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Meaningful Lives As We Age

Family Caregiving from the Personal to the Professional
Momentum Discussions Podcast from the Gerontological Society of America
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Announcer:
Welcome to the Gerontological Society of America's Momentum Discussion, where we explore groundbreaking topics in the field of aging.

Elana Kieffer:
Welcome to this GSA Momentum Discussions podcast, titled 'Family Caregiving: From the Personal to the Professional,' developed by the Gerontological Society of America. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. My name is Elana Kiefer, and I am the Director of Strategic Alliances at the Gerontological Society of America (GSA). I am pleased to serve as the host for today's momentum discussion. Today's episode takes on a critical topic that many of us can relate to: family caregiving. Our guest today will share her personal journey of caring for her father and how she turned this experience into a multimedia professional journey. Our guest today is Dr. Mindy Fried, an applied sociologist with over 25 years of experience conducting rigorous qualitative research studies. Mindy works with nonprofit organizations and foundations to help them build their capacity and strengthen their programs and policies. Her areas of focus include aging and workplace policies for growing older, the arts, and grassroots organizing. Mindy, welcome to the podcast.

Mindy Fried:
Thank you, Elana. It's great to be here.

Elana Kieffer:
Wonderful. We'll start by asking some questions. Can you tell us how you became interested in the topic of family caregiving?

Mindy Fried:
My interest started from a very personal place. My sister and I cared for our father for about a year and a half in the last chapter of his life. He was four days shy of 98 when he died, and he had a very robust and kind of celebratory and also traumatic life. He had a lot of years to pack many things in. When he was in his late nineties, he had a traumatic fall. It's upsetting. I still get upset when I think about this, but he had a doctor who had given him medication for sleep, and it created some hallucinating and out-of-control body stuff. And he fell in a very harsh way. And he had one of those alert buttons around his neck, but he had arthritis in his hand. He couldn't even push the button. And he finally was able to get somebody to help him, and he was in front of a door. And so there were just many things that made it challenging.

And the upshot is that he ended up having to go into the hospital; we had been talking to him about someday moving out of his home, where he'd been living for his 90-plus years. And not exactly in that home the whole time, but for many years, and moving into some kind of facility. We had looked at an assisted living facility in Buffalo, New York. He was strongly opposed to being there. But at this point, once he got out of the hospital, really, there was no option but to put him into that facility once he got out of rehab and all the kind of medical stuff that he had to do. He ended up living there for a year and a half, and my sister, Lori, and I spent every weekend with him.

And in between times, we were caring from afar, which is quite common. I ended up writing a book about it, titled "Caring for Red." My dad had been a communist in his early days, and he was also a redhead. You know what I found? While he was there, I had decided, 'Okay, I'm a researcher. I'm going to turn this into an ethnographic study. It's a personal experience, but I'm also a part of it." So I spent quite a bit of time documenting what it was like. At the time, I was teaching a class on aging at Brandeis, where you also attended. He was living in the facility, and I was teaching this class. I felt that I was learning more literature by teaching about the aging experience, and it feels very real.

And the second time I was brought back to teach this class, he died right before the second class. And I had to decide whether or not to teach the class. It was obviously very traumatic, but I thought, 'Okay, this is a universal experience, and why not open it up to students?' And honestly, it was the most profound class I think I ever taught on aging because sharing my own experience really opened people up to sharing their own experiences, a lot of which was losing grandparents who they'd been very close to. I became interested in caregiving, obviously, due to my own experience. I'm a writer. I process my feelings and my thoughts through writing. And that is what I did.

And after he passed away, I had a decision to make: was I going to actually do something very concrete, or not? I had a blog at the time, and I was posting things here and there. My first thought was, 'Oh, I'll just put it together all these various blog posts, and they will seamlessly flow together into a book'. And actually, that's not how books work. I decided to try my hand at it, and I took a workshop at Grub Street, an amazing creative writing program in the Boston area. It was a workshop on memoir writing.

I would say that it wasn't fabulous, but it gave me some inspiration to really try it and stick with it, without knowing if it would be a book that my family could use to process their feelings about the loss of my father and their uncles.

There are so many people in my family who loved him or was it something that would actually contribute to the literature, quote unquote, because there had been no ethnographic study on assisted living. There was a great book, *Dying at Murray Manor*, about nursing homes, and a very detailed, very rich, and wonderful and ethnographic book, but nothing on assisted living. While I was there, I gathered enough data to write a book that included an ethnographic perspective on many aspects of what it means to be a caregiver. That was very memoirish, but it also had a historical element because my dad, in the 1950s, again in the 1960s, was subpoenaed by the House Un-American Activities Committee (HUAC). At the time, he was a labor organizer and very good at his job, and effective. They went after him like thousands of other people.

