis three days a week. She considered these employees good friends and the facility her home despite its many flaws—frequent odors, understaffing, distasteful food options, and its hospital-like aesthetic.

But those flaws are neither episodic nor are they minor. They are part of a broader systemic failure that leaves millions of residents and frontline workers at the mercy of any crisis.

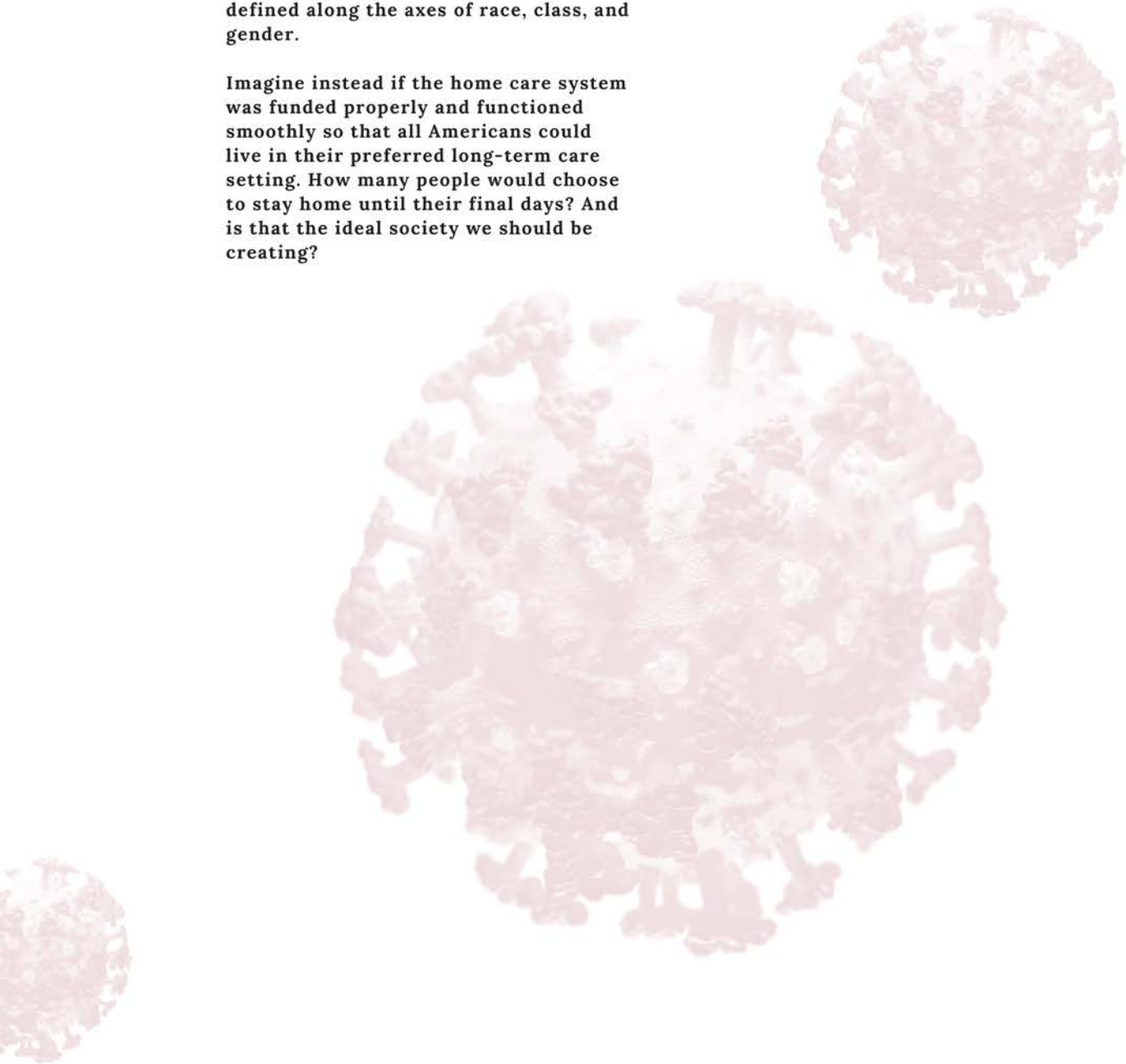
So when COVID-19 ravaged nursing homes in its first year, it revealed not just the medical frailty of many nursing home residents, but their expendability in a society that grossly devalues older adults and people with disabilities, especially if they are low-income, people of color, and women.

As David explained, nursing homes don't have enough transparency, or checks and balances, regarding who owns, and who profits from them, or how they are run. It doesn't help that government funding for any part of long-term care often leaves these homes unsafe and without adequate staffing. They continue to feel less like homes and more like hospitals.

Ultimately, while nursing homes might be the best option in our current system

for certain individuals, this assertion is less a fixed reality and more a sad commentary on our policy priorities as a country. Many people don't have an option to choose anything other than a nursing home, and those inequities are defined along the axes of race, class, and gender.

Imagine instead if the home care system was funded properly and functioned smoothly so that all Americans could live in their preferred long-term care setting. How many people would choose to stay home until their final days? And is that the ideal society we should be creating?



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EPISODE 4

# IS OUR CARE SYSTEM RACIALLY SEGREGATED?

Research shows that Black nursing home residents are more often physically restrained and hospitalized than their peers and are less likely to have their pain treated. Black and Latinx people also make up a disproportionate number of cases and deaths from COVID-19. Why is that?

In this episode of *A Question of Care*, Robert Espinoza sat down with Dr. Ruqaiijah Yearby, a professor at the Moritz College of Law at Ohio State University. They spoke about systemic racism in long-term care, the unique challenges of Black older people, and what it would take to make aging a more positive experience for communities of color.



**Ruqaiijah Yearby, JD,**  
Inaugural Kara J. Trott  
Professor in Law, Moritz  
College of Law and Faculty  
Affiliate, Kirwan Institute,  
The Ohio State University

**Robert Espinoza:** Much of Dr. Yearby's career has centered on racial disparities in healthcare and the role that systemic racism plays in the process. Systemic racism, sometimes referred to by experts as "structural racism," describes the pervasive and deeply embedded ways that racism exists within the policies, institutions, and culture of a society. As Dr. Yearby defines it...

**Dr. Ruqaiijah Yearby:** Systemic racism refers to a complex array of social structures, interpersonal interactions, and beliefs used to create a hierarchy that categorizes people into superior and inferior racial and ethnic groups. Traditionally, Black, Indigenous, and Latino Americans have been deemed as inferior ethnic groups compared to White Americans.

We can see this play out at different levels. We have cultural racism, which is



the presence of societal beliefs and customs that promote the concept that White culture is superior. That often feeds into the other levels, including structural racism, which refers to the ways that laws are used to provide advantages to Whites while disadvantaging racial and ethnic minorities by limiting their equal access to key resources such as jobs, such as housing and healthcare.

And if you couple the belief that cultural racism, [that] White culture is superior, then it allows for laws to reinforce that through the denial of equal access to housing, healthcare, and unemployment.

**Robert Espinoza: Ruqaiijah, can you offer a few examples of how systemic racism has harmed older people of color in particular?**

**Dr. Ruqaiijah Yearby:** Well, when we look at structural racism on one level, on one category of systemic racism, we see it harming older people of color in the ways that we regulate and the ways that we fund long-term care, particularly the ways that business owners are allowed to not provide equal staffing, equal financing, and equal resources in nursing homes that provide care to predominantly Black and Latino individuals. We also see it in the ways that the laws do not require that we even know who owns nursing homes or long-term care facilities to be able to ensure that they're putting in the same amount of money in predominantly Black and Latino nursing homes that they do in White nursing homes. Furthermore, the law does not require the same amount of financing or anti-discrimination regulation when it comes to assisted living facilities.

And so what does that look like? That usually means that people of color who are in long-term [care] facilities do not receive adequate care. And as you know, that also means that people of color who work in these nursing homes don't receive adequate pay to take care of the residents in long-term [care] facilities, whether it be a nursing home or assisted living facility.

**Robert Espinoza: Ruqaiijah, are there any stories that illustrate the impact that systemic racism has had on people of color accessing long-term care?**

**Dr. Ruqaiijah Yearby:** I think the story that comes to mind is the case of Ms. Belle Carney, an African American woman with Alzheimer's disease. She sought admission to a nursing home in Tennessee, but she was never able to find it. This is a case from the 1990s where Tennessee basically allowed nursing homes to decide who they wanted to admit. And because she was a Medicaid recipient, the recipient of the nursing home would get paid less.

And [as] a Black woman, she was not able to find nursing home care. She did bring a lawsuit with another woman challenging these policies, and what is exciting about the case is that, as a result of the case, Tennessee changed its admission policies to track the race of those seeking admission to nursing homes to see if they were being racially discriminated against.

Unfortunately, when it got to the federal courts, they did not rule on race-based denial of care. And so even though there was a great change in Tennessee, the rest of the country still has problems with the denial of people seeking nursing home care, particularly racial and ethnic minorities.

**Robert Espinoza: As we discuss systemic racism and long-term care, it's also important that we talk about racism's impact on home care workers and nursing assistants. These are workers who support older adults and people with disabilities in their homes, nursing homes, assisted living, and other residential care settings.**

**Historically, this workforce has been predominantly made up of women, people of color, and immigrants, and their jobs and livelihoods have long been hurt by racist policies in the U.S. A recent article written by Dr. Yearby titled "The Social Determinants of Health, Health Disparities and Health Justice," focused on these particular issues, tracking current day racial disparities for this workforce to racist policy back to slavery,**

**Dr. Ruqaiijah Yearby:** Because when we think of slavery, we think part of it is that they were forced to provide care to people in their homes. After slavery, laws limited the ability of racial and ethnigiving direct care to people in their homes.



Even when those laws were rolled back, when you see many of the bills passed during the New Deal era, which was also the Jim Crow era, they did not apply to direct care workers, people providing care to people in their homes. What this means is that the workers did not qualify for minimum wage. They do not get overtime. They are often also not protected by health and safety protections. So many of the workers suffer injuries in people's homes. They're not covered by any [workers'] compensation. They still are not paid beyond minimum wage. This is because many of these occupations were not covered, but that goes back to the racist practices during slavery.

**Robert Espinoza:** A few years ago, you and I and a few other experts collaborated on an article for the *Journal of the American Medical Directors Association* titled "Addressing Systemic Racism in Nursing Homes." We wrote this article during the height of the COVID-19 pandemic, which was disproportionately impacting people of color, older people, people with disabilities, and people with severe illness.

**I want to explore a few points in this article because I get asked about it often, and I think it's made quite an impact. The first is a study that the article cited. The study found that when risk factors for illness, hospitalization, and death were investigated, the proportion of Black residents in a nursing home was found to increase the probability of a COVID-19 outbreak by anywhere from 45% to 300%. Why have Black people borne the brunt of this pandemic?**

**Dr. Ruqaiijah Yearby:** Well, it's because of longstanding systemic racism, particularly structural racism, which again goes back to the underfunding of resources for people of color, particularly Black individuals in long-term care.

So many of the long-term care facilities are understaffed. They do not adopt effective infection control. And so when you talk about COVID-19 spreading, it will be rampant among these facilities where you don't have enough staff or infection control. You also see Black individuals, Latinos, and immigrants bearing the brunt because many of them

were essential workers. And so some people got to stay at home, and those were disproportionately White individuals who could work from home, whereas Black individuals, Latinos, and immigrants had to continue to go to work. But we're not provided with PPE, masks, infection control. We're not always able to stay six feet apart. And so you see high rates of COVID-19 infection among these individuals and communities.

**Robert Espinoza:** The article also describes how access to long-term care and its quality is "fundamentally tied to geography." For communities of color, this often means that where you live, whether it's by zip code or by a neighborhood, will usually determine how you live, especially when you're older and you need paid support. How did this country create a racially segregated long-term care system?

**Dr. Ruqaiijah Yearby:** It did so the same way that it created racially segregated neighborhoods, right? Long-term care facilities are viewed as a person's house. And so we've allowed some of the same racist policies in terms of segregation. In fact, when the majority of funding was put into place in the 1940s to fund the creation of the long-term care system that we have now, it explicitly allowed for a separate and unequal system. And so many states created long-term care facilities that did not include Black, Latino, or Asian individuals. And that continues today, even though Title VI of the Civil Rights Act of 1964 was passed to ensure that individuals would not be discriminated against when applying to enter long-term care facilities.

You have a quote by government officials saying that they did not want to apply Title VI to long-term care facilities because they did not want to force White individuals to live next to Black individuals. So, to force them to have to live in a long-term care facility with a Black individual, and unfortunately, that continues today. We've never made it fair regarding admission policies within long-term care facilities. And so many facilities remain racially segregated.

**Robert Espinoza:** In addition to that segregation, the article also talks about how Black residents are being treated, and then there are a number of startling findings in this regard. They find that



# SEPARATE & UNJUST

## How Systemic Racism Creates Harmful Disadvantages for Black Older People

A society that values older people would create affordable opportunities for everyone to access long-term care in their preferred setting. Unfortunately, the U.S. is far from this ideal. Below are four ways systemic racism has long created a racially segregated and unfair long-term care system for Black older people.

### The Legacy of Discrimination

**Generations of racist policies and systems, beginning with slavery and the Jim Crow era, have caused immense harm to Black people's lives.** They have historically faced limited employment opportunities and have been relegated to low-wage job sectors. As a result, they have earned less and often cannot save enough for the future, including retirement and long-term care support.

**\$0.63**

Pay gap between every dollar paid to Black women for every dollar paid to white, non-Latino men, amounting to an annual loss of ~\$21k

### Medicaid Under Attack

**Medicaid—which helps low-income people pay for health and long-term care—has been depleted by government officials guided by the racialized myth that its beneficiaries are too lazy to work and often exploit public benefit programs (i.e., the “welfare queen” trope of the 1980s and 1990s).** For example, baseless Medicaid work requirement policies disproportionately limit health coverage for people of color, and the general defunding of this program harms any eligible person needing either health coverage or support in the long term.

**7**

of the 10 states that have not expanded Medicaid under the Affordable Care Act are located in the South, which is home to some of the largest Black populations in the country.

### Fewer Options, More Danger

**Due to financial constraints and the high cost of home care assisted living, Black people routinely turn to nursing homes for long-term care.** They also face a higher likelihood of residing in understaffed nursing homes with inferior quality of care. These factors help explain why COVID-19 disproportionately impacted Black people and nursing homes with high percentages of Blacks and Latinos.

**3.3x**

Number of COVID-19 cases and deaths in nursing homes where more than 40% of residents were Black and Latino, compared to nursing homes with high proportions of White residents

### Substandard Jobs, Short Staffing

**A history of racist policies has also harmed the direct care workforce that supports Black people (and their counterparts) in long-term care.** For example, in the 1930s, Congress excluded this predominantly female, people-of-color workforce from critical wage and overtime protections, an exclusion that has devalued this job for decades. Every day, these workers must survive financially in low-wage jobs with inadequate training, insufficient advancement opportunities, and a lack of proper recognition and support. As a result, many of them leave this field and employers can't fill job openings. And when this workforce struggles, so do the people they support.

**53%**

Percentage of women of color home care workers living in or near poverty, compared to 38% of white men



**when compared with White residents, Black residents are more often physically restrained, more frequently develop pressure ulcers, less often receive influenza vaccines, less often have pain treated, are more frequently hospitalized, and report a lower quality of life. What's behind these gross inequities?**

**Dr. Ruqaiijah Yearby:** A little bit of cultural racism and structural racism, right? So cultural racism—it's a belief that Black patients don't feel the same pain as White patients, that they have a higher threshold, that they seek drugs. So, we don't want to treat their pain when they acknowledge the pain. Structural racism: I talked about it in terms of the ways that laws are used to advantage Whites, but it's also about policies.

And so when we go back to training nurses and doctors around pressure ulcers, they often are not trained on how they show up on dark skin. And so many times, you have staff who can't even identify when people with dark skin have pressure ulcers. And so you don't get them being identified in dark-skinned patients until it's become too late.

And so we need to change not only the culturally racist beliefs that Black patients or racial and ethnic minorities experience pain differently, but we also need to train people on different colors of skin so they understand that they are having a pressure ulcer sooner rather than later.

**Robert Espinoza: Ruqaiijah, I want to shift the conversation to interventions and solutions. What types of anti-racist policies should this country adopt to support people of color in the long-term care system?**

**Dr. Ruqaiijah Yearby:** So, I have been working with a group of individuals, Professors Lindsay Wiley, Seema Mohapatra, Brietta Clark, and Emily Benfer, on the Health Justice model. And what this does is move us past health equity [to] looking at how to address inequities experienced by communities through community-led and systems-led intervention.

And so, what this includes [are] three components. One: truth and reconciliation. I think in our article, what we tried to identify is that we have to be

truthful about the continuation of racism and long-term care and employment that is harming individuals. And to do so, we also need to make space for the individuals to talk about their experiences. During COVID-19, many nursing home workers, direct care workers, and patients experienced a lot of harm because of the lack of support they got from the government. And so we need to talk about that and rectify it.

