



## Cooking for a Loved One with Special Dietary Needs

We continue our series about food and family featuring our colleagues. When LWC Studios' senior editor Jordan learned that her mother-in-law was diagnosed with Crohn's disease, she worked to quickly figure out how to offer support and what to cook. Patient advocate Mary Mukira shares advice on caregiving around the holidays by adopting a person-centered attitude and preparing inclusive meals.

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Juleyka Lantigua:

Hi everybody. Today, we continue our series on food and family. As you know, our friends and colleagues at LWC Studios have been coming on the show to talk about the tensions, the experience with their loved ones when food and families mix.

Today, we welcome Jordan. When Jordan's mother-in-law was diagnosed with a chronic illness that deeply impacted her lifestyle and dietary needs, Jordan really wanted to figure out how to support her. This was particularly tricky during the holidays and during family gatherings, which often centered around food. Let's get into it.

Jordan:

Hi. I am Jordan Kauwling. I am senior editor here at LWC Studios. I am from California originally, but grew up on the East Coast for a bit in Southern New Jersey and in Philadelphia. Growing up, I referred to my father as father, and I referred to my mother as mom until I turned 10 years old, and I started calling her by her first name, Avis. I was the oldest child and the only daughter. I had two younger siblings, two younger brothers. Both of my parents remarried, and so we added a stepbrother on either side, and also we added a stepsister. I also have lots of aunts and uncles. So coming from a big family, family was always very important to me. I got married. I married into an Irish family, but a few years later, my mother-in-law, Catherine, was diagnosed with Crohn's disease and ulcerative colitis, and so her diet was severely restricted.

One of the things when I became her daughter-in-law that I treasured so much immediately was Saturday morning brunches that I would throw at my apartment. She would come over and I would have a huge spread. At the time, my husband and I didn't have much money, and so it was one of the only little luxuries that we could gift to her. I can remember one New Year's brunch, I had spent a lot of time creating this crab dip, seafood had been something that she really enjoyed

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previously, and when I presented it to her, you could just see the disappointment wash over her, and then it washed over me when I realized that I had made something for her that she couldn't eat. And so, the challenge became for my husband and I to show up for our weekly dinner with the in-laws with a dish that she could eat, and sometimes it was a complete failure.

We would have a ritual where before she'd eat a food, if I prepared something for her, she would need to know a rundown of all of the ingredients. She'd say, "I can have this. I can have cinnamon, and I can definitely not have that third thing that you put in there that dominates this dish." But the sweetest moments were when I would prepare something and you could see her face light up, and she'd realize that, "This is something that was prepared for me with love, and I can actually eat it." And that was like a win for me.

As her health started to really deteriorate, the interactions and the moments that we had together as a family obviously became more and more tense. Initially, before she was officially diagnosed, there were moments where she would eat a meal and something in the meal would upset her. There was on her end, a lot of food journaling and going to the doctor and being gas lit, and her having to ultimately make the decision before her diagnosis to just listen to her own body. And so, it was a process of her educating us, her family, and how we can support her. It was a lot of listening to her and also the guidance of her doctors toward the end. There was stress that existed in me trying to love on her appropriately and constantly missing the mark.

My mother-in-law was going through the most trying time in her life, and even through all of that, she was able to extend me a great deal of grace and patience, and she taught me to have patience for others that are trying to show up for me in ways that sometimes aren't on the surface helpful at all, but that the fact that they're willing to show up means something to me. And so, the lesson that she ultimately taught me is a message of love.

Lantigua: So you guys have to know that Jordan is one of the most thoughtful people I've ever worked with. It is such an honor to have her as a colleague at LWC Studios. And because I know her a little bit, I was not surprised at all by how graciously she handled the situation around the dietary needs of her mother-in-law. And I was definitely not surprised by how much effort and thoughtfulness she put into finding ways to accommodate those needs. But of course, this is our show, so I started thinking, well, those of us who are not as gracious as Jordan, how do we manage that? How do we accommodate without being overbearing? How do we show support without getting too involved and making the person feel like we're singling them out? So I did what I always do, I called in an expert.

Mary Mukira: My name is Mary Mukira. I am the manager of Grassroots Advocacy over at National Patient Advocate Foundation. And I am a first generation Kenyan American.

Lantigua: Look at that, you are perfect at the show. All right. So I'm going to start off with the same question I always ask, which is, as you listen to Jordan's story, what did you hear?

