Episode #41: The Policy of Care with Howard Gleckman and Anne Tumlinson

57:41

SPEAKERS
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Rosanne 00:43
Hello, and welcome to Daughterhood the Podcast. I am your host Rosanne Corcoran, Daughterhood 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 Daughterhood. Here at Daughterhood, we received numerous questions regarding governmental policy and the myriad of ways it affects the health care system and each of us both as patients and as caregivers. It was my pleasure to speak with two experts in the field and friends of the podcast. Howard Gleckman, senior fellow at the Urban Institute, as well as a columnist at Forbes, editor of TaxVox blog for the Tax Policy Center and author of his book, Caring for Our Parents, and creator of Daughterhood Anne Tumlinson who was also the founder and CEO of ATI Advisory a national research and consulting firm that shapes public policy and business strategy to reform care delivery for individuals with complex care needs and their families. We discuss many issues like the challenges of trying to change policy, the importance of lawmakers hearing and understanding the challenges caregivers face, how policy shapes the care we receive and the importance of making our voices heard. I hope you enjoy our conversation.

Rosanne 02:32

In the contentious 2022 midterm elections. We were inundated about the importance of our vote who was elected and the roles that they would play without sounding partisan. Why is it important to elect the right people?

Howard Gleckman 02:45
So Rosanne, you know, the right people doesn't necessarily mean partisan.

Rosanne 02:48
Okay. Okay.

Howard Gleckman 02:49
Right. I mean, there are as you know, as Anne knows very well, there are Democrats who don't care about this issue at all, and there are Republicans who care a lot. So So you, I think it's okay to say the right people because it's okay. It's not partisan, necessarily.

Rosanne 03:02
Okay. So why is it important?

Howard Gleckman 03:04
What I've, what I found in the years of watching Congress and aging policy, is that you really can divide members of Congress into two groups. And it's not Democrats and Republicans or liberals and conservatives. It's people who have had personal experience with this issue and people who have not, yes, and what I've seen is actually an interesting transformation, sometimes where people who didn't care about this issue became caregivers, and suddenly cared a lot about the issue. And people who have not had the experience, it's hard to, it's hard to even explain to them what it's like being a caregiver, how hard it is, how much it overwhelms all of your life. And when you try to explain it to them, they it just doesn't compute. The other issue that's important when you think about Congress is a lot of the work is done by staff, people who tend to be very young, in their 20s and 30s. And they've had no experience with this, you know, they barely know their grandparents who probably live in some distant city, and explaining to them what this is like, and why it's important to have legislation is also very important and very challenging. So getting the right people, if the right people means people who are aware of the needs of family caregivers, and the needs of older, frail, older adults, it really is important.

Anne Tumlinson 04:27
And I would just say, I this is your power to reminding me of a Just briefly, I was some years ago, testifying before the Energy and Commerce Committee. And so I'm sort of sitting there as a democratic witness. And I've got the Dems on one side of the room and the Republicans on the other. And there was a lot of, you know, kind of, I don't know, some partisan bickering etc and, you know, grandstanding on both sides. And then there is this and I wish I could remember that A Congressman on the Republican side, who looked at me and he was like, my Dad has Alzheimer's, and we have money, and we still can't take care of him at home. It's too hard. And the two of us just locked eyes in that moment. And I knew he knew and understood all of the nuances and complexities of what I was trying to communicate. And just so just to your point, it really was the I got a much better response from him than I did from some of the Democrats. So, you know, it's not it wasn't it didn't feel partisan to me at all.

Rosanne 05:44
That I mean, it's very interesting. And I totally believe that, but it makes me feel like Oh, my God, well, if they don't, and we talk about this in the donor had circles all the time, you don't know what it's like until you're in it. And then you're in it. And you're like, Wow, this can't be the way it is. Yeah, it is. Yes, quite frankly, this is how it is. But but then we have to hope that there's somebody who's making the decisions that also gets that. And that's really kind of depressing to me hearing, I fully understand what you mean. And I agree with you, because they have to have that feeling to say no, no, we have to pass this. We've got to get this done. Yeah. What? Well, I mean, that explains a lot.

Howard Gleckman 06:30
The other really important thing about this is not only do they have to understand it, and not only do they have to make it important, but somebody up there has to make it their most important issue. Right. One of the things and Rosanne, you and I have talked about this before on this podcast. One of the things that was so disappointing was that in the wake of COVID, when 700,000 Older Adults died, and countless hundreds of 1000s of others got sick. And 200,000 staff and residents of long term care facilities died, Congress was presented with a menu of things to do about it, and did almost nothing. And the reason was not because they didn't know or didn't care. It was because it wasn't the most important thing. There are other things that got to the top of the list. And it fell down the hip rate. As usual, as usual, as always, as always, and and I think that's part of the problem. There's not been, frankly, since Ted Kennedy died, there's not been a Senator who really was willing or a member of Congress who was really willing to make this a priority,

Anne Tumlinson 07:43
Right to make this their signature issue, and to push and push and push. And that's what we heard was that there were members who were sympathetic, and there was leadership that was willing to put it on the list. But then ultimately, the list got narrowed down and we lost out. We didn't, we didn't get a tax credit, family caregiver tax credit fell off, failing medical leave fell off, increased Medicaid, federal funding for Home and Community Services fell off, all those things fell off. So for me, it's like going forward. Like what what has to happen for this to become less of like a boutique side issue and more of a fundamental issue? I am interested? I don't know the answer. I'm sorry Rosanne your asking...

