Daughterhood the Podcast BONUS
The Crisis of Long-Term Care with
Anne Tumlinson and Dr Joanne Lynn

47:25

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SPEAKERS
Rosanne, Anne Tumlinson, Dr Joanne Lynn, Disclaimer

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Rosanne 00:40
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 Daughterhood 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. Dr. Joanne Lynn is a geriatrician, a hospice physician, health services researcher, quality improvement advisor and policy advocate who has published over 300 peer reviewed medical research and policy articles. Our conversation today covers the unpredictability of care, the necessity of change in policy regarding long term care how older Americans are viewed and strategies all of us can use to change policy. I hope you enjoy our conversation. Realizing the cost of long term care is a lot like caregiving. You don't truly understand the depths of it until you are in it. And then it's shocking. It's nearly impossible to save enough money to pay for care. insurance doesn't pay for it. How can we help people understand long term care costs? And why is it important they do?

Dr Joanne Lynn 02:01
Long-term care is very costly. And it used to be very rare. Just 50 years ago, it was uncommon for people to live into their 80s or 90s. And they usually had enough family and a home or farm that they

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could retreat to. And we didn't think we could do surgery or even very much useful medical care for people that old. The average age of death was still under 70 When Medicare passed 50 Some years ago. So this is new, that most of us who survive infancy and maybe auto wrecks in teenage years will live into our 80s and 90s. It is sad now that a person born today is likely to live past 100. But that means that there will be lots and lots of people who are living with substantial disability in old age. And we have not developed the social arrangements to allow them to be independent and to have funded that care, in part because it's highly unpredictable. There are still 6% of people who truly dropped dead. I mean, don't have any expenses. And there's probably another third of people who have manageable expenses, they are sick for a few weeks, maybe a month and things can kind of come together and hold them up. But the rest of us more than half will have substantial long term care needs. But we can't tell whether that's a year or 10 years. When I first started working in a nursing home, one of the residents that I picked up, had had her terrible stroke in her 40s. Before I was born, I had done all of my growing up coming around to being her doctor. And she had been living in the nursing home. Wow, no one can save for that. I mean, maybe Elon Musk and Bill Gates, but the fact that you cannot predict whether you have $50,000 worth of costs, or $500,000 worth of costs or 5 million, right? It is very expensive to pay other people to do what you have done in your daily tasks, to brush your teeth to help dress to help you move around to socialize to talk with you the 1000 things you do every day to just sort of be a person in the world has to be done with the help of somebody else. So people are always saying, Well, you know everybody wants to stay home. If you have no one willing to provide volunteer help at no cost, no financial costs. I mean, there's clearly a big cost but that requires five FTE people to provide around the clock care, even if you pay them miserably and pay their taxes and maybe a little bit of training and time off. You'd be at $40,000 a person that's $200,000 right there. Plus the costs of your home and heating and repairs and food and the doctor bills still don't stop. So being home without volunteer help. is very expensive. It says as expensive as the best nursing home in your area. And it is very lonely. Because mostly the people you can hire are from very different backgrounds and very different age, and they don't share your interest. It's a very expensive endeavor and widely misunderstood because it's new. So still, nearly half of people think that Medicare covers long term care. And boy, are they shaken when they discover they're always. In fact, I remember when I first started writing checks for my mother in law, who had lived with us for more than a dozen years. And then our house was flooded, and we had to move her into a nursing home and writing those $10,000 checks, and realizing that you didn't write a check that big for anything other than a kid's education, a car or a house. And I was going to be writing that check every month. It is really walks you back on your heels. And I knew that this was what was in store. But it was, I mean, it is hard to recognize just how expensive it is to have somebody else, you know, help you dress help you get to the bathroom, help you get a bath.

Rosanne 06:11
Absolutely.