The second is that the government needs to change the laws and policies so that there are structural changes. One of the key things that we talked about in our article and that you talked about in your group is that direct care workers still do not receive equal living wages, paid sick leave, and all the things they need. Some states have tried to move forward with giving power to those workers in Washington, and others have negotiated with unions of direct care workers. We need to make that a standard.

And finally, communities need to drive the change. And so if we want to improve health care for racial and ethnic minorities, then they need to be the ones at the table helping to design this because they are the ones who know the problems, right? And so if we want to improve our long-term care system, it shouldn't just be to push more people into nursing homes. It should be listening to people who want to stay at home. What do they need to be able to stay at home? What do the workers need to be able to give them the best care within their homes? And so, that's what we need to do.

**Robert Espinoza: More broadly, what would it take to make aging a more positive experience for communities of color?**

**Dr. Ruqaiijah Yearby:** Several things. I think one is that we cannot just try to fix the problem at the point that people are elderly, right? It's a long-term issue. And so that means that we need to ensure that throughout the lifespan, racial and ethnic minorities have equal access to healthcare so that by the time they age, they don't experience so much disability and harm, right? They don't need so much help. We need to ensure that they, throughout their lifespan, are getting equal wages so that by the time they retire, they have money to put forward to long-term care.



And finally, we need to invest in a long-term care system. We cannot just expect that people somehow are going to be able to pay for it all on their own and that people who are giving care to people who are in the long-term care system can afford to not have health insurance, can afford to not make living wages, can afford to not have paid sick leave.

So, we have to invest in the long-term care system just as we have begun to invest in the infrastructure in this country. We need to get more young people to become workers in this area. But to do that, we have to invest a lot of money.

**Robert Espinoza:** Thank you, Ruqaiijah. I want to end on a hopeful note. What gives you hope these days as it relates to racial justice?

**Dr. Ruqaiijah Yearby:** What gives me hope is that finally, we have an acknowledgment at the federal level about the harm that has been done.

Seeing President Biden issuing a number of executive orders and focusing on racial justice is exciting to me. But they are doing so in a way that is bringing everybody in because everybody has been harmed by racial injustice. It's not just Asians, Blacks, Indigenous, Latino Americans. It's also White Americans. And it's not just individuals from the race focus, right? It's also about Black individuals with disabilities not being able to get equal access to the care that they need in long-term [care] facilities.

And so I am hopeful that we can work together to improve this country. But to do so, we have to rectify past harms.

**Robert Espinoza:** Though my conversation with Dr. Yearby ends on a positive note, there is profoundly concerning evidence all around us that racism has no intention of stopping. In fact, it might be on the rise.

In late June of this year [2023], a conservative Supreme Court gutted affirmative action in college admissions, which had intended for decades to promote racial and ethnic diversity in colleges and universities and to provide more opportunities to students of color who had historically been underrepresented in higher education.

Consider also that Florida's public schools will now teach that slavery in this country was of "personal benefit to some enslaved people." A decision that *The Washington Post* described as "obscene revisionism."

Frighteningly, the White supremacist movement continues to grow, especially over digital media. They are guided by ideas such as the genetic superiority of a supposed White race and the fear that immigrants of color are threatening the economy and the culture of White America, among other egregious beliefs.

And it isn't just White supremacists who hold these beliefs. According to 2019\* data from the Pew Research Center, 32 percent of White adults in the U.S. believe that greater attention to the history of slavery and racism is wrong. That's one in three White adults in this country.

Yet perhaps these developments emphasize how we should prioritize racial justice, both to turn the tide on growing racist sentiment in this country and to support older people of color at a time when they want to enjoy their lives and their families as much as possible.

Our latter years should be filled with joy, not hardship, community, not discrimination, and fairness, not inequitable treatment. However, we are nowhere near this reality, especially if you're an older person of color.

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## EPISODE 5

# WHAT'S IT LIKE TO REACH OLDER AGE WHEN YOU'RE LGBTQ+?

Due to a lifetime of discrimination, millions of LGBTQ+ older adults struggle economically and face entrenched barriers in employment, housing, and healthcare. They also routinely encounter discrimination in long-term care environments, and the law rarely supports their urgent needs.

In this episode of *A Question of Care*, Robert Espinoza spoke with Michael Adams, CEO at SAGE - Advocacy and Services for LGBTQ+ Elders. They discussed the unique challenges facing LGBTQ+ older people, Michael's own experiences, and what our country should do to improve the current situation.



**Michael Adams**, Chief Executive Officer, SAGE - (Advocacy and Services for LGBTQ+ Elders)

**Robert Espinoza:** Many of us recognize the term "LGBTQ," but for those who don't, it stands for lesbian, gay, bisexual, transgender, and queer. These terms capture the spectrum of today's sexual and gender identities, from being sexually attracted to one or multiple genders to the word "transgender," which, according to the National Center for Transgender Equality, refers to people "whose gender identity is different from the gender they were thought to be at birth." And if you add a plus sign to the term "LGBTQ," it allows for even more variety of identity and expression, which is constantly evolving.

However, what's less familiar to most people are the unique experiences and challenges of LGBTQ older adults. The best available research, which is far from perfect, shows there are at least 2.4 million LGBTQ older people over age



**50 in the United States. And this number will more than double to 5 million by 2030.**

**Because this community has faced discrimination throughout their lives and to the present day, many of them suffer financially, physically, and emotionally. Researchers have shown high rates of poverty and disproportionately high rates of diabetes, asthma, heart disease, HIV, cancer, and more among older people who are LGBTQ. Likewise, depression is more than two times as common among LGBTQ+ older adults than among the general older adult population.**

**Michael Adams:** This particular older population we're talking about is a group of older adults who, among other things, tend to have very high levels of social isolation and thin support networks. A big part of the reason for that is differences in family structure—LGBTQ+ older adults are four times less likely to be parents than older adults in general, twice as likely to be single and to grow old living alone, and much more likely to be disconnected from their families of origin—all of which adds up to very high levels of social isolation and thin support networks.

And then we layer on top of that a variety of other challenges: significantly higher levels of poverty than older Americans in general, as a population; significantly greater challenges with health conditions and health disparities; and unfortunately, a significant level of discrimination in eldercare, elder services, and older adult housing that many LGBTQ older adults face.

**Robert Espinoza: You've often talked about how discrimination in long-term care settings and under the law affects LGBTQ older adults. What's the impact of that discrimination?**

**Michael Adams:** The impact of discrimination on LGBTQ older people is huge, and to start with one example in the area of housing. The fact is that housing is a particular challenge for many older folks in our country in terms of affordability and availability. So, this is a huge challenge for older Americans in general.

But then throw into the mix that research indicates that almost 50 percent of

LGBTQ+ older adults are subjected to discrimination in some form if they apply for senior rental housing. That's an astonishingly high level of discrimination. And so what that means is that the challenges that older Americans face, generally speaking, are significantly exacerbated for LGBTQ+ older adults in housing. And often, what we hear from SAGE's constituents is that the place that they feel least safe, least protected from discrimination and harassment, is actually where they live. So that's just one example of how discrimination plays out and where the lack of available and consistent protections against discrimination is a serious problem.

But it's not the only place. As you referenced, Robert, in the long-term care sector, there has been significant, anecdotal evidence over the years of discrimination against LGBTQ older folks. And that also is a real challenge because when we get to the point later in life where folks need to avail themselves of long-term care, often with that comes a much higher level of dependence and vulnerability, and therefore, fears of discrimination are much greater. So much so that what we often hear from older folks and LGBTQ communities is that they feel compelled to go back into the closet to access long-term care, eldercare, and elder services because they're just afraid. They're just afraid of being mistreated because of who they are at this late and vulnerable stage of their lives.

**Robert Espinoza: One of the subjects that we'll be exploring on this podcast is the subject of ageism. And I'm curious if you can talk about how ageism affects LGBTQ+ people in particular.**

**Michael Adams:** I mean, certainly, ageism affects older folks in general, in terms of assumptions about people's inability to contribute and ability to have agency in the decisions they make. But I think in the context of LGBTQ older folks, we see some quite particular manifestations, and some of that shows up with regards to assumptions about sexuality, for example, which is not unique to LGBTQ older folks. Still, I think it has a particular significance for LGBTQ people.

Often, there is an ageist assumption made that older people aren't sexual beings, right? And that's not true. And we know from life experience and data that's

not true. But it's often an assumption. That assumption in the context of LGBTQ people can be particularly damaging because, for many people, so much of their identity and stepping into their own as LGBTQ people was embracing their sexuality, embracing themselves as sexual beings, and being essentially denied by society or by the community that recognition as sexual beings is significant for LGBTQ people.

There's also something that I've seen over time that is really harmful to LGBTQ older folks—the ageist assumption that old people don't matter, that they're not relevant, that we're unable to make contributions and make a difference.

And here again, that ageist assumption is not unique to LGBTQ older folks. It has a particular impact because if you think about it, we're talking about the Stonewall generation. We're talking about the folks who actually built LGBTQ communities, who fought for the rights that LGBTQ people have, who actually transformed the LGBTQ experience. And to be given the message by society and, frankly, by our own community sometimes, that as older people, we're not relevant, we're not important.

But it's not just about attitudes. You know, it's also about structures and structural ageism, and there are plenty of examples of how that manifests for LGBTQ people in very meaningful ways.

**Robert Espinoza: What are the structures of ageism facing LGBTQ older people? First, many of them face discrimination in housing and long-term care settings, such as nursing homes and assisted living. The law also leaves them behind, or they are targeted by it. For example, many people live in parts of the country without enough non-discrimination protections in employment, housing, or public accommodations. And it is only getting worse. Earlier this year, the ACLU tracked more than 400 anti-LGBTQ bills at the state level. They include proposals that would allow a business or a hospital to turn away a person simply because of their sexuality or gender identity, and much more.**

**Another structural challenge is that LGBTQ older adults often don't feel comfortable in queer spaces, such as a**

**bar or online dating site, which can be unfriendly to older people. Or they don't feel comfortable in aging spaces, such as a senior center, which can be homophobic and transphobic at times. And if it's hard for LGBTQ older adults as a whole, it's even more challenging for those who are people of color, transgender and non-binary, bisexual, and living with HIV and AIDS. In turn, these groups are often the most overlooked by the public discourse, which is precisely how inequality works.**

**And yet, it might also be that these experiences have created a profound, personal, and political agency among LGBTQ older adults—resilience, for lack of a better word.**

**We've been talking a lot about the hardship that LGBTQ+ older adults have faced and are facing. Yet, we also know that research shows that hardship and a lifetime of discrimination can also build resilience. And I'm curious: what has your work at SAGE revealed in this regard?**

**Michael Adams:** I'm so glad you asked that question, Robert, because I think that it's probably one of the things that's most exciting to talk about and to think about and to aspire to, right, is the extraordinary resilience that we see among LGBTQ+ older folks.

We're talking about people who lived through generations where it was downright life-threatening to be who they were. That's still true today, particularly in certain conservative parts of the country and for some folks everywhere. But it was even more true and a more generalizable starker truth in the 1950s, 1960s, and 1970s when many of our older folks came of age.

And what is so inspiring and energizing is to see the resilience, the power that comes from struggling through difficult times—from struggling to come out, from struggling to survive a pandemic. And now I'm talking about the AIDS pandemic, right, before we even got to COVID. You know, LGBTQ folks who did live through the AIDS epidemic, in some ways, had more tools, had more resilience, had more to work with in navigating through COVID, but we see that play out in so many different contexts.



# PAVING THE WAY

## 6 Milestones in LGBTQ+ History that Shaped Today's Older Generation

### Pathologizing Homosexuality

The American Psychiatric Association labels homosexuality a "sociopathic personality disturbance," and the Immigration Act bans "homosexuals and perverts" from entering the U.S. In the following decades, many LGBTQ+ people are subjected to electroconvulsive therapy, lobotomies, and "aversion therapy" to "cure" their same-sex desires. **As a result of a lifetime of discrimination, LGBTQ+ older adults struggle with high rates of anxiety, depression, substance use disorders, and other health issues.**



Urvashi Vaid at The White House, 1990. © Associated Press

### The AIDS Crisis

The U.S. Centers for Disease Control and Prevention reports the first case of what later becomes known as AIDS (Acquired Immune Deficiency Syndrome). Between then and 2021, more than 700,000 people die from HIV-related illness, mainly men who have sex with men, transgender people, and people of color. **The current generation of older adults with HIV lived through this era and now require targeted support for their intense clinical and social needs.**

The gay rights movement is not a party. It is not a lifestyle. It is not a hair style. It is not a fad or a fringe or a sickness. It is not about sin or salvation. The gay rights movement is an integral part of the American promise of freedom.

URVASHI VAID

**Since 2015:** In *Obergefell v. Hodges*, SCOTUS affirms same-sex marriage as a Constitutional right, and five years later, *Bostock v. Clayton County* extends federal antidiscrimination protections to LGBTQ+ workers. The following year, President Biden revokes the 2019 military ban on (most) transgender Americans. Despite this progress, more than 500 anti-LGBTQ+ bills have been introduced in 2023, far more than previous years, and research shows ongoing discrimination and lack of support for LGBTQ+ people, including older adults, which compromises their safety and well-being.

### Workplace Discrimination

President Eisenhower's order bans gay federal employees, citing security concerns. **Workplace discrimination and harassment persist, hindering the careers, earnings, and retirement savings of LGBTQ+ people and creating profound poverty and economic insecurity for many LGBTQ+ older adults.**



© Grey Villet, The UK Picture, Getty Images

### Activism & Rights

Led by LGBTQ+ transgender women of color like Marsha P. Johnson and Sylvia Rivera, the Stonewall Rebellion sparks the contemporary LGBTQ+ civil rights movement. It politicizes activists for generations, forming a local, state, and national LGBTQ+ infrastructure. However, this sector remains malnourished; in 2020, foundation funding for LGBTQ+ causes amounted to only 23 cents for every \$100 awarded. **Merely 3% of this \$201 million allocated supported groups assisting LGBTQ+ older adults.**

70%

**Percentage increase in hate crimes against LGBTQ+ individuals between 2020 and 2022.**

Source: Federal Bureau of Investigation

### Hate Violence

Matthew Shepard, a 21-year-old college student in Laramie, Wyoming, is brutally murdered by two men, sparking a national movement against hate crimes aimed disproportionately at LGBTQ+ people, particularly transgender women of color. **Violence and trauma are two major reasons why LGBTQ+ older people face significant mental and physical health challenges.**

1950

1952

1969

1981

1998



In the context of activism, it was fascinating to see in 2016 and 2017 when a fiercely dramatic anti-LGBTQ president took over this country, and similar forces controlled Congress for the first couple of years. What I saw was that it was the elders in our community who were least afraid, who were most energized, and who were most ready to pick up and push and fight against that. Again, this is because of the resilience built over decades.

**Robert Espinoza: It's impossible to talk about today's older LGBTQ adults without discussing some of the significant historical moments they have lived through and the political moments they have led. Dr. Karen Frederickson Goldson at the University of Washington proposes that we consider this demographic to comprise three distinct generations.**

The oldest segment is part of "the invisible generation," born around 1920, living through the Depression and WWII, and growing up when these issues were virtually absent from the public conversation. The second generation is "the silenced generation," born in the 1930s and 1940s. They grew up when LGBTQ workers were openly targeted by employers and the government and when homosexuality was deemed a mental illness by groups like the American Psychological Association. This was also the era when electric shock therapy was considered a treatment for homosexuality. And yet, in contrast, The Kinsey Report described sexuality as a spectrum and much more widespread than imagined.

The third generation is "the Pride generation," born after the 1950s and 1960s and growing up during the Stonewall era. Stonewall was named after a rebellion against routine police raids in New York City that sparked a national movement and the gradual decriminalization of sodomy laws.

All three generations lived through the AIDS epidemic, which ravaged and helped politicize this population in the 1980s. And since then, these generations have witnessed and contributed to the growth of a national LGBTQ political infrastructure, major political victories, and disappointing setbacks.

**Now stop for a moment and consider: what has this lifetime of events—the horror, the progress, and the retrenchment—done to the physical, emotional, and economic lives of today's LGBTQ older adults? The answer? A lot.**

**You turned 60 not too long ago. What is going through your mind about how you want to live at this stage of your life?**

**Michael Adams:** Yeah, it's been interesting for me coming into this age. I'm now 61, and I joke that I have the kind of job that the older I get, the more qualified I am for the job.

So, one thing I would say is that it's really interesting to me to be the head of this organization as somebody in my sixties, right, versus somebody in my forties. Because the work of SAGE is much more immediately personal to me than it was when I was younger.

