

Paleo Solution - 338

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Robb: Hey, folks. Robb Wolf here. Another edition of the Paleo Solution Podcast. Today's guest is Nadine Grzeskowiak. Did I get it right?

Nadine: Perfect.

Robb: Okay. Thank you, thank you. She's a critical care nurse, the founder of the website glutenfreern.com and is the author of the recently released book *Dough Nation*. Nadine, how are you doing?

Nadine: I'm doing great. Thank you very much for the opportunity to be interviewed by you. Just quite the honor.

Robb: I'm really excited to have you on the show. You have a really fascinating background. Can you talk to folks about -- We have a lot of people interested in health and health care so we have interesting perspectives there. But you had a really serious health crisis that I think you could pretty easily say has kind of given the vector with the work that you're doing currently. Could you talk about your background, the health crisis, and then kind of bring us forward to the work that you're doing today?

Nadine: Sure. So, I worked for a long time in my dream job which was in the emergency departments around the State of Oregon mostly as an agency nurse. So, I did emergency. I was trained as a trauma nurse and everything I did was critical care. And I loved it. I really couldn't imagine doing anything else. Like I said, it was my dream job.

However, I was driving to a shift in Newport, Oregon one winter day and felt warm, which was odd for me because normally I felt cold that it didn't matter if it was warm outside. And I got to work and checked my temperature and I had a temperature of 102.4. And I thought that was odd because I considered myself to be extremely healthy and never missed a day of work because I was sick, and was somewhat diagnosed with pneumonia, took an antibiotic called Levaquin. And from that point on, my health just plummeted out of control for the next four years to the point of ending up in October 2006, actually stepping into the shower and looking in the mirror and giving myself less than six months of live. And quite frankly, I'm praying that it didn't take me six months to die.

Robb: I remember being in that spot. I do not tend to interrupt but I remember being in that same spot. Please keep going. I just want to throw that in there.

Nadine: Yeah, it's not a very pleasant spot to be in. But I'm an emergency nurse and I just thought, "Well, fine." Again, I just hoped it doesn't take me six months and I'm just going to keep working because I am Polish and that's what we do. But my daughter was ten. So, I went to see one more doctor like a dermatologist because I had had this eczema, contact dermatitis, dyshidrotic eczema my entire life and it just kept getting worse and worse and worse and nothing I did would make it go away. It's extremely painful.

And I went in and I told nurse Helen at that point what was going on with me, pretty much head to toe. My hair was falling out. My eyes were bugging out of my head. I had fluid in my lungs all the time. My arms and legs were intermittently numb. I look like I was three to nine months pregnant. I had 4-plus pitting edema and all my lymph nodes were swollen. On top of other things like night sweats and whatnot. Plus on top of that, the rash.

So, nurse Helen left the room and Dr. Haberman came in and she said, "Well, I know what's wrong with you. I've never diagnosed it before. It's really rare. But you have dermatitis herpetiformis and celiac disease. And I said that's really funny because I've been a nurse for 14 years and I have no idea what you just said. And she's like, "You have to eat or you can't eat any wheat, barley, rye or oats anymore." And I said that's really funny because that's all I eat for breakfast, lunch and dinner.

And then depending on how my shift went, when I go to my apartment, I might have a beer or two. And she said, "Well, you can't do that anymore." And I said okay. So, I did a blood test and skin biopsy, went home and I told my family I have a really rare disease and I can't eat. There is nothing that is going to make -- So, that was my perception at that time. And I did what I could on a gluten free diet, from what I understood at that time, this was ten years ago.

And I called in to the doctor's office and I said, "Hey, what are my test results?" And they said, "Well, your skin biopsy is negative, your blood test is negative, you have a rash because you scratch your skin and it has nothing to do with your diet." But my kids had already noticed the change. And that actually quite did make me feel like I had made everything up and, of course, I was causing the rash by scratching my skin. But my kids noticed I was better. So, I stayed in the gluten free diet.

