

Episode #25: Howard Gleckman on Policy, Caregiving and Strategies

howardgleckman.com

<https://www.urban.org/>

<https://lotsahelpinghands.com/>

Disclaimer 00:02

Content presented on the following podcast is for information purposes only. The views and opinions expressed during this podcast are solely those of the individuals involved and do not necessarily represent views of bubbled care network. Always consult your physician for medical and fitness advice, and always consult your attorney for legal advice. And thank you for listening to the Whole Care Network.

Rosanne 00:43

Hello, and welcome to Daughterhood The Podcast. I am your host Rosanne Corcoran, daughterhoods circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years, and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system, provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in daughter, Howard Gleckman is a senior fellow at the Urban Institute, where he is affiliated with the Tax Policy Center and the retirement Policy Program. He speaks and writes frequently on aging and caregiving, as well as on tax policy. He is also the author of caring for our parents, inspiring stories of families seeking new solutions to America's most urgent health care crisis, as well as two blogs, tax Vox and caring for our parents that you can find on Forbes.com. In 2016, Next Avenue named Howard, one of the nation's top 50 influencers in aging. Howard and I spoke about the policies surrounding the caregiving crisis, how we got here, and his hope for going forward. I hope you enjoy our conversation.

Rosanne 02:13

You've been involved in this for over 20 years. And I'm sure that you've heard the this is going to be better this is going to change, something's going to be different. And I was struck, because I saw in 2003 that you had written for Businessweek the coming revolution in healthcare in 2003. And yet here we still are, how does that happen? How have we gotten this far? And it's still like, Yeah, well, we're working on it.

Howard Gleckman 02:41

So it's an interesting thing. And some of this is about actually a lot of this, it's about the money. And you often hear the phrase among healthcare economists misaligned incentives, which is a fancy way of saying the money goes to the wrong place. And the money encourages people to do the wrong stuff. And until we get those, right, we're never gonna fix the problem. So I'll give you a give you the kind of classic example in the lawn care world, it's nursing homes. So we have developed this this model, where we take very frail older adults who are long stay residents of nursing homes, and we're putting him in the same building of people who have been recently discharged from the hospital. And we can't understand why there's a lot of infection that goes around in a long term care facility. Well, that nursing home model was created in response to the financing. What happened when we created Medicare and Medicaid.

So Medicaid pays for the long stay doesn't pay enough. So the nursing home operators figured the way they were going to fix this problem was put in a lot of Medicare beds for post acute care. And they make a lot of money on post acute, they lose some money on the long stay, and it evens out. But it resulted in this crazy model, where we have very frail people who are sharing a building with this revolving door of people who are coming in and out of the hospital. No one would have done that if it wasn't for the payment model. But we got the payment model we got and we got the care that we pay for this happens all the time. It also happens. You know, people ask, Well, why can't Medicaid provide more efficient long term supports and services because if it does, it will save money on the healthcare side, it will mean fewer hospitalizations, fewer emergency department visits. And when you talk to state Medicaid officials, they say doesn't do us any good. If we save hospitalizations and emergency department visits, let's say is Medicare money doesn't save us any money. So why should we Why should I as a governor spend money to enhance my state Medicaid Itss is the financial benefit of that goes to the feds and not to me? Glad you asked?

Rosanne 04:47

Well, I am because that's because it's it's been that why why is it like this? And that makes sense now.

Howard Gleckman 04:54

Yeah, and this was, I don't think people intended this. This was kind of a succession of sort of unintended consequences to a very complicated financing system. But then when you get the system in place, it's really hard to change, because now you have interests that have built their businesses around this model. And they don't want to change the model. So you go to nursing home operators and say, so we're going to change this thing. And we're going to blow this up, and you're no longer going to be able to have Medicare and Medicaid in the same building and they're gonna say, wait a minute, I just built this building to make this work, you can't change now. So it's very hard to change a payment system, even when when you step back, everybody understands the payment system is crazy. And it doesn't really help anybody.

Rosanne 05:33

So that's why we just continue to spend the same wheel.

Howard Gleckman 05:37

Yeah.

Rosanne 05:38

Because nobody's going to, nobody's going to say that, nobody's going to say, never mind, you take that money.

Howard Gleckman 05:42

Yeah, it's very hard to change a system, once it's been developed inertia is a very powerful thing. And the easiest thing to get Congress to do is nothing. And, and that's kind of where we're where we've been on this for a long time. So, as you said, for 20 years, I've been trying to convince Congress to make some changes. And I actually feel more optimistic about it now than I have at any time in the past 20 years. And tragically, that's because of COVID. Because so many older adults of the of the 600,000 Americans who died from COVID, over 400,000 of the world are adults, and half of them were living in in long term care facilities, and half of them were living at home. And that has, as they say, focus the mind. It's gotten a lot of politicians weren't thinking about this. Now saying, you know what, we cannot ignore this, we have to fix the system. So President Biden has got some very aggressive proposals. Some of them I like some of them I don't like he's got some very aggressive proposals to reform the long term care system. And now increasingly, members of Congress are proposing ideas to do this. So I'm actually fairly optimistic that by the end of this year, we will see some reforms, not as much as I would want, probably not as much as you'd want, but at least it'll be better, you know, a year or two that it is now.

Rosanne 06:55

So do we have to take that approach of at least it's something instead of this needs to be completely fixed, a little bit is better than nothing? Is that the approach?

Howard Gleckman 07:05

Take what you can get. I mean, all the years I've been watching Congress, I mean, never get perfect, but take what you get and and build on that. One of the issues is really interesting to me is caregivers for older adults, and I was one as you know, caregivers for older adults, tend to be poor advocates for political advocates for their cause. And I think there's a number of obvious reasons for that. One, of course, is you're so overwhelmed being a caregiver, the last thing you want to do is add your time talking to politicians. But nonetheless, that's a problem. And it's particularly interesting when you contrast it with people who are caring for younger people, particularly children with disabilities, were great advocates for their care.