Anne Tumlinson 06:12
There's just so many I just was like, I just want to use said Joanne made me think about my own situation and that. So Joanne, and I are our whole careers have been studying this very thing that Joanne is describing, and yet, my father was in his late 70s. And he was I guess he like age 78. He was always like to joke, we went ziplining in Costa Rica, he had a puppy, a convertible, he was riding horses

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competitively, and was working full time. And I knew rationally that anything can happen. And that it's unlikely that he was just going to continue to live like that until age 95 And then dropped it. But yeah, I think this is one of the challenges is like, even though I knew that rationally, I couldn't really accept anything else would happen. And about two years later, he was diagnosed with Parkinson's, just to the unpredictability of this. So now, I know, with Parkinson's disease, that we're in for a long period of what we call morbidity and functional decline that Joanna's talking about. And then, so I'm preparing myself for that. And then he gets this rare blood disease that ended his life a year later. So we went from like, he's good. I mean, he's gonna be like, he's gonna be that guy who's running marathons at 95 to, oh, we're in for it to now he's gone. How could you possibly ever sort of prepare, when there's so much uncertainty? And then I think people really, really do get health care and Long Term Care confused? Yes, if they've never been in a situation where somebody needs long term care, because it just you just think in terms of care. And you think in terms of the doctor in the hospital, and you don't think in terms of like, okay, the diseases that you learnt you deal with and treat and address and a medical care situation are often what make it impossible or difficult for you to do those daily tasks, like you were talking about Joanne and that those things are connected, but they're not the same. So it's sort of like I've had so many friends and you know, just be like, wait with assisted livings not covered by Medicare? Oh, no.

Rosanne 08:43
We get caught up in that catastrophic event. And it's, it can be anything. It's a slip. It's a it's it's a father that goes in the back surgery and is never the same. It's a mother who has a stroke. These are events that happen one day, you know, yesterday, everybody's fine. And today, this is what happened. And then it's Oh, my goodness, well, now we have to figure this out. Now we have to and even when you have people that know like the two of you, it's still shocking when you look at it and think Wait, none of this is covered. Really you're not. And the fact that this has changed in and you said morbidity and functional decline. We know that these things are built into these diseases and that people are living longer, but yet, the laws haven't caught up to it. And I don't understand how well I do because it's you know, it's the nature of the beast. I get that. But we have it. People aren't talking about this in a in a way that it's like wait, wait, wait, we have to look at this. Like there's no way around it. We have to look at this. How do we change that and what what's the biggest issue in trying to get that conversation going or to move that, that forward?

Dr Joanne Lynn 09:59
No one wants To truly confront that they will decline before they die. Lots of people think that it would be okay to die suddenly, in their sleep at 92. And to live, you know, the life that am described of her father, right up until the day before, so it's hard to confront the seriousness of decline now decline started a long time ago, you know, essentially, none of our kidneys are working quite as well as they did at 20, none of our livers are working quite as well as they did. So that decline is somewhat built in. But of course, we have tremendous resilience through most of our lives. So most people can handle the decline until they're very old. And when Medicare passed, the average age of death was 68. So some people could see decline, but it was very few people. And, and we didn't think we could do anything about it. But now with a combination of the newness of our demographics, and the ageism, that's built in. So I mean, could we have put any other group into solitary confinement for a year, other than nursing home residents, we put them into solitary confinement with no view of their own no voice of

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their own, we ignore the voice of their families, we thought it was okay for them to you know, wave from the outside window, do we need any further evidence that the country seriously does not consider old people to have the same birth and stature as people had 40 or 50. And yet, we're all going to be there. This is not somebody else, this is us in the future. So we ought to be terribly concerned about the way that elderly people are put out to pasture and considered to be irrelevant. I think that, without knowing it, the country is kind of on the cusp of figuring out what degree of suicide, self destructive behavior and medical aid and dying will be tolerated. Because we haven't gotten around to figuring out how to provide supportive care. I mean, wow, we are going to have millions of people who lived in the middle class, and who expected to be able to get food on the table and a roof over their heads, who are instead homeless, and without a way to support themselves. And unless we do something, that's the fate that waits. And it is not unreasonable to think that many such people will check out one way or another. Are we going to tolerate that? Are we going to tolerate having 90 year old former school teachers living under the bridge? You know, we've learned to tolerate the 40 year old schizophrenic, and we kind of say, well, you know, that's somebody who smokes a lot and drinks a lot. And you know, we can walk by and kind of not notice, or at least many people can. But that's going to be very difficult when you recognize that was your high school history teacher, we have somewhere between 50,000 and $100,000, in total assets for the median person at the time of retirement for what has become a 20 year retirement. Right, there is no way you can live on that and still have enough to afford Long Term Care, Mister help a Social Security and the help of some friends and maybe a part time job for a while you can kind of eat get together, or at least a lot of people can until they get sick until they can't take care of themselves. And then that kind of funding is just not going to last. And we haven't devised anything else except Medicaid. Sort of.