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And within four months, I was so much better. I started my first business which is RN On Call. And then my second business, the Gluten Free RN, started because I was so horrified by what I found out about gluten intolerance and celiac disease

that I started the Gluten Free RN almost immediately. And with the idea that I was going to educate my healthcare provider friends, the ones that had missed me for all those years.

Robb: And you couldn't have picked a more open medical group of people towards learning about this, could you?

Nadine: Shockingly, they weren't interested in learning. I actually quite quickly took my show on the road and started doing lectures all over the country and in my community, started small, just going to even the Farmers Market. I would put up a trifold thing and hand drawn stuff and everything. It was very simple in the beginning but I had started talking to people.

Robb: Right, right. It's interesting. I had my own health crisis where I had malabsorption so bad that I weighed about 130 pounds, hair was falling out, nails splitting. I was eating a vegan diet at that time. There were other confounders. I was trying to do a graduate program in Seattle, trying to burn the candle at both ends, I never saw the sunlight. But my mom had been sick for years, became very, very sick at this time and developed rheumatoid arthritis, or what was diagnosed as rheumatoid arthritis and lupus.

But her rheumatologist suspected celiac disease and also collateral intolerances to dairy and a number of legumes. And so we said you should probably not eat grains, legumes and dairy. And when she told me that, I was like, that's kind of whacky. What the heck would you eat if you don't eat that stuff? And that was the whole thing that got me onto this kind of Paleo diet shtick.

Where did you? I want to know, nutritionally, just on your own kind of journey, where did you go as far as figuring this stuff out? Even to the degree of the dining out. That's a whole other kettle of fish. And when people who are not super gluten sensitive, when they hear the back binge you have to do to just go out and order meal and not have to cause you to feel terrible for several days, it's kind of shocking. How did you go through that process and what do you do today?

Nadine: Well, there was nobody like me to talk to at that point. Everything was online and a lot of the information I got was from GIG or Gluten Intolerance Group of North America and a couple of other large groups, started to go to conferences and whatnot. But a lot of the things that I learned were self taught and then also trial and error. Because I started up on this standard gluten free diet, which is replacing all of your gluten containing products with gluten free products and quickly realized that that was not potentially the best way to go nutrition wise.

And then also still had sinus issues a year and a half into it. At that point I decided to go dairy free very quickly, went soy free, took out a couple more things. And eating at a restaurant is very tricky, by the way, as you know. We happen to have a couple of restaurants locally where other like a boyfriend or someone that owns the restaurant will actually be celiac themselves so they're very celiac aware. But the other restaurants are like, oh, no, no, no, this is big thing. So, it comes down from corporate that they have to have a gluten free menu. But they don't do any education for staff or keep a tab on anything. So, they really don't know what a truly gluten free safe meals mean as far as cross-contamination and every other way that you can get gluten into food.

Robb: Right, right.

Nadine: Yeah. We had a Thai restaurant in town. Katie's parents opened up 100% gluten-free restaurant so that we can eat there. Traveling, taking pre-packaged foods or fruits and vegetables was a good idea. And then after running marathons and thinking that I was completely better getting rid of what I thought was my autoimmune issues -- I had seven autoimmune issues, by the way.

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I went in and I got my blood drawn thinking that everything was going to be pristine and it wasn't. As a matter of fact, my ANA was still positive, which is the antinuclear antibody, so that I still had autoimmune issues which, of course, didn't make me happy. At that point, Cain and Tammy Credicott, we have been talking about celiac disease for a number of years. We have traveled at the same conferences and whatnot. They suggested I got on a Paleo diet.

At that point, because I was so irritated that my labs were so, so bad that I went on a Paleo diet for a year. And within that year everything shifted. My vitamins started to get absorbed. I wasn't anemic anymore. And my ANA went from positive to negative. So, at that point, I didn't have any autoimmune diseases anymore.

Robb: Amazing. So, what have you done as far as taking that information and then incorporating that into your website, your writing and whatnot? It's still kind of crazy because every other day it seems like there's a news piece that says gluten intolerance is all in your head. It's funny, I had a Mike Ruscio on the show and, I think, to date, there have been six really well done gluten intolerance tests like randomized control trials, blinding and all that.