And as I think about what it means to get older for me and get older as a gay man, I don't know why, but for some reason, I often find myself thinking about back when I was in my twenties. I was in my twenties during the worst of the AIDS epidemic, living in San Francisco at the time. And it was for a lot of us, for me and my friends, we wondered if we would get old. I think many of us thought we would never get old. Just because it was so dangerous and so unknown, and if we got AIDS—and that seemed like inevitable at some point that we all would—there was no way to survive that. And so it's not an overstatement to say that me and my friends and people of my generation had to fight to get old, right?

We had to fight to win that right to get old. And now, as I am aging, and I am in my 60s, I feel a lot of gratitude for the fact that I'm here, that I have the opportunity to live the life of an older person, an aging person, and I look forward to that. There are challenges because of the work I do with SAGE, but I also see a lot of opportunities and new chapters in life. One of the many benefits of being at SAGE is watching the people 10, 20, and 30 years older than me and seeing how they're leaning into those opportunities.

And it's pretty exciting, you know, and so I'm excited about that for me and my husband.

**Robert Espinoza: When you look at your bio, it's clear that you've had an expansive and storied career in LGBTQ+ rights dating back to the 1990s, if not earlier, working for the ACLU and Lambda Legal. Can you share a specific case or story from that time that captures what it meant to live as an LGBTQ person in those years?**

**Michael Adams:** Yeah, I had the opportunity to work on quite a number of cases during my times with the ACLU and Lambda Legal, and there was one that jumps out at me and actually in a tragic way.

I represented a man in Mississippi. It's okay to say his name because it was a public case back then. His name was David Weigand, and he had been married for a number of years. He and his wife divorced, and they had a son. His wife remarried, and his ex-wife had primary custody of their boy, and David had visitation, mostly in the summer, etc. But he was able to spend a good amount of time with the son and maintain a relationship.

And then, sadly, his ex-wife's third husband was abusive, was very physically abusive, and had substance abuse problems. And so it was a very violent household. The boy was witnessing his mom being beaten up by his stepdad, was being physically threatened by his stepdad, and was forced to call 911 repeatedly on his stepdad. He was in a very, very dangerous situation.

And so, in those circumstances, David moved the boy to come and live with him because of the really dangerous situation in the house. Recognizing that, of course, their son should maintain a relationship with both parents, but that the household he was in was just literally physically dangerous.

And that case went all the way up to the Mississippi Supreme Court in a series of horrific decisions by the Court of Appeals in the state and eventually by the Mississippi Supreme Court that didn't care what the specifics were about, the circumstances. It didn't care about the fact that the boy was in danger.

They cared about only one thing: the fact that the father was gay. And the fact that the father was gay meant that according

to six of the nine members of that court, by definition, his household was not fit for the boy to stay in any ongoing way. And so that boy was kept in this highly dangerous situation.

And I've never forgotten about that case. That would never, ever have been the result of a case like that if it were not for David's sexual orientation, and it's indicative of the circumstances, certainly, that gay and lesbian parents faced back then. But that was just indicative of the larger challenge in society at the time, where LGBTQ people were just really thought of as second-class citizens and barely human beings in many contexts.

**Robert Espinoza: This is the story that haunts me to this day. Several years ago, a former colleague told me about an older gay man who had just moved into a nursing home in St. Louis. His adult children lived outside of Missouri and had never approved of their father's sexuality and gay life partner. So, they forcibly removed him from the nursing home to another state, effectively ending his relationship with his partner.**

**Same-sex marriage wasn't legal then. And vicious acts against nursing home residents, unfortunately, go unresolved all the time for various reasons. But imagine being that father dragged against his will to another state by his own family. Or imagine being the partner left behind in Missouri. Where would you turn?**

**Thankfully, with all of these terrible stories, there are people like Michael and organizations like SAGE that are fighting to make the world a better place for LGBTQ+ older adults. So I asked Michael: What are you most proud of at SAGE?**

**Michael Adams:** I'm most proud of the level of visibility and celebration that we've been able to bring and support for older folks in our community.

I remember when I first joined SAGE, what I heard over and over and over again from elders in our community, elders coming to SAGE, is that we're invisible. Nobody sees us. SAGE's tagline is "We refuse to be invisible," and it was [created as] a refutation of the notion that nobody cared and nobody saw elders in



our community.

And back just a couple of years into my time at SAGE, we did a public awareness campaign, an advertising campaign on subways and buses in New York City that was nothing more than beautiful images of queer elders. Just to make the point that we're here, right? Our elders are here, visible, and living beautiful lives that people should be paying attention to, which was radical at that time. Because older folks in our community were so invisible. And almost 20 years later, while there's still a lot of work to do, there's a tremendously greater amount of visibility and awareness about elders and LGBTQ communities.

And then, looking beyond the community, I think more and more so, we're seeing attention in the larger aging and eldercare space being paid to LGBTQ+ older folks.

**Robert Espinoza: I want to ask you one final question. If a younger LGBTQ person were to ask you, What is it like to reach older age? What would you tell them?**

**Michael Adams:** I would say, first of all, and I referenced this earlier, that it's a gift. It's a gift that none of us should assume we're going to have. It's something to be cherished—to have the opportunity to get old. And that even though there are a lot of wonderful, incredibly fun things about being young, and I loved so much about what I experienced as a young, gay man, there's also a lot of amazing things about being older.

I have a level of peace and self-awareness in my life at the age of 61 that was nowhere in sight for me when I was a younger person, and I wouldn't trade either for the other. I mean, I loved my younger years, but I love these years, as well. So I would say cherish the opportunity, work for it, do what it takes, and keep yourself healthy so you can get old. And then when you get here, there's going to be a lot to look forward to and a lot to experience.

**Robert Espinoza: Even though I've been politically active since college, my own ageism prevented me from even**

**thinking about the needs of older people until I was in my early 30s. In 2009, I came across a press release describing a federal grant awarded to SAGE to establish the country's first-ever National Resource Center on LGBTQ aging. The center aimed to train aging providers across the country about this population and many other goals.**

**At the time, I was beginning to grow concerned about how my sister and I would support our parents as they entered their 70s and their 80s. I was soon connected to Michael Adams, SAGE's CEO, and a few months later, he hired me to lead the organization's national policy advocacy and education arm.**

**I remember Googling "LGBTQ" and "older" then and finding very little content. The LGBTQ aging field had remarkable thinkers and advocates, but their work was often localized, siloed from one another, and grossly underresourced. While researchers had produced some early, pathbreaking ideas for government reform and industry change, they had yet to be activated at the scale necessary to affect millions.**

**Fast forward to the present, and the landscape looks much different. Even though LGBTQ older adults continue to deal with immense pressures, as described in this episode, this field now has a vast network of thinkers and advocates shaping various dimensions of the health and long-term care industries.**

**Journalists, policymakers, and entertainment professionals grapple with this issue like never before. And it's less frightening, perhaps even exciting, for many older LGBTQ people to imagine their later years.**

**I often think about the greater meaning of the LGBTQ older adult experience and what it can teach our broader culture and democracy. And it boils down to this. Looking closely at the themes underpinning this population, you might see your aspirations and fears, regardless of how you identify. The need to feel safe in our homes and communities. The ability to thrive financially and in good health. The**

desire for affirmation and love. The mountains of challenges and rivers of strength that aging incurs for most of us.

And the bias codified in our laws and institutions, in our everyday thinking, because too many people refuse to see one another's humanity. Or they are afraid of what it might reveal about themselves.

The truth is that when we make life more fruitful for older LGBTQ people and remove all their barriers in this pursuit, we ultimately improve aging for everyone. Consider how a nurse who has been trained to understand the histories of queer people might also become more sensitive to the cultural identities of other elders. Or how a health clinic that offers quality care to transgender older adults might, in turn, improve its reproductive care and geriatrics expertise along the way.

A transformed, long-term care system that creates the freedom to be who we are and what we desire until our final years is a system in which all of us will flourish.

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EPISODE 6

# WHY CAN'T I FIND A HOME CARE WORKER?

Home care workers are a lifeline to millions of older adults and people with disabilities. Unfortunately, many of these workers are walking away from this sector to pursue better-paying jobs. As a result, it's nearly impossible to find and retain a highly qualified home care worker these days.

In this episode of *A Question of Care*, host Robert Espinoza spoke with Dr. Madeline Sterling, a doctor, researcher, and professor at Weill Cornell Medicine. They delved into her studies on home care workers, what they reveal about this job sector, and how the U.S. should transform these jobs to benefit everyone.



**Madeline Sterling, MD,**  
Assistant Professor of  
Medicine at Weill Cornell  
Medicine, Board-Certified  
General Internist and  
Health Services Researcher

**Robert Espinoza:** For Dr. Sterling, going into the medical field came to her naturally, driven by a passion to care for patients.

**Dr. Madeline Sterling:** I always wanted to be a primary care doctor. I love taking care of people over the continuum of their lives, getting to know them, helping them through ups and downs, managing chronic conditions from age 18 upwards to a hundred, and, you know, also getting to know their families. It's a privilege.

I love that I can have an impact at multiple levels. I love that I can care for someone on a Monday morning and work on their diabetes and help them get that sugar down. And then I love that in the afternoon, I can do some novel research, whether it's on home health or the social determinants of health or cardiovascular disease, and have an impact that way.

**Robert Espinoza:** Much of Dr. Sterling's published research has focused on home care workers, vital to millions of families. Unfortunately, news stories about home care agencies or individuals struggling to find homecare workers are published almost daily. Before we ask Dr. Sterling for her thoughts on this trend, let's lay out a few points.

By definition, home care workers assist older adults and people with disabilities in their private homes with daily tasks, such as dressing, bathing, and eating. Personal care aides may also help clients with meal preparation, housekeeping tasks, errands, and more. In contrast, home health aides perform specific clinical tasks, such as wound care and blood pressure readings, under the supervision of a licensed professional.

In 2021, the home care workforce comprised 2.6 million workers, according to PHI, a national group focused on this workforce, and, for full disclosure, my [previous] employer. When you include other direct care workers, such as residential care aides and nursing assistants, this direct care workforce is larger than any other occupation in the country.

Why is that? The number of Americans who need care, primarily people aged 65 and older, is ballooning and because people are living longer. Care is also more complex and diverse than before, which creates more need for skilled direct care workers. Even though the data shows that the home care workforce surges annually, I asked Dr. Sterling why so many people find themselves confronted with the question, why can't I find a home care worker?

**Dr. Madeline Sterling:** There are a couple of things. As you know, we have a national shortage problem right now. This has always been a tough job. Having enough workers and retaining those in the jobs is hard. So, there is a supply problem and a retention problem.

From the patient and family point of view, it's a real struggle to find a home care worker because no one's explaining how to navigate home care. Unfortunately, patients and families don't think about home care early enough. You know, oftentimes, physicians themselves

do not know how to help people with the process, or they are not even sure of what people qualify for and what their needs are.

I see this all the time in practice, where a patient's doing okay, and then, all of a sudden, they get sick, and a crisis ensues, and that's when they start thinking about a home care worker. And by that point, it becomes a scramble. Unlike in the hospital system or other places of care where you have somebody walking you through how to obtain services or get them in the home, home health, for various reasons, is separate. And the average patient and family don't have the resources to get through the system and obtain a home care worker.

And so it's a couple of levels. I think there's the shortage issue with the workforce and then on the sort of medical side of it and the patient family side, a lack of understanding and a lack of resources and infrastructure to get the worker that would be a good fit or what they need in the home at the right time.

**Robert Espinoza:** People often misunderstand these workers. Dr. Sterling, what does a home care worker do, and who makes up this workforce?

**Dr. Madeline Sterling:** Sure, so I like to say that they do it all. Home care workers are trained and certified healthcare professionals.

One piece of confusion is that the name differs depending on the payment structure and the state you're in. And so there is confusion in that sense. Still, regardless of whether you're a home health aide, personal care aide, or attendant, they are providing hands-on, day-in, day-out care, assistance with activities of daily living, bathing, dressing, getting up and about, meal preparation, all the way to aspects of medical care.

We've shown through our research that there's this public perception that they perform low-skilled care. And, when we've surveyed households across New York State and the country, we found that the majority of families say workers are doing way more than personal care. They're helping with a lot of medical tasks. And so there's absolutely a lack of awareness of what they do, but the bottom line is that workers are in the



home, not just doing personal care, but helping with many aspects of medical care and providing a lot of value.

**Robert Espinoza: As Dr. Sterling described, home care workers are vital to the lives of their clients, often fulfilling a wide range of physical, social, and emotional needs.**

**For example, they might be helping people move safely throughout their days, offering emotional support, problem-solving with family members, or managing complex conditions such as Alzheimer's or heart disease.**

**Despite the popular misconception that this work is low-skilled, it takes significant training for home care workers to acquire the right skills and knowledge. However, training is grossly inadequate for these workers. While home health aides must undergo at least 75 hours of training based on federal law, personal care aides have no federal training requirements, and states are all over the place regarding training standards for these workers.**

**Dr. Madeline Sterling:** One home care worker in my practice has shown me the value of the workforce. Her name is Marie, and she has been a long-time home health aide for one of my patients who has a variety of chronic conditions, including cardiovascular and osteoarthritis. She's had spine surgery.

And this worker is simply amazing. She comes to every visit with my patient, and they do the visit together with me. She brings a notepad and conveys all of the things that happened during the week that I need to know about. When was my patient's appetite not great? You know, what were the side effects of that medication we started a week ago?

What's been going on in terms of her other doctor visits? Oftentimes, it's these little insights. A few weeks ago, she told me my patient's balance wasn't great. And that was really helpful. We then did a neurologic exam in the clinic. We tried to figure out what was going on, and we then referred her for testing.

And I wouldn't have necessarily picked up on that. Again, I'm not the one in the

home all day. And so, if it weren't for this home care worker, I wouldn't have the complete picture. And I have so many patients where that's the case. This is a prime example of when the patient allows; it's wonderful to include the worker if that's feasible. And ask them a question or two.

And this can be very simple. Doctors need that much training on this. It's simply a matter of the patient saying this today and then looking over to the homecare worker and saying, Is there anything else you'd want to add? Especially as more families, households, and patients will be utilizing home care workers to age in place.

**Robert Espinoza: What advice would you offer other doctors to strengthen the relationship between their office and the home care worker?**

**Dr. Madeline Sterling:** There are three key things that physicians can do.

The first is to be aware that when someone comes to the visit, oftentimes they might not have gotten there alone. And so there may be someone in the waiting room, whether it's a family member, that spouse, the daughter, whoever it is, the paid home care worker. That person may have a great deal of knowledge and understanding of that patient, which could aid in the visit and offer some new data on what's going on. And so again, it is always up to the patient whether that person can be included, but if so, I would consider incorporating it.

The second piece of advice is if you have another caregiver in the visit, let's say it's a family member or a paid care worker. You should ask them questions. They have a tremendous amount of understanding and appreciation of the care or symptoms that may be going on in the home. So ask them what they notice. Very simple questions. What do you notice? What are some things we should talk about today that haven't come up already? What do you think are the patient's biggest challenges in managing their health or in getting around? Open-ended questions like that set the stage for the sharing of important information.

# FLEEING THE SECTOR

## Why Home Care Workers Leave Their Jobs in Drove

About 2.8 million home care workers support older adults and people with disabilities, ensuring these individuals can live independently and with dignity. However, despite the critical roles and growing numbers of home care workers, they face immense pressures. Here are three major challenges facing this essential workforce.

1

### Home care jobs don't pay enough, and better ones exist elsewhere.

Persistently low wages force many of these primarily female, people of color workers into poverty. It doesn't help that they can find higher-paying jobs in the fast food and retail industries, as two examples, which draw workers from the same labor pool.

### Home care work is widely misunderstood as low-skilled.

In fact, these roles require significant skill and knowledge, and this work takes a significant toll on workers' physical and emotional well-being.

3

### Inadequate training and a dearth of career growth opportunities characterize home care jobs.

Federal mandates don't apply to all home care workers, and training regulations vary widely across states. Moreover, career advancement is rare in this job sector. For many, the home care job functions more as a paycheck than a recognized profession.

## WHAT WE MUST DO

1

### More Funding & Transparency

Home care workers need a living wage, their employers need adequate funding with transparency mandates for how it's spent, and long-term care needs a new financing system.

2

### A Transformed Job

A high-quality job for home care workers must include effective training attuned to the complex needs of today's home care clientele, viable career paths, and other features of a good job.

3

### Innovation Rooted in Workers' Voices

To support workers and facilitate how employers recruit and retain them, properly-tested innovations are sorely needed. But they must be informed by what workers want and experience.



The third piece of advice is to empower whoever it is in the home. Empower them to convey what's going on. If they notice a change, they may be the first to notice it. The first person to notice that, you know, Mrs. Jones is having chest pain, or she's having more swelling today in her legs. Empower them to call for help when they need to. That may be calling the home care agency. That may be encouraging the patient to call the doctor but empowering them to say, You know what, you've been trained to observe and advise, and I want you to do that. I want you to be a partner in the care of this person. That goes a long way.

