

Daughterhood the Podcast

Bonus Policy Episode

End of Year Wrap Up with

Anne Tumlinson and Howard Gleckman

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SPEAKERS

Howard Gleckman, Rosanne, Anne Tumlinson

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Rosanne 01:06

Hello, and welcome to a Bonus episode of Daughterhood the Podcast. I'm your host Rosanne Corcoran, Daughterhood circle leader and primary caregiver. At Daughterhood, we hear your

challenges in navigating the healthcare system and how it can be both frustrating and disheartening. In each of these bonus episodes, I have the pleasure of speaking with Daughtershood founder Anne Tumlinson where we will bring the caregiving conversation to a different level with change leaders and policy experts. I hope you'll join us today and I welcome Howard Gleckman. Howard is a published author and writer whose professional expertise is founded on long term care, health care, elder care, tax policy, Budget Policy, and Economics. His book caring for our parents focuses on the delivery and financing of long-term care. Howard is a senior fellow at the Urban Institute, where he is affiliated with the Tax Policy Center and the program on retirement policy. He also writes a tax and budget policy blog tax box, which you may read at forbes.com Howard was also a senior correspondent in the Washington bureau of Business Week. In our episode today, we discuss some of the major policy happenings in 2023. That Guide program, CMS staffing standards, the decision to cover Lequimbi, and more. I hope you enjoy our conversation. Let's jump right in here. There were so many happenings this year that affect caregivers. In July, CMS announced a new program called GUIDE - guiding and improved dementia experience to support people living with dementia and their caregivers. What is guide? And what does it mean to people living with dementia and their caregivers? Anne let's start with you.

Anne Tumlinson 02:47

Okay, the GUIDE program is something that we call a demonstration. Right? So, CMS, the Centers for Medicare and Medicaid Services, which administers the Medicare program as the ability to test new ideas and new things and has this administration has made a commitment to supporting caregivers and also to do something innovative to change the way that we deliver care for people who have dementia. And so they've announced this program that is essentially providing payment for an inter what we call an interdisciplinary care team, essentially, which is care navigation that is combined with a clinician who is you know, kind of a specialist in dementia care, they can receive payment to provide care, navigation and support with a wide range of other things all have to be kind of interesting, if it is like a package of things that people with dementia in their family caregivers need there, that it's all going to be packaged up and paid for in one, you know, in one payment. So, the package is and I have a list right here in front of me, our comprehensive assessment for both the beneficiary and the caregiver. So, what's innovative about this, among other things, is that the caregiver is actually going to perceive services for him or herself as a kind of a critical component of that team that is providing care to the individual who has dementia. There's care planning, there's 24/7, access to support. There's care coordination, referrals, and coordination of like super supports and services that you might need to provide long term care, medication management, respite services, this is a really big one. So, the federal government is going to actually pay for you the caregiver to receive services that would enable you to get some respite from your day-to-day caregiving activities, and then education and support for caregivers. So, there's assessments of caregivers there's as you know support for caregivers as respite services. And then there's just this team that's going to wrap around the caregiver and the beneficiary with dementia, to provide them with support much more kind of what we call integrated or coordinated support.

Howard Gleckman 05:12

So, what's really cool about this is, you know, as you all know, the Medicare is really divided into pieces, right? There's managed care, there's Medicare Advantage, and then there's fee for service, traditional Medicare, traditional Medicare has taken the position for years and years and years that we can't pay for any kind of non-medical services. If it's not health care, we don't pay for it. It's different for

managed care where they do pay for some of these things, but in fee for service they never did. And now for the first time, they're taking the position that Well, lo and behold, the law lets us do this. And they're going to not provide for things like care navigation, and care management and respite care. And also, they're taking the position as Anne said that we can provide some benefits to caregivers who may not even be Medicare beneficiaries. And the argument they always make is, well, we start doing this, it's a bottomless pit, and it's going to cost us a gazillion dollars, and it'll never happen. But suddenly, they decided, well, maybe we can do this. And maybe in fact, we'll see what the demonstration shows that maybe, in fact, it'll save us a little bit of money. on the healthcare side, we'll see, there are a couple of things I don't love about it. One of the things is, it sort of assumes that Doc's are going to be kind of an important piece of this. And doctors don't know how to provide care navigation services, they don't know how to they never heard of respite care, they're not the right people to do this. So, it's going to be interesting to see whether physician practices where the Medicare providers will partner with community-based organizations and other folks around the country who actually know how to do this. And that's not something that comes particularly instinctively to physician practices. So, we'll see, we'll see what happens. As Anne said it's a demonstration, we'll see how it goes. But it's really interesting. The other thing I don't love about it, is they limited it only to people with dementia. And and again, it's a demonstration, we'll see what happens. But what about people with Parkinson's or people with heart failure, or people with diabetes? These are people with all long-term chronic conditions that need the same kinds of supports. And they kind of get left out of this, at least for now. And that's too bad.

Anne Tumlinson 07:18

Yeah, and I think what Howard is hitting on with the physicians in particular, are what we call Part B providers. So, this is, you know, physicians or therapists or kind of clinical folks is that, I think my concern is that we're not going to get a lot of participants by participants. I don't mean people with dementia, I mean, provider groups, because they really do have to do something that they've never really done before. I mean, there's a handful of academic medical centers that are doing this program already in limited geographies, but to kind of scale this up and hat and see it, you know, be offered in a wide variety of places to really help people with dementia at scale. We're asking regular physicians to do things that they took the horse by, they don't have to do and especially to connect, they've got to bring together a lot of different pieces of a very dis coordinated system, which is of course the value of it, but but that's not a thing they've ever done before. So like, how is that physician team gonna work with assisted livings to provide the respite care or the homecare agency they don't even know who those people are, I think but it each it like it in the consulting world in my world, like a large part of what we anticipate the work that we might be able to do or would do is to help build those partnerships at the ground level that will enable this program to actually operate. That's my my worry is that is just we won't get a lot of we won't get a lot of providers, so I'm actually applying to do it.

Howard Gleckman 08:55

The funny thing about it is I hear a lot from community-based organizations and assisted living and homecare agencies, they love this idea. And they're looking for they're scrambling around looking for Medicare provider partners, who they can work with so they can get paid. And finding the partners is not easy. Anne's right.