Rosanne 08:37
No. That was and that was my next question. If they can't do something on that, what has to happen?

Howard Gleckman 08:44
So the good news is grasping here for good news straws. But the good news is that the President of the United States made this an important enough issue, that that he he made a number of very dramatic proposals,

Rosanne 09:02
Biden's American jobs plan,

Howard Gleckman 09:04

He would have increased Medicaid home and community based funding by $400 billion dollars, he would have increased funding for a whole range of programs that are funded under what's called the Older Americans Act by 10s of billions of dollars. A number of big dramatic changes that the President was willing to put his name on, and that had never happened before. Really not since Lyndon Johnson in 1965. Was anybody talking about Medicaid and all people? Right, so that's something and even though Congress didn't do anything about it, it put the issue higher up on people's agendas. And the other thing to keep in mind is it takes a long time for Congress to act. You know, we're all used to, you know, watching television and you know, somebody raises an issue with the beginning of the show and an hour later the world change Just it's not how it goes and cons, it takes years, three years, four years, five years for an issue to first surface and then finally get get enacted. So, in my optimistic moments, I have fewer of them as time goes on, but in my optimistic moments, I think, you know, this was a start, and and, and taught as time goes on, there's better chance to Congress will respond. In my pessimist moments, I said, if they couldn't do it after COVID, when will they do it?

Anne Tumlinson 10:32
Yeah, I, I guess I am I, my part, my optimistic view of this is what I've heard some of the really smart political people say is part of what was missing, in addition to the champion. So this is kind of lessons going forward, not I don't want to spend too much time dwelling on what didn't happen. But part of what was missing was like the sense of groundswell, honestly, from the grassroots. So what So what did happen? drug pricing legislation happened, every single person going to the pharmacy for, you know, has been like, Are you kidding me? What the heck, you know, is going on with this. And so I think that care for older adults and family caregiving, just hadn't just had while we had these COVID issues, you know, in terms of sort of like, really impacting every single family, we were not quite there. However, I just want to share that. And because I look at these numbers all the time is that what's fascinating about the demographics, everybody talks about, you know, the graying of the population, or the aging of the population, but the really dramatic thing that's going to happen in just three years, is that the rate of growth in the population that is over age 85, is going to become the fastest growing part of the American population. Wow. So like everything in American politics, we like to wait until something is a total catastrophe before we actually act. And I do think, I mean, I don't mean to be, you know, Debbie downer here, negative, negative, but I do think we are what I am seeing, and Howard, I'm interested in whether or not you agree, Howard, and I like to go to breakfast and talk about these things. But we're going to just do it here instead, do it here. Absolutely. I do it here. But we like to have disagreements. But you know, so fastest growing part of the population over age 85, it's going to accelerate really rapidly from 2025 to 2030. When when when the rate of growth accelerates, that's when we always see trends really started to take hold. Okay. So why is it a catastrophe? I mean, for everybody who's listening, if you're a caregiver, you kind of already know. But, you know, what Howard and I are seeing out there right now is some very distinct so we have a disturbing trends in that, you know, I think the nursing home industry, which is the one and only setting like it or not, where we actually have funding guaranteed for care. So if you run out of money, and you need really high levels of care, essentially you are entitled to and I'm oversimplifying dramatically here, but you are entitled to a nursing home that that sector and that industry is really, in my opinion, kind of imploding right now. So we're actually running into a situation where hospitals are trying to discharge people, and they can't. And so so so that infrastructures kind of falling apart. The other source of funding for care is Medicaid, home and community based services and states are paying I was just talking to a guy the other day, who runs a

Medicaid homecare agency and a private pay homecare agency, and he's sort of like no problem recruiting aides for his private pay, he can pay them $20 an hour, he gets paid $20 an hour by the state, and then he's paying his aides and Medicaid $12 an hour. So point being like he can't recruit over there. So we so I'm just sort of watching like the one place the one safety net, kind of like so fragile, and so teetering at precisely the moment that all of these people are going to need care. So it feels to me like a moment where we have to just hit more of a rock bottom, and families are going to be like it's just going to be every family and then the hue and cry will be loud enough. And then we need to be ready with like, what is the solution? And I think we have in the policy community where we have literally for 20 years been working on these still not particularly prepared to deliver that message. But anyway, Howard, that was a lot. I'm interested in what you agree with and what you disagree.