Mukira: So she is incredible. And in hearing her story, I identified with certain aspects of it through her mother-in-law's diagnosis and trying to navigate how to be supportive while also being respectful of the different boundaries that come with it, especially when you have family members from a different generation and from a culture that is different than the more open American culture that we live in.

Lantigua: All right. So it sounds like the dynamics at play in Jordan's story are familiar to you. Is she and her family the type of people that you work with in terms of self-advocacy and education?

Mukira: Absolutely. So we have quite a mix of patients and caregivers that exist within our larger NPAF volunteer network, and people from different backgrounds regarding regionality within the United States, people who have immigrated here, and people with diverse families. And in the Grassroots Advocacy work that I do over at NPAF communication as such an important and continued discussion that we have, being able to communicate needs and support while also balancing not coming off as overbearing and not coming off as the individual that you're speaking with, you'd never want them to feel as if they're a burden.

Lantigua: So let's talk about that, because I really felt like Jordan did a really good job communicating with her in-law and probably other folks in the family specifically the dietary needs. So can you unpack for us a little bit what she did well and encourage the rest of us to maybe learn from her?

Mukira: Absolutely. She did a phenomenal job by centering what her mother-in-laws needs are. It felt as if she knew how to communicate with her mother-in-law without there also being so many words spoken. For example, when she had made this particular dish, the seafood dish, and her heart just sank looking at the reaction of her mother-in-law because it is not food that she was able to eat. And just having this opportunity of continued learning without needing to have these conversations every single time is beautiful.

One thing that we make sure to highlight is just listen. And listening isn't limited direct communication talking to a person, but observe. Observe their body language and how that may have changed. Observe if their spirits are up or down. Are they still engaged in activities that they once were interested in? Is now food not an exciting thing but it's too overwhelming? And so you want to make an effort

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to adjust to the individual you're speaking with. I think especially in first gen households, there's a level of deference that you need to continue to have with your family members, with your parents. You don't want to appear as though you're "taking care" of your family, but you want certainly for them to feel as though you're going to continue to support them, and speak to them with a level of deference that they still feel as they are the one driving all of these decisions.

Lantigua: Yeah. So I actually wanted to point that out because I feel like Jordan avoided doing what maybe some of us would do, aka some of us meaning me, which is go down a Google rabbit hole and research and research and research and how to learn and come up with ideas and make a recipe book and instead she centered the person.

Mukira: Exactly. That is so connected with what we do over at NPAF, this idea of not being patient-centered as opposed to being person-centered. Making sure that you're able to have that conversation with people about what their preferred outcomes are. They are having these conversations with their physician. When you do, the focus is specifically on your treatment, and sometimes the treatment that may be best for you may not serve you in your daily life. Maybe that takes away time from your family. Maybe that takes away too much time from your work. Maybe that's too costly. And when you are able to center the person and their needs and what they want, you come up with a much better plan with them, and alongside them, they are included in the conversation, they're included in the treatment. And what Jordan did, navigating all of that, especially as it relates to something so personal, so to your health. I think so many of us grew up with this idea, oh, you don't discuss religion, you don't discuss sports, you don't discuss politics, and health can be such a huge part of that as well.

Lantigua: Oh, it's completely taboo in so many of our cultures.

Mukira: Absolutely.

Lantigua: It's always the open secret. Everybody knows that grandma has X, Y, and Z, but nobody wants to talk about it. I think that there's a culture of secrecy and straight up denial in some instances. And so, I definitely applauded how Jordan and her family seemed to have really taken the lead in trying to accommodate and trying to be still loving with their food ways.

Mukira: Exactly. She did an absolutely phenomenal job. So again, she did a great job with just innately understanding that she wanted to be part of the solution, and she did not want to overburden her mother-in-law with having to continually communicate certain things. I mean, nobody wants to feel as if they're an added line item on a to-do list, right?

Lantigua: Of course.

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Mukira: And it's so important that you're able to address it and not directly tell the person, "Oh, I've spent four hours researching all these different recipes and meals, and I called all these restaurants." Because everyone needs to do a better job of not...

Lantigua: Throwing it in their faces.

Mukira: Exactly. I mean, you should not be communicating the level of investment that you've put into something. I mean, it's too much. Even if that's not your intention, imagine how you would feel if a friend or family member were to say that...

Lantigua: It would be an instant eye roll.

Mukira: Right, exactly. And then say, "Well, I didn't ask you to do that. I didn't ask for this."