Rosanne 09:11

As someone who went through the dementia maze of trying to get help doctors, you know, within your 10-minute appointment, they don't. I mean, let's be real, right? This is the reality of healthcare; you have 10 minutes. And right now, it's almost like, well, this is great, what a great idea. And this would be so huge to actually almost have a care manager with your primary care physician, what I'm hearing is, but there's no way to support this, and there's no way to make that connect, which is sad, because it's it is it's a great idea and it's something that's so needed because you're on your own when you have dementia diagnosis. Nobody says okay, go down the hall and see the care manager and they'll set you up with this, this and this. So it's great, but is there anything in the pipeline that will try to help set this up or No, is this just like it's it's great on paper, but it's It's going to be tough to pull off.

Howard Gleckman 10:01

Well, you basically just apply, and CMS will let you do it. So when you meet certain criteria, but what kind of kind of technical support they're gonna get? I probably not much. So I think there's a great opportunity for ATI, because we need that technical support.

Anne Tumlinson 10:23

Yeah, yeah. I hope I hope I hope that's the case. I mean, I really do. I hope, not just for you know, we'd love to do interesting and fun work like that. But I just hope that we have the chance.

Howard Gleckman 10:34

Yeah, potentially, this is just hugely important. Yeah, it is a really, really big deal. And and it's going to depend on take up, it's going to depend on whether or not the docs buy into it. And it's going to depend on whether the supports that they provide to their patients are actually the right ones, whether they actually work.

Rosanne 10:54

How do Medicare Advantage supplemental benefits factor into this?

Howard Gleckman 10:59

Well, that's the those these are the same kinds of benefits that Medicare Advantage is allowed to provide under, under the chronic act under law, which was passed a few years ago. And as the world's expert in this, you can talk about it, but it's the it's that part of Medicare, and it's already who's potentially providing this.

Anne Tumlinson 11:21

Yeah, so there's a lot of controversy is, since this is a policy podcast, I'll just get a little wonky. But there's a lot of controversy around these benefits in the policy arena. Because there's a lot of concern, more generally around this Medicare Advantage program, that now half of all Medicare beneficiaries use, essentially to access their Medicare benefits. So just stepping back for a quick minute, you know, there's two ways that you can be, there are two ways you can get your Medicare benefits as a Medicare beneficiary. One is just through the traditional program where the federal government, you know, you go and get, you know, a unit of service from a hospital or a skilled nursing facility, and then the federal government has a bill, or you can access Medicare Advantage up, which is a which is a program through which the federal government pays a flat fee to private insurance companies, and

then they effectively deliver the benefits plus some extra add ons. So why would we let the private insurance market get please get into Medicare. And the reason is, because they've essentially come to us and said, Give us the money. And we'll do some things that are a little bit better or new. And we'll fill some of the gaps in the Medicare program and also reduce some of that out-of-pocket costs and in which are substantial and Medicare, traditional Medicare, if you don't have some kind of secondary insurance to pay the co-payments and the cost sharing the deductibles and things like that. So, a lot of people have availed themselves of these things. And in one of the extras are these things called supplemental benefits. And they range from things that you've seen almost every single policy now dental vision, to now some new and innovative things like you know, and home support services or family caregiving services, or there's a whole category now called supplemental benefits for people who have chronic illness, special supplemental benefits. And so, plans can identify individuals in their plans who have chronic illness, and then they can offer them things especially designed for them like food, you know, general supports for living meals, like so groceries or meals, which are the big ones, the big ones in that in that category. So, the controversy is that there are a lot of policy wonks who feel that we're overpaying these private insurance plans, and they want to cut back on those payments for some very legitimate reasons. But that extra is often what the plans use to pay for these extra benefits in order to get more people to enroll in their plans to get the extra money. It's like a little bit of a cycle. So, So you know, I think my concern, and a little bit of what we're seeing in the data right now is that more and more of these plans are actually, I wouldn't say they're dropping benefits, but they're, they're pivoting a little bit to a handful of them. They're definitely really loving the grocery cards or the food cards right now. Sort of giving people it's like turning Medicare into an income support program to some degree. She has an interesting twist. And the bet the regulations have kind of made it harder for plans to offer these benefits to people with chronic illness. So, we're now seeing more and more carriers kind of take their plans into this demonstration space anyway. This is probably like even more walking than even we want to talk about today. But you know, it is an evolving space. I think that's the message is that this is a kind of wrap but the changing space and it is definitely no guarantee. Like, this is not how most Medicare beneficiaries are going to be able to access long term services and supports, it's just too, there's just too many variables that dictate whether a plan is going to offer this and for how long

Howard Gleckman 15:22

A couple of things to add to it and said that make it especially interesting is one of the things is that the value of the benefits is still very low. Uh, you know, we're talking to you think about long term care needs, and you're talking about hundreds of dollars a day. And here, you're talking about benefits that are maybe \$50 a month, right? So it's very small. The other thing is the theory of this, that kind of backs up the whole thing, the theory of this is, if you provide if you're an insurance company that has a Medicare Advantage plan, and you provide the supportive services as additional benefits to your members, those benefits will help your members stay healthy, and stay out of the hospital. And that is, you know, we always talk about aligning incentives that in theory is a great, well aligned instead of the insurance company doesn't want you to go to the hospital, and you don't want to go to the hospital. So if these benefits can actually help you stay out of the hospital, the insurance company wins, because his aunt said it's getting a per member per month fee for Medicare to take care of you, if you land in the hospital, it's going to eat up all that money right in the first day. So they want to keep you out and you don't want to go to hospital. So in theory, that's how this should work. We don't know in practice, whether it's working at all. And I have been working on this project now for a couple of years trying to

encourage the plans to share some of the data so we can actually know whether it works. And the plans are not very willing to do that yet. They claim that competitive advantages and they don't want it, they don't want to share it and the government doesn't really require them to but recently, there have been some changes, and it looks like they're going to have to acquire some information. But so we don't know a lot about whether this working all we know is and said is kind of the the choices that the plans are making. We sort of can look at that. And we can say that some things seem to be working and some things don't. So but we'll see, it's, it's again, it's just another experiment.

Rosanne 17:16

Why do you think they don't want to share their data?

Howard Gleckman 17:18

Anne why don't they want to share that?

