WWL - Caregiving Transcript

[AD Reader]
In the quiet of winter, even the smallest act of kindness can echo for years to come. This new year, take a meaningful step toward your legacy. Create your will at no cost, with FreeWill. It only takes 20 minutes, and your plan will protect the people and causes you care about most. Get started today at ctpublic.org/visionary. We recommend consulting with an estate planning attorney to make sure your wishes are properly formalized.

Sujata Srinivasan
This is Where We Live from Connecticut Public Radio. I'm Sujata Srinivasan, in for Catherine Shen. More than 60 million American adults provide essential care for their loved ones with a medical condition. That's a 50% increase in the past decade, according to the AARP. But caregivers are largely unsupported, untrained, and face their own personal struggles. Today, we are highlighting the often invisible role of family caregivers. Are you a caregiver to a loved one? Tell us your story. 888-720-9677, that's 888-720-WNPR or email us wherewelive@ctpublic.org. Joining us now is Laura Mauldin, a sociologist at the University of Connecticut. Laura shares her own caregiving experience in her upcoming book: “In Sickness and Health: Love Stories from the Front Line of America's Caregiving Crisis”. Laura, thank you so much for being here with us today.

Laura Mauldin
Thank you so much for having me

Sujata Srinivasan
And Laura teaches at the University of Connecticut, and she lives in New York. She's on Zoom from New York. Laura, your book begins with a love story in New York City. You're sitting on the steps of Madison Square Garden before a WNBA game with some friends, waiting for their other friend to show up. You write, and I quote, this passage: “I was squinting into the sun when I caught sight of a woman walking across the plaza from the subway toward us. She was taller than me, and in my just-arrived sensibilities, she seemed to embody a kind of New York City confidence that I felt immediately awed by. Jay strutted up the steps wearing yellow Nike high tops, her brown hair piled high in a men's style Pompadour, and I was practically in love with her before she reached the top step.” You were 27 then, Laura. Tell me about Jay.

Laura Mauldin
Oh boy. When I think about Jay, there are so many quirky, funny things that stick with me, and I'll share one of them, which is, Jay was a chef, and would be obsessed with having the best meal possible wherever we were. And this was a long time ago; This was 2005 when we met, and she would carry around a very tiny piece of paper in her wallet with little tiny print of whatever neighborhood she was in with her list of restaurants. So that was something that still sticks with me today.

Sujata Srinivasan
And then, just like that at the start of your romance, you became “The One”. Would you mind reading an excerpt describing your role?

Laura Mauldin
Yes, absolutely. So before I read this passage, I'll just say I talk about “The One” as this the myth of finding our person right and falling in love so we find the one, but then somehow you get transformed

into “The One”, capital T, capital O: “”The One” is tasked with the very real, ongoing and unpaid work of caring for loved ones who are ill or disabled. In almost every family, someone is “The One”. These caregivers are bedside at the hospital; on the other end of the phone when a loved one is in crisis; they make the appointments, manage medications, and track symptoms. They are the person on the floor with their loved one when they cannot get up, the person who gives up sleeping through the night, who struggles against their guilt when they can't be there. They are knowledgeable about the intimacies and intricacies of their loved ones’ preferences and coordinate the 1000s of tasks that need doing. Data show that the one is usually, but not always, a woman. It may be the daughter raised and socialized to care, the person we think of as someone who naturally likes to do that work and seems to somehow have a knack for it, but in actuality, was taught that they should. Maybe it's the youngest child who is emotionally closest to a parent, or the oldest who was always given more responsibility. Maybe the role is simply delegated to the person we think of as having the most caring heart. Each of us is either already the one or knows someone who has or will step into the role. And that's because disability and illness are the most average thing that can happen to us. Six in 10 US adults have a chronic condition. Four in 10 have more than one, and nearly 29% of the adult population is categorized as disabled.