Howard Gleckman 15:21
So, so a lot to unpack there a couple of a couple of things in response. So one of them is, and you mentioned the labor shortage issue. This is already a crisis. Right now. It's a crisis that isn't getting a lot of attention, because who are the care workers, they're women, they're immigrants. There are people of color, there are people who don't have a lot of influence in Washington, but they'll people they work for have influence in Washington, and that labor shortage is truly is catastrophic. It was terrible before COVID, it's much worse now the industry has lost hundreds of 1000s of care workers who just aren't coming back, they're taking jobs, it's it's a lot safer, it's a lot easier, and you get paid more to be a warehouse worker than you do to care for a frail, older adult. So that labor shortage is was a problem that isn't going away and is if it isn't confronted, people aren't going to be showing up with the proverbial pitchfork for saying I can't get anybody to help mom in any price, right? The question of how this change happens, you know, and is great at producing data, I write about data, including the data that it produces. Data is only part of the story, you need to combine that with narrative. Yes, families. And I understand people don't have time, and they don't have energy and all the rest of it. But it's so important for family caregivers to say to men to stand up in internal meetings, to say to their member of Congress to say to their state legislator, let me tell you what my life is like. Let me tell you a stereotypical 50 year old woman who's caring for her mom, let me tell you, I had to quit my job in order to do this. And let me tell you what that's meant for my family. And I think going back to what we're talking about before, I think members of Congress don't really understand this unless they live through it. And part of the job is to help people understand it. Right. The nursing home question is a really interesting one. You know, nursing homes are imploding. It's a strange phenomenon, actually, that that the nursing home industry is collapsing at the same time that when people buy nursing homes, the per bed price is higher than it's ever been. So you sort of look at this and say, How weird is this, people can make any money in the nursing home business, but the people buying nursing homes, you're paying more money than they ever paid before to buy them so so this kind of completely crazy environment that people are trying to understand. The last thing I'll say about it. And again, it's just kind of punctuates, what Anne said is, is we're seeing this growing gap between the private pay world and the Medicaid world, if you're rich, you can still get plenty of good care, you can move into a continuing care community, you can move into a high end assisted living, you can move into a $15,000 a month Memory Care Unit, if you've got the dough, but that's a tiny slice of the population, then we have the very poor people, the lifetime poor, who are medicated, and we can take care of them not especially well, but we can take care of them. You know, as Anne said, you're entitled, if you're poor enough, you're entitled to a bed in a nursing home, you're probably going to be sharing a room with a stranger,

but you can get into a nursing home. The people I worry about the most are middle income people who aren't rich enough to afford 13 or $14,000 a month, and are poor enough to get on to Medicaid. And what happens to them. Those are the people whose daughters have to quit their quit their jobs who aren't getting the care at all. You know, we've talked I think before about when I went to back when I was doing research for the book I wrote on this the most shocking thing, most absolutely shocking conversation I ever had was with with aunties, who would tell me about what it was like to come to somebody's house who had died days earlier. And the only reason they knew it was because of the postal worker or somebody had smelled something that and these are women who were living alone, you know, in here in the Washington area in a row house, that they've been in for 50 years, raised their families in their husbands had died, their children moved away, and they just died. And nobody even knew. And that's the fate that a lot of those soon to be 80 year olds that Anne was talking about, are looking at, if we don't do something to fix the system.

Rosanne 19:35
It's very discouraging. I don't understand how with nursing homes being the highest to buy right now, how does this happen? How did we get here? How do we go from from here? Like how does this happen? That this is this is where we are?

Anne Tumlinson 19:51
Well, I'm gonna take a really big, big, big, big picture. So I think we created In a safety net, for a very what was a very small part of the population, it historically, the crazy thing is that what we have effectively done as a society is made it possible to live these incredibly long lives, what we call longevity gains or lifespan gains, but what we haven't done is kind of created an environment, a health care system, or an environment that enables us to live long health fans. So, you know, anybody, anybody who has a parent overage or feeling member, I should say, over age 75, especially over age 80, you know, you, you, you understand this very intuitively now, because you're seeing, and there's an enormous amount of variation, that you're seeing it right, you know, equal, bodies begin to break down, but we have this incredible sort of set of tools that enable us to at least address enough of that sort of those clinical issues that we can keep people alive for a really long time. And so we have just despite that, we knew this was happening, you know, 20 years ago, but we just haven't there's, you know, for all the reasons we've been talking about, we haven't updated the infrastructure, you know, meaning when what I mean by that is sort of like, just like, think of as like the roads and bridges of the care delivery system. They just don't exist, we haven't built that, you know, for the realities of old age in this country, and really, across the globe. Although I think other countries have done a better job in preparing that some of them are even farther ahead than us in terms of the grain. But that's that, you know, and it's expensive. It's expensive. This is not I mean, I think the resources are there, we're spending them in ways that we shouldn't be now, but it's still, you know, we're talking about paying other human beings to do really hard things for other human beings. There's not a robot or an app that you can sort of I we can get, technology can help. But it still doesn't change, like somebody has to be taken to the bathroom. Yes.