Anne Tumlinson 17:20

It's just, it's super competitive, they are so competitive with each other. This is a very lucrative market. So, getting to the policy concerns, right. But the companies are, there's, you know, there's a lot of money. That is it, think about this for just a second, you know, for every Medicare beneficiary that signs up in one of these plans, those plans are getting paid, you know, anywhere from \$10,000, or, you know, \$12,000 per year to \$25,000 per year, depending on how complicated that person's kind of medical profile is. So, you got 33 million Medicare beneficiaries sign up for Medicare Advantage, this session for those dollars. And so, they don't want to give up any information. It's, it's it's just very and also just so it's very proprietary, it's very competitive. But also, just as a practical matter, their systems aren't that great. Your ability to pull data and clean it and send it to the government, it's going to just cost it's going to be an administrative hassle for them as well.

Howard Gleckman 18:33

And keep in mind that as Anne said, it's very competitive business. In many places, there may be a dozen plans or more that are available to consumers. And the plans are in the funny situation, right? Because they don't want their their benefits to appear to be too generous. Because then they have a what they call the insurance business a problem with the risk pool when the when if you have the most generous benefits in the market, you're gonna get all the sick people. And you don't want that. On the other hand, you want enough benefits to be able to market your plan and say, See, we're doing these good things. And this worked very well with the traditional supplemental benefits like the Silver Sneakers and in the eye exams and the hearing aids and all that they don't really know how it's going to work with these kinds of benefits. So that's kind of another kind of piece of this. This problem.

Rosanne 19:20

I'd oh my goodness, it

Howard Gleckman 19:23

It just all says makes your head hurt. That's the problem.

Rosanne 19:24

It makes my head hurt. It makes my head hurt because it because in the big, big scheme of things here, it's like here, we're gonna we're gonna contract with you, but you're not going to tell us if it's productive if you're actually helping people, but we're going to continue to pay you and, in the meantime, is it trickling down? We don't know. Well, we're not sharing that with you. It's like, well, how is that possible? I mean,

Howard Gleckman 19:46

So Congress made a mistake. You know, I mean, they should have when they created these benefits, they should have required the plans to make some reporting to CMS and they didn't.

Rosanne 19:58

All right, yeah. fair enough.

Anne Tumlinson 20:00

Yeah, I have a long list of things that Congress made a mistake with.

Rosanne 20:09

I can I think that's a blog, or it could be a whole nother a whole nother that'd be a three-hour podcast of that one. Well, you know, we'll we'll go right into long term care cost because that's another I mean we hear about it and it's the the positive thing is that it's getting a lot of play, it's getting a lot of attention. And and hopefully that will change something. But are there any you know, what type of state based public Long Term Care Insurance initiatives are out there? Are there any and are they working?

Howard Gleckman 20:42

So it's interesting, you know, the there were efforts on the federal level to do something public Long Term Care Insurance program, they tried this as part of the Affordable Care Act 2010 13 years ago, and it completely failed. And there have been some efforts since there, there have been a couple of a bill in Congress called the wish act. But unfortunately, the guy who sponsored the wish act, quit Congress alone, always thinking about coming back. He was he was the guy who, by the way, had the George Santos seat.

Rosanne 21:10

Wow.

Howard Gleckman 21:11

And now that Georgia sort of had a problem, the congressman is interested in coming back to Congress. So maybe there'll be some interest. But more interestingly, is what's going on in the States. So Washington State, actually enacted a public Long Term Care Insurance program a couple of years ago, it's had a couple of starts and stops in a couple of problems, but they actually started collecting premiums are collecting a payroll tax last July, and they'll begin collecting benefits of paying benefits in a couple of years. It's a universal program, if you work in Washington state, if you're on payroll, you have to pay this payroll tax, it's about six tenths of a percent of payroll. So for a median income worker, it's about 350 bucks a year. So it's not a huge amount of money. What you get for that is what they call in this world, the front end benefit. So as soon as you trigger the need for a benefit, you will receive

basically \$100 a day for a year. So \$36,500, after that you're on your own. That's not a model I love. I've worked on a couple of groups that have proposed a public Long Term Care Insurance Program was differently. And the alternative model is a catastrophic benefit. So you would be responsible for paying for a period of time yourself. And then if you had a true catastrophic need, for example, people with dementia, and then the government would pick up a significant not all of the costs, but a significant amount of costs for the rest of your life. And the interesting thing about all this is, it turns out that because a relatively large number of people need benefits for a short period of time. And a relatively small amount of people need benefits for a long period of time, that the cost of providing a Washington State kind of front end benefit to six tenths of a percent of payroll is almost exactly the same as the cost of providing a catastrophic benefit, say \$100 a day for life? Why? Why would that be because so few people require that that long term catastrophic benefit. In any event, the Washington State model is one that a number of states have looked at. So California, is in the process of doing I've got Commission, which is supposed to report within the next month, actually, about what is going to do. The state of Minnesota is looking at a number of alternatives for public Long Term Care Insurance Program, as well as some other alternatives. Illinois is thinking about doing this. There are a number of states around the country that are starting to their legislators are approving funding for actuarial analysis to try to figure out who this can benefit and how much it's going to cost. And we'll see, one of the reasons why states are interested in this is because a public Long Term Care Insurance program would at least in theory, reduce the state's Medicaid costs for long term care, and Medicaid is eating up state budgets. And if they can get a fully funded insurance program instead of Medicaid. That's something I think a lot of states like so we'll see. Wow. But meanwhile, the cost of long term care insurance is just getting out of control. Yeah, yeah, it's already unaffordable. And with labor shortages, which I guess we can talk about. The labor costs have gone through the roof, and the costs which are already unaffordable, or even less affordable,

Rosanne 24:39

Right, and that we'll get back to labor in one second. It's, I feel like there's a major disconnect between when, and I see it all the time, and I hear it all the time. Well, you know, when your parents get old, then Medicare pays for them. People still interchange Medicare and Medicaid. And there's still the disconnect between those two. So In, in people's minds, you know, they people get older, and then they're taken care of by the state. And it's like, no, that doesn't work. And it's not until they get into the situation that they realize that's not what this is, this does not happen. And then it's too late to do anything. Because the fury that you feel you can't deal with, because you're dealing with caring for the person. So you, you know, the unjust pneus of oh my god, it's how much \$10,000 for memory care a month? Are you kidding? It's \$6,000. in assisted living, are you kidding? How do we pay for this? But because there's no the the before you get there, nobody thinks about. And I think that's part of the Oh, my goodness, what's happening, and everybody is out here is like, Hey, we're trying to tell you this is what's happening. And I don't know how we bridge that education gap. Because I can't imagine all of the people that that we talked to and all of the people and that we come in contact with. If they knew this, I can't believe that there wouldn't be that push

Anne Tumlinson 26:04

to fix it.