Sujata Srinivasan
Thank you for that. And as a sociologist, you write with so much heart…as a caregiver, and you've studied, and you've taught caregiving from the perspective of politics, from the point of view of culture, but when you are a caregiver yourself, when Jay was diagnosed with cancer…What was…what was a revelation to you?

Laura Mauldin
Yes, I was, at the time, a graduate student, learning about theories and the structures, healthcare structures, that we have, and how people navigate them, and how people make sense of having an illness or interact with a doctor. And I also was studying Disability Studies, which argued, you know, disability is a political thing. That we don't need to talk about the impairments, the limitations, that that's-that's something that we should keep private, and instead, we should focus on creating an accessible world and fighting for that on that political level. And what struck me the hardest was how deeply ambivalent and angry and sad and all the things that I felt that did not show up in any of the theories or the data that I was learning in school.

Sujata Srinivasan
And you get into the emotions, you sort of weave the moments in and out, and it was for you a calling of love. You were deeply in love. And becoming a caregiver was it was an extension, was a part of that love. And you write about Jay: “The more caregiving I did, the less lovable she felt. Such is the dehumanizing logic of ableism.” Could you explain, Laura, in the context of America's caregiving crisis?

Laura Mauldin
Absolutely. We often talk about the caregiving crisis without talking about the politics of disability that are involved in it. And what I mean by that, and I'll just briefly define ableism, which is simply a devaluation of people who have bodies or minds that don't seem, quote, unquote, normal and aren't productive for the economy. So we have these different hierarchies of who is worth more than others? And if you can work and you're able-bodied, you are seen as more worthwhile. And in this country, this seeps into our care: every single care policy, care system, that we have. We have access to health care for people who work, right, because you are deemed worthy of it. And so these kinds of values that devalue people who are disabled or chronically ill show up in the care crisis, because we've abandoned those people, and then we expect the people who love them to fill in the gap of what services we don't have, what structures we don't have. So we are always asking that family members who love someone--and I was a partner--but people have all kinds of caregiving relationships, right? Older adults

to their adult children perhaps, siblings, etc. So these kinds of--this kind of devaluing of disability and chronic those with chronic illnesses broadly is what has left us, both caregivers and disabled people, in a lurch right. So I say in the book that we devalue caregiving because we devalue the people who need it.

Sujata Srinivasan
And perhaps seen through this lens of ableism, it's not that incongruous that even though nearly 29% of the US adult population is disabled, the social safety nets are so weak.

Laura Mauldin
Absolutely. And I think too, because there's so much negative stigma around talking about disability or chronic illness, people don't tend to identify, even if they are disabled, they don't tend to identify as such. Which means this becomes a further erased, invisible thing, because people are isolated from one another, and so are caregivers. We all, caregivers and disabled folks, we're all sort of trapped in the same system that that devalues us.

Sujata Srinivasan
And worldwide, to some extent--in some countries, more than others. I was a caregiver to my father who had cancer. And looking back, I think one of the hardest was the isolation. Ot was managing a full-time work, being young in the labor force, emotional labor, financial labor, and the experience was one dark tunnel of isolation.

Now your book is a memoir and a biography, and you step out of that loneliness of a caregiver, the-the you know, the sheer drudgery of the activities of daily living, the emotional support, navigating insurance, and you find other people, you know, like you in similar experiences, similar stories. And you write about Angel and Kim: Angel is this burly, tall, you know, bearded, hard-working, family-loving Latino who works as a house painter, and he shows up at the ER with an astronomical blood pressure reading. I had to read those numbers twice to make sure that, you know, I was reading them correct, Laura, and ends up having a stroke. You write, you know, starting with the many steps that led to Angel's life with a disability, it begins even before his stroke. You say that his stroke was not inevitable, it was preventable. So let's talk about access to health insurance. It's where it all began for him.

Laura Mauldin
Yes, absolutely. So in this country, we don't have a universal health care system, and what we do have is work-sponsored health care, right? That you can have access to. However, increasingly, we have something called the gig economy, meaning people are classified through federal labor law as an independent contractor. And there are more and more–the numbers of people in this kind of role are rising every year, and those folks do not have access to health care through their employers, and that is exactly how he found himself without health insurance, because being classified as an independent contractor is standard in the construction industry, which is what he worked in, right, as a as a house painter. So yea.