**Robert Espinoza: Much of your published research examines the home healthcare workforce supporting people with heart disease. You found that home care workers increasingly provide care for people living with heart failure at home, either immediately after leaving the hospital or in the long term. Yet, your research has also revealed that home care workers often find the topic of heart failure frightening and unpredictable. They offer this support without much training in heart failure, and they can feel poorly supported by other healthcare professionals, especially when their clients' symptoms get worse.**

**What interests you about home care workers and the topic of heart failure?**

**Dr. Madeline Sterling:** I saw that a lot of adults with cardiovascular disease tend to be older and have a lot of comorbidities.

And these are tough illnesses to manage at home. And so I began to see in my clinical practice that a lot of my patients were, of course, asking their families for help, but often that didn't seem like enough, and they needed help from paid home care workers.

And I have to say, this got me thinking, you know, I never thought I'd be making a whole research career in home health. But I saw once we got out there in the field and interviewed patients and workers about what they're doing. I thought, oh my goodness, in all my training in medicine, no one mentioned this workforce. And my gosh, they're

doing a lot. We saw that they were helping patients get to doctor's appointments, reminding them to take medications, helping prepare low-fat Mediterranean-style diets, weighing them, and taking blood pressure. All these activities we know in medicine are important to managing those symptoms. And I thought we had to study this. We have to show what the contributions to care are.

And then, of course, are there gaps? Are there things where workers are doing and contributing but may need more training? Or, are they providing this care, and the system needs to be made aware of it because we have yet to measure it and show the value? And that's where I thought to myself, we need to do a lot of research here. There's a lot to unpack because these workers are, especially for chronic cardiovascular disease, where outcomes are poor, so patients are in and out of the hospital frequently. Quality of life can be really bad. And so, here's a workforce waiting in the wings already in the home.

I saw an untapped opportunity to not only show the value but almost prove it scientifically.

**Robert Espinoza: Has your research revealed anything surprising about the nature of home care jobs?**

**Dr. Madeline Sterling:** You read all the time, and my work has shown that this is a really tough job. The wages are poor. Conditions can be challenging. The hours are erratic. And yet, what surprises me over and over again is workers have this calling for it. Workers are passionate about helping people, and the same passion drives many of us into health care.

And what always surprises me but also makes me smile is that despite some challenging circumstances, you generally have a workforce with high job satisfaction. And much of that when we go out and ask them about that, they always say, I'm here because I care about this patient or this client. I want them to do well. It's a calling. And there's so much good here, and people need to know about this.

**Robert Espinoza:** Despite the emotional rewards that many home care workers report receiving from their daily work. These workers also face numerous challenges that make it difficult to make ends meet and stay in these jobs.

For example, the median wage for these workers in 2021 was about \$14 an hour. However, because many of them are relegated to part-time work by their employers or the economy, the median annual income that year was about \$19,000. As a result, 43 percent of these workers live in low-income households, and more than half receive some form of public assistance.

Home care workers also struggle with inadequate training or advancement opportunities. They lack recognition and respect both by the health sector and society. And because this workforce is made up predominantly of women, people of color, and immigrants, they must navigate the widespread bias and discrimination that are too often leveled at those populations.

One of the answers lies in understanding how doctors and nurses relate to home care workers.

Dr. Sterling, you published a study in February 2020 examining the workflow of home health care among people discharged home after being in the hospital with heart failure. You found, "The roles of home health aides and agency nurses were unclear to physicians, patients, and family members alike." One physician remarked, "I don't have a clear grasp of how the system works. I don't know exactly where the aides are coming from. The whole process is confusing."

**Why is that? Why do clinicians and so many others misunderstand the roles and responsibilities of home care workers?**

**Dr. Madeline Sterling:** I think we haven't been trained. So, first off, in a typical medical curriculum, unless you're going to do a geriatrics fellowship, the majority of doctors are not made aware of all the people who help patients at home. So that's the first thing. And that needs to change, right? We have 75 percent of older adults who want to age in place, and it can't all come at the backs of family caregivers who are already stressed and overwhelmed and have

conditions of their own. We need a paid workforce that can help. And so the first step is [recognizing] there's a lack of awareness because they haven't been taught about it.

The second thing that makes it challenging is that the care is being delivered in an environment that's separate. The home is a separate place of care. Only recently, COVID may have helped with some of this. Only recently have we seen that other models of care don't happen, you know, that aren't tied to the hospital or the clinic. We saw during COVID—and there have been studies that show [this]—that if you got home health care after COVID, you did better in terms of meaningful outcomes.

And so [it's important to make] the medical system and traditional team-based care in the hospital and clinic aware that there are other providers in the home that have meaningful insights about patients. Their observations can be truly impactful if we just had a way to connect them better.

**Robert Espinoza:** In July 2022, you co-authored an issue brief for the Center for Home Care Policy and Research at VNS Health in New York, the largest not-for-profit home and community-based healthcare organization in the country. This brief examined the catastrophe of the COVID-19 pandemic concerning the home healthcare workforce and pandemic preparedness.

**What are the key lessons from this brief, and how should they inform the healthcare sector as we prepare for the next pandemic or health crisis?**

**Dr. Madeline Sterling:** I was so honored to be involved in that work. This was work led by VNS Health. And I think key lessons were: this workforce went through hell and high water. They were on the front lines day in, day out, and often, you know, putting their health at risk to care for people. And often, that lack of awareness and underappreciation really came through.

As we saw early in the pandemic, at least here in New York City. There was a huge celebration for all of these various healthcare providers. I mean, we were clapping and pots and pans every night. And yet, if you go out and talk to workers, they feel that they were out



there and, again, not seen. Their contributions are not seen or valued.

So the first thing is that the pandemic has taught us we have a workforce that has rolled up their sleeves. This was not a job you could do from home, and they were essential. And in future pandemics, they need to be classified as that and have all the protections that other essential workers have.

The second thing we saw from the policy arena and the work with VNS is that many stakeholders needed to be at the table to make change for the workforce and home care agencies.

**Robert Espinoza: How were home care agencies affected?**

**Dr. Madeline Sterling:** It wasn't just the workers that experienced challenges. Home care agencies experienced challenges. Again, unlike the healthcare system or the hospital system, where there's a sense of coordinated activities, home care is fragmented; it's not connected; it's out over there.

And so, unfortunately, when a pandemic happened, we saw a lack of coordination. It wasn't clear who was going to supply all the supplies and PPE we needed. Was it the city? Was it the state? Was it the federal government? Were agencies? We saw workers themselves buying supplies. Take that one example, and you can see how a lack of coordination among a variety of stakeholders led to inefficiencies. Moving forward, there needs to be more concerted effort and more policies to protect the workforce.

There were policies, but often, they were policies for family caregivers and essential workers. And then there were always loopholes where not all the workforce received the protections and pay they needed. And so, you know, we learned a lot. My hope is we can take the good forward and then learn from maybe the not-so-optimal moving to the. Hopefully, we won't have a future pandemic, but if there is one, maybe you can take those lessons learned looking forward.

**Robert Espinoza: If one of your colleagues were to ask you why home care workers are important to the health care system, what would you tell them?**

**Dr. Madeline Sterling:** I would tell them that I see a patient for 20 minutes a day, and the rest of the time, they're at home. And, you know, what happens there matters a lot for their health. And so if a patient has a home care worker, I view that as an asset.

And we need to be, as a system, not only valuing what they do but working on ways to integrate what's happening back to other healthcare providers like myself. That would be key, and that is where we need to head.

**Robert Espinoza: If you had the power to change how home care workers are recognized and supported, what would you do?**

**Dr. Madeline Sterling:** Pay them? It's wages, wages, wages. They do not do low-skilled work. These are really hard jobs, and they need to be fairly compensated. As a society, we need to do that. So, any policies that can strengthen the workforce, recognize what they do, build in ways to increase minimum wage policy, protections, hazard pay for the next pandemic, benefits, health insurance—all these things that allow the workers to do their job and do it well. I think that would not only benefit the workforce but it would improve the quality of care delivered and, ultimately, patient outcomes.

**Robert Espinoza: When I describe the plight of home care workers to my friends or audiences in different parts of the country, the most common question is: why are these valuable jobs for home care workers so inadequate?**

**I respond first with the most evident reasons. These jobs are invisible to most people and often wrongly understood as low-skilled. Then, I tell them employers vary in how they support these workers. Some know what to do but need more resources, while others need help recruiting and retaining workers. Overall, the sector needs more transparency in spending public funds without overburdening employers with paperwork.**

**And I explain how our country's public financing system for long-term care, which is Medicaid, is financially strained and politically attacked, which prevents many employers from doing right by these workers.**

But the core of this problem, as with so many other issues today, rests within the confines of history and can largely be explained through the lens of injustice. The truth is that direct care jobs are inadequate because the people who make up most of this workforce—women, people of color, and immigrants are the same ones who have always borne the brunt of history's most significant inequities. For example, women, specifically women of color, have been portrayed in the sexist policy imagination as innately inclined toward caregiving. Thus, this work is seen as a labor of love and not a real job, which is a gross misconception.

Another factor is systemic racism, which has relegated people of color to low-wage sectors like direct care that routinely exploit their physical labor and then deny them a fruitful existence. And immigrants, specifically those of color, increasingly sustain this job sector and our national economy. Yet they are routinely stripped of their rights and humanity in a country that sees them either as threats or as physical bodies to fill jobs that "no one else wants," as if anyone deserves a lousy job.

The other reason these workers remain undervalued is that the people they support—older adults and people with disabilities—have long been neglected in the public and political narratives. I can't help but relive the shock and the rage of the first few months of the COVID-19 pandemic, which was ravaging nursing homes and explicitly targeting older people, people with disabilities, and people with severe health conditions. Yet all these groups were generally left out of mainstream telethons, as just one example.

The ultimate injustice is that the same people who routinely sacrifice their livelihood for our country, willingly or not, are then virtually ignored by the government and the public alike. We clap for them from our homes but don't take that applause to state and federal lawmakers to demand a fundamental transformation.

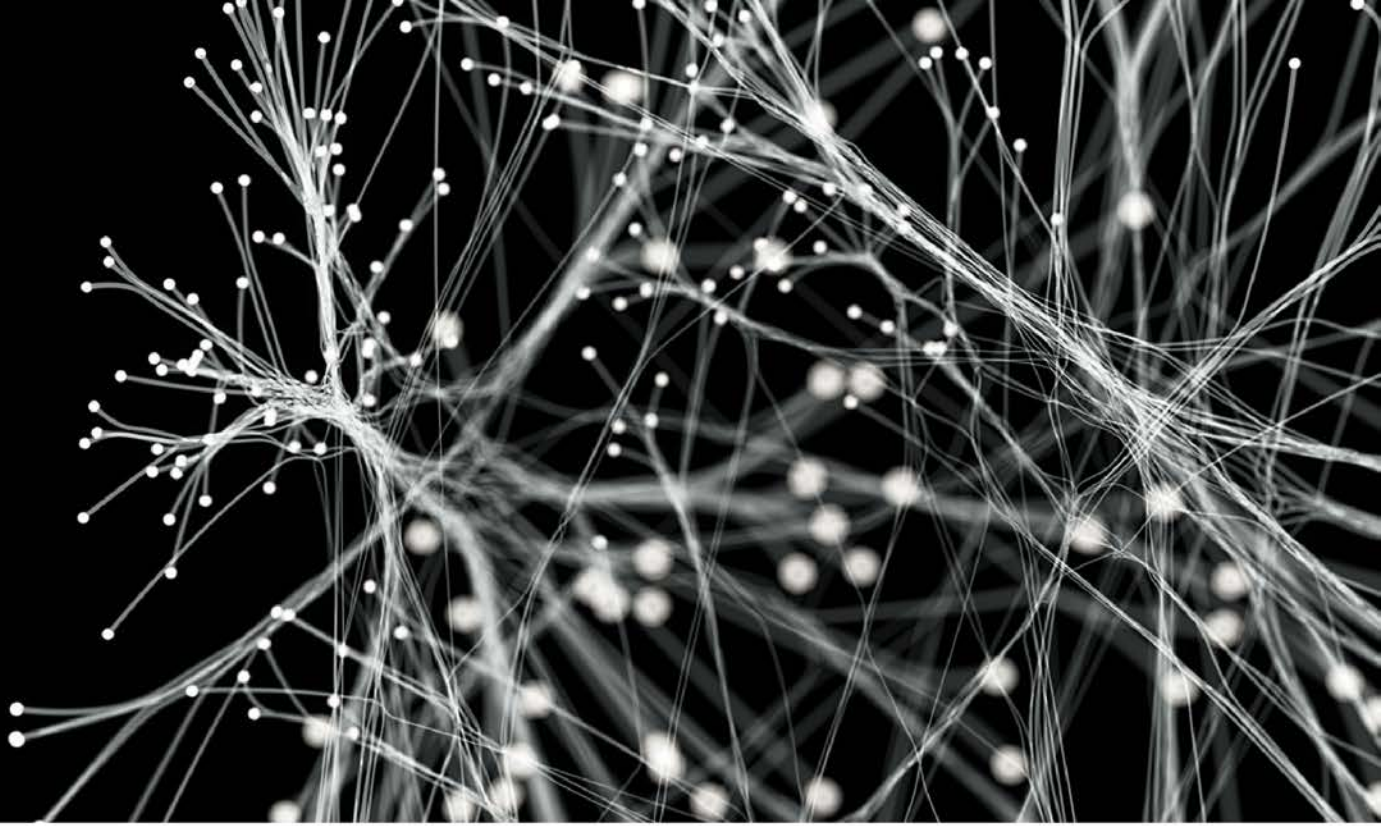
Perhaps these jobs won't be improved until more of us face the personal consequences of being unable to find a home care worker. What will you be forced to do? Who will you turn to?

And will it be too late?

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## EPISODE 7

# HOW DOES DEMENTIA AFFECT THE ENTIRE FAMILY?

In 2023, an estimated 6.7 million Americans age 65 and older are living with Alzheimer's, which will likely double to 12.7 million by 2050. Yet our health and long-term care systems aren't prepared to support this population or their families, many of whom are strained financially and emotionally.

In the seventh episode of *A Question of Care*, Robert Espinoza was joined by expert guest Jason Resendez, President and CEO at the National Alliance for Caregiving. They discussed the latest trends in dementia, its impact on millions of family caregivers, and how our country should support everyone as dementia cases continue to rise.



**Jason Resendez**, President & CEO, National Alliance for Caregiving

**Robert Espinoza:** Dementia is a subject that has impacted many of us. It exerts a profound impact in the United States, placing an emotional toll on individuals and families and straining healthcare systems and social support networks. As the older adult population grows, the prevalence of dementia-related conditions poses significant challenges, which will require more resources for caregivers, medical professionals, and researchers to alleviate the burden on everyone who's affected.

**What is dementia? As Jason defines it...**

**Jason Resendez:** Dementia is a family of symptoms related to memory loss and loss of executive function. The most predominant form of dementia, and the one that we often hear about in the news and making healthcare headlines, is Alzheimer's disease. So, it makes up a significant number of the cases of dementia or dementia caused by

Alzheimer's disease.

Alzheimer's is a progressive neurological condition that, over time, erodes executive function, erodes memory ability, and erodes an individual's ability to connect with family members, friends, and loved ones.

And because of the progressive nature of the disease, it has a tremendous impact, not just on the individual, but on the individual's family, particularly the caregiver of an individual living with dementia. And in turn, it has ripple effects throughout a family and throughout communities.

So, because of the progressive nature of Alzheimer's, for example, we see a lot of folks over time because symptoms become progressively worse... Individuals have to leave the workforce. Eventually, they need round-the-clock care. So, it's that round-the-clock care that then necessitates the active participation of a caregiver, oftentimes a family member. So that means, particularly in instances of individuals living with limited resources, individuals are having to leave the workforce to provide that care, or they're having to put their loved one in an institutionalized setting, often a nursing home.

So, it's one of those issues that has ripple effects. It has ripple effects for the individual, family, and communities. It's one of those issues that's really destabilizing families and communities, and often, it's doing that in the shadows. It's one of those things; there's a lot of stigma around dementia, particularly around Alzheimer's disease.

But we're starting to see that change. Thanks to conversations like these and the work of organizations like UsAgainstAlzheimer's, where I spent nearly a decade of my career, and leaders like you and others, helping to raise awareness and destigmatize the conversation around dementia.

**Robert Espinoza: When you look at the numbers on dementia in this country, as you know, they are startling. They show that an estimated 6.7 million Americans age 65 and older are living with Alzheimer's in 2023, which will likely double to 12.7 million by 2050. You've touched on some of these points, but what does this mean for our country as a**

**whole?**

**Jason Resendez:** Yeah, it has the effect of destabilizing families and communities. This [issue] is one of the most under-addressed health crises in this country. We're starting to see that shift. There's been a lot of progress in the fight against Alzheimer's and other dementias, but primarily Alzheimer's, over the last three decades.