Howard Gleckman 22:36
There's another new study that came out just today that confirms what we've been hearing for years and years and years, which is the United States spends more money per capita on medical care than

any other country on the planet. At the same time, we know that the United States government spends less than almost any developed country on supports and services. When you add to to up, the United States, in most other major developed countries spend almost exactly the same amount of money. The difference is we spend it all on medical care. And they spent that on supports and services, they get longer life expectancy than we do they get families that are more satisfied. We all know that is answered. We've known that for decades. But we can't bring ourselves to do anything about it. So why can't we do it? So one of the reasons, of course, is there's a big medical care establishment out there that likes it the way it is, this is really kind of nice, getting all this money, you know, the classic, you know, stereotypical example, if you have a heart attack, Medicare will spend whatever it takes to take care of you, they'll do big heart surgery, they'll keep you in the hospital, they'll do post acute rehab, they'll spend whatever it costs doesn't make any difference. If you have the wrong disease. If you have, let's say dementia, where there is no medical treatment, the medical system will pay or Medicare will pay nothing, essentially. And you sort of sit there and you say this, this is kind of crazy. Why is it that some people get one disease in there, and the government spends unlimited amounts of money to care for them, and they get a different disease, and the government spends nothing, but that's what we've created. And, and as right, you know, in 1965, when we created this system, people didn't live really long time. And dementia, for example, is a disease of people over 80 people, not a lot of people live to be 80. So they don't think of it, it didn't occur to them. Somebody once said that the problem is that Medicare was created by a bunch of old guys to take care of all guys. And they didn't they didn't think about how things were gonna change and what answer is exactly right. You know, the change in medical technology has made it possible for us to increase life expectancy in the United States from the turn of the 20th century. You live on average, and in your 40s, you live to be 48 or 49 years old. Now you live to be 79, an increase in 30 years in life expectancy in a century is unbelievable. Life expectancy didn't change practically at all, from biblical times until the 1950s. You know, we got penicillin, which made extraordinary difference. We had changes in public health, we had, you know, indoor bathrooms, these kinds of things made extraordinary improvements in life expectancy in the United States and not and by the way, when I say this, people say, well, it's just because of, you know, life expectancy at birth. And it's, you know, infants are living longer. But if you look at life expectancy at age 65, is doubled in the last 50 years, it's gone from seven years to 15 years. So we figured out how to help people live longer, we haven't figured out how to take care of them during that period of time when they become frail. And that's where the system has fallen apart. And there needs to be more money in the long term care system. Some of that's going to come externally, but some of it probably ought to be coming from the medical side. But how do you get the medical people to understand that?

Anne Tumlinson 26:09
Yeah, my, my mother was telling me a story yesterday about so she's 82. And she's having a lot of speech therapy right now, because she's having some trouble swallowing. And she's very healthy. But she, we were noticing, right, you know, she was starting to cough a lot and show. So she's getting a lot of this. So her speech therapist told her the story about a woman who had such severe reflux and weakening of the muscles that she started aspirating a lot, you know, in this, it was this cascade of things, where she ended up with somebody basically wanting to put her on a feeding tube. And because she was on a feeding tube, she was then isolated from all of her friends who with whom she used to go out to lunch at that event. So you know, it's just like this. And then finally, somebody figured out a way to just treat the reflux through a number of different sort of alternative and homeopathic and

sort of gentle ways. And like, she got off the pager when she could resume her life. But just, that's such a classic example of like, oh, you're aspirating you're ending up in the hospital, that's very dangerous, we don't want that to happen again. So we're gonna put you on a feeding tube, and the feeding tube isolates you. And then you get depression. You know, that's a good, like, there's our medical system. Not only is it highly technical, and really advanced, but it's also, quite honestly, the business model of healthcare is to do things. You know, the more you do, the more you get paid. And it's not that any one doctor or hospital are sort of nefarious in any way. It's just like, that's ingrained. Now, you know, just just like doo doo doo doo doo, instead of trying to take a step back and see how we can adjust or underlying issues. And so that's kind of on the sort of policy and change and pull it up politics and stuff. I think one of the things that I don't know how to solve for that I don't know how to fix but I'm really committed to through toddlerhood is, every single family encounters all of this. And then they set about essentially, on their own, you know, setting up their own complete and total health care and long term care delivery system within their own home. And they don't, I think, because when it happens to you, first of all, it's it's traumatic, and it's overwhelming. And you kind of can't believe it's like that, but it because just the nature of what you are having to do in that moment, you don't think to yourself, This is a political problem. This is a systemic problem. This is This is unacceptable. And there needs to be the community, and the politics and the sort of we all live in this country together. And we should be able to change this together. So we can have a reasonable society in five years when everybody's going through it. So I think people don't like our to your point about you know, I wrote it down, let me tell you what my life is like, I don't know that they understate can really function in that moment. To be like, this isn't an individual problem. This is a political problem. I don't know how to help make that connection for people.