Anne Tumlinson 13:41
Yeah, we have a safety net. So let's talk about that. I want to I really want to get your perspective on what's going on with nursing home today in just a second. But I I do want to say a couple of things about sort of why not? I think that there are two things that are there related. One is that the people who make the laws, the policymakers, the people on the Hill, the White House, etc, have not felt the pressure politically that they need to feel in order for this to happen. So as in contrast, we did just get legislation to begin to address prescription drug prices. That was a very big lift, but policymakers knew like the pressure was on I mean, how many more news stories can we have about people not being able to get their insulin and their diabetes, you know, so, you know, I think that's the key thing, and this is a hard thing for them to do without that political pressure because it does require government funding. I mean, somebody has these are the as Julian was explaining earlier, these are expensive services they have to be paid for. And we we can talk all day long about you know, there's plenty of money to pay for it but just not prioritized and And but there's a perception that we already spend too much money on older adults because of Medicare and Social Security. And these are both programs that are encountering sort of a perception of financial challenges right now because of the way that they're financed. So Medicare is financed partly through a payroll tax, those payroll taxes are not sufficient, really to cover the costs as we enter into the baby boomers, older adult years, and we haven't come up with another mechanism for for essentially, financing that we can. It's totally possible. But Joanne, and I combined fund everything that older adults need, but just a couple of tweaks to corporate tax law. But really, yeah, I mean, you know, so I think this all can be there are solutions, there is money, there's just not the political pressure to go and find it. And so I think that's the piece that we

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need to work on. And I would also say just one less thing about that, which is just that I worry about being able to build that political pressure by leveraging the people who are already really stressed out and busy and working hard and be how, you know, family caregivers, who are primarily an older adults and people with disabilities are, are all in situations in their in their lives, where it's hard to mobilize, I do think maybe we'll get to a tipping point. And in a few years, like five, five ish, but in the meantime, we have this safety net program called Medicaid, that is technically really, truly does it purpose built to keep people off the streets. And that's it. So it is purpose built to give people up roof, minimal nursing and attention and support with activities of daily living, so that we don't have homeless people who are 90, but that industry in that system has been both sort of under resourced and under attack, and which has kind of driven the bad actors into it. In a way, this is my personal thing. I can't wait to hear what Joanne thinks. But I actually think we've been like, you know, so like anti institution in our approach that we've made the institutional business so unattractive, that all it's done is attract the worst people to run it and invest in it, which is creating this almost like what I call like a death spiral. And so increasingly, the good actors are just like, we're done, we're out. I don't want to be in this business. There's a lot of other businesses I could be in and make money and do good. So anyway, Joanne, I'm interested if you agree with me or not.

Dr Joanne Lynn 17:46
However, you see Medicaid, today, we do have to forecast what Medicaid will be in 12 years, Medicaid now spends a little less than half of their total money on elder care. We, in most states, we will double the number of people who need Medicaid, some states more, some states a little less, but basically, we will double the number of elderly people. Wow, there is no state that can afford that. So the only thing that states can do is lean on the feds to pick up more of the tab or raise the requirements before Medicaid chips in. So some states are already requiring three activities of daily living that you are dependent in most states are two, but some are already a three one is it for and they can go back to warehousing rather than trying at least a little bit to have decent care. There were whole states where the average person in a nursing home was tied down every day. There were whole nursing homes with more than half of the residents being on psychotropic drugs. We had a nursing home in Washington DC, where more than half of the people had pressure ulcers through to the boat. We were warehousing people in many situations, not every I mean, there were some wonderful nursing homes. They were usually philanthropic or religiously anchored. They were supported on charity and Medicaid. And they were wonderful, but not the average. So those weren't evil people back then. They were people who thought they couldn't do any better. We have done better. I mean, it's not it's not entirely good or bad nursing homes and we have bad experiences in nursing homes, but it has come a long way and we could lose it all in just a couple of years. Or we could accept that people stop medical care and or seek ways to be dead. So as not to face terrible nursing home care.