Sujata Srinivasan
Sorry, Laura. I meant to say that his stroke was in 2018, but his last medical checkup was in 1983 when he was discharged from the Navy, so his blood pressure had never been monitored. And this is what he says, you know, when asked when his last checkup was: "You people don't understand what you charge. I can't afford it." And after the stroke, Kim was unable to get–his wife, Kim–was unable to get healthcare for Angel via the VA, you know, again, he says, "I'm a…I'm disabled and a veteran, but I'm not a disabled veteran." The fine print. So he falls through that gap. And then Kim had a part-time job, so that doesn't provide her with health insurance. And then they finally got on ACA, but I mean this, this

struggle for this, this family to-to get back to what would know, seemingly normal, some semblance of normalcy was, was not that isolating, because story after story in your book. And people that I talk to who are caregivers, this is a common theme, the struggle with insurance, this losing of a job, this concern about not being able to pay mortgage, the retirement savings wiped away, you know, some some clause in the insurance that doesn't pay for long-term coverage. It goes on and on. So what, what is, what is the takeaway? I mean, if there was a policy takeaway from this, what would be it?

Laura Mauldin
Well, there are several, but I do think that one of them is extending and expanding access to health care, and one way we could do that is by loosening some of the requirements to get access to, say, Medicaid, for example, and to better fund the ACA subsidies. Those are two great ways to prevent strokes and prevent these debilitating chronic illnesses and disabilities, if we can.

Sujata Srinivasan
Right, and now, with the federal cuts to Medicaid and also the reimbursement rates to nursing homes, and then we have this entire immigration process unfolding, with the limits on who can come into the country, which is shrinking the already small nursing workforce at nursing homes. So all that is: we are expecting it to compound a crisis, which already, you know, is of concerning proportions. And I quote sociologist Jessica Calarco…am I pronouncing her name right?

Laura Mauldin
I think it's Calarco, Jess Calarco.

Sujata Srinivasan
And you mentioned in your book: “Other countries have social safety nets. The United States have women”.

Laura Mauldin
That's right.

Sujata Srinivasan
It struck me. It struck me deeply. As a daughter…I've been a caregiver. It was expected that my mother step into the role…I remember the days when I when I booked the appointments, when I pored over the finances, when I worried about payments, when I had to, and I told nobody at work, by the way, because I was young and no one knew, you know, I was I kept work and my family life separate. I would show up at work, get my work done, and during the lunch hour, I just disappear and take my dad to his radiation treatments. And I remember those days, and a lot of people around me did happen to be women. I don't think it's a coincidence.

Laura Mauldin
No, I think we're quite socialized to do this. I am also an eldest daughter, so there's a way that we learn. We watch other women be socialized to do it. We see what they do, then we are expected to do it, and we also expect it of ourselves. So we start to feel like if we don't do a good job, or if we have negative feelings, that that's a personal failing rather than a structural failing, right, rather than a policy failing, a social safety net failing.

Sujata Srinivasan
Yeah, right, right. And Laura, I think the system is designed to be that way: for this one person to be the be-all and the end-all. And the amount of money that is saved, if we were to monetize family caregivers.

So this is a big win for the system in terms of cost savings. But then you talk frankly about your own expectations. I mean, you seem to be the type AA+.

Laura Mauldin
True!

Sujata Srinivasan
Your expectations on yourself. You know, your demands on yourself, your questioning, and I, and I love how frankly and honestly you explore being a young caregiver, you talk about sexuality and romance in the relationship, and physical needs. And these are very real, very real lives that people are living, but we don't have a space to talk about it in a way that that…I would not even use the word acceptable, but in a way that is breathable, understandable, relatable, because we do this in silos.

Laura Mauldin
Yes.