Elana Kieffer Blass:
Yeah. And did he know that you were writing not necessarily a book, but that you were writing about the experience of him living in this assisted living?

Mindy Fried:
No, and honestly, I couldn't be truly forthright about the experience until he was gone. Writing a memoir is a tricky thing because you have to respect all the people you write about. And there are things that I didn't reveal about his life out of respect for him. However, there are other aspects of our complicated relationship that I did reveal, that I didn't feel a need to share them with him at that stage in his life.

Elana Kieffer Blass:
Definitely. And you touched on this already, but can you talk about some of the themes that came up in the book that you covered, or how you organized the chapters, as a primer on the book?

Mindy Fried:
First and foremost, I wanted to capture what it was like at this assisted living facility, which I called Harmony Village. That's not the real name. If you like, I could actually read a portion of the book.

When I first saw it, Harmony Village looked like a faux castle and ominous red brick structure, extending one full block in each direction with four floors and tall, round turrets on each corner. I imagined that this fort-like building, which housed about 200 residents and apartments, was meant to evoke a sense of safety from outside forces, as if any place could guard old people against the inevitable death. At the front desks at either John or Myra. If it were John, you knew you would get a straight answer. A former military guy in his twenties, he was reliable, kind, and looked you in the eye when he talked to you. John was super with it. If you got Myra, you were better off taking care of things yourself. She mixed up names and numbers. She looked at you as though she had no idea who you were, even if you'd talked to her on a daily basis for the past six months. I always wondered how she kept that job. Perhaps thanks to the kindness of some administrator. The first time I visited Harmony Village, I couldn't imagine my father living there. I barely tolerated the tour myself. The hard sell of the too-chipper marketing person who painstakingly tried to convince me that "your father would be very happy here" made me want to puke.

I tried hard to persevere. The overzealous guide led me through the dining hall, populated with a small group of women who were sitting together at a circular table, negotiating the food on their plates, but barely communicating. She boasted about the amazing chef and how much the residents loved the food. It was over the top. Harmony Village was far from a four-star hotel, but she would've liked me to believe otherwise. Later, I learned that the food was decent. The usual institutional fair was prepared with care and made more palatable by the affable food service director and wait staff. They were kind and loving with every resident. Knowing that my father was a professor, the last of his many careers, my guide then took me to the library. She was thrilled to tell me, "There's a professor here that your father would really enjoy" as if being in a similar profession is the tie that binds souls. When these two former teachers did eventually meet a year or so later, they found they had little in common.

Elana Kieffer Blass:
It's beautiful writing, Mindy, and paints a good picture of the scene. And as someone who worked in that area as that that chipper marketing person, I can relate.

Mindy Fried:
I think in response to your earlier question, the book tries to bring readers into the nuts and bolts of what it's like to live in assisted living and the dynamics of a hierarchical institution that tries to prioritize patients but also has issues around staffing, and I'm sure the staff didn't make a lot of money, and people who were hard to deal with. There are just so many issues going on. And I wanted people to understand the the feel of what it felt like to smell and live and be in a place like that. And I also wanted people, as I said, to understand the history of my father's story. And I think, most of all, to understand the caregiving experience. My sister and I were quite lucky that we get along; we adore each other.

She's so much older than me, and I was worried when we took this on together that she might be bossy. But quite the contrary, she welcomed my role. And I would say that we divided the work pretty evenly and really supported each other. I'll tell you one little story. When we would spell each other, and I was there for a weekend with my dad, my sister showed up, and she arrived with chocolate, which we often got from across the street, this place called Watson's that had sponge candy. And when she walked in, his first words were, 'Where's my chocolate?' And my sister said, 'Dad, Mindy's leaving right now, so why don't you first say goodbye to her?' And he said, 'But I want my chocolate!.' And she said, 'Say goodbye to your daughter, whom you adore.' He and I said goodbye, and I handed the baton over to her. But it was just sort of classic. At that point, he was still with it, but he loved his chocolate.

Elana Kieffer Blass:
He had his priorities straight. I get it.

Mindy Fried:
Switch out his daughters for the one with the goodies.

Elana Kieffer Blass:
Switching gears, wou started not one, but two podcasts related to aging and growing older. What themes about caregiving have come up in one or both of those podcasts?