Part of it is practical. You know, if you've got a child with a disability, that they're they're getting some schooling they're being cared for during the day. And if you're caring for a parent, they're not you know. So parents of children disabilities have time that people caring for older adults don't. The other reason is, you know, sad to say, when you're caring for a parent who's failing, you know how the story ends, it's gonna end when they die. When you're caring for a child with disability, that child may live a normal lifespan, they lo lve 60 or 70 years. So so you're kind of thinking about this in a very different way. And the last thing I think that happens is when our caregiving ends, when our parent dies, that might be an opportunity to then advocate but what happens, of course, is you just want to get past it, you don't want to relive it. And, you know, to answer questions from some politician about what it was like, you just want to move on at that point.

So I think for a lot of a lot of real obvious reasons, it's very hard to get caregivers to advocate. But it's very important. And one of the things I would urge the Daughterhood people to do is advocate make some noise, as hard as it is find some time to, to let people know what your experience is like. One of the things I realized, it's kind of an interesting thing. When I talk to politicians, I discovered a long time ago that that you and this issue, you don't really know why politicians into Democrats and Republicans or liberals and conservatives, you really divide them into those people who have had a caregiving experience themselves. And those people who have and people who have not been caregivers have no clue. They have absolutely no idea what it's like now, and to the degree that people who are caregivers can explain to a politician, what that experience is, like how overwhelming it's how complicated it is to put together a care system, and nobody has any answers for you. All of that is really, really important. And helping them begin to understand that they're still not going to understand it until they do it, but in helping them begin to understand that I think really makes a difference. So advocating is really important.

Rosanne 09:53

I agree with you. And it's interesting because you're right caregivers are lucky if they can get a shower, let alone go to Washington and march, we're not doing it, you know. So it's hard to get that, that experience out. And when you're caring, you're so overwhelmed and you just want people to understand how hard it is you want them to understand what you're dealing with, and what you're doing on a daily basis. And sometimes that doesn't come out in the most productive way because like you said, if you don't do it, you don't get it. You don't understand the isolation, you don't understand the fear. You don't understand the worry, you don't understand any of that, because you're looking at it like okay, well, what's so bad, at least you're home? And it's like, that's not what this is. And you mentioned that you were a caregiver. Who did you care for? And what was the circumstance on that.

Howard Gleckman 10:40

So our experience, so everybody's experience is, in some ways, the same and in some ways different, right?

Rosanne 10:46

Absolutely.

Howard Gleckman 10:47

So this was our experience. My wife, and I live in the Washington, DC suburbs, both her parents and my parents were retired and living in Florida. One day, I get a phone call, my wife is out doing something, and I get a phone call. And it's my father in law, who's calling to tell me that my mother in law has had a stroke. So my wife and I get on a plane and we fly to Florida to figure out what's going on. It turns out that my mother in law is on life support. This was a very, very bad stroke. And it turns out that my father in law was ill with cancer that they didn't tell anybody about. They didn't want to worry the kids. So they didn't tell anybody. So we had to make two decisions on the fly is what always happens, right? The first decision was we had to decide whether to take my mother in law off life support. And then immediately after that, we had to decide how we were going to care for my father, my father in law was a great guy. He had a very successful career but like many people in his generation, like many men in his generation, he could not take care of himself. He couldn't boil water. So we talked about it, he, of course, wanted to stay in their house. So he did for a while, it became impossible. So it made a decision to move him up to Washington. So he came up, lived with us for a while, while he is here, I get another phone call. This time is my mother telling me that my dad was in the hospital. So back down to Florida, and discovered that my dad had very severe very advanced congestive heart failure. We talked about it and he became a hospice patient, he stayed at home, we fortunately, were able to hire a live in aid, who's wonderful, my dad who everybody thought would die in two months, lived 18 months, and I was a blog distance caregiver, I flew down to Washington down to Florida every couple of weeks to help my mom and help the a care for my dad. So we were juggling both until and that died and

then caring for my dad. So it was extraordinary. It was I always tell people, I think everybody says this, it was the hardest thing I ever did in my life. But in many ways, it was the most rewarding thing I ever did.

Rosanne 12:52

Right.

Howard Gleckman 12:53

It gave me the opportunity to give back to my parents. And it was it was in that sense, wonderful. But boy was it hard.

Rosanne 12:59

It's an AND not a but.

Howard Gleckman 13:01

Yeah, that's right.

Rosanne 13:01

It's an it was it was the most rewarding thing AND it was the hardest thing I've ever done.

Howard Gleckman 13:07

Exactly. So it's a it is an and that's right. Both things. I think it's really hard because you're when you're in the middle of it, it's the it's the hard part that overwhelms you.

Rosanne 13:19

Yes.

Howard Gleckman 13:19

And it's it's very hard to step back and think about the good parts about this. So I was able to have conversations with my dad at the end of his life that I never had before. And that was really important. I think it was important to him, I know is important to me. So there are parts of this, that that can be incredibly rewarding and incredibly powerful and important. But it, of course can be so hard. And then with some some diseases, dementia, for example, it's just so much harder, because the communication is so much more difficult. But even there, you learn that you can do nonverbal communication, you can still communicate with your loved one, even if it's kind of an unusual ways. But it takes patience, and it takes hard work and it takes mistakes. And here's the other thing that we do as caregivers is we beat ourselves up about the mistakes. Years later, you know, both my wife and I would talk about this. And we've talked about, you know, what we wish we had done that we didn't do. And at some point, you really got to let that go. And you got to say I did the best I could do with the

information and the resources and the time and the experience that I had. And you know, that's the best you can ask because they do the best you can do.