Howard Gleckman 29:33
Yeah, it's really interesting, because, you know, you think about its political problem in a couple of ways. It's a political problem in the sense of the money that this is a whole industry that's sort of built up on government money. You know, I have a joke with people you know, the the long term care industry is a little bit like the defense industry. All of its money comes from the government. And and because of that, the government and its rules drive all of the business decisions. And when people complain, for example, about why nursing homes, certainly some nursing homes are so bad part of it is because the government in a perverse way, pays them to do it the way they do it. Any good businessman is going to go to the payer and say, This is how you want me to do it, you get what you pay for. And so, you know, it gets really kind of boring for people to hear about, you know, regulatory process and administrative rules and all that. But the truth is, that's the, that's the stuff. That's the policy that the government is using to create the incentives that the long term care industry responds to. And if they tell you that, to take up the COVID example, if the government says to nursing homes, you, you are prohibited from allowing families to come and visit your loved ones in a nursing home, because we're afraid it's going to help spread the COVID infection, the nursing homes are going to say, Okay, you're gonna argue about it, they're gonna say, Okay, we're gonna close the doors. And then when people come back and say, Do you know what you're doing in terms of creating social isolation? The nursing homes, you're gonna say, well, but the government told us this is how we had to do it. And you know, the funny thing about that is Anna, and I and a few colleagues wrote a paper at the beginning of COVID, saying, Don't do this, this is a really bad idea. And nobody listened. They eventually did. But it took a while. And that's what happens, you know, that there was a time when the when the government said to hospitals, you

said nursing homes, you have to accept COVID positive patients. And the nursing home said, Well, okay, that's what you tell us we got to do. That's what we're gonna do. And the Biden administration, again, to its credit, is trying to rethink in some fundamental ways, the way it's regulating nursing homes, how it pays, some of those ideas, may be good ones, some of them may be not so good. But it's it's trying to at least confront some of these issues. For a long time. We didn't we just ignored them. We just pretend to these. These were not problems. They were problems.

Rosanne 32:07
Well, and when you start talking to people about the regulatory Commission's and how they decide who gets paid, and all it's kind of like that really awful word problem that everybody just kind of glosses like, okay, whatever, okay, you guys have it figured out, that's great. But all of that is part of these issues, right? I mean, all of that. It's almost like it comes home to roost at the nursing home. Because when they initially started, they were taking Medicaid patients and Medicare patients, and it would balance out and you know, you had a certain amount of number. And now I feel like that has gone out the door. And now what's been what's been happening is part of this strain. And I feel like CMS comes up with their own logic that the consumer has no idea about, but everybody that deals with the nursing homes know full well, how to work it, and how to maneuver it and how to make it to go to their benefit. And the consumers like well, I don't know, I think this is a good place. And meanwhile, all of these, and I hate to say back room deals, but that's what it feels like as a consumer. All of this is happening over there. And we have no idea. And I don't know how that that is fixed. Because again, that's more of the same. It's a business model. This is their business model, this is how they have to do it to remain in business. It doesn't necessarily help us. It doesn't help the people that are living there. But this is their business model. So how does that change? Or does it change? Or how do we make that better?

Howard Gleckman 33:41
So part of the problem goes back to what I was saying before, there's a there's a there's a gap between consumers and payers. And any business is going to listen to the people who pay them in any sales we do. The customer is the payer, right? I go into a store and I buy a shirt, and I bring it home and I discover the shirts got a rip in it, I go back and I say, I paid you for that shirt. Give me a new shirt. Right? The nursing home business, not the same thing. The customer, the consumer, the the older adult who's living there, their family members, don't pay. So that that disconnect between where the revenue comes from and who the customer is, to my mind is a fatal flaw in the system. Yeah, I've proposed for years, the idea of creating a public Long Term Care Insurance program. One of the great benefits of that program is the customer and the payer become the same person. I'm now taking that money from this federal program that I paid for, and I'm going to the nursing home and saying, if you don't clean up your act, I'm not going to use you. That still requires other things. It requires more transparency. You know, I need more information as a consumer about what this nursing home is really like. And to its credit, CMS is trying to provide some of that it's moving too slowly, in my mind, but it's trying to try to improve quality and transparency. But fundamentally, I think that, that until the money comes out of the pocket of consumers, and they need to get that money from somewhere, the system's ever really going to be fixed. And you could disagree with that if you want.