Rosanne 19:46
Where do you see homecare fitting in

Dr Joanne Lynn 19:48
the enthusiasm for home care is terrific. It's you know Currier and Ives and Norman Rockwell and you know everybody wants to be at home but being at home when you're 90 and on loan is kind of dangerous and your house is falling down around you and you don't have the money for repairs, and no

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one's coming to visit except maybe, you know, once a week or once a month. So being at home is appealing from a distance, but not necessarily in every case. And it can be expensive, as we pointed out, very few states will provide around the clock care. So most states have a limit at six or eight hours a day of paid care. And after that you must move into a nursing home. But if you don't have the payment for nursing home, then what happens? Right? So housing is an enormous problem, just straightforward housing, the number of people who are living in four bedroom houses, because that's where they raise their kids, and they are now at eight and living alone and can't even do the steps. This is crazy making meat, why are you paying a mortgage and taxes and so forth on a suburban house with four bedrooms, and you're lonely, and you're a danger of falling and no unknowing, and all sorts of bad things. But a piece of it is we've never built housing appropriate for elders. So in Washington, DC, when last I checked in when I was working there at 1% of our available housing available to a person in a wheelchair 1% We have expectations of having 12% of people needing a wheelchair we are building for that. And we are and we're building three bedroom and four bedroom places, not one bedroom with a study or a studio apartment that's quite usable. And we are not thinking through whether we want this housing to be integrated with other housing. So one big problem is housing. And the other big problem is workforce. We have not paid for the paid workforce, we have not made it easy to be a caregiver, it's almost like we set out to make it just as hard as it could possibly be. And we still have 70% of our long term caregiving for free by families. And we have made it as hard as possible to do it. Absolutely. So my hat's off. And it is the case now that women spend more time taking care of an adult than they do raising children. Yeah, but we don't even talk about that. Because of course we've discounted elders anyway. So there's a major change in substantive things like housing and workforce. And there's a major change in attitude. That values the caregiving that notices that a person, woman or man of any age, who takes two or three years to take care of a family member has done something terribly valuable. It should be on their resume, it should point out the skills they learned, just like somebody who spent a couple of years having been in the army, we're in the National Guard. Yeah, but we don't do that. We hide that, you know, why were you out of the workforce from the time you were 23 to 26? I was taking care of my grandmother? Oh, well, let's go on to what else you've done. It says you're just treading water for three years. No, you were learning a lot of skills. And you learned how to deal with death and dying and you've got a great deal of perspective on life.

Rosanne 22:53
It was more than just watching The Prices Is Right. It was more than just being there. It was everything that went with it. And caregivers, I believe once you've been a caregiver, you can do any job doesn't matter, any job. And we should elevate that. But the interesting point you brought up with Medicaid, I don't know if people realize you have to have nothing left to access Medicaid. So in that safety net that we talked about, it's like okay, well, you can always go on Medicaid, yes. But you've exhausted all of your funds, and then you're going to a nursing home where they don't have enough workers, the workers they have they don't pay enough, you don't know if you're going to wind up on a psychotropic drug, which you probably are going to because they don't have enough workers, the pressure sores are going to happen because of the lack of workers. So it's like, yeah, we've got this, but that's your safety net. And that has to change. And and I'm wondering how these people have been able to infiltrate this system to then say, Hey, this is the place we're going to make money. How did that happen?

Anne Tumlinson 23:59

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Yeah, that's a lot of us are trying to figure that out. But, but but but here's what here's what it fundamentally comes down to, and is that long term care and housing are intricately connected. So where you live really matters with respect to how you are cared for. And at the end of the day, a nursing home is both sort of an institution where care is delivered and it is your home. And as such, it is it attracts investors who are primarily real estate investors, not healthcare, operational health care, not the same investors who say buy a physician practice and or invest in health care technology or, you know, provide capital to develop some new You know, a way of of conducting surgery, you know, these are like, Hey, I've got an apartment building over here and a shopping mall over here and a nursing home over here, because the government has not valued the care. So what is valuable is the real estate. So we have attracted the owners, essentially, of the real estate to this business.