And that's for good reason. Until recently, it was one of the only top 10 causes of death that had no therapeutic that could modify the underlying cause of the disease. But we're starting to see really great progress and strides in addressing the ripple effects of dementia.

When we think about what those effects are, there are tremendous economic costs associated with dementia. One, in terms of individuals leaving the workforce, but also in terms of the cost of caring for someone living with dementia or Alzheimer's, right? The costs of the Medicare and Medicaid programs are tremendous when we think about how we are navigating and how dementia is addressing or affecting individual families.

And so there's a tremendous economic cost in specific communities—in the Latino community alone, we projected that by 2060. This is a partnership with the USC Roybal Institute on Aging... By 2060, the cumulative economic impact of Alzheimer's on the Latino community would reach \$1.3 trillion. That's \$1.3 trillion of Latino wealth wiped out by one disease: Alzheimer's disease. That was a conservative estimate.

And so there's tremendous economic impact that is easy to quantify. What's not easy to quantify is the emotional toll on families and individuals. That psychological toll [it's] taking on individuals from a family or shifting the way that individuals participate in a family.

I grew up in Latino households, which are very intergenerational, right? We grow up with our family members living with us; care is part of that equation. But when you have Alzheimer's dementia, in that equation, things change. There's a lot of stigma. There's a lot of hushed conversations. There are a lot of folks leaving the workforce to provide care. So,



there are tremendous impacts when it comes to Alzheimer's and other dementias on our communities and our families.

Luckily, we're starting to see some tides shift. I'm hoping we can talk a little bit about that. But we're starting to better understand, for example, the role that prevention plays in addressing the impacts of Alzheimer's and other dementias.

We're starting to see more therapeutics come online that can help address not just the symptoms of dementia but also start to address the underlying causes of the pathology of Alzheimer's and other dementias. So it's a really exciting time, but it's one that comes after many, many, many decades of impact. Many decades of not understanding how we best effectively address this disease. And we're starting to feel that, right? When you think about caregiving and the demands and hardships of care, when you look at the data, Alzheimer's and other dementias are one of the number one reasons why folks have caregivers in this country.

**Robert Espinoza: I want to shift the conversation to the role of families and family caregivers. I think many of us have experienced what it means to be a family caregiver, including what it means to be a family caregiver with someone living with dementia. Who is the typical family caregiver, and what are their primary responsibilities and tasks?**

**Jason Resendez:** Yeah, so caregiving is one of those things that impacts all of us. When we think about who the typical caregiver is, you know, it's a mom, a son. It's a daughter. It's a neighbor, right? Caregiving manifests in so many different ways. And we all perform caregiving duty at one point in our life, either in receiving care or providing care.

But when you look at the data of the caregiver providing care today, it's a woman in her late forties providing care for a loved one, typically an older adult spouse, either a mother or father or an in-law. And in terms of the kinds of care that she's providing—she's providing care around assisting with activities of daily living, two or more activities of daily living. So, [she's] helping a care recipient get out of bed to feed, change, and move from a bed to the bathroom, for example.

Helping individuals live in the home as well—a family caregiver is doing.

We know that a large number—over 50 percent of caregivers—are helping with medical and nursing tasks. So, these are complex care tasks. It's particularly the case of dementia, where, over time, symptoms become worse, and individuals can't care for themselves. So they're providing complex care that could involve changing a catheter. It could involve feeding tubes. It could involve a number of things that are more complex.

And we see a large number of caregivers who are providing that type of care, often without any training. In fact, just 30 percent of caregivers have said that their provider has asked them: what can we do to help you provide care for your care recipient? So, most caregivers are providing complex care but providing that care without any support from the healthcare system. And so there's a lot of hardship that gets placed on the caregiver, a lot of responsibility that gets placed on the family caregiver. And that responsibility increases for individuals providing care for someone living with a serious illness like Alzheimer's.

Then you also have folks providing care for someone that might be more sick, someone recovering or in remission from cancer, for example. Or recovery from a stroke and sort of a more cyclical kind of caregiving responsibilities.

It's not easy. Care is something that we do. I think about my mom. I watched my mom raise three kids while working a full-time job and caring for my grandmother, who lived with multiple chronic conditions. She did it with extreme love and compassion for her mom and her family and was working to juggle all that. But she also did it out of necessity—there was no other option for her, right? So, just because she did it with love doesn't mean it was easy. So, there's this level of complexity involved in caregiving that caregivers are navigating every day.

**Robert Espinoza: According to the research, Black and Latino caregivers are more often in high-intensity care situations than other racial and ethnic groups. But they are also more likely to report that caregiving provides them with a sense of purpose. What lessons do you draw from those findings?**

**Jason Resendez:** I think one of the most fascinating things about that data is that when you look at a sense of purpose and emotional fulfillment for Black and Latino caregivers, we see that it might act as a buffer for some of the emotional levels of distress that we see in care. So, despite being in higher-intensity care situations [and] having worse financial impacts due to caregiving, family caregivers of color who report higher levels of fulfillment from caregiving [also] report lower levels of emotional distress.

That suggests that there's a buffer effect when it comes to levels of fulfillment and purpose from caregiving, and that speaks to resiliency, a resiliency that we have to invest in as a system. And right now, we're not doing that adequately, right? We're not prioritizing the needs of caregivers, particularly caregivers of color. We're not investing in training. We're not investing in economic opportunity. We're not investing in support. [We're not] looking at how we can support caregivers through more affordable and accessible direct care support, for example.

It's an area of research that's promising because anywhere we can see caregivers feeling emotionally fulfilled and how that might relate to addressing the mental health effects of caregiving is a positive. But [this research gap] still underscores the need to invest in supporting these caregivers and their care journeys.

**Robert Espinoza: Jason, I want to talk for a bit about solutions. As we look at the growing numbers of people living with dementia, what do you think our country should prioritize to support families?**

**Jason Resendez:** Yeah, that's a great question. I think about what if I had a magic wand. What could we do to better support family caregivers? One, from a policy perspective, there's so much more that we can be doing to build the care infrastructure in this country to make caregiving, whether it's for someone living with dementia or someone living with a serious illness, more sustainable, more dignified, and more equitable.

And when I think about what policy solutions exist to help us do that, one is policies that recognize the tremendous economic value that caregivers provide. Then, there can be policies like paid

family and medical leave. We know that 60 percent of family caregivers are navigating care while working. That's true for dementia caregivers in the same way that it's true for other caregivers. And so we have caregivers who are making the hard choice of—do I continue to provide quality care for my loved one, or do I go to work so I could put food on the table?

And without a paid family and medical leave policy, that decision can become untenable over time. We see a lot of caregivers, particularly dementia caregivers, eventually leave the workforce to provide care that disproportionately impacts women caregivers and women of color caregivers, and caregivers who have lower levels of education. So, it becomes a really urgent equity issue. Paid family leave, while it's not a silver bullet, can move us in the right direction in terms of helping support economic pathways over time for family caregivers, and research supports that. We see research in states that have passed paid family leave suggesting that, over time, it contributes to economic opportunity and stability, particularly for women.

I think another really important policy to help support dementia caregivers and caregivers over time is things like caregiver tax credits. This [policy] is particularly true for a dementia caregiver who becomes vital over the course of a disease. And in providing care, we see folks going into debt to provide care. There are a lot of out-of-pocket costs associated with caregiving; whether that's paying for things like adjustments to a home to ensure mobility or personal care things, you name it. And that all comes out of pocket and is not tax deductible. So, some legislation has been introduced to help make those caregiving expenses tax deductible, which is a step in the right direction.

I think one of the big issues is how we put in place care infrastructure that better supports the family caregiver and the person receiving care. What are those things that bridge those two issues? And that's where the direct care workforce is, and investing in our direct care workforce through better wages and other policies is critical. Because we're asking so much of the unpaid family caregiver, we need to consider what



# CARING FOR DEMENTIA

## The Vital Role of Family Caregivers in Our Country

**What is dementia?** "The Centers for Disease Control and Dementia defines it as, "not a specific disease but is rather a general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities. Alzheimer's disease is the most common type of dementia. Though dementia mostly affects older adults, it is not a part of normal aging." Between 2023 and 2050, the estimated number of people in the U.S. living with Alzheimer's will grow 90 percent from 6.7 million to 12.7 million.

### A Glimpse into Family Caregiving

Families are increasingly supporting their loved ones with dementia, and family caregivers play a particularly important role in ensuring that the person with dementia has adequate support. Yet, family caregivers—about 53 million, according to the latest research—have their own emotional pressures and financial challenges.

**Dementia Care at Home.** Each year, more than 16 million family caregivers provide over 17 billion hours of unpaid care to loved ones with Alzheimer's disease and related dementias, typically in homes.

**Reduced Quality of Life.** According to the 2022 National Strategy to Support Family Caregivers, released by the Administration for Community Living, when "family caregivers do not have training, support, and opportunities for rest and self-care, their own health, well-being, and quality of life suffer." The literature shows that dementia caregivers are at greater risk for anxiety, depression, and poorer quality of life than caregivers of people with other conditions.

**Lost Income.** Family caregivers lose \$522 billion in wages every year while caring for a close relative or friend.

Additionally, 10 million caregivers age 50 and older will lose a total of \$3 trillion in wages, pensions, retirement funds, and other benefits due to their caregiving duties

**Racial Disparities.** Black and Latinx caregivers are more often in high-intensity care situations than White and Asian American caregivers, but they also are more likely to report that caregiving provides them with a sense of purpose.

**A Long Journey.** Fifty-seven percent of family caregivers of people with Alzheimer's disease and related dementias provide care for four years or more, far more than caregivers of people with other types of conditions.

holistic support looks like and how they can better engage and be supported by direct care workers [since family caregivers] are more accessible and affordable. Make sure direct care workers are making a living wage yet are still accessible to families who need them. And so that's another critical area.

And then, when we think about dementia. For the first time, like I alluded to earlier, we're starting to see more progress when it comes to delivering therapeutics to support or address the underlying causes of Alzheimer's and other dementias. And so this has been a long time in the making, but over the last year, we've seen a sea change when it comes to new therapies available to individuals with Alzheimer's, specifically.

That can help because you buy time, and the more time you have to plan for care over time, make decisions, and have hard conversations. So, being able to stay at a certain level of cognition for longer really helps to address some of that hardship. Making sure that those therapeutics are effective, safe, accessible, and affordable might be another area from a policy perspective that we need to focus on. And that'll have ripple effects, not just for the individual, but for the caregiver as well in Alzheimer's and other dementias.

**Robert Espinoza: Let me ask you one more question. If you had all the power in the world to immediately change one thing in this country regarding family caregiving, what would you change?**

**Jason Resendez:** If I had a magic wand and could put in place changes to better support caregivers, I would focus most on addressing the stigma associated with care. I think one of the biggest issues we see is that—and it's why it's so hard to address the care crisis—is that not everyone sees themselves as caregivers. And so making sure that folks felt comfortable identifying as a caregiver who saw themselves in the culture around care. I think it can help us have more of a conversation and create the political will we need around supporting care.

**Robert Espinoza: I remember the first time I heard the term "long-distance caregiver" and its impact on me. When my mother entered a northern Colorado nursing home at the end of 2015, I lived**

**more than 1,700 miles away in New York City.**

**I knew she was receiving round-the-clock skilled care and that my father was visiting and supporting her almost daily. However, I didn't consider myself a caregiver, even though I called her frequently and visited her three times a year. I reasoned then that I wasn't at her side, assisting her physically throughout the day, so the term didn't apply to me. And I was wrong.**

**I would learn over time that the emotional support I offered from afar was an authentic form of caregiving. According to the National Alliance for Caregiving, I was part of the 15 percent of long-distance family caregivers in this country, totaling 15 million people and growing. Through research, this organization has uncovered, along with AARP, that 47 percent of long-distance caregivers are likely to report emotional distress, as compared to 43 percent of caregivers who are living with their care recipient or 28 percent who live less than one hour away.**

**All of this distress exploded when COVID-19 emerged. At the time, my mother had lost function in both arms, which meant she needed support from staff to use her cell phone, along with other activities. However, this crisis devastated nursing homes and strained their staff, which meant they weren't able to help her with calling home. And when I would dial the nursing home directly, the phone would ring endlessly. So I asked our family in Mexico to send me digital photos, and I used an app to create postcards from these pictures and mail them to her every day with updates on my life, our family, and the pandemic. I lay awake late into the night, imagining how it must have felt for her to be separated from our family, to watch the daily news and see that nursing home residents were dying in droves, and sensing this fate would come her way eventually.**

**In December of that year, I was at her side the day she was diagnosed with COVID-19. She looked away as she told me this news, quiet and forlorn, knowing her fragile body would not withstand it, given her other health complications. I told her I would be nearby and that we all loved her. Her nursing home, like others around the**



country, was experiencing another COVID outbreak, and staff rushed around us wearing PPE. Three days later, she was dead, and as with many fatalities that year, there was no service, no memorial with family and friends honoring her incredible life and presence.

The truth about the distress experienced by family caregivers is that it doesn't go away when a loved one passes. It simply transforms into grief and perches itself on your shoulder, whispering vivid, sometimes gorgeous, and often harrowing memories. The bond that many family caregivers form with the people they support, especially in their final moments, imparts lessons about mortality and how we wish to experience our final days if we have a choice.

It can also teach us about the types of lives we want to live.

While preparing a eulogy for her that I would post on social media that week, I reread an anthology of poems she published in Mexico in the 1980s. I was a child at the time, and she addressed one of her poems to me. In this poem, she implores me to remember her and my father as they reach older age. She asks me not to neglect them simply because they are old.

It's startling, and it reads like prophecy, given my career. But it was also her way of using art to share a message we should all be spreading widely.

We have a political imperative as a country to support older people and their families and to create a culture that assists all of us to live, age, and die on our terms. And there could not be a more urgent moment than now.

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EPISODE 8

# WILL IMMIGRANTS RESCUE THE HOME CARE SECTOR?

For generations, immigrants have contributed significantly to this country, including our health and long-term care sectors. Unfortunately, our divisive political climate prevents a constructive conversation about the potential of immigrant workers to support people with care needs.

In the eighth episode of *A Question of Care*, Robert Espinoza spoke with Ai-jen Poo, President at the National Domestic Workers Alliance and Executive Director at Caring Across Generations. They talked about the experiences of immigrant home care workers, why immigration is a contentious issue, and the future of caregiving.



**Ai-jen Poo**, President at the National Domestic Workers Alliance and Executive Director at Caring Across Generations

**Robert Espinoza:** Apart from her significant expertise in the field, Ai-jen has a profound personal connection to home care workers and immigrants, which fuels her commitment to the cause.

**Ai-jen Poo:** I come from an immigrant family. And my grandmother, before she passed away a couple of years ago, was cared for by a series of immigrant home care workers who enabled her to stay at home and really live a pretty full life, even as she became more frail and needed more assistance. And she was able to live independently at home and then in my mom's care until the very end. And we were really proud of that. And I don't think we could have managed to keep her at home, where she wanted to be and live to the end, without the support of many immigrant care workers. So, I feel very personally indebted to immigrant care workers.



And then I also, at the National Domestic Workers Alliance, have organized alongside immigrant care workers for almost 25 years—first in New York City and then nationally, across the country. And I have just seen so many immigrant women who have come to this country with an aspiration for giving their families and their children a better life and found themselves in the care economy, working as home care workers, direct care workers, childcare, and early educators. And [they] have found their calling doing this work and have become an indispensable part of millions of families across the country. And I know that work means the world to them, and I think it means a lot to the families they support. So, yeah, immigrants are a huge part of our care economy.

**Robert Espinoza: Ai-jen, can you give our listeners an overview of the immigrant workforce in the home care worker field? What are some of their experiences? What are some of the issues that you've seen?**

**Ai-jen Poo:** Well, home care work is a unique occupation in our economy because if you think about it, you could go into any neighborhood or community and not know which homes are also workplaces, [or] which homes have a home care worker working there. There's no list, registry, or place where all those relationships get organized or documented.

And then when you're in the home, it's you and your client or the person that you're supporting and maybe, a family caregiver that you're dealing with—but it's a very intimate relationship and a very interdependent one.

Oftentimes, the home care worker is the one who knows when or if medication's been taken and whether moods have shifted. They're on the frontlines of the health and well-being of the people in their care. Oftentimes, doctors, nurses, and other members of the health team or family members know way less than the home care worker in terms of how a person is doing.

And so we're talking about people who are in the most intimate aspects of their clients' lives and also quite invisible in our broader society and in a very difficult negotiation. Oftentimes, you're either negotiating with a relative or an agency,

and you have very little bargaining power, so to speak, in that oftentimes, if you raise an issue or have a concern about the job you're in, you could just be let go. And you really have no job security.