Sujata Srinivasan
So are you a caregiver to someone? We'd love to hear from you! **[Music Comes In]** Call 888-720-9677, 888-720-WNPR, or find us online @wherewelive. From Connecticut Public Radio, this is Where We Live. I'm Sujata Srinivasan. You've been hearing from Laura Mauldin, associate professor in the Department of Social and Critical Inquiry at the University of Connecticut. Laura was a caregiver and author. Her book is forthcoming: February the 10th. She'll stay with us after the break.

We want to hear from you. We'll be right back!

[Music Swells]

Sujata Srinivasan
This is Where We Live from Connecticut Public Radio. I'm Sujata Srinivasan in for Catherine Shen. Today, we are exploring the often invisible work of family caregivers. Still with us is Laura Mauldin. She is an associate professor at the University of Connecticut. Joining us now is Cindy Eastman. She is the author of “True Confessions of an Ambivalent Caregiver.” Cindy cared for her father and again became a caregiver to her grandson after her daughter died of cancer two years ago. Cindy, thank you for being here.

Speaker 5
Thank you for having me. I'm so honored to be a part of this conversation.

Sujata Srinivasan
And we want to hear from you. Are you a caregiver? Call Us 888-720-9677. Cindy, what's it like to be a grandmother and then be suddenly thrust into a parenting role again?

Cindy Eastman
It's challenging…I think I want to say so I don't forget to say it: My overarching feeling for both, you know, experiences when I was caring for my dad and now caring for my grandson is, is gratitude that I'm able to do it. But I think when we are, you know, so that's, that's the that's the overarching thing. But it is very challenging, because all the support systems that maybe you once had when you were raising your own teenagers, they're not, they don't exist anymore. So you don't have, like, a, you know, couple of friends that you who are also raising a teenager that you can call or text and say, “Oh my God. What's happening today?” So the support systems change, and it can be, I think, I think Laura even mentioned this, or you mentioned, it's very isolating to take on this role.

Sujata Srinivasan
Right. In any caregiving role. This is something we hear over and over again-The isolation. Before you became a caregiver to your grandson, you took care of your dad in your home. You were 59, I understand, and he was 86. What, you know, people dream of aging at home now. And with people, you know, living longer, given the advancement in science, this is possible. But however, the systems in order for people to age in place aren’t there. The social safety nets aren’t there. Long Term Care Insurance, for instance, without that, you know, there are caveats, the double-digit rates and long-term care prices, and it's about $10,000 or so per month…to for a facility, for a long-term care facility. And what is it about aging in place, aging at home, when you had your father at home, what made it harder than it should have been? In terms of the absence of social supports?

Cindy Eastman
Well, I think that because I was, I was 59 and sort of on my way into my, you know, aging, thinking about retiring, and my husband as well. So that, so taking my dad in, which, again, we, you know, we were grateful to do, but it was, it was quite challenging. You know, we had to rearrange, well--when I, what I mentioned in my book is that we thought we were bringing him home to live with us, when, in fact, we now live with him in, you know, our home. Because our entire schedule changed, and we were lucky to be both self-employed, but we had, you know, I mean, everything changed, you know, just I became “The One”. And there's a 24/7 vigilance you have to kind of have as a caregiver that you know, every little every little fall, every little sound, every little you know, sneeze is kind of like–“What, what happened?” So, so thinking about my or thinking about my husband and I thought, you know, our, all of our plans, well, maybe we'll go travel, or maybe we'll sort of start winding down. So it all revolved around, what was we were able to do--what my dad was able to do--which was very little. And thinking about putting him, finding a place where he could stay on his own was also challenging his-his long term, he was a type one diabetic, and finding a care for him that wasn't as institutional, you know, is

more around his needs than--than the institution's needs was nearly impossible, and his long term care insurance was canceled because of the diabetes. So like any kind of pockets that we might have been able to kind of dip into, just disappeared.

Sujata Srinivasan
And then soon after, you, you stepped into a parental role for Luca--for your grandson, I understand he's Luca, and he's 14. Now, tell me about Luca. What's he like?

