Chris Velardi: It's a 'Cuse Conversation with Syracuse University alum, Mindy Fried, a sociologist, a teacher and author and the creator, producer and host of The Shape of Care, a podcast that tackles the many issues associated with elder care and caregiving in this country.

Mindy Fried: Generally, we live in an ageist culture in which youth, especially through the commercial world, is kind of glorified, and we don't want to acknowledge that we have wrinkles, or that we forget somebody's name, or whatever, some of those things that are sort of normal parts of aging. What's really important is that we try and break some of those unspoken rules and start having conversations within families about the experience of aging and decline and just be honest about it.

Chris Velardi: Glad you're listening. I'm Chris Velardi. It's a conversation that may hit home for a lot of you. It's such an important topic that's affecting or will affect so many families. Mindy approaches her work and this issue through the lens of both her education as a sociologist and her experience as a caregiver for her father before he passed away about a decade ago.

Mindy Fried: Well, I think a lot of work that we do, the inroad that I had to it was through a personal experience, but then as a sociologist, I couldn't help but bring a sociological eye to that experience, so when my father passed away over 10 years ago now, he was almost 98 and before he died, he had a very full and rich life. But in the last year and a half, he was on a major decline, and my sister and I shared the care of him. He lived in Buffalo, which is where I grew up, and my sister is in Pittsburgh and I live in Boston, and so the two of us, between us, we basically were with him every single weekend.

We had moved him into an assisted living facility after he was living independently for many years and doing really well. But as you mentioned before we got on air, he had a fall, and that is the number one reason why people end up going into some kind of an institutional facility, but we had some foresight. We had spent a bunch of time, my sister and I, looking at a variety of places, and we found someplace in Buffalo that we liked well enough. He was absolutely resistant. But after he fell, there was so many underlying things going on that there was no option but to move him there, and he was welcoming of it at that point in time.

Over that period of time of a year and a half that we cared for him, I was putting on my sociological eye, and kind of considered it both a personal experience, but also sort of an ethnographic research study in a way, that I was observing the power dynamics within the institution, how it was laid out, what the other residents were like, the relationships that they had to one another, the norms of how things operated.

I ended up, after my dad died, writing a book called Caring for Red, which was both an ethnography because I had spent all that time looking at the experience

and being in it, and also a memoir about the experience of caring for him. We had been very close, we had a complex relationship, like I think a lot of adult children do, and I wanted to be able to capture that, and just not gloss over it. Caring for Red was really that story. Then I ended up spending over next year and a half doing 27 book talks all over the country. That experience was a real wake-up call for me because I could see that my personal experience was also a universal experience.

Chris Velardi: That's exactly what I was going to ask you about is in sharing your story of your experiences and having, for background, my wife and I have been caring for my wife's mother who is in her 90s, she's been living with us since just before the pandemic, and sorry, her father, my father-in-law was in a nursing home in the Syracuse area as well until he passed a couple of weeks ago. That type of dynamic, when you are in it, you are living it, right, and you're experiencing it through the person you're caring for, through yourself, through members of your family, but when you have an opportunity to go out, and in your case, give those book talks, you found that there were a lot of common threads, I'm sure.

Mindy Fried: Oh, absolutely. I spoke to people at all age levels and backgrounds, so I was in university classrooms, in book festivals and bookstores, synagogues, other kinds of faith-based institutions. I have to say that I got tired of telling my own story. Okay, I get it, I know it, but in hearing other people's stories, it was fascinating to hear the kinds of struggles that people had.

I happened to have a lucky situation in which my sister and I worked really well together, but I heard many stories about siblings who did not work well together in caring for a parent, or whatever. I heard stories of people caring for spouses and the painful experience of caring for somebody with a degenerative disease. I've heard stories from people of different socioeconomic backgrounds with varying degrees of being able to navigate a very complicated system with not enough money to be able to pay for the kind of care that they needed and wanted, so yeah, that part was so brilliant.