And what happens for immigrant workers is you layer on top of that the insecurity of immigration status and the fears associated with that. So, if you're already concerned about losing your job, if you raise an issue or ask for a paid sick day, imagine also doing that from a position of being an immigrant. And potentially, if you're out of status, the fear of being reported and deported and separated from your family.

And, you know, the domestic work context from home care to childcare to house cleaning—work in the home is the part of the workforce that has the highest concentration of undocumented workers of any part of our workforce. So, there are a lot of immigrant women doing this work and providing an indispensable role and contribution to so many families and individuals' lives but lack any security for their own life and their own family.

And it's a constant negotiation. It affects every part of your life, including getting to and from work, getting on the bus, getting on public transportation. You know, you live in fear of being deported and separated from your families. And so trying to care for somebody else's family and your own amidst that set of insecurities and fears is incredibly challenging.

**Robert Espinoza: Ai-jen, is there a personal story you've heard that really captures the complexity of living and working in this country as an immigrant home care worker?**

**Ai-jen Poo:** Yes. So, we have a member who has become a very strong leader in our movement, worked as a home care worker in Florida, and still does. She's an immigrant from the Caribbean, and she faced sexual assault and harassment from a client that she cared for and was afraid to report it or to say anything. And [she] was trapped in a situation that was incredibly abusive and traumatic as a result of that. And I think it's partly because she was concerned about her economic security. But first and foremost, as an immigrant, I'm not sure



about whether she would be safe if she reported it. So, she was caught between two scenarios, both of which she felt unsafe inside.

**Robert Espinoza: You mentioned the issue of undocumented immigrants and additional challenges that they face. According to estimates from the Pew Research Center, there are more than 10 million undocumented immigrants in this country. And I've noticed in my own work, there is no issue we discuss on social media that gets as much vitriolic reaction as immigration. And it seems to be aimed almost entirely at undocumented immigrants.**

**Why do you think so many people have negative attitudes about undocumented immigrants?**

**Ai-jen Poo:** Well, people have negative attitudes right now because there are real pain points that working Americans are facing. The cost of living continues to rise, and wages are not rising to keep up with that. So, there are a lot of people who are struggling in this country. Actually, 60 percent of the workforce earns less than \$50,000 per year. And when you start to add up the cost of housing, food, transportation, and childcare, you start to realize that it's just not enough to make ends meet for a lot of people. Let alone pay for something like care, which is why we have been so passionately organizing to try to expand access to care and to raise wages for the care workforce.

And when people are struggling economically, it creates a ripe ground for pointing fingers when you try to make meaning of why things are so hard. The truth is nobody deserves to struggle as hard as so many people are struggling in our country. And when you ask yourself, why are things this way? There will be people on Fox News who will point fingers at immigrants.

And the truth is that when we blame, usually there are two scenarios. You blame yourself, or you blame somebody else, and they're usually of a different race or different immigration status because of the way that our country has... because of the long legacy of racism that's so deep in the lifeblood of our culture. And we're pitted against each other when, in reality, none of us are benefiting from the status quo. And the

other part of the reality is that immigrants are completely interdependent with all of us and completely embedded inside our economy, every single community. They are our neighbors, and it turns out they are also our caregivers. And there's no point in denying that. It's just our reality. In fact, there's a lot in our self-interest to embrace that.

In fact, when we think about the fact that we have 10,000 people aging into retirement per day and people living longer than ever, actually care in America is an all-hands-on-deck situation. There is no way we will care for the growing aging population in the United States of America without a strong contingent of immigrant workers who are supported to do this work.

And so, whatever we may be hearing from Tucker Carlson in our living rooms at night, the reality is we are going to be dependent on immigrants to take care of us. And the best thing we can do for ourselves and for them is to embrace that fact and support it.

**Robert Espinoza: Early on in his presidency, President Biden recognized this potential of drawing on undocumented immigrants to fill jobs in long-term care as home care workers, nursing assistants, and much more. He proposed the U. S. Citizenship Act of 2021, which would have provided lawful prospective immigrant status to approximately 11 million undocumented immigrants, including essential workers such as direct care workers.**

**In your opinion, why hasn't this act become law?**

**Ai-jen Poo:** Because there is a growing Far Right wing—a White nationalist, white supremacist grassroots movement in this country that has captured the media narrative about immigration in this country and has also captured a huge contingent of elected officials who are therefore afraid of facing our reality, which is as we've just said, completely interdependent with immigrants.

And so there's just a ton of toxicity around this issue that really shouldn't be, and that is deeply rooted in fear and hatred and is also deeply divorced from our actual history and reality.



# A STRONGER FUTURE

## How Immigrants Can Bridge the Gap in Direct Care

Immigrants have contributed their talents to this country and our economy for generations. As demand for direct care workers has increased, and many long-term care employers report being unable to fill these critical jobs, a growing number of leaders are rightfully considering whether immigrants can help address this staffing crisis. Below are eight ways to meet this moment and support immigrants as direct care workers.

1

**Create a "caregiver visa" for foreign-born people** to work in direct care in the U.S.—with worker protections and a pathway to citizenship

2

**Fund training programs for immigrants in direct care**, ensuring they're free or low-cost and accessible in relevant languages

3

**Translate relevant information and resources** for direct care workers into multiple languages, as needed, whether in print or digital

4

**Offer a pathway to citizenship** to approximately 11 million undocumented immigrants, including direct care workers

5

**Invest in new research and data** on immigrants in direct care, including a study on the gray market, where workers are hired "off the books"

6

**Extend legal and technical assistance** to immigrant care workers and their employers to navigate the immigration system

7

**Enact policies that support immigrant workers**, including improving health coverage access and immigrant visa applications

8

**Support framing strategies and public education campaigns** that help impart the enormous value of immigrants to our care system



Historically, immigration has been good for our country in many ways and has enabled history to move forward. And that is exactly what they're afraid of in this instance. They want to take us backward. And so that is a great concern.

And I also think that on the other end, there is a growing movement of caring people in this country who recognize that America is the democracy it is because of immigration and are going to continue to fight for it.

The President of the United States continues to try to take steps to make life better for immigrants despite the political hostage-taking on this issue from the Far Right. He recently announced that he was going to extend access to health care to "dreamers" and DACA recipients, and I think that's really, really important.

And we're just going to have to keep making progress where we can. My organization is very interested in creating a pathway to work authorization and citizenship for the immigrants who do care work as part of the solution to how we're going to care for our growing aging population and the families who need care.

**Robert Espinoza: It seems that at the same time as these issues are being discussed politically, there are many U.S. based industry groups in long-term care that are also primarily interested in recruiting workers from other countries. They're asking for the legal ability to recruit workers abroad to fill jobs here in the U.S. as home care workers or as nursing assistants.**

**But a few of these proposals make the visa temporary and don't include protections that would prevent a worker from really being at the mercy of their employer. What are your thoughts on a guest visa program in long-term care?**

**Ai-jen Poo:** You know, I am a proponent of any guest work visa programs having equal protections and rights to workers who are here in the United States because I worry about these programs being used to downgrade the quality of jobs in these industries where we already have a hard time retaining and recruiting workers.

In fact, we lose some of our best, most committed caregivers to fast food, retail, and other industries because the wages are better. No offense to fast food and retail, which are also really important, dignified jobs, but we really need people to stay in care, especially those who want to. And I worry that the imposition of a guest worker policy that doesn't have very strong worker protections and rights and wages—that isn't about quality jobs—will then drive down the quality of work in a sector where we actually need to drive it way, way up.

And there's this whole conversation that started during COVID, where everybody was talking about labor shortages in the care economy. We kept saying, "There's not a labor shortage. There is a shortage of good jobs that you can actually sustain yourself on." And I still believe that to be true. And I'm open.

If we want to bring people from other countries to do this work, I think [we need] two things. One is we've got to make sure that those jobs are equally protected, the workers have rights, and that there's real equity between those workers and the workers who are currently here in those jobs. And I also think that we should first offer a pathway to work authorization and citizenship for the immigrants who are already here, many of whom are already doing this work. But they're doing it under the radar. And really recruit from that base of workers first. And maybe even before any of that, we should make these jobs better so that we can retain the workers that we currently have in the workforce instead of dealing with the unbelievable rates of turnover that we currently see.

**Robert Espinoza: Ai-jen, a lot of the work that you do through Caring Across Generations is focused on our culture and on the public narrative around care work. If you had the ability to create an ideal public narrative on immigration and on immigrants in direct care, what would that narrative be?**

**Ai-jen Poo:** It would be that we are all part of one caring majority in this country that is focused on making sure that the people that we love—that we can all live, work, and age with dignity in this country. And immigrants are a part of that care squad that's going to care for



the caregivers, immigrant and non-immigrant, has to be a part of our story going forward.

**Robert Espinoza: Let me ask you one last question. What is the most pressing need that should be addressed right now for immigrants, in your opinion?**

**Ai-jen Poo:** We should make sure that immigrants have the ability to get on a pathway to becoming citizens here. And they are already functioning as full citizens in so many ways. And so many of us have friends and neighbors who are immigrants and know this—that we would not be who we are without their participation, contributions, and friendships. And so, we should have a pathway to citizenship for the 10 million.

And we should embrace the role that immigrants can play in a strong care infrastructure and care economy of the future... I mean, what could be more important than nurturing the human potential of our children or ensuring the dignity and agency of our loved ones with disabilities and our older adults who cared for us and raised us?

It's a really important task, and we don't want to shortchange it. We want to have the best people doing this work. And that will include lots of immigrants. That's what I think.

**Robert Espinoza: I also have a deeply personal connection to immigration. My mother, Aurora, immigrated to the U.S. from Mexico in the 1960s, and she met my father, Robert, who was on leave from the war in Vietnam. They met on a bus heading to San Diego from Los Angeles, fell in love, and exchanged contact information. They married a few years later and remained so for 50 years until my mother's abrupt death in December 2020.**

**When I hear others describe their immigrant upbringings, I recognize their experiences—learning two languages, navigating the culture back home with the traditions in the U.S., and that persistent feeling that you belong in two worlds.**

**I remember the gratefulness in my mother's spirit, coupled with the sadness of migration, a sense that she never stopped missing her life and loved ones thousands of miles away.**

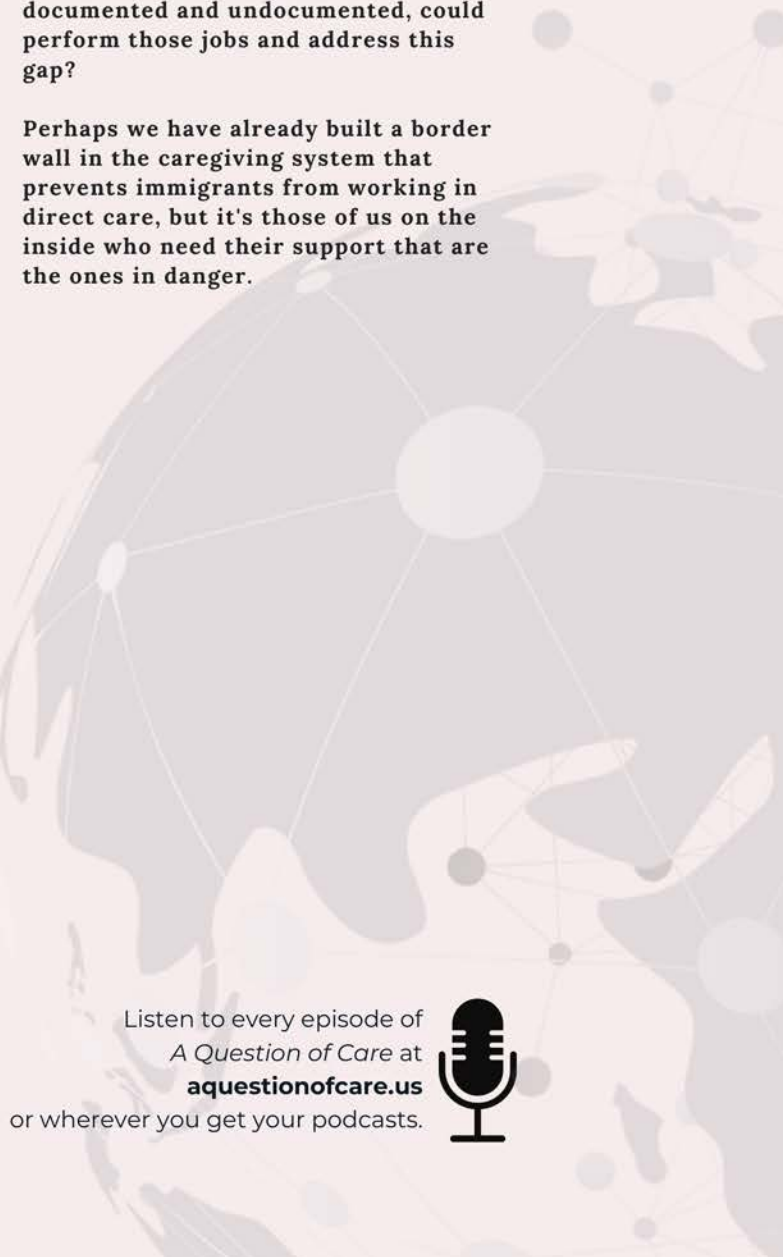
**Unlike many immigrants, she didn't flee a collapsed state or violence or even extreme poverty. Instead, she had this nomadic orientation that compelled her to live somewhere else. She said to herself, "My story doesn't end here."**

**Do you recognize that feeling? Have you ever left home or a life searching for a new horizon? Have you ever been forced to flee an untenable, even dangerous, situation? Have you ever scanned a map and said, there, right there, is where I want to live?**

**In this sense, we might all be immigrants at our core. So, why do we punish only those who meet certain criteria?**

**And in the context of care, what does this mean for millions of people who are struggling to find workers to support them when we know that immigrants, documented and undocumented, could perform those jobs and address this gap?**

**Perhaps we have already built a border wall in the caregiving system that prevents immigrants from working in direct care, but it's those of us on the inside who need their support that are the ones in danger.**



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## EPISODE 9

# IS OUR CULTURE DEALING PROPERLY WITH DYING?

Death and dying are difficult subjects for most of us. Yet how our country deals with these issues might inadvertently hurt how health professionals approach end-of-life care and serious illness, all of which incur a significant cost.

In the ninth episode of *A Question of Care*, Robert Espinoza spoke with Dr. Joseph Shega, Chief Medical Officer at VITAS Healthcare and Co-Managing Editor of *Essential Practices in Hospice and Palliative Medicine*. They touched on our country's relationship with death and dying and how a different approach to these topics would improve the end of life for millions of Americans.



**Dr. Joseph Shega**, Chief Medical Officer at VITAS Healthcare and Co-Managing Editor of *Essential Practices in Hospice and Palliative Medicine*

**Robert Espinoza:** People in this country view death and dying from a range of perspectives, often reflecting their cultural, spiritual, or scientific viewpoints. While attitudes toward death vary widely, there are some overarching trends that we should explore.

**Dr. Joseph Shega:** So, over the 25 years, I would say the one thing that's remained consistent is death and dying still seems to be a taboo topic. People still don't feel comfortable talking about something that's gonna happen to all of us. So we continue to work hard every day to engage in conversations and normalize the conversations, recognizing that for better or worse, we're all going to face serious illness and end of life, whether it's our parents or ourselves or other family members or friends.

And so being open and having honest conversations and normalizing those conversations is our hope to try to



continue to get people more comfortable talking about it, with the whole goal of honoring people's wishes and values and making sure their care is consistent with what they want.

**Robert Espinoza: One of my favorite books on this topic is *Being Mortal* by Dr. Atul Gawande, and in it, he writes, "Scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by healthcare professionals." He adds, "Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and deny them the basic comforts they most need." How do you think modern medicine is helping people, and how do you think it's hurting them when it comes to death and dying?**

**Dr. Joseph Shega:** So, modern medicine has come up with some amazing approaches to treatment that have transformed care for certain populations. Obviously, cancer is one that readily comes to mind where, when I trained at University of Pittsburgh, survival rates for many cancers like lung and colon were six to 12 months. And those survival rates have doubled, tripled, quadrupled with some of the innovations that have happened in tumor-directed therapy. So there's been some great advances.

But despite those advances, cancer is still the second most common cause of death in the United States. So even with those great innovations and prolongation of life and hopefully prolongation and quality of life, people still die from the same chronic illnesses they did 30 years ago: heart disease, cancer, lung disease, dementia. And so, despite those great advances and improvements in quality of life, people are still dying from those conditions.

And we need to continue to remind our partners that we appreciate all the advances that they're making, but at the same time, you have to have conversations about expectations and what the future will look like.

And I often like to use my dad as an example. He was diagnosed with metastatic colon cancer. I had very realistic conversations with him, my mom, and my siblings about what to

expect. And at that time, the average life expectancy was two years. Having those conversations, he responded to first-line anti-tumor treatment, and he was on first-line anti-tumor treatment for 11 years. And now he's too sick to tolerate first-line treatment. And so now we talk about end of life more, and he himself made his decision to not be resuscitated the last time he was in the hospital, which surprised everybody but me. But everybody understood and accepted because we've had those conversations and, with each setback, what those setbacks meant.