Anne Tumlinson 35:25

Yeah, I don't know. I don't know. Because I don't know I just kind of the analogous private pay system is assisted living. And it's certainly less grim than a nursing home that the industry argues constantly for differentiation. That's kind of the whole point of it. But I think it's still shockingly slow, to innovate, to try to meet the needs of the of the residents and the families. And you know, what an assisted living operator said to me not that long ago, you know, he's like, you know, we have we were created as sort of the answer to nursing homes. And we're like, really trying to kind of fill in all of the gaps in people's lives. And now, we've sort of, we're not doing it. And maybe part of one of the biggest challenges that I see in talking to caregivers of all socio economic means whether they're in a nursing home, or their parents in a nursing home, or assisted living or at home. It's this incredible disconnect between what we what are industries that provide daily supports and services, whether you know, like a nursing home, or assisted living or home care agency, and the medical system. This is especially annoying and problematic when somebody lives in assisted living or nursing home, because in theory, that should be an environment that really supports like efficient delivery of primary care and preventative care. And, you know, you should be getting like really easy access to vaccines, and to labs and to pharmacy and like pharmacy management. And yet, even in those settings where you have literally everybody there is somebody who has a really high need. There, there's like the healthcare stuff is just far flung, and disorganized. And then that family caregiver is left to essentially be the Sherpa of all things, health care, whether you're in a nursing home or assisted living. So that problem exists. And a lot of problems exist, even though people do have their own private resources to deploy. So I feel like Howard, the thing I would layer on to what you're saying is, yes, we need to have more sort of consumer power. But also somehow we need to have a better way of articulating like what is good and what is not good. And who is good and who is not good. And that's incredibly hard. Because what's good for you, you know, you had a good experience, because your mom had a good aide and this person, and then I had a bad experience, and also families. And I can say this can be really difficult. We're not the easiest people to deal. Because we're all like ahhhh.

Howard Gleckman 38:33
So I think another interesting piece of this, and I think and you're just hinting at it is is the care management.

Anne Tumlinson 38:39
Yes. Thank you.

Howard Gleckman 38:41
And, and that's the piece that's that is missing for so many people, you know, as written beautifully about this about about what it's like to have to play all these roles. At the time, you're under enormous pressure. Because you know, your dad's very sick, and you're trying to make sure your mother is holding it together. But you've got to deal with the homecare agency and the doctor and the pharmacy and all this. And it's really hard if you've got the dough and if you understand that you can hire navigators. You can hire geriatric care managers who can do this work, but most people can't. So what can we do to make sure that there's somebody in this process to put it all together? You know, and I, for a long time have both been very interested in in the opportunity that Medicare Advantage provides, because Medicare Advantage courses in an environment where it's in the interest of the insurance company to reduce health care costs, and if they can use care management or supportive services, to

keep people out of hospital and keep costs down. It's a win win for everybody. That's the potential. It hasn't really achieved that potential yet, but it's the only place in our system Were the incentives of the insurance company and the families, or at least potentially aligned. And if we get that to work, right, I think that's an opportunity fee for service, it's so much harder, because there isn't anybody putting this together. So there's the doctor. And then there's the pharmacy. And then there's the homecare aide, and there's no incentive for them to work together.

Rosanne 40:26
But the problem with the Medicare Advantage plans is that they're also finding that way to then incentivize them, and to create that into their own little business practice of, we're gonna rate you based on your condition, and then they get more money based on that rate, based on that score. So then you have those people taken care of, and then you have the other people that have SilverSneakers, but they can't get their MRI. So it's, we're giving you all of these things, but we're not giving you the care that you need, because that still costs us and that still takes away from our bottom line. So it's almost, it's almost like in every situation, it comes down to the business model.

Howard Gleckman 41:09
So how do we fix Medicare Advantage? So it does, in fact that she has the potential we both see it?

Anne Tumlinson 41:16
I know, it's so frustrating, um, the potential is there. So again, kind of back to what Howard was saying about the nursing homes, but now talking about just commercial insurance plans that now essentially supply the Medicare benefits to half of the Medicare population, you know, are sort of, I would call them policy tools. You know, so we, federal government sits here, and they make decisions about sort of how to pay for this stuff. What does that method of payment look like? What are the rules? What do you have to do, all of that stuff is very carefully thought through by really smart people. And, you know, surprisingly, who do a lot of that work without politics intervening to a large extent, and yet, it's clunky. And when you're talking about this, I mean, what I'm just struck by is just, it's so much money, it so much I think about like I don't know, like forgetting what the like it's, we're at like 600 $700 billion a year in Medicare dollars, half of which is now going to these private insurance plans. So when you make one teeny, tiny little tweak, that changes, that how those dollars flow, like the entire industry goes wrong. It's like steering a ship, if you've ever been sailing, and you know, you change your rudder, just a hair, and then all of a sudden, all the wind goes out of your sail. That's what it's like. So I think we have a lot of work, I think these big engines will respond and do what we want them to do. If we pay them to do it, we just have to figure out how to reward the right behavior. And I some of this is educating federal policymakers and the regulators who are so smart that this program is really not serving the needs of the frail list older adults yet and their families, but it could, and the one little, tiny, little shiny, bright light, and all of this is that we are seeing these plans, begin to recognize that family caregivers are a thing. Just that little that just that in and of itself is a big step forward.

Rosanne 43:40
Well, and that's that's my other question. Because when you think about this, and you look at all of this, it beats you down a little bit. So what do you see? Because and I know that you say a lot of times you

feel like there's a change coming? There's a change a common? What would change look like in both of your perspectives? What do you feel? What do you see? What do you think is going to change?