Five of them have shown a clear connection with what we would call gluten intolerance or suggestive of gluten intolerance. One of them was unclear so the weight is very heavy on this side that there is something there just on the gluten

sensitivity side to say nothing of celiac. But this is just a hell of a problem to educate people about. You're talking about some of the tastiest foods that we have in the food system, one.

So, people really want to eat it. And when we start talking about interfacing with the medical community, every single sub-discipline could probably go away if we got people eating something like a Paleo type diet. Like all these sub-disciplines are just the genetic and epigenetic interactions of basically having mismatched food like from gastroenterology to cardiology, dermatology. I mean, you're really throwing a huge kettle of fish on folks. How have you been working on that talking to both the lay populous and then also health care providers?

Nadine: Sometimes, it's harder to get through to the medical providers. They honest to god, they really just don't want to believe it, that it is only a diet change that people do get better. They just think that it can't be that simple. But the reality is that all of the studies are in their medical journals and if they would just read them it would make my job a lot easier and your job too.

But gluten sensitivity and celiac disease are, I think, that there's still a fair amount of gray area. Even though celiac disease is defined as you must carry DQ2, DQ8 and have documented villous atrophy, I see people quite frequently that don't carry DQ2 and/or DQ8 and they still have villous atrophy. Significantly, it's like Marsh 4. So we really need to reevaluate what celiac disease is especially since there are 39 other genes that are associated with celiac disease.

So, I think, over the next couple of years, we're going to really see a lot of interesting things come out and a lot of backlash about what gluten intolerance and what celiac disease are. And actually, it makes significant change because it's a political issue. It's a social issue. It's a financial issue. There are so many different components of this that it's going to be a huge cultural shift.

It will happen. It is happening. And people are feeling hopeful again. Once you tell them you can change your diet and you will feel better, which they do, for the most part. There's still some other things that we tend to have to go back and treat the diet just a little bit, maybe address some low FODMAPs issues or something else after a year. But if people are truly on a Paleo diet or at the very least a gluten free dairy free diet for a year then we have something to work off of so that they can continue to get better. But if they continue on the same SAD, the Standard American Diet, really honestly, they don't get better.

Robb: Right, right. That was definitely the case with my mom. I was able to keep her gluten free but she could not put down the dairy and we know pretty clearly that there's some serious cross reactivity there. And so my mom got a little better but not a ton better.

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Nadine: It is hard to get people to change because those molecules in that food are addictive. And so you will literally have to break that addiction component for people to start to feel better and go, "Hey, that's not really food." But up until that point, even sugar or some of the other addictive components are very difficult to give up because people believe that they need them because on some level they do.

Robb: Right. There are some folks out in the interwebs that very flippantly -- So, there's some indication that some gut microbiota shifts may be at play here and may precipitate or predispose people towards either celiac or non-celiac gluten sensitivity. There's some reports of people addressing some gut issues and then being able to better tolerate gluten. I applaud those folks.

I have done everything I can possibly imagine to do and I don't even knowingly consume any gluten. I just get cross reactivity from trying to eat out occasionally. And what would you say to the folks that are just kind of dismissing this stuff that there's some sort of an easy fix to this? That still means that we get to consume day in and day out.

Nadine: I would say that if you read any of the research and every time researchers are using the term neurotoxin or toxin when they're talking about gluten, I would say assume that your gluten is toxin or neurotoxic which means it causes damage to your nerves, and it never a good idea to eat those things. So, not for anybody. And that's what people need to understand. That gluten is potentially dangerous to absolutely everyone.

So, anytime somebody says, "Well, I can take a pill and it will take care of the symptoms," or whatnot, what I've discovered over years of researching this and looking at it is that there is no pill. There'll never be a pill. People won't be able to eat gluten. And even if there was a pill, you would still have to be 100% on gluten free diet 100% of the time. And so, why are they spending all this time and energy and money trying to come up with a pill when the reality is that you just can't eat it? Nobody should be eating it because it is a toxic substance to the body.