Rosanne 26:05

Congress to say we this is this is unacceptable. We can't deal with this. So and I don't know, I don't I mean, you you see it on the policy side all the time, but and it is that matter of getting it out there, but it's just that people don't it's one of those situations, you don't realize you're in the quicksand till you're in the quicksand. And then, what am I supposed to do?

Anne Tumlinson 26:23

Oh, I think that's why I think it's a big part of why we haven't seen the kind of federal action that we need to see is like, you know, when we confront high drug prices at the pharmacy, you know, we feel that immediately. And everybody there is a groundswell of very bipartisan Republican or Democratic, red consumers who are asking for, you know, this is a ridiculous situation, and we need to address it, oh, long term care is so different, because, you know, they're either you're in the situation yourself and in need of it, or you're a family caregiver, confronting it. And in both of those situations, you're not really in a position to get it, you know, to get much more sort of vocal, you know, kind of in this federal discussion in federal conversation, I do think that that is what it will take, I think we have to be like, we really have to kind of rise up and make our voices heard. And to Howard's point, I definitely agree, you know that the design is important, because if we're going to ask people to pay taxes, we want to make sure we're giving people the maximum amount that we can and benefits for the amount of taxes that they would have to pay. And for those who are listening and wondering, like, why would I have to pay taxes? Like, you know, why can't I just buy a private insurance policy, and it's an in you know, the way I like to say it is like, this isn't about liberal social, we love government, blah, blah, blah, this is about like, this is actually a mathematical problem, which is like, it's because of just the nature of this thing. We really need absolutely, everyone kind of paying into the what we call a risk pool, right? We every everyone has to contribute to funding the risk, the possibility that we might all that we might individually, we might face the risk of needing this kind of care in the private market just cannot get that done kind of in the same way that health insurance, it just doesn't work when you ask people to individually self insure. So. So the only way to do that is through the government and through taxes. So you know, that becomes politically difficult. But again, nothing's too difficult if the if the voters are asking for it, and we just haven't really been asking for it. And maybe the one other thing I would just say to Howard to kind of what you said is that what I like about what the states are doing, even though I'd really like to see something more uniform across the country is that, you know, this is just so massively underfunded, just so massively underfunded, that \$36,000, for every resident in Washington state is going to do a lot to just make that long term care system in Washington state more robust, and I think, higher quality and better overall, you know, I'll take it. If that's all we're gonna get, that's definitely better than nothing. And we need those funds kind of flowing into that system to get the workers to get better care options and things like that. So, so I, you know, big fan of what Washington state has done,

Howard Gleckman 29:35

you know, so it's a funny thing. Rosanne, you're talking about the confusion that people have about Medicare and Medicaid and who pays. And it's not only consumers, not only ordinary people, members of Congress and knows it's members of Congress don't understand what Medicare pays for when Medicaid pays for. And the other point about this is we were talking before about the Medicare Advantage plans and and the supportive services that some of them do provide, and in some way that It makes this conversation harder. Because it used to be, I could say to people, Medicare doesn't pay

for this. Full stop. Medicare doesn't pay for this. Now, I have to say to people, well, Medicare mostly doesn't pay for this. But it's sorted does pay for this. And there is Special Needs Plans that you never heard of. And there are Medicare Advantage plans that have supplemental services. So it actually makes it harder to even have this conversation with people and for people to plan. But the big point is, as we talked about before, while Medicare Advantage is providing these benefits there, it's like 50 bucks a month worth of benefits, nothing near what you're going to need. And the last point is about insurance. So it's a weird thing, more than half of us are going to need some long term care after age 65. We just don't know which pot we're in. When we're when we're working with 30. We don't know whether we're going to be the one who needs it, or the person sitting next to us who does it. And that's why you want to have insurance. But we're Americans, and we believe in taking care of ourselves. And we don't want to and why should I buy insurance if I'm not going to need it? And that's the that's the political rural people have to get over and the hurdle of I don't want to pay any more taxes.

Rosanne 31:08

Yes. Well, and the direct care workers go right back into that, because the cost of long term care, it feels like it just keeps it's it's just going it just keeps growing and growing. What is the shortages with the direct care workers this year? What's being done to mitigate that? Is there anything that can be done to mitigate that?

Howard Gleckman 31:29

So So what's been done about so one of the things is the market to some degree is responding to this. homecare agencies, nursing homes, assisted living facilities have to pay their staff more money, because people won't do this work. But what it means is that the, you know, I live in the Washington DC area and hear a homecare a now is \$35 an hour, and sometimes more, I'm hearing about \$40 an hour in some places, if you hire through an agency, and the aides, you know, if the agency pays \$35 an hour, the aides getting half that they're getting 17 or 18. And you can't live on that. So it's it's this paradox, that what we pay for long term care is insufficient for people to make a living, but at the same time, it's more than families can afford to pay. So what do you do about this? Well, one thing you do about it, as we were just talking about is you have to get more money in the system have to have more money in the system. But there are also other things that can happen. And we have to fix immigration laws. There are people all around the world who would love to come to the United States and do this work. Americans don't want to do this work. So that people from you know, everywhere, you know, from the Philippines, from Thailand, from Eastern Europe, from South America, would love to come here and work, but we don't let them in. And we're competing with the rest of the world for these aids, everybody wants them, and a lot of other countries are happy to have them. And we're not. So we gotta do something about that we've got to have better training, we've got to have career advancement. You know, nursing homes assisted living often are very hierarchical places. You know, if you're, if you're a CNA, a nursing assistant in a nursing home, you're basically treated as fungible, you know, you just shut up and do what you're told. And if you don't like it, we'll just get somebody else. And it's not a surprise, people don't want to work like that. So I think there's a lot we can do in terms of changing working conditions in terms of paying them more if we can find money, and in terms of their career advancement, to encourage people to do it. The other thing is technology. This is very difficult work. The injury rates are extremely high. There are ways you can use technology to make life a little bit easier for the ages. Well

Anne Tumlinson 33:40

Yeah, that's a pretty that's a very, very well thought. And I think but you know, everything, we have to get more money flowing into this system in order to be able, I mean, that's kind of just fundamentally the problem.