Howard Gleckman 44:03
I'll give you my ideal state, which we're not going to get to, but it's always nice to aim with the ideal state love it. So my ideal state is there is a fully coordinated, fully integrated health care and long term care system that is easily accessible by people who need it. And that it goes back to the old triple aim that they used to talk about the Institute for Healthcare Improvement, the idea that you get the right care at the right time, in the right place, and that the context of that always was within the health care system. We take that and broaden it out and say within the entire ecosystem of supportive services and medical care. And my ideal regulatory state, and Anna's heard me say this many times in the past is the government says to the insurance companies in the riders, if you can provide good quality care, properly measured, we don't care how you do it, we are not going to give you 1000s of pages of regulations telling you how to do it, we don't care. Just, we want to know that at the end of the game, you are providing your members, your patients with the best possible quality of care and the best possible quality of life. And if you do that, do it any way you want. Problem is dual problems. First of all, we don't know how to measure that in state very well. And the second thing is, regulators are terrified of abuses, that if we don't write all the rules, and tell people exactly what to do, that we're gonna get in trouble, we're gonna get hauled before Congress, and we're gonna get yelled at, because we allowed this money to get wasted. Because again, it's all government money. And we allowed all these abuses. So getting there is not simple. But I have in my head what the there is, no one can tell us how to get there.

Anne Tumlinson 46:02
Yeah, no, well, I just think it's so important articulate a vision and Howard, I love your vision. And I think that I really kind of, like I get up every morning trying to like my personal purpose is how do we change? How do we change healthcare so that it is less complex, and it is less expensive, and it is, you know, it's simpler and more effective for everybody. And because I think it's the complexity and the cost that ultimately gets us all in the end. And what that looks like, is something that's coordinated and integrated in where it makes sense, and it's rational. And I in terms of like, I do feel like the tectonic plates are just starting to kind of like, vibrate under the surface, because it, you know, just just the fact that there's just a lot more all of a sudden in the ecosystem about family caregiving, and connecting the dots, that, you know, you have an older adult, you probably with a lot of needs, you probably there's a family member somewhere, and that that's a connected thing. And that. So I think there's some movement at the community level, where smart sort of organizations that are dealing with this, at the community level are starting to kind of come together and say, like, let's have a conversation about this. Now, there has to be better funding, you know, for those community based organizations and a new charter and sort of a whole new way they've got to innovate, who they are and how they do what they do. But ultimately, it has to be an infrastructure that's community based, because Roseanne and I talked about this all the time, you know, what works in Pittsburgh is not what's gonna work in Atlanta, because these are very unique communities. So and there's micro communities within that. And we have all kinds of issues that people of color have to deal with and face that we hear about from our childhood circle leaders who are navigating that world. So all of that has to happen at the community level, but and there has to be support for that at the state and the federal level. And I think, ultimately, that's how it's going to get how

we're going to begin to get some resolve around this. And maybe that's that's sort of my vision, ultimately, is that we all have a place to go, you know, yeah. And our communities where that we all know is there. And we understand we're entering into this together.

Howard Gleckman 48:32
So it's an interesting thing. I'm on the board of a community based organization exactly like what Anne's talking about. And we are in the process of trying to develop a caregiver training and support program. And one of the big challenges we face is who's going to pay us for this? Right? Yeah. And it's hard to get an answer. Medicare won't pay for it. Medicaid doesn't pay for it. Private pay is going to be too expensive for a lot of people who really need it. You know, we can rely on philanthropy to start a program, but we can't rely on philanthropy to keep it going. So it's exactly what and said this is this is a need that everybody sees, but nobody wants to pay for it.

Anne Tumlinson 49:10
Well, and so Howard just my idea, just doing just to connect these dots is that is that I have been, we have these Medicare Advantage plans that are making lots and lots and lots of money, that aren't yet quite doing what they need to be doing. But it's still offering a solution that addresses some problems, that we have these community based organizations that are trying to solve problems. And I really have this idea that what perhaps would be the cleanest and easiest thing to do would be to charge private insurers a user fee, and create a pool of funds out of user you know what you you want to deliver health care in this market. You want to get all these lives and all this premium dollars for Medicare. Well, we have to fund essentially, the community based organizations are going to help people navigate because you're not doing it and you can't do it very well. And rather than try to put these community based organizations in a situation where they're having to like pitch to a Medicare Advantage Plan, which doesn't work, let's just everybody pays to create the infrastructure that the family caregivers need.

Rosanne 50:16
I love that.

Howard Gleckman 50:17
Yeah, the big incentive, I think, for plants to do that is goes back to what we're talking about before, when there's a labor, when there are no aides to do this work. Essentially, the plans are going to have to rely more and more on the family members. But to get the family members to do it, right. And again, let's put this entirely in terms of monetary situation, to get the family members to get it right. So that they don't mess up and and their loved one doesn't end up in the hospital, we're going to have to do something to train them and support them. So maybe that works.

Rosanne 50:53
Oh, I love that. What a great idea to charge the insurance companies. What a great idea. Why hasn't somebody thought of that before?

Anne Tumlinson 51:01
Somebody probably has.

Rosanne 51:04
Think it got shut down. Listen, between that. And Howard, I love your idea on paying into a long term care fund for yourself. Can you just can you talk about that for a second, I think that's just brilliant. Because you can't save for this.