And I understand that there might be some arguments about that. Like you've been eating it for a long time. But I'm happy to have those arguments with people because the reality is that it's just gotten more toxic. There's DNA components to the grains that are--

Robb: Quite different than what they were 50 years ago, yeah.

Nadine: Absolutely. And we're just exposed to it more. It's in everything. It's in your shampoos, your conditioners or lotions, your food. And not just food that you would kind of assume it would be in. It's not just in the pastas and the breads. It's in everything.

Robb: Every once in a while -- I love Thai food and every once in a while there will be a - - I'll hit a new restaurant and they have a seafood green curry and I'll order it and forget to ask do you have crab in it? Because the crab inevitably is fake crab and the fake crab is held together with gluten. And so I'll get this meal and I'm like, oh, okay. So, I need to order a different one and this is all going to get fed to the chickens. Yeah, I mean, it's kind of crazy thing on top of all the different -- And that's not even getting into like modified food starch and dyes and colorants that can be gluten extracts. So, yeah.

Nadine: Right. And so, I'm always looking for ways to get healthier and things to do. So, my boyfriend and I who've been dating for two years, we're on the Whole30 now just because I was -- I was actually taking a class on microbiome and we had to, through the University of Denver, and we had to keep a log of our food that we eat for ten days. And I think I eat extremely well. I know I do. But there's a question there that says, "How much processed food did you eat today?" And my answer was always zero. And I went back and I thought, no, I actually eat quite a bit of processed foods whether it's my almond milk cheese or my nut cheese or some type of product or bar that I eat at work or whatever, a protein bar.

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And so I had to reevaluate what my processed food consumption was. And so doing the Whole30 actually helps me kind of reconnect with just what whole food is and making everything myself again. So, it's just upping the ante again, upping another notch.

Robb: Right, right. So, one of the interesting trends, like the largest trend in just kind of food-dom is that people are cooking less and less. And they have been cooking a lot and they're eating more and more prepared foods. Apparently, there are a couple of pilot stores in like Chicago and New York where you walk into the door and it's just aisles and aisles of refrigerated cases where they have basically like lean cuisine type stuff and then they also have locally prepared -- They'll find celebrity chefs in town. So, it's both frozen and "fresh" food locally prepared.

But the prepared food scene is actually exploding and is anticipated to be the largest growing segment of kind of food stuff in the next like five to ten years. How do you think we could influence that scene? I mean, try as we might, I think

we're going to try to get people to cook but, I think, that we're kind of peeing in the wind in that regard. How can we affect some change so that some of these meals are legitimately prepped in legit gluten free kitchen? How do we get to the chefs and the people prepping this food so that they're doing it in a way that is good as doing it at home, hopefully?

Nadine: That's a very good question. Typically, what I have found over the years is that the chefs or the doctors or whoever else that is, actually don't get gluten intolerance and celiac disease until it either happens to them or their family members or friends. And at that point then they really start to take it seriously. So, until we hit that tipping point of there's a critical mass of people that actually get gluten intolerance and celiac disease preparing food or seeing people and actually diagnosing them correctly, then we're still going to struggle.

I know that's a hard thing to -- We're going to struggle as far as getting food that is perhaps safe but maybe not safe to eat. Maybe it has a cross-contamination issue, maybe not. I just see too many times when food that has been prepared or corporations that are trying to make gluten free products, their food is being recalled because of contamination risk or something else got in there, who knows that.

So, I really encourage people to just take a cooking class or go in your kitchen and actually open up the cupboards and find out which tools you have in there even if it's a crackpot and get connected to how you cook your food or what it is you're eating. So, you actually know what's in there. And I tell people all the time if you can buy it in a package you can make it at home. There's lots of opportunities to figure out how to make even a protein bar or something.

Robb: Right, right. It's a little bit work. That's one thing. Sushi is one of those things that you can do at home but it's kind of nice to do without because it's kind of a laborious task. Yeah.

Nadine: Agreed, yeah.

Robb: What would you recommend as far as testing? Even before the testing and -- This question is kind of loaded.

Nadine: It is loaded already.