Rosanne 14:32

Well and it's so it's so final, obviously I mean that's you know, no kidding Rosanne it's so final that you don't get that last conversation of no you know what, you did a great job and thank

Howard Gleckman 14:44

Yeah.

Rosanne 14:44

You and you never get that so you torture yourself with the what could I have done? Should I have done what could I have done better when in reality, you did everything that you could do.

Howard Gleckman 14:55

And you know the funny thing is the people who beat themselves up the most of the people who care the most And the people who probably did the best job?

Rosanne 15:02

Yeah.

Howard Gleckman 15:03

If you don't care, you beat yourself up.

Rosanne 15:06

Exactly. Right.

Howard Gleckman 15:07

Right. And we've all got this is getting the kind of classic story we've all got the other relatives, whether they're siblings, or aunts, or uncles, or whatever it may be, who aren't in the picture, who are second guessing. You know, I had a care manager once, who referred to the out of town caregivers, as are out of town relatives, as the pigeons, as what does that mean? Should they fly in the crap all over everything? And they fly out. And and I think all of us have to, at some level with those people, too.

Rosanne 15:43

Yes, absolutely. And then and then it, it plants, little seeds of self doubt. Well, and it's funny, it's not even funny to me. It's not like everyone in Congress doesn't have a mother, a father, a friend, a somebody. And you know, you know how this goes, Howard, you say, yeah, I'm taking care of my mom, oh, my goodness, I know, my blah, blah, blah. Everybody has a story

about caregiving or knowing caregiver or something. So it's not like this happens in a vacuum, they have to have some sort, you would hope that there's some sort of a connection for them to say, we need to do this.

Howard Gleckman 16:17

You would hope. But I will tell you a story. Some years ago, I met a member of the State Senate went into the senator's office and had a meeting and talk to them about long term care issues. And it was very clear in that meeting that they were not getting it. I mean, whatever, whatever was happening here, I was not good. So you write it off. Like a couple of years later, I was at a party. And that same senator was at the party. He came up to me didn't remember my name, but said you're the caregiving guy. So yeah, and started asking you all these questions. And what's this about? And I made a couple of calls after the party. And I realized, I learned that what this was about was the senator had become a caregiver, the senator and Senator his dad had gotten sick and suddenly become a caregiver. And while you're probably right, Rosanne, probably this senator probably had friends or distant relatives who were caregivers who had this experience. But it wasn't the same when it happened to this person, then suddenly, it was different. And now this person is, by the way, very engaged in electric chair issues. But it took a person experience.

The senators who a couple of years ago got very important legislation passed it allowed Medicare Advantage plans to begin to offer some supportive services to senators, a democrat and republican democrat was a Senator John Warner from Virginia, and he was a caregiver for his parents. And the republican was Johnny Isaacs, and Senator Isaacson from Georgia who had Parkinson's. So he was a recipient here now, so they got it. I mean, they knew it, they know what it was like. But that's what it takes. It takes some personal experience. And, you know, going back to the advocacy point, you know, if you're a caregiver, you don't necessarily have to come to Washington. So members of Congress often have these town meetings, or whatever they might call it, where in their districts, they have little meetings, and it's an opportunity for constituents to come in for them to hear what concerns on your constituents. What if a caregiver goes to one of those meetings and doesn't even ask for anything but says, you know, Congressman, let me tell you what my day is, like, that's gonna have an effect. Those members of Congress have, you know, some kid who's writing down all these questions, and they'll bring that back. So I think just to the degree that caregivers can explain their stories and help people understand how challenging it is they can have an effect and you know, war it lets you know, people like Anne and other people who are that policy experts, figure out how to take those those challenges and and turn them into legislative solutions. But just explain this what my day is like, I think we have a powerful effect on members of Congress, state legislators.

Rosanne 18:43

Well, now would a call or a letter have the same weight of not going to that because you say go to a meeting. And I right, there's like, again,

Howard Gleckman 18:52

How am I gonna do that right. Now again,

Rosanne 18:53

Right so you call them? Can you write them a letter? What can you do?

Howard Gleckman 18:57

You can do a letter, if it's not a form letter, a mass form letter, which they sort of just count and throw in a pile. If it's an actual letter, there will be somebody on the staff who will read it. And it may get some attention, not like talking with a stamp, not a with a stamp yet better letter than an email. So yeah, I mean, you can certainly do that phone calls, a phone calls to congressional offices or a lot. So all the congressman is going to know is that Rosanne Corcoran called at 10:30 on Tuesday, but the details of your call are really not going to matter very much. If there's a specific piece of legislation, it can matter you can you can say I call the congressman at 10:40 to support passage of the better care act that matters but an in person conversation is way better if you can find the time to do it. You can get somebody who can fill in for you for a couple of hours one evening so you can go to one of these not easy to do I get it but if you can do it, it really can make a difference.

Rosanne 19:53

Okay, well listen, can always write something. Yeah, because they in trying to explain like I said, it's it's hard but If you can compose this over time, and there is a definite someone is actually going to read this, it's helpful to know that you're not screaming into a void.

Howard Gleckman 20:11

Right and you know, and the other thing, Daughterhood actually helps, too, I know, I know, it's not a political organization. But if you have a Daughterhood circle, it's got 10 people in it in one town and if all 10 of you write to the member of Congress, that's gonna get some attention, this guy's gonna say, Oh, what is this, I get 10 constituents are really concerned about this. And you know, don't write the same letter, write your own letter, right, make it personal. But that's the kind of thing that can have a real impact that a good politician is not going to forget that.

Rosanne 20:39

That's a great thing to know. Now, when it comes to long term care, I think people do think about a nursing home. And they don't realize that, yes, that's long term care. But long term care happens every day all over the country. In I believe I read something it said 70% of older adults in the US will require help with dressing, hygiene, moving around, taking medications,

cooking, all of that. And I don't know if that thought if it's a one to one, if people see that connection.