Howard Gleckman 51:19
Sure. So the idea that it's not my original idea. But the idea essentially, is that we would, we would create a public catastrophic Long Term Care Insurance Program, who would pay people a cash benefit, the idea is that you would be responsible for paying for a certain level of care for yourself. And that level might depend on how much income you got. And then once you exceeded that level, the government Long Term Care Insurance policy would kick in. We did an analysis of a program a few years ago, which showed that you could give people $100 a day, $3,000 a month in benefits, and they could use in cash benefits. And they could use that any way they want. And that can be purchased by raising the payroll tax by about six tenths of a percent. So for immediate income family that would cost 350 or 400 bucks a year. For that, I have talked to a number of members of Congress about this idea. Many of them have said to me what a great idea, we love it, we're not going to raise taxes to pay for it not going to happen. So that's the hurdle that we've got to get over, we've got to get politicians willing to say this is important enough problem, that we are going to be willing to raise taxes to pay for the solution. And by the way, one of the things they recognize is, if you did that, right, you could reduce Medicaid long term care costs by as much as a third. Right? So they're paying for it anyway. But they're paying for it not in a dedicated fund. They're paying for it with a regular tax base. And by borrowing the money, which of course politicians love to do. This would be a program that was fully funded internally. So wouldn't require anybody the government to borrow any more money, we would all be paying for it ourselves. But they're terrified of raising taxes so we can get it done.

Rosanne 53:06
I have to tell you, though, that's a great one two punch. And and you two are a great one, two punch that idea of from both of you. I don't know, let's try to advance that, shall we?

Anne Tumlinson 53:17
I was trying to explain like, it's a math problem. Yeah, like we can't, like, everyone's like, Oh, private sector, let people do what they want to do. But the problem is, like, resilient, if you go out and buy long term care insurance, and I go out, but Howard doesn't, and five other people don't, it doesn't work. Mathematically. This is like, such a classic case of we have to share, we have to share in the risk, and it's not perfect, because yes, then it becomes a government program. And then like we have to raise taxes, if costs are higher than we expect, which they probably will be. And then it's like Republicans get upset and worried because of its government spending. And then these are problems that other countries are facing right now like Germany, you know, France, everybody, they do this, it's called social insurance. But that's what it has to be. That's it. That's the way forward.

Howard Gleckman 54:15
And as it says, every other developed country in the world, except for the United States. And England has a system something like what I described a little different in every country, but it's more or less

what I described. And it works. It does cost more than people think and the taxes have to go up. And that's a problem. But it works. And we were Americans, you know, we're all John Wayne, we're going to take care of ourselves. And you know, we buy insurance for everything else, right? We buy car insurance, we don't give it a second thought we buy homeowners insurance, and it's the same model and the private insurance long term care model has failed. And nobody disagree that I've been saying this for a long time. People used to disagree nobody disagrees anymore. No, you cannot buy true catastrophic Long Term Care Insurance. because the insurance companies will pay for it, as his aunt says the problem is the only people want to buy it are the people who are sick, or who think they're gonna get sick and the insurance doesn't work like that. So ultimately, it's going to have to be some kind of a government program. Honestly, this is a is another one of my really pessimistic thoughts. But honestly, you know, it's too late for my generation. It's too late for the baby boomers. We've already messed it up for us. The The issue now is can we make this work for the Gen Xers for turning 50? Yeah, I mean, that's how long we've put this off.

Rosanne 55:37
Gen Xers are pretty tough. We're pretty tough

Anne Tumlinson 55:39
Yeah we don't expect anything.

Rosanne 55:40
We're pretty tough. We don't expect a thing from anybody. But I agree with you.

Anne Tumlinson 55:45
Yeah. And I'm not giving up on the baby boomers, because we really need to figure out a way for you guys to get taken care of because we're tired already.

Howard Gleckman 55:53
Well, we blew it. We don't do it.

Rosanne 55:54
Yeah. So with all that being said, what are the next steps? What can we do going forward?

Howard Gleckman 55:59
The critical missing piece here is the family caregivers need to get themselves in front of politicians, and they need to tell them, This is what it's like. And if you don't do something about it, I'm gonna go vote for the other guy. That's it, but he's gonna do some of that. Because this is killing me.

Rosanne 56:19
Okay.

Anne Tumlinson 56:19
And I think we've got to organize ourselves better, elevating the voice of the family caregiver in an organized way in order to impact change.

Rosanne 56:27
A big thank you to Howard Gleckman and Anne Tumlinson for being my guests today. To learn more about Howard Gleckman you can find him at HowardGleckman.com And you can find Anne's blogs, resources, and support group Circles at Daughterhood.org

Rosanne 56:43
I hope you enjoyed our podcast today. Head over to Daughterhood.org and click on the podcast section for shownotes including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at daughter hood, the podcast and on my blog HeyRoe.com. Feel free to leave me a message and let me know what issues you may be facing. And we'd 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. 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'll join me next time in Daughterhood.