Robb: I was going to ask you what are the potential symptoms of celiac and gluten sensitivity? But the list is so damn long. I don't even know if it's worth -- It's everything, right?

Nadine: It's everything. It is everything.

Robb: I mean, literally everything. And that's part of the problem. You sound like a crazy person because you're like, "No man." It really can affect everything. Could you talk a little bit about tissue transglutaminase and why it can affect everything?

Nadine: Okay. So, just to answer the bigger question, there's a number of -- If the testing is positive, if you go ahead and you get any testing for celiac disease, even if it's the standard celiac panel that most doctors, that every doctor can order which should have six components on it, they always should test the total IGA, total IGG, always should do the tissue transglutaminase 2, EMA, which is the endomysial antibody, and some do the deamidated gliadin peptide.

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I miss for the most part the antigliadin antibody, when the labs don't do that, because it's a good indicator, it's a great indicator for gluten intolerance or non celiac gluten sensitivity, but most labs don't do it anymore. One of the problems, the lab work, the blood test itself is 70% false negative nationwide. That's just the way it is. And that explains partly why my test was negative. And the other problem with the testing is that the docs actually or whoever is reading it has to know what they're looking at and then it's helpful. But, unfortunately, I don't think a lot of care practitioners actually get a class in celiac disease, go figure.

So, you actually have to have enough IgA to have a positive blood test so that most of the people that come in and they say, "Well, my doctor ordered the test, here's the test results and it was negative." I said, "Well, do they actually mention the fact that you're IgA deficient?" Because the test can't be positive because you're not producing enough IgA. And frequently the answer is no and then we have to go back for more testing, if that's what they want.

One of the problems with the tissue transglutaminase is we're only testing for the tissue transglutaminase 2 routinely for most of labs. And what we know is that the tissue transglutaminase 3 is skin and tissue transglutaminase 6 is primarily neurologic and it will show up. The interesting thing is that celiac disease is primarily neurologic. So, anybody with migraine, headaches, seizure disorder, sometimes missed diagnosis of MS and ALS or Parkinson's or many different things, gluten ataxia, they're not going to be caught in the standard celiac blood panel test because we're only testing for the tissue transglutaminase 2. Does that make sense?

Robb: No, no, no, no. That's what I was fishing for sure.

Nadine: Okay. So, if we actually could, like Cyrex Labs does the entire panel for celiac and it includes the TTG 2, 3 and 6, which I encourage people to get that lab, if they can. You can do a stool analysis through EnteroLab which some people balk about that but the reality is that it gives extremely good information especially in the fecal fat score. And I just had a five-year old get her fecal fat score back and it was over 1100, which means that she's extremely malnourished because normal is less than 300. And if you're eating fat and absorbing it correctly your fecal fat score should be under 300. But hers is 1100.

So, she's very malnourished, not absorbing her fat, and believe it or not, that's how they used to diagnose children in the 1920s, '30s, '40s, and '50s in this country, was with the fecal fat score. So, I find that information extremely useful. I just wish the testing was easier to get for people. And if it's easier to interpret for people to have somebody knowledgeable help them, and then just so they absolutely get the right information because, otherwise, it's extremely confusing this testing business. Because there's nothing cut and dry.

Robb: Right, right. And that means some of that is just because it is so complex, like the various isoforms of transglutaminase, which is what's affected in celiac disease, can affect every organ, every tissue in the body. And so it can manifest in different ways depending on the various folks. And each one of these tests is a completely separate entity and it has its own confounders and error rates and whatnot. So, yeah, yeah.

Nadine: Yeah. It doesn't need to be this difficult but that's why I like clinical trial sometimes for people, even when they all have negative blood tests and they don't carry the DQ2, DQ8, they just try a gluten free diet and they feel better. That's great. We like that. And it's potentially preventative for so many other things happening and I tell people all the time you're just dodging bullets every time you just up your diet a little bit, take out the things that are toxic and shockingly you get better.

Robb: Right, right. Yes. The 30-day test and you pretty much know what the story is at the end of that. Yeah.