Dr Joanne Lynn 25:27
It's also the fact that the manager of the nursing home is being judged on kind of keeping your nose clean, you're not ending up on the headlines of a newspaper, but returning a substantial rate of return to the investors. And so there are two ways to get fired. One is to have some scandal happen at your nursing home. And the other way is to only get a return of 3% instead of the expected, you know, 9% or 12%. And that's the way we've set it up. Now, when as we start trying to figure out how to fix things, we have to remember that we are mired in our past. So just this last week, when Massachusetts announced that they were going to require that all nursing homes convert to one and two bedrooms, a whole chain of nursing homes in the western part of the state announced that they would close because they had mostly three and four bedrooms and couldn't convert. That means that there are a whole chunk of counties out there that have no nursing home once they close. So you know, it's a complicated set of issues. It's, and it reflects that we have ignored them for a very long time and have put our head in the sand and tried hard not to learn about them. I live for the day when the real estate act out, you know, this is a this is a house in a wonderful community. It has great schools and terrific homecare, and nursing home care is one of the best hospices and PACE programs in the state, you know, because people ought to be buying on that ground. To know that the community they're moving into has has made investments in having your 70s 80s 90s and hundreds be good, and they can be good. But all you face is a miserable nursing home. Yeah. impoverishing yourself and your family losing your business losing, you know, the set aside you thought was going to the grandkids for their college education. Uh, you may well decide that that's not appropriate and decide not to take your your expensive insulin or whatever other you're supposed to take. But the medical care system, the Medicare paid medical care system has become rapacious. I mean, it is just built on greed. Yeah, I recently had a family member who was spending $20,000 a month of Medicare and Medigap coverage for drugs and treatments and bankrupting the family on the cost of homecare because of course the drugs are covered, and the treatments, but not the homecare, and that's ludicrous. The drugs and treatments were doing nothing for him in his 90s. But homecare was doing a whole lot. But it shows our valuation. Now we are stuck with what we've got. I mean, I'm a hospice doctor. And you know, you don't rail against the fact that the person smoked, you know, you deal with the fact that they now have lung cancer. And in the same way, you know, the country has what it has. And the fate for the boomers is largely written, we didn't save enough, we didn't buy insurance, we didn't develop a workforce, we pretended that we were going to live forever or die suddenly. And there's going to be an enormous number of boomers who do not have financial resources, and who depend upon that safety net, and it will overwhelm the safety net, and the safety net will have to get worse, but we could be putting in place

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arrangements that would make the next generations lot so much better. We could let things drift and make it worse. Right now a 25 year old faces three mortgages, they have their school debt, they have the house they want to buy, and they have the costs that are being passed down in the family from caregiving, we could alleviate that by developing a national level insurance plan. It has to be at the national level because people move around over a lifetime. And because they change employers, it can't be just the GE offers it. It can't be just that Washington State offers it

Anne Tumlinson 29:27
And just to be clear, I just want to jump in here for a second Joanne and clarify because this is a really important point, right is that being insured for this risk is really different than being insured for a medical catastrophic risk. Those things are kind of think of like when you have health insurance like stuff that's going to happen to you is gonna happen to you when it happens to you and that year, right? You have your health insurance and it's an immediate kind of a thing, long term care is you you will get insured or you have insured rents, it's a little bit, and then something's going to happen far into the future most likely. So you have to be able to hold this insurance over your lifetime, which is why it's in, I should just maybe make a quick side note here, we used to actually have something of, for a brief window of a private insurance industry that did, in fact, sell products to people in their 50s, like me, that would then pay for their long term tariff for a variety of really technical complicated reasons, that industry did not really survive. And it has to do with how they turned out, it's really hard to do a private product, that's only insuring a handful of people relatively speaking, for something that's going to happen really far into the future, what we, we it's kind of like, I always like to say to people, like, I wasn't really good at math, that's why I'm not a doctor. And Joanne is good at math and science. But I I'm good enough at math to know that you have to I took basic statistics, right. And in order for you to be protected, in forwards and to be protected. And for we all three of us have to be in the risk pool, meaning like we can't create, we can't none of us can individually protect ourselves against risk, the whole point of insurance is that we're all kind of like, we don't know, if it's gonna you or me or that other person. So we're all going to get in, and we're going to share, and then when one of us has a problem, we know that that'll be taken care of. So this national this concept of it, and people flip out about how you know, being forced to debt health insurance, and I'm just like, it's just math people, just math, everybody has to be in in order for it to work. So the best way, and the most efficient way to get everybody in, is to create a national system.