So, it's just important to remember with those advances, we need to continue to recognize people who are dying from those conditions and continue to have those conversations when the natural history of the disease progresses, despite those treatments, what it means, and what the future will look like. And for everyone, hopefully, that future will be hospice care because it improves quality.

**Robert Espinoza: One of the leading causes of death that has emerged in recent years is COVID-19. In fact, the data shows that as of June 2023, the COVID-19 pandemic has claimed more than 1.1 million lives in the U.S. and almost 7.7 million globally. Though some experts say that those figures are actually closer to 15 to 20 million.**

**What has this pandemic taught us about serious illness, death, and older people in particular?**

**Dr. Joseph Shega:** I think it was a wake-up call for many that, at any time, we could transition from healthy to serious illness. And that at any time, we can become seriously ill and could impact and take our life. With that, what we've noticed is that more Americans seem to be open to talking about wishes and values in advanced care planning.

We did a survey that showed one in five respondents to the survey actually had loved ones who died from COVID, and they did not know their loved one's wishes and values. And that was a wake-up call for them and an opportunity to start having those advanced care planning conversations.

**Robert Espinoza: Joe, you graciously**

**shared your story about your father. Are there any personal stories from your career that illustrate the complexity of dealing properly with death and dying?**

**Dr. Joseph Shega:** So, that's a great question. I would say, in aggregate, what they have taught me is that what people want at the end of life is so individualized.

The most important thing to remember when we talk about end-of-life care is to create individualized plans of care and make sure that it's not a yes/no when people think about hospice but how can we meet them where they are, to help them transition and understand that they're suffering from life-limiting illness? And how can we focus on optimizing life and making life as good as it can be for however much time they may have left?

A perfect example was when we had a gentleman come to our inpatient unit. At VITAS, we're often the second, third, or fourth hospice people choose because people often have preferences, but the care they want isn't consistent with what that hospice was willing to provide.

So this was somebody who had had metastatic rectal cancer. He was in his 50s. He was married. He had kids that were teenagers. He had progressed through four lines of antitumor treatment. He had a large rectal abscess. He was bed-bound. He had just had a bilateral pulmonary embolism. He was very short of breath on oxygen, on three or four IV antibiotics, and completely deconditioned. And his goal was to try to get stronger and tolerate more antitumor therapy.

Everybody knew that was not possible. He had been turned down by an LTAC. He had been turned down by multiple skilled facilities. No home health provider would sign up for him. Two other hospices had said no because his goals weren't consistent with the care that they wanted to provide.

Clearly, there was a lot that needed to happen because when I saw him, his life expectancy was days to a week at most. But we were able to get him to the inpatient unit, continue the IV antibiotics, control his mixed nociceptive

neuropathic pain from the infection invading and the tumor invading some of his nerves. And get him and his family to recognize that he was dying. And that we could honor his wishes in that he didn't die in the hospital. What that looked like may not be what he initially envisioned, but in the end, he had closure, his family had closure, and no doubt completely changed the bereavement for his wife and kids.

And so, how I started about creating those individualized care plans, right? End-of-life care isn't always perfect, but we do the best with what we have to help people understand what's happening to them and make sure that their wishes are honored.

**Robert Espinoza: Joe, you mentioned the concept of hospice care earlier, and I find that people often confuse hospice care and palliative care. Can you help us understand—what are the key principles and goals of hospice care and palliative care and how are they different?**

**Dr. Joseph Shega:** Yeah, that's a great question, and often, people confuse palliative care with hospice care. So, I like to think of it simply. Hospice care is palliative care in the last six months of life and is a defined benefit by Medicare. It covers medications, equipment, an interdisciplinary team, a physician, a nurse, a social worker, a chaplain, a volunteer, and a health hospice aid—all there to try to create a care plan to meet one's wishes, values, and goals. Decades of research show it helps improve quality of life while decreasing costs for the patient, the family, and the health care system.

Palliative care has been around more recently in the last 10 or 20 years. I think of palliative care as for people who have serious illnesses, but the prognosis is greater than six months. The challenge in the United States is it's not a defined benefit. So, if you've seen one palliative care program, you've seen one palliative care program, and the services that they offer are quite varied. Some may be a physician, some may be a social worker, and some may be a nurse. But what they provide is very different.

Most insurers don't have a defined palliative care benefit, or if they do, it's



very limited. That just leads to a lot of confusion among families as well as healthcare clinicians because they don't understand the difference.

Unfortunately, what's happened is so often now, healthcare professionals will refer to palliative care instead of hospice when people need hospice, and they're not matching the services with what they need. And so that's one gap that has widened, and my hope is that if CMS can come up with a palliative care benefit, it will help people with serious illnesses, pre-hospice, and then that transition to hospice to provide the best and end of life outcomes.

**Robert Espinoza: You've hinted at some of this, but what are some specific barriers that patients and their families face when they access hospice care or palliative care services in this country?**

**Dr. Joseph Shega:** Yeah, for hospice services in particular, one of the challenges is not all the services that they provide are the same. So, by law, all hospices must be 24/7, 365-coverage, meaning available any time, day or night, to support the patient and their family. They must include the core disciplines—physician, the nurse, social worker, chaplain, bereavement services, and volunteers. They have to pay for medications and equipment, but then, after that, hospices are very different in their philosophy and approach to care. Neither one is necessarily right or wrong, right? It's just how they envision the Medicare hospice benefit.

And so, at VITAS, we're very open to things like antibiotics, IV fluids, tube feeding, high-flow oxygen—some of the more complex things that patients may need to support their end-of-life journey.

Whereas other hospices may not be as open to some of those treatments. It doesn't make it good or bad, but there's such variability in the type and approach to care. At the same time, CMS doesn't adjust for acuity and complexity when it looks at hospices, which leads to further confusion about what hospices can and can't do in the marketplace.

**Robert Espinoza: In November 2022, ProPublica, an investigative media outlet, published an article that caused quite a stir within the hospice industry and the**

**long-term care sector. This article shed light on the hospice care landscape, revealing how what was once a noble mission to offer dignified, end-of-life care had been tainted by lax regulations and profit-driven motives resulting in rampant fraud and exploitation.**

**Following this exposé, the four major hospice trade associations directed a memorandum to the Centers for Medicare and Medicaid Services, outlining 34 recommendations. These proposals advocated for more stringent regulations in areas such as ethical marketing practices, ownership transparency, comprehensive disclosure, and heightened scrutiny during the intake of initial patients, among other essential measures.**

**In light of these developments, I was interested to hear Joe's thoughts on where the hospice industry requires reform to restore its core values and ensure ethical, high-quality care.**

**Dr. Joseph Shega:** So, while many people struggled with some of the things that the *ProPublica* article focused on, it did create this great synergy among the four organizations that you mentioned to step forward and lean into this is what we need as an industry to help ensure patients and families get consistent, high-quality end-of-life care. And so, to me, that's one of the big wins for an article that was very hard for some people to read when your whole life is focused on providing the best end-of-life care.

I think the common sense solutions focused more on newer hospices, making sure that they, in particular, meet the standards and policies set forth by CMS and ensuring that they're not able to be sold. People understand ownership is extremely important as a first step. Decades of research show hospices that have been around for over 10 years have superior quality and probably don't need as much focus as the newer hospices, ensuring that what the benefit was set out to do—improved quality—happens. I think that that approach makes sense, and the 34 measures put forth by the four organizations are a great first step.

Of course, there's a word of caution in that you don't want to overstep what

# FACING MORTALITY

## Exploring Death Trends and End-of-Life Decision-Making in the United States

Death is inevitable, yet many people delay creating essential end-of-life documents to help them and their families navigate life's final chapter. In fact, only one in three people in this country have produced any advance directive for end-of-life care. Below are 10 essential documents to ensure a more dignified death for you and your loved ones.

### 10 ESSENTIAL END-OF-LIFE DOCUMENTS\*

**1. A last will and testament** to legally ensure that your assets and property are properly distributed after your death.

**2. A living will ("advance directive")** to communicate your wishes regarding medical treatment and life-sustaining measures if you become incapacitated and are unable to make decisions.

**3. A durable power of attorney for healthcare ("healthcare proxy")** to designate an individual who can make medical decisions on your behalf if you are not able to do so

**4. A durable power of attorney for finances** to appoint an agent to manage financial matters on your behalf should you become incapacitated

**5. A HIPAA authorization** to designate a person who can access your protected health information, ensuring seamless communication and decision-making

**6. An organ donor registry enrollment** to express your desire to donate organs and tissues after death, potentially saving lives

**7. An instructions letter** to guide loved ones on personal preferences, funeral arrangements, and other non-legal matters after death

**8. A revocable living trust** to allow for the management of assets during your lifetime and the seamless transfer of those assets to beneficiaries after death, bypassing probate in some cases

**9. A life insurance policy** to financially protect your loved ones after your death

**10. A comprehensive list** of important contacts, online account information, and passwords to assist family members or executors in handling practical matters and accessing digital assets

\*It's important to consult with legal professionals to ensure these documents comply with state laws and accurately reflect your wishes. Also, be sure to update them.



should be done, which could lead to people being too cautious and not wanting to accept certain patients because of their acuity, complexity, or struggles with end-of-life care. And those patients and families may end up suffering an over-medicalized death, which would be a really bad outcome if there was too much over-regulation in how that looked.

But that's why the four groups set forth and leaned into what they think could improve hospices and make sure end-of-life care and the robustness of the benefits remain.

**Robert Espinoza: You and I were on a planning committee focused on the serious illness workforce that was part of the National Academies of Sciences, Engineering, and Medicine.**

**How do we adequately prepare the entire workforce to meet the needs of people with serious illnesses?**

**Dr. Joseph Shega:** So, the things that I focused on to help VITAS meet the workforce needs, not only of our organization but healthcare overall, are two main perspectives.

One is to be actively involved in the educational process of healthcare professionals. And so working with colleges, universities, and postgraduate education to be part of training the next generation of learners and leaders in health care is paramount. We have that opportunity to teach them, number one, what does interdisciplinary care mean? How does it change outcomes? Then, see the value of end-of-life care by better appreciating what an end-of-life care experience will look like.

The second is that so many high schools, colleges, universities, and even professional training require volunteer hours, and hospice is unique in that to be a Medicare-certified hospice, you must provide a certain amount of volunteer hours directed towards patient care. And so it creates this win-win opportunity where you can work with colleges, universities, and professional training schools to be the source where they can get their volunteer hours within hospice doing end-of-life care.

And so we've tried to create innovative programs for VITAS to support that—whether it's our VITAS individualized pampering program for patients to help define that individualized plan of care. Helping our volunteers work with patients and families to create life biographies. Most recently, we've been engaging with virtual reality and trying to leverage it to be a therapy that volunteers can provide for patients and families.

Getting volunteers involved from colleges, universities, and professional schools to understand end-of-life care but also to participate in that care to recognize the impact they can have.

**Robert Espinoza: Joe, I want to get your thoughts about solutions to many of these problems and questions that you brought up. How can public policies and health care regulations be improved to enhance hospice care and palliative care services?**

**Dr. Joseph Shega:** So, I think one of the main things when we look at policy and healthcare regulations is to recognize the research that's gone into establishing the Medicare Hospice Benefit. The Medicare Hospice Benefit was the first at-risk payment model for Medicare. Established in the 1980s, [this benefit] was passed into law under Ronald Reagan because it improved quality and saved money. It was the first value-based care model CMS had ever entered.

Despite that, patients continue to benefit from hospice services but for a very short period of time. The median length of stay in hospice remains around 18 days. That hasn't changed for decades. At the same time, only about 50 percent of Medicare beneficiaries ever benefit from hospice services. So that means half of patients who die that are older adults never receive hospice care.

So, the real question is, how do we further integrate hospice into our healthcare system to encourage earlier access and greater access? Palliative care is part of that solution, as is continuing to double down on advanced care planning and the role of advanced care planning in understanding wishes, values, and goals.

And so I think those two things—

investing in a palliative care benefit that's aligned to incentivize hospice utilization and, at the same time, increased advanced care planning and training the primary workforce in doing advanced care planning and having goals of care conversations.

And policies and regulations that encourage those things will provide a great solution to expanding the hospice benefit and improving end-of-life outcomes.

**Robert Espinoza: It seems that our ability to pass these types of policies relies in many ways on our ability to discuss death and dying in ways that are productive and constructive for our families and our lives. How can we promote open and honest discussions about death and dying within our families, within communities, and within healthcare settings to foster a more compassionate and understanding approach?**

**Dr. Joseph Shega:** So, it's a really interesting point you make in that there's so much fear and anxiety that comes with engaging in goals-of-care conversations and end-of-life discussions.

I mentioned earlier that one of the keys is to normalize it. When I had my geriatrics practice, I spent a lot of time in the memory disorders clinic—and so diagnosing many patients with neurodegenerative diseases that were progressive, not curable, and ultimately fatal.

As part of that process, the initial piece focused on diagnosis and treatment. And it just wasn't about disease-modifying therapy, which is very limited. But it was also about understanding what was important to people and taking the time when people had mild dementia to complete an advanced care plan. And then, along the journey, talk to families about the goalposts of decisions that will be coming up, what end of life will look like, and when hospice will be needed.

And so if we normalize that process as part of the care continuum, then there's less shock when it comes up when people are near the end of life. So, to me, the most powerful way is to encourage healthcare professionals to incorporate it as part of the disease management trajectory. Now, we're focusing on this.

This is how we know disease will progress. Ultimately, it may become end of life. And when that happens, this is what we're going to do.

**Robert Espinoza: Joe, let me ask you one final question. If you had all the power in the world, what would you change about our end-of-life care system?**

**Dr. Joseph Shega:** If I had one wish about our end-of-life care system and how to make it better, it would be to get people to understand that end-of-life care is still about life.

We don't focus on death. Death is going to happen whether or not somebody enrolls in hospice. And studies show hospice care doesn't change life expectancy. One study showed you might live a little longer. Others show no difference. But in the end, end-of-life care is about life.

It's about embracing life. It's about making the best of whatever time we have left. And how do you want to spend that time? And then let's put a care plan together to try to make that happen.

If I could change one thing about our system, it would be to change the outlook about what hospice and end-of-life care is. To not make it about dying but to make it about living until death occurs.

**Robert Espinoza: In early 2016, at age 39, I experienced a severe heart attack that nearly ended my life. One minute, I was walking near Prospect Park in Brooklyn, New York, and a week later, I was waking up in a hospital nearby from a weeklong coma. I was being told I had gone into cardiac arrest, and I was lucky to be alive.**

**My heart had stopped for a whopping 45 minutes, and an EMT had kept my brain functioning through CPR. Three weeks later, my heart surgeon told me I had a 6 percent chance of surviving at the time of the attack. I would spend much of that year coming in and out of hospitals and medical appointments, my brain fogged with uncertainty.**

**An expert in near-death experiences once told me that the two biggest questions facing people who go through these moments are: Why me and why did I survive? And what did I see when I went**



under, into that space near the beyond?  
In truth, I don't remember what I saw in those 45 minutes. And if I did, I erased it from my memory.

But what I've seen in the years after this near-death experience is a care field that struggles with its relationship to death and dying. Like many others, I routinely question where healthcare professionals, thanks to advances in medical technology, are crossing the line in keeping people alive beyond their preferences or even quality of life, which can vary from person to person.

Suppose we genuinely embrace our life as finite and our experience on this planet as microscopic, relative to the age of the universe. Would we embrace the here and now and take death and dying as a natural given? Would we transform our billion-dollar healthcare system and shift our national funding priorities from unnecessarily prolonging lives to creating an affordable, person-centered social safety net that embraces a natural life and death?

As for the question, why me? I'll never fully know the answer, but that might be the point. Because why not me?

And regardless, isn't it a better use of energy to imagine a better life and death for all of us, irrespective of our circumstances?

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EPISODE 10

# HOW SHOULD THE LAW SUPPORT OLDER ADULTS?

In recent decades, legal cases have incrementally broadened services for older people and strengthened legal protections against age discrimination. Despite these advancements, our country has a long way to go in extending legal rights to older individuals.

In the tenth and final episode of season 1 of *A Question of Care*, Robert Espinoza is joined by Kevin Prindiville, Executive Director of Justice in Aging, a national organization that uses the power of law to fight poverty among older people. They discussed how the legal system should assist older adults with their economic security, health care access, and more.



**Kevin Prindiville**, Executive Director, Justice in Aging

**Robert Espinoza:** Founded in 1972, Justice in Aging is a nonprofit organization in the U.S. that advocates for the rights and well-being of low-income older adults.