Cindy Eastman
Well, Luca is amazing. Luca has, you know, it's funny, because I was thinking about this last night when I think about, you know, the losses and the changes and the caregiving and all the things that that I've been through and our family's been through, I just--it kind of became very stark to me recently that Luca, at a very young age, was also exposed to caregiving and cancer and loss and grief and death. And so he was quite…he, you know, when I, when I used to bring my dad, I have this picture of my car that has a car seat and my dad's cane, you know, next to it, because I was kind of doing double duty during the time, but so he was exposed to that very, very early. So I think it's just made him such a really thoughtful and sensitive and aware person human. He is 14, so he's totally embracing 14 right now. So, we are definitely going through some of those teenagers things. But he's quite thoughtful and and and sensitive, and he's, you know, he's a delight. I'm again, grateful that I can be available to to be able to do this with…for him.

Sujata Srinivasan
He sounds like a wonderful young man. We have a caller, Lynn from Brooker Memorial, and she's going to chime in on grandparents raising grandkids. Hi, Lynn, how are you?

Lynn
I'm good. Thanks for taking my call!

Sujata Srinivasan
Pleasure.

Lynn
Brooker Memorial is a nonprofit. We're based in Torrington, and we have offered a support group for relatives, raising, raising their their, their kin--I'm sorry, I'm stumbling over my words--since 2017. And I wanted to bring up this concept of that Cindy is actually experiencing of grandparents raising their grandchildren, because it's sort of an unknown thing that is quite common, both here in Connecticut and also the nation. More and more parents have are out of the picture for various reasons. Sometimes they're they there's been death, sometimes there's, it's drug addiction issues, but the grandparents have had to step up and do and take on this task at a time when they really did not expect it. So we offer a monthly support group so we can sort of combat that loneliness that Cindy was mentioning, and the…we have a core group of about 10 families that is involved right now and given them a chance to talk with one another. And we also offer speakers on a variety of topics that are important to them. Some of the families are involved with DCF. Some are not. Some are guardian, you know, legal guardians. Some are not. So it's a lot. They have a lot of challenges, but they really enjoy being able to talk to one another. And the other thing I wanted to mention is we offer family activities four times a year, so the the whole group can get together, and the kids can meet other kids that are in the same situation there. And it's been very popular, and it's really grown over the past year.

Sujata Srinivasan

This is terrific. Community based groups like this really reinforce the fact that, you know, this is not an isolated thing, and that people don't have to be alone. And there's a…there's a place for people to come together and support each other and and grow together, and before, before we let you go. Lynn, tell me a bit about yourself, are you a caregiver?

Lynn
I am not. I am…I started here just over a year ago. I have a background in communications and marketing, and this is a program that they offered, and I took it on as part of my duties. I am just about to be a grandparent.

Sujata Srinivasan
Congratulations!

Lynn
So I'm of the same age as many of the people that we're supporting, so there's a commonality there, and so I…if anybody's interested in joining us, they can find out information at Brookermemorial.org.

Sujata Srinivasan
Thank you, Lynn, appreciate you calling in and keep up the great work.

Lynn
Thank you very much.

Sujata Srinivasan
So what does your day look like, Cindy? How often, how frequently do you take care of Luca? And what do you do?

Cindy Eastman
Well, I…his dad travels for work, so I'm home today. Actually, I'm home this week. It's, you know, it can be any-anywhere from one night a week to, you know, three or four nights a week. And I stay there because he's in school and there's a dog, and, you know, his all his stuff is there. So I, I go, I and it's close, it's close by. So it's not a hardship in any stretch, by any stretch, but, but it is, but because, you know, I'm going to be 68 next week, you know,

Sujata Srinivasan
Happy birthday in advance!