Dr Joanne Lynn 32:03
I mean, in long term care, especially elder care, the alternative would have to be that you are actually willing to ignore that a person who did not take care of themselves and, and save or buy insurance or whatever, it's you're willing to let them die on the street. But you are willing to say, Okay, you made your choices when you were 2030 4050, I'm willing to walk by and say it's all on you. Since mostly, we are not actually willing to do that. We need to have everybody in the pool. And it needs to be insurance, I think it actually needs to be catastrophic insurance, that the rates of needing some long term care are high enough that people should buy insurance for the first private insurance for the first year or two, or they should raise enough children who are going to take care of them, or they should save enough money in the bank or whatever room IRAs or whatever. So I think that we can leave it as a personal matter to save for the front end, very common needs, and then ensure the back end, it's essentially like a big deductible on your auto insurance, instead of having a deductible of $50 have a deductible of 5000. If you're somebody with that with adequate assets that 5000 would be okay. And in the same

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way, you know, over a lifetime, people who've earned well maybe can cover themselves for three years, people who come in to old age already on Medicaid can maybe only have enough coverage to save for nothing at all, you know, and really rich people maybe have to wait five or six or seven years. But whatever it is, it is catastrophic for your wage history should then be part of the insurance pact. So one out of seven of us actually needs Long Term Care in old age for more than five years. So that's not a low risk. At the present time. You can't buy insurance in general, very few people, well, many people can't buy insurance at all because they have an established diagnosis of something. But even if you could buy insurance, you can't really get it for more than about $250,000 or more than about two years of coverage. So okay, let's say that's the marketplace. Let's cover the let's cover the time past that have everybody in the in the pool and recognize that that we're all going to be drawing from it. Right. I think that medical insurance has been flawed in having us not deal with very low yield very high cost medical care. So you know, the fact that in the example I gave earlier, there could be $20,000 drugs being given for very small benefit to a person in their 90s ought to have raised a lot of questions, but it doesn't, doctor can. It was a sweep of my panic and right for a $20,000 drug.

Rosanne 34:51
And Medicare will cover that.

Dr Joanne Lynn 34:53
Yeah

Rosanne 34:53
Medicare will cover that but they won't cover what you really need

Dr Joanne Lynn 34:56
They won't cover housing or food.

Rosanne 34:57
No, no.

Dr Joanne Lynn 34:59
Or a personal aide Yes, somebody to get you out of bed and get you dressed, right, which is wrongheaded. So maybe in the long run, we need to have a choice in Medicare for supportive services, so that you could say, you know, at my age and with my circumstances, I actually am willing to give up on resuscitation, I'm willing to give up on transplants, organ transplants, I'm willing to, I mean, I still want my hip repaired if I break my hip, things, pain and disability, of course, things that are very effective, yes, I want emergency treatment for a stroke. But I don't want last ditch treatments that are very expensive for very small yield. And we have to work someone what that is. And for myself, I'd say something like, you know, anything that's going to cost more than $1,000 a day, not a chance, and I'm only in my 70s I'm probably going to cut that back when I'm in my 80s or 90s. People need to understand their trade offs more than they do now. We need tremendous education. But we also need what Ann was speaking to earlier, we need lots of people to raise their voices. We don't even need them to be terribly astute. We make mistakes. I mean, give up on trying to be just the right message. Just call your congressman just call your Senator, just call your mayor call your state representatives

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say this is crazy. You got to find a better way. If anybody spends any time on it, they will find the better ways because the better ways are out there. They've been tested. We know what they are. But there's no will to do them. I mean, the midterm elections, was there any mention of long term care? No, there was a little bit on, on climate change. There was a lot on abortion, there was a lot on immigration. So those were just all smoke and mirrors against the real issues. And I would list some things in addition to long term care, but long term care ought to be there on the on the table. And only if a lot of people raise their voices, and to be safe for any politician to propose something in long term care.