Howard Gleckman 21:08

So let me throw out some numbers. I try to not be too boring about this, but we just throw out some numbers. To put this on in perspective. You're right. The research that we've done at the Urban Institute estimates is something like 70% of people over 65 will need a significant amount of long term supports and services before they die. That might be as you say, how bathing or beating transferring on average, it'll be for a couple of years, men will need it for an average of about 18 months and women about two and a half or three years, nearly all of that care actually happens at home.

Probably 85% of long term supports and services occur in people's own homes only about less than 10% a day 9% occur in nursing homes, and another 7% occur in assisted living and other supportive communities like that. The rest of it happens at home among the 80% who get care at home. 80% of them will get care exclusively from family members only about 10 or 15% will have paid aids and others will get a little bit of help from other people. But this is mostly a story and I need to tell you and Daughterhood about this this is mostly a story of adult children caring for their frail parents by themselves. I always remind Anne of this, I'll remind you of this, even though 60% of those caregivers are women. 40% are men. And actually the percentage of men who are caring for parents is actually increasing. We're doing this a little more than we used to the research is interesting because it suggests we do different things.

So men, male caregivers are more likely to do things like run errands, balance the checkbook, manage the medical appointments, all of that daughters are more likely to do the personal care, the bathing and the feeding and all that but men are getting more engaged in it actually interesting things as younger men are getting more engaged in this. This is an interesting phenomenon. People are now talking about, you know, the baby, we all know about the baby boom caregivers, but but now people are starting to think about the Gen X caregivers. So that's kind of an interesting. I remember one of the demographic things that happened was people were not having many children, but they're also having children at an older age. Right.

So what was happening was that younger people were starting to care for their very frail older parents at a younger age. The other issue that's very important to think about is the ratio of available family caregivers to people who need care. So my friend Don Redfoot at AARP, some years ago did a great study where all he did was he looked at the number of people of caregiving age, and he made caregiving age people between 40 and 60, and the number of people who need care, and those are people aged 80. And oh, that's a very rough calculation, obviously, are people younger than 80, who need care, but but just to give a kind of a rough

sense of it. Now, what he found was in 2010, there were seven people of caregiver engaged for every one person who needed care by 2015, there's going to be three. And that was a function again, of the baby boomers not having children. So that means that the just the gross number of available caregivers relative to the number of people who need care is is shrinking dramatically.

And that doesn't even include the long distance caregiver. The fact that we're so dispersed that mom may live in Chicago, but her kids may live in LA in New York, so they're not available caregivers. And the other thing it doesn't it doesn't address is the tremendous change in the nature of families in America. So today, half of children who were born are born to single mothers. So that means that you have the fathers who are increasingly disconnected from their families, from their children, and from the mothers of their children. And that means when they age, who's going to be available to care for them. We have increasing the number of increasing numbers of women who never marry. And that means there's nobody to care for them and their old age. So there's demographically there's an awful lot that's going on and all of its in the same direction. Follow that means that the available numbers of family caregivers are shrinking. Just as the numbers of people who need care, the baby boomers is rising rapidly.

And the important number to remember about the baby boomers is, you know, everybody made a big deal of the fact that well, you know, baby boomers are now turning 65 doesn't matter, people at 65 are relatively healthy, what really matters is what happens when when the baby boomers start turning 80. Baby Boomers are going to start turning 80 in four years, in 2025. And, and that's when, as they say, it's really going to hit the fan. And we're not prepared for this. I often tell people, you know, people talk about the crisis of aging and the senior tsunami. And it's important to remember that that this is the result of a very good thing. 100 years ago, life expect the United States was was was 45. Now it's over at life expectancy of somebody at age 65 has doubled since 1950. You know, now if you make it to 65, here, you're likely to make it to 80 or 85. And for most of that time, you're going to be pretty healthy. Yeah, you'll have your aches and pains. And you know, you're not going to be able to play basketball anymore, but you'll be okay.

But there will be that period of time, that couple of years where you're going to need help. And what's happened is our capacity to keep people alive, all the advances in medical technology and public health, that have done extraordinary things of keeping us alive and keeping us alive and active. For a long time. The Long Term Care System hasn't kept up with that 100 years ago, there wasn't any long term care, because you got sick, you died factly, you got kicked by a horse, you got an infection, you you were dead, you got cancer, you are dead. Now we have turned cancer into a chronic condition, the number of women who survived breast cancer has increased by more than half just in the last 30 years. So we've

done extraordinary things in terms of medical technology. But we haven't kept up we don't have a system for carrying people when they become frail. And that's where we need to fix this. And we especially need to do it now. Because so many boomers are going to really need help very soon.

Rosanne 27:21

Do you think it's because people always just thought, well, your kids will take care of you. Well, it's your parents, of course, you have to take care of them. Do you think it's just been kicked down the lane?

Howard Gleckman 27:31

So it's a funny thing Rosanne. Think about the way we think about families in the United States is very weird. We provide all sorts of support to parents of children, right? We have public schools, we have daycare, we have child tax credits, we have all of this stuff we're talking about family leave for mostly for parents of infants, but but weirdly, you get to the point where you're aging, even though this is just part of the life cycle, and there's nothing and you're right, there's this expectation that well, you know, you're responsible, you're supposed to do this, but we do provide all this assistance for people with children, why don't we provide some assistance for people with frail parents? And you can ask me, Well, why? And the answer is, well, we never thought of it. Because it's a new problem, like having children is not a new situation. We've been having children for a long time. We don't have aging, we have not been having aging parents until the last 100 years. And and it's really taken a long time for people to understand this. The other problem is, and this is this is a weird thing. But true. The other problem is there is this expectation that Medicare will take care of it.