Rosanne 33:56

So that that does bring us back to staffing. And in September, CMS proposed minimum staffing standards for long term care facilities. Anne what are your thoughts on that?

Anne Tumlinson 34:06

You know, I think on the face of it, you might say to yourself, This is not a difficult issue. Every nursing home should be staffed according to the standards that the research shows are adequate to deliver. You know, I'm kind of a minimum standard of care. And, you know, I think every single one of us has a story, or multiple stories of, you know, loved ones or family members or somebody we know, in a nursing home, getting really poor quality care, because, you know, largely because there aren't enough people on the floor to attend to their needs. So, you know, so we absolutely have to staff nursing homes at an adequate level. This regulation is feels to me look a little too little too late. It's coming at a very weird time in our economy where at the precise moment, when I think even, you know, the handful of nursing homes, and maybe more than a handful, any operators that really do want to staff adequately and do want to do the right thing, or are struggling enormously, they're having to rely on, on agencies, essentially, to provide the staff to them, in their costs are going through the roof as a result, because that's a very expensive way to do it, and it doesn't ensure a lot of consistency. And so, so it's, it's, you know, like the ramifications of this are that I think it will be very, very hard for most RCGroups, actually, even when they're doing their best to meet the standards, at least many of them. And so they'll be out of compliance, you know, CMS has provided a long ramp, but I think, you know, I think they'll still be out of compliance. And I think we are seeing, unfortunately, we're seeing a lot of nonprofits choosing to leave the business entirely, or D, you know, taking their, their long term beds out of out of commission, so to speak. And so we're left with kind of the, you know, the more I don't know, like, how to say it, just, you know, for profit organizations that have really figured out how to make the costs as low as possible. And, you know, I don't know what, you know, I don't know what the ramifications of the staffing standard are on them. But I do know that even if they try, they'll struggle to meet them. So. So I have very I feel when people ask me, What do you think of this? I'm like, I don't know what it's just? I don't I don't know. I just know, we're not paying enough for care.

Howard Gleckman 36:54

That one of the things that's interesting is, is the people who research this. And there are, there are a number of people out there, a guy named David Grabowski, who's a professor at Harvard who and I both work with over the years, David and other people have very carefully said that low staff correlates with is connected to poor quality, but they don't say that it causes poor quality. And that's because there's lots of other factors in nursing home. So one of the things I think about a lot is, you know, a nursing home with a with strong staff probably does a lot of other things very well, too. And a nursing home with with with poor staff ratios, probably does a lot of other things poorly. So in a sense, staff is kind of the canary in the coal mine, it's the most obvious, most easy to measure, metric. And CMS is

always looking for kind of an easy thing to measure. So that's kind of I think, one of the reasons why this is so all fall on on staffing ratios. But it leaves out a lot of things that are also very important to, to the quality of nursing homes, not just the safety of nursing homes, but the quality of nursing homes. So it's a it's a kind of a crude measure. And it creates a lot of problems. One of the other things that bothers me about it is in any other industry, one of the things we want to create incentives for is better productivity. How can we use technology and management structure and other things to make the work as you have more productive? Well, weirdly, with a minimum staffing standard says we don't want you to make workers more productive, you have to have a certain number of worker hours per resident per day, whether it's the most efficient way to deliver care or not. And that seems counterproductive to so you know, everything answered is right. I mean, we all have stories about horrible nursing homes, because there's just nobody on the floor to take care of residents. So we have to fix that. But this may not be entirely the best way to do it. But unless we have more money in the system, we're not gonna be able to do it anyway.

Anne Tumlinson 39:03

Oh, my goodness, we have a journalist, and on the other call to help take what I'm saying and make it absolutely that's, that's really well put. I mean, that's, that's the conundrum.

Rosanne 39:19

So then, Howard, what would you do if you had a magic wand?

Howard Gleckman 39:23

So if I had a magic wand, what I would do is completely change the way we think about this. And I would find better ways to measure nursing home quality. And, and, and really understand what it takes to make nursing home patients and residents get the best care that they deserve. And then I would say to nursing homes, you know what, I don't care how you get there. You can do whatever you want. As long as the end of the day you provide your residents and your patients with the best care possible. The problem is I can't wave my magic Wand and figure out how to create those metrics, those measurements. Some of them I, I know what they should be, but I don't know how you measure them in any sort of good way. But you know, you think about, you know, a nursing home is run well, and it's things like, you know, things you can measure, like, how do they improve the ambulation of patients? Can a patient who comes into a nursing home not able to walk, are they able to walk? Something's its quality of life? You know, do residents feel like they're being heard? Do they get their own choices about when they want to be bathed, or when they want to eat? Or what they want? You know, are there Patient and Family councils? And are they actually being listened to? All sorts of things like that, and it's all a soft stuff, and the regulars hate it, because you can't really measure it, you can't put a number on it. But we all know, that's what really matters to residents of nursing homes, you know, things like, you know, does the nursing home keep you from falling out of bed. I mean, that's a that's sort of should be a minimum. But But I could imagine if we all can imagine a nursing home that that had no falls it but never had a fall, but I never want to live there. Because I mean, basically, they keep me either with chemicals or with ropes tied to my bed. So I would rather live in a place that said, you know, what, how are you have a certain amount of agency, if you want to get up and walk down the hall, you have the right to do that. And maybe it'll fall. But you know, what, you have the right to make that choice, just like any of us. That's