Cindy Eastman
Thank you. It's just, it's, it takes, it's a little bit, it takes a lot more energy, takes a lot more focus to, kind of like, move my stuff over to another household and sort of be available to that household, you know, to, you know, take care of whoever, whichever creatures are there at the time. And then, you know, move back to my household, and, you know, take care of my home, and, you know, my relationship with my husband. And it's just, um, the it's, it's takes more energy than I recall when I was doing this much younger, but it's…so that's, I think that's the biggest part, is, just like the transitions are more challenging. But I also wanted to mention, you know, I do, I do have a huge support group in my daughter Annie's friends who would come over at the drop of a hat if I needed help with something or… And family has been very supportive, too, but, but the days, you know, the days are different as-as a, you know, as a writer and a freelance writer, I kind of and I teach, so there's just all these like little pockets of things that I need to like focus on, and it takes time sometimes.

Sujata Srinivasan
Now you're at that stage in your life where you've earned time for yourself and after Luca became your responsibility, what are some of the things you haven't been able to do?

Cindy Eastman
Well, we were going to back when we about 10 years ago, my husband and I were sort of doing a proof of concept trip to Italy, because he's from there, and we were thinking about going, maybe spending some time there, and maybe doing some back and forth travel and and I have, I have a daughter in Arizona with a couple, two grandchildren who I don't see very often because my travel, traveling is restricted. Working different kinds of, you know, jobs is restricted. You know, there's I made this. I made this choice. I have chosen to do this, but, but, but it came at some, you know, at some compromise about doing some of the things that I, I my husband and I thought we were doing, or that I thought I'd be doing, you know. Again, there's, it's just, it's such a conflict, you know, you with the caregiving is, it's this very sort of “both are true” kind of conflict. It's like, I'm so grateful to be able to do it, but it's one of the hardest things ever to do.

Sujata Srinivasan
Are there financial setbacks? You hadn't planned to parent your grandchild.

Cindy Eastman
I'm still a grandma, so when I'm there and he says, “Oh, should we go get, like, takeout?” And I think, “Sure, we'll just go get takeout.” I do tend to spend more money on groceries and hoodies and takeout and things like that, and not being able to, like, you know. Maybe pursue a more regular, consistent. You know, work is also impacted by that.

Sujata Srinivasan
What do you do? You said you teach.

Cindy Eastman
Yes.

Sujata Srinivasan
Where do you teach?

Cindy Eastman
I'm an adjunct at Naugatuck Valley Community College and and I have, I'm a I I'm a writing instructor, so I do have some writing groups that I hold. But everything is everything is kind of like little pieces of a puzzle I can kind of put together when possible, and they don't always fit…sometimes. But, yeah.

Sujata Srinivasan
Laura, would you like to add to what we just heard from Cindy about working her life around caregiving? About not being able to work as many adjunct hours, or traveling to Italy, or the finances, unexpected expenses, all of that, which is sudden, I'd love to hear your thoughts!

Laura Mauldin
I had a couple of thoughts as Cindy was talking, and one of them is there are statistics showing that family caregivers are losing out on billions of dollars a year in income, in acquiring, you know, payments towards retirement, the credits that you earn through Social Security in order to, you know, bank those for later in retirement. So if we actually look at the numbers, it's billions of dollars a year that family caregivers are missing out on. It's not just the income in the moment. It's actually that cumulative effect

of loss over time, which is extraordinary, absolutely extraordinary and staggering. And the other thing I was thinking about, Cindy as you were speaking, is going back to taking care of your father. And you had said, Yeah, you know, I became the one. And what's interesting to me is that if we look at the data from older adults, and you ask them where they would like to live as they grow old, 95% of them, or thereabouts, it's approximate, it's in the 90. You know, 90 percentage say they want to age in place. And as you mentioned earlier, Sujata, we do not have the structures to do that. And so there has to be someone who is willing to be the one. In order for aging in place to happen, whether that's an adult child or a partner or spouse, there has to be someone who is the one. And that is not something that we're talking about.

Sujata Srinivasan
Now we just have a few seconds here, but I want to ask you, Cindy, what kind of social support would make caregiving easier for you?