I'd say after doing that travel, which gets tiring after a while, because it wasn't my job, I had other paid work that I was trying to juggle with it, I thought that I would try and do something that allowed me to deal with those stories, look into those stories in a more broad way, and that was podcasting.

Chris Velardi: Yeah, and again, this is beyond just sharing your story, this is finding those common threads, but each one of these circumstances is unique and individual in its own way. This is why I hesitate to ask this question, but also feel the need to ask the question. If there is a family, maybe an adult who's looking at their parents and seeing them aging and thinking, "Wow, we may be going down this road. Is there some type of preparation, some type based on your experiences?" Also, the stories you've heard, and your observations, is there something that families can do to prepare for this?

Mindy Fried: Well, I think that first of all, we live in a culture where people don't like to talk about death and dying or decline. I think that we need to really challenge that kind of presumption, or that kind of fear that we have about speaking openly with people that we love about what is a natural part of life, which is decline and aging and eventually leaving this universe. I mean, there's different cultural approaches that people have to that experience, but generally, we live in an ageist culture in which youth, especially through the commercial world, is kind of glorified. We don't want to acknowledge that we have wrinkles, or that we forget somebody's name, or whatever, some of those things that are of normal parts of aging. I think that back to your question, what's really important is that we try and break some of those unspoken rules and start having conversations within families about the experience of aging and decline and just be honest about it.

I with my own daughter at one point, she's in her early 30s, and my spouse is an amazing cook, and I'm not, so I was just using the example of my crappy cooking as a way into talking about what I might do if I were to survive beyond the time when my husband does, so I just was joking around about how I better look at all those recipe books and figure out how to do this, and she laughed about it, but underlying that is a reality that somebody's going to go first, and hopefully not for another 20, 25, 30 years, who knows, but I think it is important to talk about those things, and to think also, I do think that the advice that I have been given by experts is to start thinking about the kinds of support that you want.

Most people want to stay in their own homes, or as in a case, what you have in a multi-generational home where you're able to care for your mother-in-law. Nobody says, "Gosh, I hope when I get older I can live in a nursing home." There are some major problems with institutional care, so I'll just stop right there, but I'd say talk about it. Talk about it, normalize the conversation, and that's the way to go.

Chris Velardi: Well, and I think as you mentioned, talking about something that maybe isn't quite as heavy as some of the things you can talk about like cooking is a good door-opener, it's a good start to the conversation because yeah, it's real, but it's not quite those heavy topics that you know might be able to talk about one thing, and then you're done. You can start there and then it may shift in other directions and move. I think there's just so many layers to it that it's not one conversation, it's going to be multiple ongoing conversations about all those layers.

Mindy Fried: Exactly.

Chris Velardi: One of the parts of it that is a reality from any families when they are in a situation like this is, okay, what does that mean for my job? How do I balance those things? How do I find a way to not let my work down and not let my family down, whether that's the older parent I'm caring for, maybe the younger children I'm also trying to care for? I know you've spent some time looking into

that world of family care. Have we gotten better in this country about it? Where do you see us in terms of allowing for those types of situations?

Mindy Fried: Have we gotten better? Ironically, because of the pandemic, so many people are working remotely and that's become more acceptable, more norm. I did a study in 2000 was released in which I looked at five Fortune 500 companies and their approach to flexible work policies. The companies wanted to know, "Is this going to be okay for the bottom line, and our workers happier?" Those two things are connected. At the time when we released the findings from the study, it seemed pretty revolutionary, and there was so much resistance. People would just talk about, workers would talk about how they're being able to work at home on a couple days a week or work flexibly was really resented by their coworkers.. If they got a promotion, it was really resented. Some of that has shifted, okay? Has the workplace changed dramatically to accommodate people's needs? It kind of depends on what kind of work people are doing. There's some kind of work that people can't work flexibly, and people who are in those kinds of jobs really still struggle and suffer with that balance.