Anne Tumlinson 41:39

That's what family caregivers deal with all the time, all the care is looked like that, okay, we know we're constantly making that decision about or not making the decision to standing by gritting our teeth, while we watch our loved one and make a choice to do something that we know could lead to a bad outcome. But we realize that we recognize or we don't have any control over the fact that they are independence, and their goals are very different than what ours are. And so the nursing home setting, we have created the setting over decades, that is completely oriented around kind of minimizing like maximizing kind of safety, over over any kind of, you know, independence, you know, personal autonomy. And even over, you know, kind of the softer elements of that care delivery, you know, that the, you know, the time that it takes to provide the assistance necessary for them both to be have the personal autonomy and the safety at the same time, that takes that takes humans and maybe technology someday, and we do not fund the humans, we fund the real estate, we fund the building, we maybe fund a little bit of food, and then whatever's leftover is what's leftover to fund the most important aspect of it, which is the actual care delivery which we don't value at all. And if I'm gonna be really philosophical, I think, you know, I think this is about in this country, we don't value care. We value a lot of other things, but we don't value care. It's something that we're all doing off the sides of our desk, not as a central part of what we do. So the people who are paid to do it as a career are not valued. And what they do is not valued until we change that through better policy and better payment. And the transparency thing though, I just wanted to touch on that. I do think that's really important. Because if we are going to get the money to the people and value the care, we do have to make sure it's not not going we need to understand where it's going. And these real estate, things are complicated. They're really complicated. There's a lot of different there's banks, there's there's lenders, there's real estate investment trusts, there's private equity, though sometimes those are the same thing. Assumptions are not the same thing. It's, I barely understand it, if at all. And we do need to understand that well enough to know when the money is going into the returns for the investors versus when it's going into care. And we have to make a decision like when is it acceptable in one bucket versus when is it acceptable be in another bucket?

Howard Gleckman 44:32

So CMS has proposed it's actually issued now final regulations to require more transparency require owners of nursing facilities to disclose who they are. And you know, a lot of these events are incredibly complicated transaction. So you have a nursing home. It's owned by a limited partnership. It's owned by a different limited partnership. It's owned by another limited partnership, and and the CMS regulations would require disclosure of the ultimate owner. The disclosure that they've required, I think it'd be very useful for people like and for researchers, but CMS hasn't told us how they're going to make this available in, you know, in an easy way for consumers. And while the hope is that consumers will be able to look at this and make a judgement, right now, that can't, these datasets are I mean, they make talking about making your head explode, these things are incredibly complicated. There was a there was a paper that was just written for the the Federal Department Health and Human Services by a professor named David Stevenson and some colleagues looking at based on what we know, now who owns nursing facilities, and he had to use six different sets of data to figure this out, you know, that's not going to work for consumers, consumers won't want to go to someplace and just say, Who owns this place? And what's their track record, one really important issues is, as you have changed ownership of nursing homes, so if you have a company that's got a really bad track record, and they buy a new

nursing home in your community, there's no way right now for consumer to know who that owner is, and what their track record was, are there other facilities in, in theory, what these new transparency rules will allow you to do, is you can look, and you can say that Smith and company bought this, and Smith and company has, you know, 10, other nursing homes, and five of them are in trouble. And you can say, you know, maybe I don't want mom leaving it. But we're a long way from that. And that's where we eventually need to get to.

Rosanne 46:32

You know, when there are investors, they want a return on their investment. They're not worried about, you know, I'm hiring people, and I'm training them, they're not worried about the training that goes in, because you need to be trained when you're working with people, depending on their condition and all of that. That doesn't, that doesn't get there. They're concerned about the return on investment. And I'm, I'm wondering how that was even allowed to happen, that you're, you're delivering face to face care. And there is no regulation on that, Howard?

Howard Gleckman 47:04

Well, let me say this is this is probably gonna get me in trouble with some people. But I don't think there's anything wrong with making money in the in the providing aging services. And when you look at the data, and and you can, you can correct me if I'm wrong, but there isn't really a clear cut distinction between the quality of not for profits and for profits. You can't say a lot of people do it. But you can't really say supported by the data that not for profits are better than for

Rosanne 47:37

No, no, no. But to use it as a return on investment, I think is the part.

Anne Tumlinson 47:41

Well so this is this is yeah, I mean, this is I love this conversation, because so few policymakers have this conversation, here's the thing, nursing homes, our homes, right, that's its real estate, like it's a roof over a head, and it's four walls, and there are services being delivered within that home that are also paid for. So the way these investors think many of these investors, not all of them, there's flow, so many different structures, but most many of them think like it's a nursing home, or it's a shopping mall, or it's a hotel, or it's, it's, you know, that's they're in the real estate business, they're not in the health care care business. So, you know, they're trying to maximize return per square foot, period. But and that's their job. And that's what they do. So it's the so I don't know, like, that's just like, not good or bad. That just is what it is. And we can sort of demonize them or whatever. But I think the bigger issue is that we have to separate those things a little bit in this country. And we have been loath to do that, because it has a lot of implications for the like, has a lot of kind of financial implications for the programs and things but, but I think that ultimately, we if we really, you know, kind of get into the magic wand is we, you know, there's there's probably a structure through which we say, we do this in insurance, right, we say, look, you're an insurance company, you manage risk, like, that's your thing you do that business, there are benefits that have to be delivered. And this is the minimum amount you have to spend on those benefits. So we can say to the real estate industry, look, you got to get a return on your investment, because that's how real estate works. And people need a place to live. But there's a whole bunch of services being delivered inside this building. And at a minimum, this is how much money

needs to be spent on those services or on some, you know, the kind of benefits inside that building. And I think that's kind of the model that we have to move towards, rather than sort of trying to regulate this industry, which is going to be really complicated and we're gonna get it wrong because we don't know as much as they do right.

Howard Gleckman 49:51

Yeah, I think that the really important point that Angela's made that really can't be repeated often enough is particularly with the big chains. To the operators, and the owners are different. So you have a company like Genesis that operates hundreds of nursing homes around the country, they don't own them. They lease them, as she said, from some real estate company, and the real estate company wants a return on the on the property. And as she said, they don't care if it's a, it can be a shopping center, it can be a nursing home, they don't care. As long as they maximize the return, the operator has got to figure out a way to pay the rent, to pay that lease every month, and pay all its other costs and make a profit. And that's what makes this really complicated.

Rosanne 50:40

For me, it always comes back to that care piece. Yes, you can still make money, but how are you caring for the people that are living in these places? And that's, I think we lose sight of that sometimes as it's just another way of making money. But there are lives that are attached to this. And that's the part that just, you know, is hard.