Rosanne 28:43

Yes

Howard Gleckman 28:43

They do public opinion surveys, and the public thinks that Medicare will pay for this. And I talked to members of Congress, and they don't know the difference between Medicare and Medicaid, they think Medicare will pay for it too. And it takes a good bit of education for people to understand both for ordinary people and for politicians to understand that Medicare doesn't pay for it. It's for the very few exceptions. So there has to be some system to do this. Either. You've got to put away a huge amount of money, or the government's got to do but somebody's got to be there to pay for this.

Rosanne 29:10

It's very specific. They don't even cover adult daycare, and you would think that adult daycare to be covered by Medicare would be a no brainer. You would think that, but it doesn't.

Howard Gleckman 29:21

Medicare has built this wall. And it very explicitly says if it's not medical treatment, we don't pay for. So we will pay for a limited amount of home health. If it's a visiting nurse who's coming to change a bandage on a surgical wound, but we won't pay for an aide who helps you get out of bed because that's not medical. We won't pay for adult day because that's generally not medical. And Medicare is very careful about this. And in fact in recent years has even been cutting back on the amount of medical care that they would pay for because Medicare's budget is being squeezed and they're looking for places to save. So there's, you know, the the example that a lot of people have run into is this thing called observation status, go to the hospital. And if you are, if you even though you're in a hospital bed, if you're there under observation, you're there for less than three days and you're discharged, the family is responsible for paying for any post acute care you need. Even in a nursing home, Medicare, would pay for that only if you've been in the hospital for three days. Most people these days are not in hospital for three days.

So Medicare is always looking for ways that it can not pay for things. So yeah, so you're dealing with a program that's in financial trouble, and is looking for ways to not pay, and culturally just doesn't deal with social supports, it's just not one way to think about. So part of what I work out a lot is getting people to understand the importance of integrating supports and services with healthcare. And that's something that people don't think about. I have had the opportunity over the years and not in the last year and a half. But I've had the opportunity over the years to visit with medical residents and talk to about this issue about caring for older people. And one of the things I tell them is, it's important for you to understand that much of what happens to improve the well being of older of frail, older adults, you don't do it's not medical care, it's it's those supports or supportive services.

Rosanne 31:23

Right.

Howard Gleckman 31:24

There's no pill for a lot of what happens to you and go I mean, notwithstanding what what people may have read over the last month, there's still no pill for Alzheimer's disease now. So the medical system can treat some of the consequences of Alzheimer's, if you fall, you know, they can treat the fall, but they can't treat Alzheimer's. So what happens to improve the well being of somebody with dementia, it's the caregiving, it's the visits, and somebody to hold their hand and somebody to play music for them, and somebody to make sure that somebody gets to the grocery store so they can eat and cooks for them is all of that. And none of that is medical. And helping doctors understand that is a real, it's a very interesting experience. I've had attending physicians yell at me at some of these meetings, because I am, you know, not respecting what medicine does. And I say to them, Look, you guys do what

you can do but you've got to understand there are limits to what you can do. And your job is to communicate with family members to help them find their way through this maze. And doctors will say I love talking to doctors, because they they're not there's no filters when you do this. They'll say that's not my job. And nobody pays me for that. So why should I do that? And you know, they're not wrong.

So one of the things you can think about is, so what if we had a system where they did get paid for that the docs are still not going to do it, I don't imagine that a doc is ever going to be able to give you advice on where you can get a home health aide, or, you know, a good Adult Day Program. But there could be a social worker who is connected to a medical practice, and they may, and there's no reason why a physician couldn't say. So we have just diagnosed the older adults with a chronic medical condition that's going to result in them requiring some personal assistance. In my perfect world, what happens when that diagnosis is made is it triggers a whole set of communications where the patient and the patient's family can learn about what is available to them to learn about what the progress of the prognosis of this disease is going to be how things are going to change how they can adjust to those changes. That's my perfect world. But we're not anywhere close to that the Academy of Neurology just last month updated its code of ethics for neurologists, treating people with dementia, they hadn't done in 25 years, if you can believe it, but they did it last month, and they say in there relate to never, they say in there that it is an ethical responsibility of neurologists, to communicate candidly with patients and their families about diagnosis of dementia, because for a long time, they didn't for a long time, they said well, we don't want to scare the patient, we're not going to tell them now they're obligated by their own code of ethics to do it. And they're also obligated by their code of ethics to engage family members, family caregivers, in discussions of the diagnosis and and what's gonna happen next. So this is neurologists, this isn't you know, primary care Doc's there's a lot of other physicians who need to adopt the same kind of thing. But there's a lot here that has to happen on the physician side to make this more seamless than it is. And what I found around the country is there are really good examples of this are popping up here and there, but they're not replicating they're not happening as frequently as they should. And, and why not goes back to what I was saying before it's because of the money. There's there's there's no financially stable model to create these things. So you have to get special waivers from Medicare to be able to do some of these things and it's really hard to do but that's that's what has to happen. It's not It's not that we don't know what to do. It's the we don't have a system for making it really happen.

Rosanne 35:03

It's horrifying to me to think that they hadn't updated their procedures in 25 years. It's also horrifying to think that we, as the caregivers are going into these offices and thinking, well, they'll tell me, well, they'll tell me what's supposed to happen. Well, they're going to tell me what's going to.. and to think that, why don't get paid for that. So I'm not going to say, Listen,

this is a no win situation, or this is what's going to happen or as a person, you think that's all part of what a doctor does?