We still don't have a paid family leave policy in the US. We're one of the very few western industrial countries without that kind of policy. I mean, earlier in my career, I studied parental leave, and wrote about that. Now, I'm looking at leave for elder care, and it's the same story. Things are really not where they need to be, so we need a paid leave policy that's longer than a 12-week unpaid leave policy we have now. It can't be company by company, that's not acceptable. We need to have flexible work policies, everything from telecommuting, which people are doing more of now, but also flexible work hours, and shared work.

Then people also, I mean, we don't often think about this when we're talking about those kinds of family policies, but there's an enormous wage gap in this country where women earn less than men still and people of color earn less than in comparison to white people or white men, so that also needs to be equalized, looked at. The other thing I'll just add is that there is a caregiving penalty in this country from a wage perspective, and if you are earning less in your younger years, that will then play out in terms of the kind of social security income you get when you're older, so being poor when you're young can lead to being poor when you're older. There's so many policies we need to look at and those are just a few.

Chris Velardi: So many layers. You talk about the flexible work policies and remote work and those things. I think some companies are seeing that those are things that employees or potential employees are absolutely considering when it comes to, "Do I take this job or that job? Is this the opportunity for me or is that the opportunity?" But across the board, there's not a lot of consistency. There's a lot of Wild West.

Mindy Fried: That's right. That's right. I think that you're pointing out something really important. I did ethnographic study of a financial services company, which had a fantastic childcare center. I called it a kiddie condo. People would choose to work there because they had a great childcare center. People would not want to leave their jobs because of that childcare center. But that center was not the whole picture. You had to look at workplace policies and culture because it wasn't necessarily true that people loved working there, but they were stuck there.

Chris Velardi: The one benefit outweighed everything else.

Mindy Fried: Exactly.

Chris Velardi: Yeah. Well, and when you're the parent of a young child, sometimes that becomes the most important priority, right, when you're considering all of the pieces. It's an interesting thing. But as you pointed out, when you are the parent who is caring for a parent, that may become equally important at a different time when you're at a different stage in your career.

Mindy Fried: Absolutely.

Chris Velardi: Yeah, it's fascinating, and there are just so many layers that are involved that play into this, from company policy, to government policy, to familial relationships. I mean, there's just so much that is at stake here.

Mindy Fried: Right. I'm glad that you just said that because I think that when people are in a situation, now just talking about elder care where they have to figure out how to navigate the system. It is not easy. It is daunting. People often are, they're in this situation alone. Part of the problem is that Medicaid is actually not serves people who are low income, and if you are well-resourced, you can then afford to get care, whether it's home care, or some kind of nice institutional facility, whatever. Everybody in the middle, that's working-class people, middle-class people, and there's millions of people, are really without any financial support, and so people end up impoverishing themselves in order to support a loved one because there's no supports out there.

Chris Velardi: Yeah, and look, that person who's impoverishing themselves to support a loved one may be in that similar situation of the loved one in 25, 30, 35 years, and then where are we?

Mindy Fried: Yeah, exactly. Because basically Medicaid right now, and this is not the fun stuff, but it's the reality that we have this program, Medicaid, which pays the bulk of the cost of nursing home care for low-income people, and then there's this sort of wild and wacky waiver system state by state where people can apply to their states to get a waiver to use Medicaid money for home care, to bring somebody into the home to help them out. Who knows how to do that and where do you go to find out? There actually is this whole infrastructure called area agencies on

aging, AAAs, not the kind for cars, but the kind for care. They exist all over the country, so if you're in any part of the country, you can look up your area agency on aging, go to them, and they hopefully will help you navigate the system. But most people don't even know that that exists.

Chris Velardi: They don't know where the resource is to help them find the resources they need to make it all happen, yeah.