Lantigua: All right. So actually, let's talk a little bit about the very practical ways that you advise folks on how to just integrate the new lifestyle that their loved one has to observe. How do we accommodate without coming across as overbearing or condescending?

Mukira: That's a great question. That's going to take time and you're going to certainly have to learn. For example, I think when you go to a family gathering, you don't want to be the one person with the special plate. Just continuing to have that level of variety and having it available. And especially if you know a loved one is going to be coming over to your home, you don't want them to have to have that direct ask of, do you have my special milk? Are you just serving white bread or brown bread? Or whatever that conversation, we just have it available. And also making food and having place in your pantry, in your fridge that combines these different types of recipes. So maybe make the meal for everyone and not just the one person that has a specialized diet and everyone well then have an opportunity to expand their palette without othering the person that you're attempting to adjust or be inclusive of.

Lantigua: Okay. So let's talk a little bit about when it gets a little bit difficult, because Jordan was really transparent in that later on as her mother-in-law's condition progressed, it did become a little bit tough and a little bit tense around food and other things. What are some of the ways that we can manage things when they do get tough as they will?

Mukira: Right. I think it is worthwhile to have a conversation with members of their care team, because they also observe and they're paying attention, then they've seen what has worked and what hasn't worked. Of course, it's going to be different per individual, but there tend to be overlapping themes, and having that conversation of, has she communicated this with you or is there something that I could be doing better? Because you're not going to be perfect, you're going to get it wrong. And sometimes people have to get through that morning or that grieving phase of it

being tough without being overbearing in a sense of trying to overwhelm them with happy because they're just not in a place to receive it.

Lantigua: Wait, wait, wait. I really want to emphasize this because I've never heard it put so succinctly. You said don't try to overwhelm them with happy.

Mukira: Right. We hear this idea of happiness is a choice. You can certainly make choices and decisions to better your immediate situation. However, there is the reality of allowing yourself and allowing people to acknowledge what they're feeling. The more you continue to push it down and be dismissive of yourself and what you're feeling, especially when you're trying to appease other people, it's only going to weigh on you more. As a family member, as a supporter, as an ally to these different diagnoses, it's so important for you to allow them to be in that process, and be supportive, and be there with them. I mean, of course, you want people to be happy, but there certainly is a level of dismissiveness and you are doing them a disservice when you try to be overbearing and shifting their mood. It's so important that they have to feel it and acknowledge it. And that's just something that we all have to learn.

Lantigua: Yeah. I mean, that's part of the first point that you made, which is be person-centered, follow their lead, how are they feeling, how are they understanding and processing what's going on. And it goes to your second point about listening. Pay attention, they will give you all the information you need. My last question is really, really simple, which is, where can we learn more?

Mukira: Yes, of course. So I work on the advocacy side of things of the organization, so I provide more general outreach and educational resources. You can visit our webpage and sign up to volunteer that way [npaf.org](http://npaf.org). And if you are somebody diagnosed with a chronic or debilitating condition, you are able to visit our sister organization Patient Advocate Foundation at [patientadvocatefoundation.org](http://patientadvocatefoundation.org). And there, you'll find a wealth of resources and a financial resource directory where you're able to put in just four details about yourself and get some support on your condition.

Lantigua: Mary, thank you so much for being on the show.

Mukira: Thank you so much for having me. I enjoyed it and I hope that people are able to take a little bit away from this conversation.

Lantigua: All right. Here's a recap of what we learned from Mary. Focus on the whole person. A relative with a new diagnosis is so much more than a patient. Keep in mind that they have needs and wants beyond medical treatment, like feeling comfortable in their own home, enjoying family meals, and maintaining important social connections. Pay attention to better understand your loved one's changing relationship with food, observe their behavior around meals. Listen to what they

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tell you, but also notice how they communicate with their body language. And remember, embrace negative emotions, don't try to make your loved one feel happy all the time. Let them be sad, angry, worried, and detached. Instead of suppressing these emotions, acknowledge them and allow everyone, including yourself to fully feel them.

Thank you for listening and for sharing us. *How to Talk to [Mamá & Papá] about Anything* is an original production of LWC Studios. Virginia Lora is the show's producer, Tren Lightburn mixed this episode. I'm the creator and host Juleyka Lantigua. On Twitter and Instagram we're, @talktomamipapi. Bye everybody. Same place next week.

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ERASING THE MARGINS