Howard Gleckman 35:31

Yeah, it's not the doctors will tell you, you know, I don't have time. These are long, complicated conversations. I've got, you know, eight minutes or 12 minutes per patient, I don't have time for this. And for me to make a living and keep my office going and doing that I can't do it. Somebody's gotta pay me, and they're, you know, they're in business. I mean, yeah, you're right, it would be nice to think that doctors would think differently. The other thing that's important is they don't actually have the knowledge either, you know, even a well meaning doctor, I think in a lot of places, if I were to have, I have a wonderful primary care doctor, if I were to say to him, I need Adult Day, where should I go? I don't have a clue. So I mean, they don't have the time, they don't get paid for it. And they don't actually have the knowledge. And if you talk to physicians, they say, you know, unconstant doing so much reading, I've got to keep up on all the changes in my specialty. I don't have time for that. So that's why I say, you know, I don't think you could ever expect the physician to actually have these conversations. But there could be somebody in their office who could.

Rosanne 36:28

Agreed, yes. And let's be clear, listen, I I don't know how they I don't know how physicians even do what they do. And I'm thankful for every one of them. And you know, it's it's hard but yes, can't there be a section in their office? Can't every and I don't know what that costs, though, Howard, because then we were still on that treadmill of what's it going to cost me. So that would be that would alleviate so much pressure, and stress if, okay, here's your papers now go see, go see Madeline down there at her desk, she'll help you figure everything out. That would be lovely. It's like a care coordinator in a hospital.

Howard Gleckman 37:06

Yes that's right. One of the things that I think everybody should have is some sort of a care manager, case manager who can help them navigate all of this. And there are people like that, you know, pay for them.

Rosanne 37:19

Absolutely.

Howard Gleckman 37:20

But a lot of people can't afford them.

Rosanne 37:21

Right

Howard Gleckman 37:22

So so what can we do to make make that possible? You know, the system is so complex. And again, all of your listeners know this, but it is so complicated, there's so many pieces you have to assemble. And the jargon is so unfamiliar that it's just impossible to figure this out on your own, especially when you're doing it under this enormous pressure. Nobody thinks about this in advance. I mean, who has this conversation in advance? They never think about it until mom has the stroke.

Rosanne 37:55

Right.

Howard Gleckman 37:55

Right. And the hospital says mom's gonna be discharged at noon. And now you're saying, Oh, my gosh, what do I do? I have no idea what to do. And you ask the discharge planner, you said discharge planners gonna say, here's a list of nursing homes.

Rosanne 38:09

Yup, pick one.

Howard Gleckman 38:10

There's a list of nursing homes go to nursing home, because it's easiest thing for the discharge planner.

Rosanne 38:14

Yup.

Howard Gleckman 38:14

There are some hospitals that are doing it in a different way. They are beginning the discharge plan at the moment a patient is admitted.

Rosanne 38:23

Okay.

Howard Gleckman 38:24

So you have a patient to go to the emergency department versus department admits them to the hospital. At that moment, there will be a social worker available to talk to the patient and to the patient's care partner about. Okay, so this Mrs. Jones just had a stroke, our assessment is that she will recover. First of all, she is going to survive this, and she's going to recover pretty well. But she may have some deficits, walking, talk to me about where Mrs. Jones lives, that she has stairs going up and down to her apartment, is there somebody who is living with her who can take care of she's going to have trouble cooking, so we can have an

occupational therapist who can come but until she recovers enough to cook for herself, who is going to do that for her. So you start having those conversations immediately. And then you can begin to work with everybody and plan what the discharge is going to be like. So you can say Mrs. Jones lives in a third story walk up, her husband died. There's nobody there to take care of her, then the right answer might be she's going to need nursing home or assisted living or something until she recovers fully and could go, that may be the end that may be the right answer.

On the other hand, she lives in an apartment building with an elevator who has access to the lobby with a with a ramp. Her husband is is there to take care of her he's still in pretty good shape. There's no reason why we can't send her home. But But you've got to begin to talk about that, you know, not 10 minutes before the discharge, you got to begin to talk about that days before the discharge and be Get to work all this out. There have been models I've seen around the country to do that. And it works really well. Weirdly enough hospitals do this for some conditions, but they don't do it for others. So some hospitals will have patient navigators for cancer patients, or for some cardiac patients, but they weren't for other conditions. And I don't know why they don't.

So, you know, one of the things that I talked about all the time is, if these programs are working for oncology, expand, right, do for other conditions, why not? So it's there, but it's not, it's not there enough. We have to we have to do more with these. And and you know, the the bit of advice, I'm probably, you know, the 50th person to say this on your show. But when you're a care partner, and you go to a doctor, with with a patient with a parent or a sibling or spouse, it's the old device, go there with a list of questions and and ask your questions. And if enough people ask a doctor questions like, where do I get help? At some point, they're going to figure it out? They're gonna say, you know what, I think I'd better find answers to those questions. So but but it's really important to do that it's important to have the list and write down the answers, because especially when you're getting a really bad diagnosis, you know, the Doc's will all tell you, nobody hears anything. After I have said, You have Alzheimer's, you have cancer, they don't hear a thing after that. So it really requires people to write it down, ask questions, ask follow up questions, but I will tell you going back to my own experience, so I was a journalist, my wife is an attorney. We ask questions for a living. And that's what we did. Suddenly, we have this crisis in our families, and we're blithering idiots, we don't know what to say. We don't know what to do. So yeah, I mean,

Rosanne 38:41

It doesn't matter.

Howard Gleckman 39:50

No, it doesn't, right so you use those little prompts, use those little crutches and they really can make a difference.

Rosanne 41:51

I always kept the minder and it, I felt like it made people stand up a little straighter, like, Uh oh, this one's writing things down.

Howard Gleckman 41:58

That's right. And when you're seeing multiple physicians, which of course, seems to be what we always do, you can bring the binder and you can say to physician B, physician A said we're supposed to do this, you sound like you're telling him telling us we're supposed to do something different. Explain why it is I should do what you want me to do and know a physician A why. So yeah, it makes it a lot easier. And you don't have to rely on your memory and this time of stress. It really helps.