**Kevin Prindiville:** We were founded out of the war on poverty. So, at that time, there was a lot of action at the federal level to address growing rates of poverty throughout the country. And part of that effort was to redesign the way that legal services were being provided to low-income communities, and part of that redesign was to add a component that hadn't been there before. That component was referred to then as a "backup center" or "support center." And so centers were created to focus on particular issues like health law or employment law, and then also particular populations like older adults, youth, women, et cetera.

These support centers were created to



help support the local providers of services by providing training on important legal topics so they could better represent their clients and, importantly, provide advocacy support. So, when local legal programs were seeing the same issues impacting clients over and over and over again, they could work with us and other support centers to come up with a system-wide fix.

That led to a bunch of important pieces of litigation at the Supreme Court brought by our organization and many others that were really influential in building the rights of low-income people in the United States. So that's how we started. And that's still true to who we are today and the role that we play today.

There's now a much more robust network of service providers that provide all kinds of assistance to older adults across the country: legal services, social work, and all kinds of support. And we back them up. We help them by training them on the legal rights of their clients. Then, we help them design advocacy campaigns to solve problems that their clients face over and over again.

And we do that through every way that you can change and leverage the law. We work with administrative agencies that run programs to make sure that they're running those programs as the law intended. We work with legislative bodies to pass or amend new laws when needed. Then, we use the courts to force change, mostly around how governments run programs that people rely on.

**Robert Espinoza: Kevin, what are some of the most common legal issues that older adults face in today's society?**

**Kevin Prindiville:** Yeah, so that's a great question. And I'm going to go back to our founding. Soon after we were started, there was a legislative effort to pass what's known as the Older Americans Act. This federal law provides funding to state and local entities to provide a wide array of services to older people. And one of those services is legal services.

So, as they were designing the law, they went out into communities and asked older people, have you needed or used a lawyer in the last six months? Most of them said, Nope, why would I need a lawyer? And then the question was

reframed: Have you faced an eviction in the last six months or a year? Have you had trouble accessing healthcare in the last six months or a year? Have you had a dispute with an employer in the last six months to a year?

And the answer to those questions came back, Yes. People were struggling with all these problems but didn't realize they were legal issues. And were issues where they would benefit from working with a lawyer. So, we take a pretty expansive view when we think about the legal issues that older adults face; we look at any of the challenges that older adults are facing and how the law is a help or a hindrance to them addressing that issue.

So, health care comes to mind as a huge issue that older people face. Long-term care is a huge issue that older people face. Economic security, whether they have enough money to meet their basic needs, is an issue that has legal elements to it. Housing we increasingly see as a big issue that older adults are struggling with and where legal rights and protections play an important role.

Then there are some areas that you think of as... The first time you think of them, you'd think of them as a legal issue for older people. Guardianship is an increasingly important and difficult legal issue that states and families are struggling with across the country. Age discrimination in the workforce—another big issue that squarely you would think of as an aging issue.

And then there's another category: anything connected to civil rights has tremendous implications for all of us as we age. So, those have been some hot-button, big legal issues in the last several years. LGBTQ rights. Issues around race and racial discrimination. Gender rights. These are all issues that are important to older people because older people own, occupy, and live in all of those identities.

So, any rights that we create, or when we take away rights for communities broadly, are going to affect the older people in those communities and sometimes even more. And certainly, if they live at an intersection of multiple identities and where those rights come into play. I would add in that category, too, that I didn't mention: voting rights as another example of something that

applies to everybody and has some unique issues for older people.

So, that was a long-winded answer, but we think of legal issues broadly because the law is really about the rules that set parameters for how we move through society in our lives. And so, for older people, laws in any number of areas are going to impact how they do that.

**Robert Espinoza: You touched on this issue a bit, but we know that older people are incredibly diverse, and with that diversity comes a range of inequities and disparities across various issues. How do the rights of older people differ for older people of color, as one example, or for other marginalized populations?**

**Kevin Prindiville:** Our work at Justice in Aging, at our founding, was focused on poverty and addressing the needs of low-income older adults, and today, that's still the case.

Our focus is squarely on using the law to alleviate the impact of poverty on people as they change. Then, we do that with a clear focus on these inequities that come with aging and living in systems that often treat people equitably throughout their lifetime. And so, we've worked to both address poverty and advance equity for all of us as we're growing older, and there are tremendous inequities in how people age.

Age is a great equalizer because we all will grow older and face some challenges and decline. The idea that that's a common experience and that that somehow equalizes a lifetime of inequality is not true.

People who are from communities of color, women, LGBTQ, people with disabilities, and immigrants face a variety of systemic barriers throughout their lives that then mean that their aging process is different and inequitable. And more likely to lead to aging into poverty, aging into poor health, aging and having difficulty accessing many of the services that we know that we all need as we grow older.

Food, housing, community support, long-term care, health care. So, there are real disparities, and the law can be a tool for addressing those disparities. If we build systems that are mindful of the needs of

those communities first, we're likely to be able to build systems that can serve all of us well.

**Robert Espinoza: I'd love to pick your mind on the legal landscape over the last few decades. What are some of the most important court cases or developments related to older adults in the last 50 years?**

**Kevin Prindiville:** Yeah. So, it's hard to say over a 50-year period. It goes beyond my time, but certainly, I could identify a few. Going back to our history in the 70s and 80s, there were many important cases that established the rights of low-income people to the support that we provide as a society.

Those were cases that were sometimes brought on behalf of older adults but were often brought on behalf of other communities, but the precedent set in those cases also applies to all of us as we age. So, going way back to cases like *Goldberg v. Kelly* that established due process rights so that people relying on systems like the Medicaid program for healthcare, it established that they had a right to those services. It was reasonable for them to rely on the idea that those services would be there for them, creating a fundamental structure upon which legal rights have been built since then.

Another case from the past that's still very important today is the *Olmstead* case. This case is often thought of as a disability rights case but is really important to older adults. It found that people who have long-term care needs have a right to receive services to meet that need in the least restrictive setting. So, whereas those services used to be provided almost exclusively in nursing homes and institutions, *Olmstead* created a right to receive those services at home and in the community, services that are less restrictive than those institutions. Again, that case was thought of as a disability rights case, but it really applies increasingly to older people who are aging with disabilities and need that support. [It has] now provided a framework for all of us to build and advocate for a system that supports more people at home.

And then, more recently, I think of some of the important civil rights cases that



have been part of our nation's history. I think one shining positive example would be the Obergefell case, from several years ago now, which established a right to marriage for all people, particularly for LGBTQ communities. That has a tremendous impact on the economic security of older adults. We know that being married confers tremendous economic advantage. And so having not had that opportunity until just recently was a driver of LGBTQ people aging into poverty, and now having that equitable access to marriage and the economic benefits that come with it is a huge driver and an important case for older people.

**Robert Espinoza: I want to get your thoughts on a few different issues that are facing older people. and I'd like to start with the issues of economic insecurity and poverty. What are the unique challenges that older adults face when experiencing poverty, and how do these challenges differ from those faced by younger people?**

**Kevin Prindiville:** Yeah, there are some important differences. And we see two groups of people living in poverty when they're older. One is people who have lived in poverty for most of their lives. And if you live in poverty for most of your life, work in low-wage jobs, and don't earn enough that it's realistic for you to save, maybe you live a lot of your life in debt because your work is not providing enough income to meet your needs. You know, you're not going to grow older and then suddenly move into middle class or upper class. So that's one group.

The second group is older people who have middle-class lifestyles when they're working age. But again—because wages until very recently hadn't kept pace with inflation, because of the inequity we've seen and where wages have been distributed across the workforce—they have a middle-class lifestyle while they're working, but they haven't had opportunities to save enough to continue that lifestyle when they grow older.

And, so when they grow older, they experience poverty for the first time. And we're seeing this acutely right now in the homelessness crisis: that the fastest growing portion of the homeless population is older adults. In many areas

of the country, older adults, people over 50, represent about half of the homeless population, and about half of those people are becoming homeless for the first time after age 50. So, there's that group in poverty throughout their life, and then there's the group aging into poverty.

The solutions are different for older people than for younger people because building wealth and creating more employment opportunities is less likely to be an option for addressing the poverty that they're living in. Especially when you think about what we might call the “older-old” people in their eighties or older. It's not realistic that we're going to address their economic security by re-education or getting them new jobs. We need to provide different types of services and support.

So, those are some of the things that are unique about poverty for older people and how we need to think differently about how we support them.

**Robert Espinoza: You mentioned the issue of healthcare and the challenges that older adults face in terms of healthcare access and outcomes. What legal protections are in place, and what is the general challenge that older people are facing?**

**Kevin Prindiville:** That's an excellent question because one of the things we think of around an issue like healthcare is, well, “Older people are taken care of. When you get older, you qualify for Medicare, and you're set.” It turns out that it's never that simple. Anybody who's been in a position of needing healthcare support when they're older or supporting a family member has seen that coverage is not the end of the process to get access to care. Coverage does not equal care. So we see a lot of issues that come up with people getting what they're entitled to under the Medicare program. And then also for those that also qualify for Medicaid under the Medicaid program. So, lots of legal issues there.

We've been part of work with partners to bring some cases to ensure that people have access to the services that they need; our colleagues at the Center for Medicare Advocacy have led litigation on something called the Medicare Improvement Standard, where people

# Beyond the Gavel: 8 Legal Milestones for Older Americans

## 1935

**Social Security Act (1935):** Created social insurance programs, providing financial support for older Americans during retirement and disability



## 1965

**Medicare and Medicaid (1965):** Provided healthcare coverage for older and low-income individuals, improving access to medical services



## 1965

**Older Americans Act (1965):** Aimed to address needs of older people, enhancing their well-being through community services and programs



## 1967

**Age Discrimination in Employment Act (ADEA) (1967):** Prohibited age-based employment discrimination, safeguarding older workers' rights



## 1990

**Americans with Disabilities Act (ADA) (1990):** Prohibited discrimination based on disability, benefiting older individuals facing age-related disabilities



## 1999

**Olmstead v. L.C. (1999):** Ruling reinforced the rights of people with disabilities, including older individuals, for integrated community-based services



## 2006

**Pension Protection Act (2006):** Addresses pension and retirement savings issues, impacting older individuals' financial security in retirement



## 2010

**Patient Protection and Affordable Care Act (2010):** Improved healthcare access, including preventive services and cost controls, benefiting older Americans





were being denied services because they “weren't improving,” so they couldn't continue to get the services. This was a fiction that was created and doesn't exist in the law. So, we brought litigation, or they brought litigation to challenge that.

We partnered with them on an issue in Medicare called the “observation status,” where hospitals were admitting patients overnight but saying that they actually hadn't been admitted; they were just being observed, and that impacted what services and at what cost people could receive them when they left the hospital. So, there are lots of access issues that come up even when you have coverage.

Another issue we're learning more and more about is age discrimination in the healthcare context. So much of the healthcare system is designed to treat illness and treat all patients sort of the same, and not to see what's unique about the needs of older people. And often to see older people as simply in a state of decline and therefore, to maybe miss what might be an acute health care issue because there's an assumption that the issue the person's coming in with is simply because they're older.

We're dealing with that right now with a family member who we were noticing some decline in mental capacity, and that everybody, including doctors, assumed was some age-related dementia. But now we've also learned that this person has widespread cancer in their body. We're waiting to see if there may be cancer in the brain and that that might have been what was causing some of the changes we saw in that diminished capacity. If she was younger, that's probably one of the first things they would have looked for. Since she was older, they were assuming decline was related to age and treating her from an ageist perspective in thinking about what could be causing the symptoms. So, those are some of the things that we're seeing.

And then, the last thing too is that even with Medicare, there are so many things that aren't covered. There are so many costs in Medicare. It's a wonderful program, but it does cost beneficiaries. So, too many people don't have coverage for what they most need, and that's particularly true for long-term care services.

**Robert Espinoza: Are there any**

**strategies or initiatives being implemented at the community or national level to help alleviate poverty among older adults?**

**Kevin Prindiville:** Not as much as there should be and could be. We think it's still an under-told story: just how many older adults are struggling to meet basic needs.

I was looking at data this morning in California, and this matches the national trend: during the pandemic, older adults are actually the group that has seen the greatest increase in poverty rates. There was, of course, for kids, a dramatic decline because of support provided during the pandemic and now a dramatic spike since those supports have come off. But that's also true for older people. So, the data I saw this morning in California: 15 percent of older adults are now living in poverty, whereas just 13 percent of people aged 18 to 64 are living in poverty.

And people don't understand that that's what's happening. People think that once you've got Medicare, once you've got Social Security, that you're set. But the Social Security benefit is a wonderful program that lifts lots of people out of poverty but also pretty modest given the cost of living increases that we've seen across the country in the last several years but even the decades prior. So, a lot of older adults are struggling.

We are working with partners to increase and expand the Social Security program, particularly with an eye toward middle-income and lower-income people. What can we do to lift the minimum benefit in that program so that more people are brought up to a level where they can meet their basic needs? Social Security has always been the world's most effective anti-poverty program, and we can leverage it even more by targeting support to the people that need it most.

And then continuing to build out a robust healthcare system because that is a major cost driver that weakens the economic security of older people. So, how can we build a better, more efficient, more consumer-friendly, less medicalized system to provide the full array of support that people need to live in the community?

**Robert Espinoza: I'd like to shift our conversation to solutions and possibilities to improve a lot of these**

**challenges that you've described. Are there any recent policy developments that give you hope regarding the legal power of older adults?**

**Kevin Prindiville:** I think the thing that gives me the most hope is the action we've seen to strengthen protections for older adults in nursing facilities where, during COVID, there was just tragedy after tragedy for the people living in those facilities, the people working in those facilities, and the families that support them.

So, we've seen some strong federal action to try to increase staff ratios in nursing homes, increase transparency of nursing home ownership, and increase rights and protections for folks in nursing homes. We're also seeing a lot of resistance to all those things because they cost, so the nursing home industry is pushing back on many of those proposals.

I've also been heartened by a tremendous increase in understanding of the care that we all need as we grow older and throughout our lives. And the care that we need sometimes and the care that we provide sometimes. And the conversation about care and the way that it's bringing together, the needs of older people, people with disabilities, parents that are caring for kids. I think that's very positive and resulted in some great policy changes.

Again, during COVID, there was an increase in federal funding to support home care programs for older adults and people with disabilities so that more of them could stay out of those nursing facilities and instead get the care and support they need at home.

A lot of money went out to states. A lot of states innovated by creating new policies and programs to strengthen the workforce, increase access to services, and reach new populations with those services. So, there's work to do to keep that momentum moving and then to try to build to more transformative change, but those have been some positive policies in the last couple of years that give me hope.

**Robert Espinoza:** Let me ask you one last question. If you had a magic wand, what are one or two laws you would put in place to improve support for older adults?

**Kevin Prindiville:** Yeah, yeah. So, do you have the wand there? Are you ready to hand it over? So, one I mentioned a minute ago is that we would expand the Social Security program so that the basic benefit is higher and should be high enough that you can support yourself and meet your basic needs. People think that's what it does today, and it doesn't. It's far below that. So, we would lift that minimum benefit so that no older adult is living in poverty [and] that we've got people covered. They've contributed throughout their lives; we should have them when they're ready to leave the workforce. So, that's one.

The second is when people need that long-term care I've referred to a few times, the system forces them to receive that care in nursing homes and institutions. The federal Medicaid law creates a right to receive the services in a nursing home, but there's no similar right to choose to receive those services at home and in the community. We call this the institutional bias. And it's baked into the law.

So, if there were a law that I could change there, it would be to end the institutional bias in Medicaid. And to say, when you have a long-term care need and are in an economic situation where you need the support of Medicaid to pay for those services, it's your choice; you can choose where you get them. If you want them in a nursing facility or you want them at home and in your community, you can choose. We're not going to push you into one of the other because of the way that we've structured the funding and the laws around the programs.

**Robert Espinoza:** Legal rights are at the core of civil society. In the ideal, they help regulate our country, protect people against abuse and unfair treatment, and ensure that services are delivered appropriately. In actuality, designing and maintaining these legal rights has been a perpetual struggle, as evidenced by the civil rights movement, which has made so much progress yet continues to face hurdles. It seems that with every step forward, we take a few steps back.

As Kevin described in this episode, older people need the law to protect them from discrimination in employment, housing, and other spheres. And they



need it to fund and regulate a wide range of services that will help them age with dignity and independence—though that promise also remains unfulfilled. It's one of the reasons his group and others like it exist.

Law and culture also go hand in hand. The law can denote what a culture believes and values. And when it fails to deliver equal treatment and services, the law can help influence a new way of thinking. However, what happens when a law is ahead of its time and our culture needs more time to accept certain legal decisions? In contrast, what happens when a law is enacted after years of public debate? How do we make sense of all those people who were punished in that time frame because society wasn't ready to accept a modern way of thinking?

I ended the first season of *A Question of Care* with this episode because it unites the law and our culture. As advocates like Kevin help strengthen the legal power of older adults, this podcast will hopefully change a few minds along the way. It's up to you, our listeners, to amplify these messages.

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