Mindy Fried: Exactly, exactly. I mean, there is one of the things in my current season, I feature an incredibly innovative program out in Washington State called WA Cares. WA Cares is the first publicly-run social insurance long-term care program, so basically if you have put money into the system, just like Social Security or Medicare, if you put money into the system through your job, you're then eligible to get money towards any kind of home long-term care supports and services that you need. They're just starting it now, and so in a few years, people will start to be able to reap those benefits, but they can get up to $36,000-plus over a lifetime, rather. Its an incredible program, and there's other states that are considering doing that outside of the Medicaid system, so you don't have to be really poor to access it.

Chris Velardi: Yeah, you just have to know it exists, and know where to find it, and all that.

Mindy Fried: Yeah, yeah. That's right, all that good stuff.

Chris Velardi: Go through the process of applying, right.

Mindy Fried: Exactly.

Chris Velardi: That is, as we have found, can be a full-time job just trying to track all of that stuff down.

Mindy Fried: Yeah.

Chris Velardi: This is a 'Cuse Conversations podcast, so we would be remiss if we don't talk about Syracuse a little bit.

Mindy Fried: Absolutely.

Chris Velardi: Let me ask you, going back, what was it that drew you to Syracuse when you were making those decisions?

Mindy Fried: I have to say it's pretty simple. My sister went to Syracuse.

Chris Velardi: We love stories like that. Simple's fine.

Mindy Fried: Yeah.

Chris Velardi: We've been talking about heavy things, so simple's actually good probably for this conversation.

Mindy Fried: Yeah, simple's good. She loved Syracuse University. She's a lot older than I am. I mean, I would say eight-and-a-half years older, not that much older, but when I was a very young kid, I got to go visit her, and I got to be the kid who was with her older sister, hanging out, meeting all her friends, and going to M Street, and all those fun things, and I was enamored, and so I really hardly gave it a thought. I applied to Syracuse as my first choice and a couple of other places that I didn't really care about. It was kind of fantastic. I loved being there. In the tradition, I have a best friend who's like a sister to me. We grew up, we knew each other from age five on. She followed me. She was a year younger than me and she came the next year.

Chris Velardi: Wow.

Mindy Fried: I ended up, after finishing my undergraduate degree, I left Syracuse for a teeny bit, came back, and did a master's in social work at SU, and then settled in, so I was there for a total of 12 years. Really wasn't until 1980 that I decided to make the big move and leave Mama. It felt like such a comforting home, it was really hard, but to move to Boston for a variety of reasons.

Chris Velardi: As someone who has that in your family with your sister and then your own experience and that thing that Central New York and Syracuse tend to do, which is they hold onto you, they grab you, and they keep you around a little bit, what has been your relationship with the university? What does it mean? Are there times in Boston where something happens, or you see someone, and suddenly, all of that orange comes back?

Mindy Fried: I think it would have to be certain professors are still kind of in me. There was this duo named Wiggins and Miller who taught a religion class. It was my freshman year and it was a lecture hall and I really will never forget the experience of being in this enormous lecture hall and the two of them. It was stadium style, so we're looking down at them on the stage, and the two of them would debate theological issues. It just took my breath away. I was just so blown away with all the thoughts that came piling in. Those kinds of memories are really still in me, the amount of reading that I did in literature classes. I will never forget some of those classes and some of those professors. I feel really grateful that it got me in it. I became a reader because of that, so that's something that I still hold on.

Also, I think just because I'm still in touch with a lot of my old friends from Syracuse, and it's just really fascinating to see the direction they've gone in. Some of them are not too far from in the Boston area, so I don't know, it was something special. Plus the fact that this person that I mentioned who's like a sister to me is still very much in my life, and so we still have Syracuse memories together.

Chris Velardi: Yeah. I know you've taught and lectured at colleges. Do you find yourself drawing from some of those professors who stood out to you?