Rosanne 42:23

Yeah, totally agree with you. Now, going forward, Howard is there a positive? Do you see positive changes in other areas in, is there anything out there that you know, that starting that things that are happening, that people can adapt or try to adapt in their own lives or in their own communities?

Howard Gleckman 42:43

Yeah, I think there's a lot positive that's going on. In terms of business. I think that there are many more people getting into the home health and home care business. This was a business that was widely the sort of small mom and pop local mom and pop businesses. Some of them were really good. Some of them were not so good, that businesses is getting bigger, it's changing. I think it could create some opportunities. There there is more integration, more linkage between home health and managed care, at least Medicare Advantage, they're beginning to work together in areas where they never did before. So I think that helps in terms of public policy, there is more funding for programs like Meals on Wheels, and elder abuse programs and falls prevention and a lot of that for years, we had no increases in funding. And now there's more where there is more money, there will be more providers, more people are going to sort of get involved in this. A lot of places there are long waiting lists for meals on wheels, I don't know if the waiting list will go away, but they should at least shrink. That's going to make a difference. Those Medicare Advantage plans I was mentioning are beginning to offer some limited supportive services for the first time, that's an important change. Medicaid is becoming more flexible.

If you're on Medicaid, you have opportunities to do things that you couldn't do before Medicare wouldn't pay for before. Still not nearly as flexible as it shouldn't be. But but at least a little bit more flexible. states are thinking more in terms of home care, and part of that is

because they're getting they're getting more money from the government in legislation that passed at the end of last year. You know, the flurries of bills in response to the pandemic and a bill that passed at the end of last year gave states an additional 10 or 11 Billion dollars for 2021. For this year to provide more home and community based services for people on Medicaid. President Biden has proposed \$400 billion more of federal money for people getting home and community based care on Medicaid over the next seven years. Whether that passes Congress or not, we'll see I suspect something will pass but it's not going to be 400 billion dollars.

Rosanne 44:50

No.

Howard Gleckman 44:52

But something will and there'll be more money available for home and community based care there. There is a lot more attention being paid to the nursing home industry and what we can do to reform that industry and we'll see how that goes. But I think that we're gonna see some significant changes there. The market is also forcing changes. There are though some downsides to what's going on. The biggest one is there was even before COVID and enormous shortage in aides. Aides are being paid 12 bucks an hour, on average. Nobody want to do that work.

Rosanne 45:24

Nope.

Howard Gleckman 45:25

The immigration policy and the Trump administration closed the door to many people who serve as aides so that made it even harder. So we had this shortage of aides before COVID. COVID hits 2000 aides died during COVID, many more quit or got sick. And now they're not going back. We've all heard about the labor shortages and low wage workers. It's whether were the restaurant servers or people cleaning hotel rooms. It's also true with with aides, both home care aides and aides working in facilities, they can't get them. That labor shortage is driving up the cost. They're having to pay them bonuses. They call them, you know, pandemic premiums, and they're still reluctant to come back. Some will probably come back when school starts because a lot of women were not going back to work because they had to take care of their kids who were at home because schools were closed. When schools reopen assuming schools do reopen in September, I think some of those will go back into the labor force. And we'll get a few more. But there's still a terrible shortage. I'm hearing this from operators of nursing homes and assisted living facilities, I'm hearing a lot from just ordinary people who are trying to hire help very hard to get them right now. So that's a downside. The overall cost of long term care is going to go up not only the labor costs, but all the personal protective equipment, the PPE you've been hearing about with COVID, that's here to stay, the

testing is here to stay for facility based care nursing homes are going to have to spend a lot of money to reconfigure their interior design to make it safer to prevent viral infections. And remember, this isn't just COVID. This is the flu, and norovirus and all these other viral infections that have been going through nursing homes for years, and nobody's been paying any attention. So I think for all those reasons, it's going to be much more expensive. And that means that families are going to have a greater financial challenge than they did before we estimated before COVID, at the Urban Institute, we the analysis we did we estimated that, on average, on average, it would cost about \$180,000 over someone's lifetime, to provide them with the long term care they need. But that 15% of people would spend \$250,000 or more.

Rosanne 47:42

Wow.

Howard Gleckman 47:42

And nobody has \$250,000 they just don't.

Rosanne 47:46

No....no.

Howard Gleckman 47:46

So that was before COVID. And I imagine if we redo these numbers, or when we redo these numbers, they're going to be significantly larger than that. So the financial problem is worse.

Rosanne 47:58

Yeah.

Howard Gleckman 47:58

The cost of families is higher, but the sources of care, the delivery of care is beginning to change. The other place where we're starting to see policy changes that are very positive and very important is in the financing. Washington State a couple of years ago enacted a public Long Term Care Insurance Program, everybody pays a little bit more in payroll tax. And in return for that they get a Long Term Care Benefit, very limited. It's only about \$100 a day for a year. But it's a benefit. I've worked with a number of groups over the years that have promoted the idea of a long term public catastrophic Long Term Care Insurance Program. And the way that would work is you would be responsible for paying for the first period of time on your own, and after that, this public catastrophic program would kick in and it would pay for care for the lifetime of the person who was eligible. A bill has been introduced in Congress by congressman from New York named Tom Suozzi. I don't know if that bill's going anywhere anytime soon, but it at least there's there's legislation, there are people talking about it. There's a recognition that this the cost of this was excessive before, and it's even

worse now. So yeah, I think there's there's discussion, there are ideas floating around. As I say I'm optimistic. I think at least some of this can happen over the next year.

Rosanne 49:19

I hope so. It's interesting, because the long term care companies can't keep up with this. I just saw something the other day that said there they put limits, a few companies have put limits to \$4,000 for three years, and it's like \$4,000 isn't going to get a whole lot of anything, Is the idea just for everybody to run through their money and then go on Medicaid?