Cindy Eastman
I think so many, so many things that need to be done on sort of a social level. And the care that we were able to get from my dad is, you know, like we, well, at one point, he fell, he broke his ankle, he was in a rehab. We couldn't. Medicare said, you're done, but he was still in a wheelchair, so we couldn't bring him; wouldn't fit in our house, so we had to find an assisted living facility. And it was fine, but, but assisted living comes after you sign the paper, then it's-it's not just there assisting you as you bring your, you know, loved one there you have to, like now, add on tiers or different levels of assistance and and it can get pricey, and it did. And so we did it. We did once he was out of the wheelchair. We-we brought him home, but, but even like with with just the you know, just you know, the caregiving force, the caregiving you know…you know, the opportunities that…It's very limited, as far as, like, for example, with Luca, I would, I would be a lot more comfortable. I would be a lot more comfortable if, if there was somebody, if we, if there was somebody, we could get consistently, like, because my choice in this is part was made, partly because I didn't want, he had suffered the greatest loss. And I did not want, “Oh, he's…oh, this one's coming this time, and he's going there this time.” And, you know, I really wanted some consistency and love and support for him. So, so just, there just aren't that many options available to specific needs of caregivers, because every single caregivers and caregivees. These are specific and different and unique.

Sujata Srinivasan
Right and affordable, affordable care, definitely. So thank you so much for joining us today, Cindy and I know you've heard this over and over again, but I say this with all my heart to find ways to take care of yourself, if it's pranayama, if it's a walk in the sunshine, if it's a cup of tea, but do take care of yourself.

Cindy Eastman
Thank you. I think having this conversation is doing that. So thank you.

Sujata Srinivasan
Glad to hear. From Connecticut Public Radio. This is Where We Live. I'm Sujata Srinivasan. We've been speaking with Cindy Eastman, author of “True Confessions of an Ambivalent Caregiver.” Thank you. Cindy. Also with us is Laura Malden, an associate professor at UConn

[Ad Reader]
At Connecticut public we celebrate Black voices year-round through storytelling, reporting and the arts. This February, as a part of our ongoing Black voices initiative, we're highlighting authors and artists to honor Black history and celebrate the creativity and lived experiences shaping our communities today. Discover their stories this February, watch, read and listen now at ctpublic.org/blackvoices .

[Ad Reader]
Join Connecticut public as we celebrate America's 250th anniversary over the coming months, we'll share reflections on our nation's history, ideals and ongoing story with programs, news, stories and events. Connecticut has played a pivotal role in shaping our country. Our Towns, battle sites and historic figures are woven into America's roots. To learn more, visit ctpublic.org/250

Sujata Srinivasan
This is Where We Live from Connecticut Public Radio. I'm Sujata Srinivasan in for Catherine Shen. Think family caregiver, and you'll likely picture an adult taking care of an aging parent. But across the US, millions of children are working as family caregivers too. Sue Lloyd-Davies is the author of the upcoming book "Pinkie's Turnabout." It's a children's book about the struggles of caring for a loved one with dementia. Sue, thank you for being here.

Sue Lloyd-Davies
Oh, thank you so much, Sujata for enabling us to share our experiences on your show. We appreciate it.

Sujata Srinivasan
And Sue is on zoom from Florida. And Laura Malden, sociologist at UConn, is still with us. Sue, can you tell us a little bit about the book? Who is Pinkie? And what is the book about?

Sue Lloyd-Davies
Pinkie is an 11-year-old girl who fights to adopt a snarky stray cat in the hope that he will help her save her Great-Gran's memories.

Sujata Srinivasan
How did this idea come to you?

Speaker 8
Two things: I mean, I was a caregiver myself. My mother made the decision to come and live with us after 40 years in small town, South Dakota, and she was a fully participating member of our household when she came to live with us. But within a month, she fell and broke her hip, and within another month, she had full on dementia.

Sujata Srinivasan
I'm so sorry.