Anne Tumlinson 50:59

I know, I know, that's the part that's so heartbreaking and so hard. And embedded in it. What it boils down to is that is that there just kind of getting back to your point earlier, Rosanne was like if we know if we knew earlier, I mean, there the thing is, there's nothing you can do as an individual. This is this is always makes me really popular with reporters, right? It's like, you're like, so what do we tell people to do, I was like, I got nothing, I got nothing. There's like you could buy long term care insurance, but the policy won't be that great and will be really super expensive, it can't really save because you'd have to save a lot. And then, you know, like, it's it's an impossible situation that practically every American family will face in one way, shape or form. And yet, we have this 1960s sort of financing and delivery system for it. So you know, I am encouraged by a lot of the work that the states are doing. And I think, you know, gay, gay, Minnesota, and Washington state. So maybe they'll have a lot of old people living there. But you know, I think we can continue to talk to our policymakers about this. Yeah.

Howard Gleckman 52:16

So here's the other interesting thing I wrote that I don't know if we want to talk about what Lequimbi and talk about some of the Alzheimer's drugs. But one of the really interesting things about this is we will pay massive amounts of money for drugs, that may or may not work. And we do it without a lot of thought. There's no input from Congress, we just do it. But when the question is, will we spend the same kind of dollars for supports to services that can be more beneficial to more people, then suddenly, we can't afford that. So the priorities are a little bit inside out, I think,

Rosanne 52:58

I totally agree with you. And I would love to talk about that with you. Or because it's it is it's infuriating to think of all of that money that could be used on literally on a day to day basis to the people that actually need it. And we're, I don't know how that all happened. And you've written about it brilliantly. And everything that you write about it is so clear, and lays it all out. And yes, what what, what, what, how did we get there?

Howard Gleckman 53:24

Okay, so so the the really exciting thing about what's what's happened in the last year or so is that after decades of no progress at all, in drug research, for people with Alzheimer's disease, we've started to see some interesting progress. But it's a very complicated story, I'll try to simplify it and not get into the science because it's going to be just too much. But essentially, the the theory that researchers have used for more than 20 years now is that Alzheimer's disease is caused by an excess protein in your brain called amyloid beta. And the theory for the drug research was if we could get rid of that amyloid beta, we could treat or maybe even cure Alzheimer's disease. But the story turns out to be more complicated than that. The story really is not that amyloid beta causes Alzheimer's disease. It is just that people with Alzheimer's disease or many people with Alzheimer's disease, have amyloid beta in their brain. But there are some people who have very high levels of this protein in their brain who never get Alzheimer's. And there are some people who get Alzheimer's who don't have this. So that's the kind of the scientific basis of it. In the last couple of years, the FDA has approved two drugs, one of them called Aduhelm and one of them called Lequimbi that have actually had extraordinary success in reducing the amount of this amyloid beta in people's brains. For the first time. They've they've actually found a drug that succeeds in Getting rid of this protein. That's the good news. The bad news is that the clinical benefit to actual patients from this great progress has been practically nothing small, a very modest slowing of the progression of the disease. So basically over at an 18 month drug trial, the progression of the disease was slowed by about four months. But even that probably overstates things, because we don't really have a very good way to measure Alzheimer's disease at the baseline. And we also don't know what happens after the 18 months is there's some evidence that towards the end of this period, the benefits started to slow. But again, we don't really know. So the FDA approved both of these drugs, there are at least a half a dozen other drugs, just like them, that are in the pipeline, that FDA is gonna be under enormous pressure approved, the political pressure on the FDA to approve this drug was I've never seen anything like it. It was just extraordinary. They approved it. When they approved, it was it was strictly one of the strangest things I ever saw when the FDA approves a drug and puts out a letter saying this is why we're approving the drug. And they said in the letter explicitly, that we don't see any particular clinical benefit from this, but we're approving the drug anyway, because we think that this is a useful line of research, we want to encourage drug companies to continue, essentially said this is we did this with cancer research 20 or 30 years ago, and it worked. So we want to do the same thing. Now with this research. So we're left with drugs that have some very, very modest benefit. The other thing to say about them is, unfortunately, they also have some very difficult side effects. For probably half of the people who take the drug or took the drug in the trial, they cause bleeding in your brain and swelling of your brain. For most of those people, they don't even know it, the side effects are minor, and it's not a problem. But for a fraction of those people, they died. And we don't yet know enough to understand why some people had the blame brain bleeds and some didn't, and why some people died from them, and some didn't. So for consumer, and I guess the last thing I should say is, so the FDA approved these drugs, and then Medicare agreed to pay for one of them this drug called the cambie.

They're gonna pay for it. But because of the way it's paid for under Medicare, if you're a Medicare recipient, you have a 20% copay. So this drug cost \$26,500. And you'll pay about \$5000 for a year, and you have to take this drug for the rest of your life. So that's kind of where we are. This is going to cost Medicare billions of dollars, you have to make some judgment about how many people are going to take it and all of that, but probably reasonable to predict eight \$10 billion a year, at least to start incredibly expensive for Medicare, it's gonna cost families \$5,000 a year at least as long as the copay is required. You also have to have regular PET scans, the drug is an infusion, which means you have to get yourself to an infusion center twice a month to get the infusions. There's a lot of issues. The researchers I talked to, are really excited. I mean, they say we're learning a lot that we're this is this is really, really important advancements, the clinical physicians, I thought the geriatricians, the neurologist I talked to basically say, so I asked them the journalist question after we go through all this stuff, I say to them, so would you have you put your mother on this drug? And very few of them say yes,

Anne Tumlinson 58:53

Hmmmm.

Rosanne 58:54

I believe that

Howard Gleckman 58:55

Because of the risks and because of the very limited benefits. But going back to where we started, Medicare is going to spend billions of dollars on these drugs. What if Medicare spent those billions of dollars on homecare aids or wheelchair ramps, services or adult day programs? Or respite care or caregiver support? We could get? Well, we could do a lot. Right. But they don't do that. Congress doesn't have anything to do with it. We're just going to approve these drugs and kind of roll from there. Why? Because the drug industry has great lobbyists.