Howard Gleckman 49:39

Yeah. Basically,

Rosanne 49:40

That's just the plan.

Howard Gleckman 49:41

That's to the degree that there's a plan. That's the plan.

Rosanne 49:43

Wow.

Howard Gleckman 49:44

Yeah, long term care insurance. Last year in the entire United States they sold about 50,000 standalone long term care insurance policy. Essentially nobody's buying this insurance anymore. And and no insurance companies are paying or selling it or very few are selling it. There are these so called combo products where you can buy an annuity with a rider that provides Long Term Care Benefit. But it's a very limited market, you got to be rich enough to buy an annuity. So the private long term care insurance coverage is, is a small piece of this, it will continue to be a small piece of this, but it's only going to be a small piece, middle income, people just can't afford it, there's got to be something else. That's why the idea of a public program I think, is really important. It would also be really good reverse mortgages, which make it possible for people to tap in the equity of their homes, but they're very expensive. And they're very complicated. And it would be nice if we could design a simpler, cheaper model for something like a reverse mortgage where you could use your home equity.

But beyond that, I mean, we cannot expect people to save for this, it's hard enough to get people to save for kind of a healthy retirement, getting them to save an extra couple of \$100,000 to save for for this kind of care it's just not realistic. The one other thing that one other bit of optimism, I'll throw out there is I think there's a recognition because family caregivers are less available than they ever were, there's a recognition on the part of communities that there is an obligation for all of us to take care of our neighbors. And you're

starting to see senior villages which are popping up around the country, which are just local nonprofits, where people get together, volunteers help people who need volunteers, there are in the Washington, DC area, there are dozens of them, San Francisco's a lot of them elsewhere in the country, there are a few here and there. But it's a very interesting model. And essentially, it's just a way for people to get to know and help their neighbors. faith communities are another model that is interesting to me.

For a long time, faith communities really abrogated their responsibilities in this area. And now they're slowly beginning to kind of recognize how important it is to provide support for older adults and for their adult children. So we're starting to see faith communities that are also providing kind of volunteer programs where you can have people who visit the sick or cut off a ride. And those programs are again, slow, but they're starting to pop up more and more. So you know, Mrs. Jones, who went to church every Sunday and suddenly hasn't been coming the last few weeks, somebody can call her and say Mrs. Jones, okay, everything all right. And maybe she says I hurt my leg, I can't drive and volunteers and say, Okay, we'll come pick you up, it can be that simple. Or it can be more than that it can be delivering meals to somebody who can't cook for themselves. So I think we're starting to see at a very local grassroots level, people making efforts to replace the care that we're losing because of what's happening to families. And so some people refer to this as kind of a new way, a new form of long term care insurance. In a sense, I'm buying insurance by offering to help you now. And in return, you're going to help me when I need it. So it's a I think I think we're looking for systems like that same things happening in housing, we're starting to see all kinds of interesting models for senior housing, even things like group homes, where you get groups of friends who say let's all get together and share a house and share in

Rosanne 53:03

Like The Golden Girls with an extra room.

Howard Gleckman 53:05

Like The Golden Girls, exactly, exactly. And it's not easy, it takes a lot of work to make something like that happen. But you can do it. And there's some interesting models around the country where it's it's actually working.

Rosanne 53:15

It comes down to, we have to figure this out. So we're all going to go bankrupt. Or we're going to wind up in a system that is over populated and over everything. So we have to figure this out ourselves almost, which is what it sounds like.

Howard Gleckman 53:30

That's right. I mean, one of the things that I often tell groups when I talk to them is, so I work in this whole public policy world, and there are public policy changes out there. And many of

them as we've been discussing are for the better, they're really gonna improve things. But you can't count on the government to get you out of this, that ultimately, this is going to be you and your support system. And the idea is identify that support system and try to build out some sort of a model where you can all help one another. And that's what you're doing with daughter hood, at least helping one another, supporting one another. But you can even do more than that, you know, you can actually provide practical support. I'll come and sit with your mom for a couple hours when you have to go out if you can help me on a different day when I have, you know. So I think those kinds of informal systems are going to be critical in an environment where government benefits are going to be limited and family members are just not going to be provide the care that they historically have.

Rosanne 54:31

You're absolutely right. And there's 1000 different apps that are out there now that you can communicate with and set things up

Howard Gleckman 54:38

Even more simply than that there are these you know, online calendar programs.

Rosanne 54:42

Yes.

Howard Gleckman 54:43

You know, Lots of Helping Hands is is one of the more common ones. And it just takes one person who's willing to keep the calendar and you plug your name in and you're there to provide a ride or a visit or whatever, whatever it is. So it's not you know, technology has made this pretty easy. It's a matter of finding time. And of course, one of the things about COVID is now more of us are working from home. We, we have more flexible schedules. So if I were going into my office and somebody said, you know, so Howard can you look at my mom from two to four? I would say I can't I'm downtown. Now somebody says can I do it? I say yeah I can make that work.

Rosanne 55:16

Right.

Howard Gleckman 55:17

So this is kind of an opportunity for us to sort of rethink some of that kind of support.

Rosanne 55:22

A big thank you to Howard Gleckman for being my guest today. For more information about Howard, The Urban Institute and more, check out [Howardgleckman.com](https://howardgleckman.com). I hope you enjoyed our podcast today, head over to [Daughterhood.org](https://daughterhood.org) and click on the podcast section for show

notes, including the full transcript and links to any resources and information from today's episode. You can also find us on the Whole Care Network as well as anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram, at daughter hood the podcast. Feel free to leave me a message and let me know what issues you may be facing and would like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song Mamas Eyes, from her album Lessons In Love that you can find on the iTunes Store. I hope you found what you were looking for today, information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you join me next time in Daughterhood.