Mindy Fried:
After I wrote the book "Caring for Red," the subtitle is "A Daughter's Memoir." It was published by Vanderbilt University Press. And while they didn't set up book talks for me, they supported all the work that I did to set up book talks. I traveled the country and visited about 27 or 28 cities. It was a lot. It was exhausting. And my daughter at the time was getting pretty excited about the podcast world. And that got me thinking: maybe I could stop traveling and create a podcast about caregiving without going anywhere. Going places without moving.

There are so many different kinds of caregiving. I knew that I wanted to focus on caregiving of older people. I put the word out on Facebook and asked if anybody had a caregiving story to tell. A few people responded, but I ran into a friend in the local park who was with her wife at the time, and she said, 'I saw your Facebook post, and I have a story to tell.'

And I said, 'Oh, yeah, what is it?' And then she looked at her wife and said, 'I can't talk right now.' And that person is Laura Barr. And Laura was caring for her wife, Jean, who had early Alzheimer's. This is a number of years ago. The Shape of Care follows Laura's story across multiple episodes. And the first one focuses on bringing joy into their lives. She came from an RV family, and she bought an RV so the two of them could take off on weekends and have adventures. Then, in the next episode, she started talking about how things were getting sadder. Alzheimer's, of course, is just a wretched, horrible disease. She watched her wife decline over the following number of years and eventually had to live in a nursing home because she obviously couldn't take care of all her extensive needs.

And to take a quick leap, and we can get there in a moment again, but my new podcast, which has just come out, called Next Chapters, also features Laura Barr. At one point during the pandemic, when nursing homes shut down, Laura was unable to visit Jean. And Jean no longer recognized her on Zoom or on a phone. And Laura woke up one morning and said there was actually a snowstorm coming to Boston, and she said, 'I am getting out of here.' And she got into her RV. And she has been on the road for five years. There is an episode in Next Chapters called On the Road: Adventures in Aging. Laura is near and dear to my heart and has quite the story to tell. It's fascinating.

In the Shape of Care, I interviewed Lori Sheridan, who'd been caring for her husband, who had Parkinson's disease, and also followed her through her story. However, the Shape of Care also took on a range of issues. When the pandemic hit, I decided to follow the lead of many podcasters at the time and create a home studio. I Googled it and did all the things. I was interviewing people on voicemail. I mean, it was really just a paper and a paperclip situation here. But I put out an additional 11 episodes of caregiving during the virus. This was really fascinating because I was able to capture the stories of essential workers, including those from a policy perspective. I also spoke with researchers who were trying to capture their experiences in conversations with me in Greece, Italy, and other places around the world.

I also followed up with Laura Barr. The first season of The Shape of Care did not have an arc, per se. There were many stories that I felt needed to be told. When the second season came along, some time had passed, and I had had an opportunity to think, and the pandemic had eased. And I'd had a chance to think more about what I wanted to fashion as a story. For the second season, I wanted to tell stories that revolved around caregivers and care recipients. I found two people who had a dual story to tell. And I had two episodes that focused on home care. And then I had two episodes that focused on living in a nursing home.

Elana Kieffer Blass
So I have one more question for you. I could listen to you for a very long time. But you had mentioned when we had talked earlier about a caregiving support group that you started in Boston. Can you briefly tell us about that support group and why you think it was so necessary?

Mindy Fried:
Sure. Well, I'll say, first of all, I'm part of this secular Jewish organization called the Boston Workers Circle. I had given a book talk about caring for Red to folks who were part of that group. And I am also part of a subgroup within the group called Aging and Community. People were familiar with the book, and they were discussing caregiving issues with me informally. One of the people who was a leader in that group asked me if I would run a support group for individuals experiencing caregiving. And I was really busy at the time, and I said, 'Yeah, how about I'd be glad to do it. How about if I do three sessions, and then people can be off on their own?'

I did what I often do, which is to do a lot of homework and dive into it, considering it almost like a class. I loved the people in the group. It was an amazing experience. And after three sessions, they talked me into doing three more sessions. After the six sessions, they went off on their own and did their own thing, and they are still meeting to this day. And they've supported each other through so much loss and challenges, and finding joy in the midst of all that. It was a great thing to do. If I had a little bit more time, I would do it again. Honestly, that was one of the more profound experiences I've had.

Elana Kieffer Blass:
Well, I have many more thoughts and questions, but we'll wrap up for now. And I want to thank you so much, Mindy, for sharing your story and talking about your book, and your dad, and the real influence you've had on so many people. It is such a universal experience, family caregiving. Thank you for the work that you have done and continue to do.

Mindy Fried:
It's been lovely to talk with you, Elana. Take care.

Elana Kieffer Blass:
My pleasure. I would also like to thank all those listening to this episode of the GSA Momentum Discussion podcast. We hope you found it informative and enjoyable.

Announcer:
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