Anne Tumlinson 37:03
That's right, it's really going to take that I just want to emphasize that point, it's going to take that because otherwise it is not safe. So we have to make it safe for them by by making our voices so loud, and so constant, that it's just it's like they can't afford to ignore it.

Dr Joanne Lynn 37:22
And there has to be a penalty if they do. I mean, we have to make it safe for those who are willing and dangerous for those who are not.

Rosanne 37:32
So how do we do that? What how do we do it?

Rosanne 37:35
Well, we talk to the newspapers, we talk to the television stations, we talked to CNN, we talked to News, Fox News, we yeah, we talk to each other. We recruit our neighbors, we recruit our family, we say we go to townhall meetings, we set up an appointment with our Congress person that comes in the home district. And if you have an axe to grind, you say, Look, we need more workforce, we need more people who are willing and able to do this work with my mother who has bad dementia Fine, go for that. If it's that you want the housing that is affordable and appropriate for a person in a wheelchair go for that it almost at this point doesn't matter. It matters that you push elder care onto the policy agenda, and trust that will make some mistakes we're bound to I mean, Winston Churchill said Americans always do the right thing after we tried everything else. But you know, we will get around to doing the right things. There's a certain wonderful set of outcomes for catastrophic Long Term Care Insurance at the federal level. So eventually, everybody will line up around that. So I mean, it reduces the strain on that aid, it allows people to, in fact, save for their upfront costs one way or another, because the back end costs are going to be largely covered. I mean, there's a whole lot of very good things that happened with that. So people will come around to it. But right now, no one even knows it.

Rosanne 38:59
What is that? What is it that we can reference?

Dr Joanne Lynn 39:01
Well, if you go to my website, just DrJoanneLynn.org. Yep. Dr. J o a n n e L y n n.org. There's blogs that tell you how to advocate for what was called the wish Act, which is catastrophic, federal long term care insurance. So that gives you one thing to advocate for there is a bill in Congress about the essential caregivers. I can't give the citation to that quite off my head, but maybe one of you know,

Rosanne 39:28
Yes, I have it. Joanne it's HR 3733. The Essential Caregivers Act of 2021.

Dr Joanne Lynn 39:34
The Essential Caregivers Act was introduced in the last Congress hasn't been introduced again, but will be the so you can line up being those things you can line up behind housing, if you go to Medicaring.org There's a set of issue briefs that were set up for the election of 2020. But they're still relevant and have housing financing elder abuse and so forth. That would are arm, any advocate who wanted to pick those up, okay, and we need to update those things and we need there needs to be an entity that's actually pushing this right. And one of the things that's missing is that the caregiver entities on the whole had been willing to accept the crumbs from the table. Oh, thank you very much for increasing the funding of the Older Americans Act by a couple of percent. No damage, the funding of the Older Americans Act is lagging behind Medicare by hundreds of percents. And the caregiver groups have mostly been so beaten up, that they've been willing to advocate for tiny changes. No, no, we need to edit for big changes. Yes, there's plenty of things to push. But fundamentally, we will all fail at everything we're trying to do, if we don't get sustained funding, because there will be so many of us needing it in just about 12 years. So we must find a better way to get funding into the system, without relying upon the present arrangement with Medicaid, that Medicaid is going to have to still be there. But you can't just double the numbers of people.

Rosanne 41:09
Anne I know you have some thoughts.

Anne Tumlinson 41:11
Well, I Well, just to Joanne's point about people calling their members of Congress and making their voices heard, we do need an organizing mechanism we do need to be I mean, I think everybody can have their individual, I encourage everybody, I don't want to discourage anybody from making their individual voices heard. But it would be awesome. If we had something or some we had some way to organize ourselves. And I will just say Javi, as the founder and leader of Dr. Hood, and you know, trying to bring people together in local markets to share information, it's very hard to do. It's hard to do, it takes money. It takes a lot of time, it takes a lot of effort. And we do we need philanthropy to step up and fund organizing family caregivers at the local level so that they can host town hall meetings, organized letter writing campaigns. I love philanthropy for all the research that they find, but they need to fund organizing, in my opinion.