Sue Lloyd-Davies
Thank you. I was completely unprepared for dealing with the challenges that came from that moment on. I made a lot of mistakes and…and she-she because she didn't know who I was, she thought I was someone that she really disliked. She was living with a stranger, and so was I. So I was providing all those caregiving…I was dressing her, bathing her, managing her medications, handling her bank account, giving her shots for her insulin shots for her diabetes. And yet, I became the enemy. She would…I'd have dinner on the table at six o'clock, and she would say, it's too late, and no amount of pointing to a clock would convince her that it wasn't 10 o'clock at night, because perception is reality for people who have dementia. So…we were lucky. We-we found a medication that helped take away her paranoia, which normalized us a little bit, but she was never the same person. Fast forward a couple of years. Sorry, did you… Fast forward a couple of years, and we moved to Florida, where I volunteered to mentor a 10 year old girl at the local elementary school, and she was amazing. She was smart, she

was an avid reader. She had a big, open personality. But her parents were not in the picture, and she lived with her grandmother and her great grandmother, and she had a lot of caregiving responsibilities at home and missed a lot of school. And what I realized was that her classmates, all the opportunities that were available to her classmates, she'd never be able to take advantage of just because of her circumstances. And so she and my mother were the catalysts that that made me want to write “Pinkie’s Turnabout.”

Sujata Srinivasan
Now, so we have just a few minutes here. I'd love to hear from the book. Would you read an excerpt please?

Sue Lloyd-Davies
Yes, thanks. “’Stay out of the Christmas cookies,’ GG yells. ‘I’ve been baking all day.’ I look around the kitchen. No cookies. It’s always almost Christmas in our house. Mom says we came to live with GG because her mind is going. It’s a freaky way of saying it, like her mind is going out to lunch or on vacation and someday it will come back. Sometimes I think an alien from another planet took over GG’s brain. The real Great-Gran battles the alien in her head and takes control back again. That’s when she sounds like her old self, the one who used to tell me stories and bake cookies for me and my friends. I wish GG could be her old self all the time.”

Sujata Srinivasan
Heartbreaking. What do you hope kids reading this book will take away from it?

Sue Lloyd-Davies
Kids are really isolated too. They are…they're really silent sentinels in their homes, picking up the ball when caregivers aren't able to, because they're just so busy. And I'd like them to understand that there are other children out there that are experiencing the same things they are. I'd like them to understand better how to talk to someone with dementia. I'd like them to just have someone to relate to and learn when they are the one that helps great grand with the with the remote, like Pinky does, or fixes her a snack, or brings her an Afghan from the from the couch because she's cold, all these little things are actually add up to a big contribution in the household, and often they aren't acknowledged at all. And these kids have experienced tremendous loss, because these people in their lives are no longer the same people that they used to be. So they need help in learning how to deal with that loss, just like adults do. And oftentimes they just don't open up about-about how they're feeling. And they need permission to do that from us.

Sujata Srinivasan
We have just barely over a minute. So I have this question for Laura to wrap up, how best can we support children who are caregivers, Laura?

Laura Mauldin
You know, I really love here. I can't wait to read the book, Sue, and get it for my eight-year-old. And what I'm thinking about Sujata, as we're talking about this, is how, again, we don't talk about how disability, including dementia, is part of life for so many. It's something that we can expect many people to age into. And if we can have books like this for younger caregivers, then at least it gives them the opportunity to have language to put to their experience and be able to say, “Oh, this person's body or mind is changing, and that's part of this thing we call life.” You know, this is just part of it, but because, like culturally and broadly, we don't often talk about it, books like that, and telling these stories, that's what keeps that isolation from carrying on.

Sujata Srinivasan
Thank you, Laura. You've been listening to Sue Lloyd-Davies, author of Pinkie's Turnabout. Also with us, Laura Mauldin, University of Connecticut, thank you both for being here. I'm Sujata Srinivasan. Isaac Moss produced today's show! Tess Terrible on the phones. Our technical producer is Dylan Reyes and Eugene Amatruda. Thanks for listening. Be well. **[Music comes in]**