Anne Tumlinson 59:33

Yeah, that was a really good explanation. Howard, I really appreciate hearing you kind of walk through that verbally. And I would say that I sort of have so much trepidation about all of this in how much it's going to cost and the implications for things like access to value based care, you know, programs where we really like guide or other things where we really do need people to be in these integrated sort of programs where there's some degree of financial alignment between the payment of the providers. And if the providers have to be at risk for this huge cost. I don't know, I just don't know what the implications of access to care and access to save, for example, you know, screenings for dementia to Medicare Advantage plans really want to know, if you have dementia now, because what they get paid is not going to match for quite a while how much it's going to cost them to deliver this therapy, if you decide that that's what you want, and they have to go ahead and cover it. So, you know, I think we're just at the very tip of the iceberg in terms of understanding what the implications of this are and

Howard Gleckman 1:00:43

The other related issue is, there's also a controversy out there about diagnosing Alzheimer's disease. So the it's a it's a bizarre story. But the Alzheimer's Association and the National Institutes of Health, for a period of time worked together to create these new standards for diagnosing Alzheimer's. And the

standards included a diagnosis of Alzheimer's disease before you have any symptoms. And it became incredibly controversial, and the National Institutes of Health took its name off of the project, it this is all essentially unprecedented, that they had their name on it in the first place, and that it took their name off of it. So this is now an Alzheimer's Association show pretty much entirely, there's a lot of criticism, there was an expert panel that developed this as a lot of criticism of the panel, because a lot of them were being paid by the drug industry or being paid by the Alzheimer's Association. And what it does, on one hand is if this, this is finalized, it's still being, it's still in draft form. But if this is finalized, what it's going to do is significantly increase the number of people in the United States who have I don't know if people can see my air quotes on the podcast, but who have Alzheimer's disease, even though they have no symptoms, that's going to have incredibly important implications for insurance. You know, try to get insurance if you've been diagnosed with Alzheimer's disease. And if you don't have it, it's going to have very important implications for policy. And, again, there's a lot of pushback from the medical community about this, where people are saying, well, wait a minute, you know, I have to, I have to say to a patient, so a patient, a patient comes in to my office, I'm a primary care doctor, patient comes into my office, and they have some what's called mild cognitive impairment, you know, they forgetting names, they're, you know, it's not a huge issue, but it's a problem. What this would have me do is, give a diagnosis of Alzheimer's disease. And the I think it's important always, there's dozens of dimensions that are not Alzheimer's disease, right. And physicians are usually not well enough trained. And so they just, they just go to the default and say, Well, you have Alzheimer's. And then what, and this, this goes to where we started with all of these questions around guide, in, in, in an ideal world, and in my ideal world, you would get a correct diagnosis. And then the physician will say, now, we have somebody in our office, who is a social worker who can now help you or nurse who can now help you with the support that you need to manage this. Instead, what happens is, they give you a diagnosis, they say, Well, you can take this drug, we don't really know if it works, but you can take this drug, other than that, you know, get your affairs in order, because there's nothing I can do for you,

Rosanne 1:03:41

Which is horrible.

Howard Gleckman 1:03:42

Horrible

Rosanne 1:03:43

And it's and it almost feels like the drug company, then from what you said, from what I'm hearing is the drug company has gotten involved with the Alzheimer's Association, in some way, shape, or form, and kind of advanced this narrative?

Howard Gleckman 1:03:58

Yeah, the Alzheimer's Association, they don't make this information particularly easily accessible, but it is largely funded by the drug industry. And it's a it's a, it's a very complicated thing, right? I mean you have researchers, you have academic researchers who also get lots of money from the Alzheimer's Association from the drug industry. It's good, they're doing the research. I mean, I nobody would be more excited that if if we actually found a cure or actual treatment, so the research has to go on, the

research is going to get funded by drug companies, just who else is going to do it. But it creates conflicts of interest. And it makes it very hard to know who to believe and who not to believe.

Rosanne 1:04:38

Wow. Wow. And they have they have many years of being like the place and now it's changed. And that's that's a shame. Yeah, that's, that's Oh, my goodness. Yeah. Well, I could talk to the two of you forever, literally forever. Any final thoughts on what we've wrapped up for? 2023 Anything you're looking forward to for 2024?

Anne Tumlinson 1:05:00

Yeah, I think I I am excited about, you know, I think the thing I'm most excited about watching in long term care is what the states are doing. So definitely expect in 2024, we're going to see some more, you know, more proposals and innovative program design from states around financing long term care. And, you know, I remain fairly optimistic about the work that the federal government is doing to try to incentivize and align payment with much more integrated care delivery at the ground level. So do you think they're working hard to try to improve the way that a way that care is delivered so that it's a lot more navigable and integrated?

Howard Gleckman 1:05:53

So I guess the thing I worry about the most in 2024, is funding for all those programs under the Older Americans Act. There's enormous amount of pressure to cut domestic spending. And those programs are really at some risk. And I worry that they've been flat funded for for much of the last decade. These are programs like Meals on Wheels, like respite care, and adult day, they're not paid by Medicaid. They're paid by a different pot of federal money, and they're available to middle income people. And those programs, I think, at some risk, and I worry a lot about what's going to happen to them in 2024 and 2025.

Rosanne 1:06:39

Is, is there a push to try to save those programs? I mean, I would hope that they they would there would be?

Howard Gleckman 1:06:44

Yeah, so So rather than, you know, getting into too much into the political weeds of Congress, so the Republicans have proposed a budget for the Department of Health and Human Services, cut the budget by about a third Senate in the Senate Democrats and Republicans have agreed to a budget that would basically hold it flat. So there's going to be a series of negotiations over the next month to try to figure out, you know, what they're going to do. And we'll see and, you know, whatever they settle this year, we're gonna have the same fight again next year. And as long as Congress is divided, and and, you know, there's politics going on here, it's going to be hard to see any additional funding for these programs. And my fear is that they'll be they'll be cut. I agree completely with and I think the most interesting work that's being done right now in lawn care has been done in the States. And, you know, the good news about that, you know, states as you know, places for, you know, trying out new ideas, but having different, you know, different kinds of care in different states also creates real problems. You know, polling community based care we haven't talked about much, but you know, there are some

states that are very enthusiastic about providing that, and there are some states that are very reluctant to provide, and that that creates, I think, some real problems.

Rosanne 1:07:58

A big thank you to Howard Gleckman, for being our guest today. You can find more information about Howard at Howardgleckman.com on forbes.com or at taxVox.taxpolicycenter.org. I hope you enjoyed our podcast today, head over to 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 find Subscribe and Like us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood, the podcast as well as on daughterhoodthepodcast.com Feel free to message me on any of these sites 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 bonus episode theme music, Even My Guitar. I hope you found what you were looking forward today. Information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.