Dr Joanne Lynn 42:12
You know, they have become so scared of, of the lobbying issue Yeah. That you almost have to repeatedly educate them. No, actually, as long as your education and you're not supporting a particular candidate or a particular bill. You can do as much as you want. And even to support a particular bill, you can use up to a certain amount of your funding, but our conventional philanthropy is going to be very scared of organizing advocacy. They want post tax dollars to do that.

Anne Tumlinson 42:45

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Yep. Somebody asked to see if we can fund people to organize.

Dr Joanne Lynn 42:50
And but let's just call it education, let's call it advocacy to get elder care on the agenda is not lobbying advocacy to aid your congressperson do have a position is not lobbying advocacy on behalf of a whole array of let's say, um, workforce issues is not lobbying. It's only when you are pushing a particular bill, that it starts to count as lobbying. Well, that philanthropy is going to be very scared to fight. Yeah, but up to that point, we're

Rosanne 43:20
Good to go.

Dr Joanne Lynn 43:21
We can use philanthropy dollars.

Anne Tumlinson 43:22
Yeah. It's, it's, it's a lame excuse.

Rosanne 43:25
But it's the whole situation and you look at it, and you try to think, Okay, well, we have to, we have to do something. But then how do we do something and it feels like your hands are tied. Can we do this? And if we organize to do this, because remember, caregivers are tough, but they're tired. And it's hard to then at the end of the day, say we need you to say blah, blah, blah, and it's like I can't I'm lucky if I can say my name right now. So if there's a way

Dr Joanne Lynn 43:54
I've been there, right, and they're done that

Rosanne 43:56
Absolutely. So if there's a way that we can then put it and I don't want to say put a bow on it because this isn't a both thing. What are some concrete strategies we can put in place right now, whether we're organized or not to try and move eldercare policy forward.

Dr Joanne Lynn 44:11
Some things have been proposed. For example, having a honor giver day, the day after Thanksgiving when all the families are together, making it a day for advanced care planning, but also for telling stories online and contacting your congress person or whoever you could have call in days, people can usually find the strength for one phone call taking five minutes or less. Even once a month, you could have you know, the first day of every month or the Ides of every month, the 15th of every month love that. Everybody call your congressman, your senator and have an easy website that will remind you of how to do that asked to talk to their health assistant and give them holy hell about the situation you're in. Then remember that most of us have a period of time after caregiving where we mostly just say oh, yeah, glad I can finally sleep in But if instead But it sort of became a time in which you say, well, now some of the energy I put into just surviving, I'm going to try to make it better for the next time I have to

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do this or the next person who has to do it. And we also anticipate caregiving. I mean, you know, Anne was thinking about the fact that her dad was probably going to need some help sometime, you know, if you could tap into that, then people could say, you know, I don't want it to be as bad as I saw my mother go through. Right, exactly. So I think that there are ways and there are a kind of cheap ways. I mean, in terms of the burden you place on people, it is scary to first call your congressman's office, most of us have never done that. But there are employee, we pay their bills, and you'll find that mostly, they are very accommodating to the caller. They may or may not do anything, but they don't yell at you. Right, you'll get the first dozen people to do it and report back and that will get the next you know, 100 to do it. And then you know, the next 1000 Let's, let's mobilize this. I mean, it's our experience, it's our futures. Let's raise our voices.

Rosanne 46:05
A big thank you to Dr. Joanne Lynn for being our guest today. For more information about financing eldercare, how to contact a member of Congress and more, check out her website, DrJoanneLynn.org. And if you do reach out to your representative or Congress person, I would love to hear about your interaction. I hope you enjoyed our podcast today, head over to daughter hood.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 daughterhood the podcast.com. Feel free to message me on any of these sites 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 bonus episode theme music, Even My Guitar. 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.

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