Mindy Fried: Yeah, I think especially when I ended up selecting a major, I was a psych social work major, and I think that some of the small group stuff that I experienced, the kinds of conversations that we had were really meaningful. I ended up, when I was in the MSW program, I ended up doing an independent study with a Gestalt psychologist named Sam Graceffo, who's probably still out there in the world somewhere. He was a really wonderful mentor to me, and that I hold onto, that just one-on-one mentoring that I got from him.

I worked closely with this guy, Jonathan Friedman, also a professor at the time who was passed away now, who ended up, well, he very much nurtured my career. When I ended up going back to the MSW program, he was a huge support. Actually, he was one of my recommendations for getting into the Ph.D. program that I went to at Brandeis. Turned out I had no idea that he had a Ph.D. from Brandeis in sociology, so yeah, a lot of those folks have still remained in my life beyond the years that I was at SU.

Chris Velardi: Yeah, it's amazing how those branches continue to grow and continue to make those connections throughout your life and just stay in touch. The idea that your friends, you're still in touch with them, I mean, that's just the kind of experience, social, educational, it all kind of ties together.

Mindy Fried: Yeah.

Chris Velardi: Where do you see yourself now? I mean, you're an author, you're a speaker, you're a consultant, you're a podcaster. I mean, this is quite a nice life you've built here.

Mindy Fried: It's kind of the Bippity Boppity Boo method of career building.

Chris Velardi: Love it.

Mindy Fried: I'd say right now, I did run this consulting practice for well over 20 years, and mostly what I was doing was evaluation research, and I'm really grateful that I had that experience. I'm doing less of that now, but I do like to do a lot of things, so there's a bit of a juggling act going on.

One of the projects that I just want to mention, which is really exciting, some people might recall a book called Our Bodies Ourselves, which came out in the 1970s, and had kind of its heyday over those years, and then kind of faded out of existence, no longer was being published. One of my sociology friends and colleagues who teaches at Suffolk brought the project over to Suffolk and raised a lot of money and we were and pulled me on board along with a lot of other people, we were able to launch just this past Thursday an online resource called Our Bodies Ourselves Today that is so incredibly timely and important. There's

nine topic areas that we're taking on initially. The thing that I'm doing, not surprisingly, is called Growing Older, but we take on issues like abortion, contraception, gender-based violence, mental health, heart health, so many different issues that are really prescient in today's world, and so if people are interested in taking a look, it's just a click away. It's Our Bodies Ourselves Today. It's really worth checking out. It's a brilliant resource and I'm honored to be a part of that.

The other thing that I've been working on, I co-started a small nonprofit called Hoopla Productions, and we started developing or producing kind of neighborhood-type art-based events. But the latest thing that we're doing is, it's called Finding Home: Immigrant Stories and Music from Boston and Beyond. We're producing an event this coming Saturday, so help, there's so many pieces to pull together, but it's 25 artists coming together in East Boston, which was major ports where people from immigrants from other countries entered this country, this city, and so we're telling those stories through music, dance, and storytelling, so that's also been on my mind.

Chris Velardi: It's also very clear that you appreciate the learning aspect of life, always learning, always experiencing, observing, and processing, and moving forward. That tends to send people in the Bippity Boppity Boo direction, I think. It took a while, right?

Mindy Fried: Yeah.

Chris Velardi: "I've learned here, but I'm curious about that, too, and I want to do that," sounds like. That's great.

Mindy Fried: Right, that's true. I mean, I have to say, I didn't know anything about podcasting when I started, but in Boston area, we have this place called the PRX Podcast Garage, which is kind of an incubator organization that has a studio and workshops to help new people like me at the time learn how to be a podcaster, and so taking on new things, as they say, as you get older, keeps those brain cells alive, and so it's fun to do stuff that you don't know how to do.

Chris Velardi: That it is. My thanks again to Mindy Fried. I encourage you to check out her podcast, The Shape of Care. There's a link in the description to this episode, and I hope you'll subscribe to the 'Cuse Conversations podcast so you don't miss an episode. Thanks for listening. I'm Chris Velardi. Go orange.