Nadine: Right. It's hard talking people into the test sometimes.

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Robb: Right, right. Yeah, it is. But it is funny, I've been, after a couple of glasses of wine, sitting around the table of doctors talking about this, has been nearly in fistfights over this stuff. I mean, literally, with a couple of gastroenterologists. I remember one time here in Reno when we did a presentation and they were just like, "You know, this is all interesting but it's all bullshit. There's nothing to this."

It escalated pretty good. It finally came down where this one guy who's a well-known GI doc in town, I made him a bet. I told him we'll get ten of your patients that have like IBS, Crohn's, you pick what it is, we'll stick -- I'll design the gluten free diet. We'll have our dieticians monitor them. We'll support them as best we can. And I made a one way bet. I said if, "They don't get better I'll pay you \$10,000, if they do, you don't have to pay me a dime but you just have to tell me that I was right."

And this guy initially wouldn't take the bet. I hazed and harangued him literally until it almost turned into a fistfight. But we finally got the guy to just try it and this group of folks that he tried it on immediately. I mean, within a week, these people were calling him saying, "Oh my god, I can't believe how much better I'm feeling." And then even his crusty old self, he's like, "Okay, there might be something to this." And then I started loading him up on research.

He's a pretty good advocate now. It's funny. I don't even think he can believe that he's seeing what he's seeing but part of that is just that he's been practicing, I think, like 30 years. And I think he kind of looks back and he's like how many other people slid through the cracks because I wasn't aware of this?

Nadine: And I hope we all, as practitioners, look back and go how many people did we miss? And how can we do this better? That is one of the goals, to make sure that people are aware enough of this so they -- Celiac disease is always on a differential diagnosis no matter what. It has to be. And if it's not then that's a failure.

Robb: Right, right, right. Nadine, it's been great having you on the show. Can you let folks know about your book and then also how they can track you down on the interwebs and social media?

Nadine: Yes. I am actually internationally known as the Gluten Free RN. So, I'm on Instagram, Facebook, Twitter as the Gluten Free RN or Gluten Free RN Nova. My book is called Dough Nation: My Nurse's Memoir of Celiac Disease from Missed Diagnosis to Food and Health Activism. I'm currently working on the second book with a physiologist, biologist and geneticist so that we can revamp what celiac disease is based on all of the research that's already been done and we're just going to put it back together the way it should have been done.

Robb: Fantastic. Any proposed timeline on that?

Nadine: Hopefully, that will be out by early next year or sometime next summer.

Robb: Okay, okay. You promised to come back on the show when that's ready to go?

Nadine: Yes. That will be the big one. This is the intro.

Robb: Okay, fantastic. Well, Nadine, it was really a ton of fun having you on the show. It's kind of interesting like, I think, to the degree that this kind of Paleo diet concept didn't go the way of Atkins or the Zone and what have you is the fact that it really did focus on gut health and neither really concerted focus on gluten issues in general and potential problems with grains at large.

People often forget that Loren Cordain wrote this amazing paper almost 15 years, Cereal Grains: Mankind's Double Edged Sword, and it really stood the test of time. Many slings and arrows are fired at both the gluten free camps and the Paleo camps and it's labeled disordered eating and all kinds of different stuff but there's a basic reality though that we're literally changing the world and it's a difficult process because the things that we're suggesting are maybe problematic or relatively inexpensive. They're super tasty. They're hyperpalatable. They're addictive. And there's tons of big money wrapped up in them.

And so there's really not -- The only upside to adopting this stuff and thinking about it is that you individually will feel better. And that's oftentimes a tough road to hold. But I'm really very, very excited that people like you who are doing what you're doing. 20 years ago there was not a gluten free RN. She did not exist. I'm certainly grateful that you do now.

Nadine: Yeah. I'm glad I actually spend ten years and I cannot imagine doing anything else. And I still pine for the emergency department every once in a while. But I absolutely love seeing people get better. And it's so simple. Really, they just -- a lot of people just have to have that nugget of hope that they're going to get better and then to see results and they do get better.

Robb: Right.

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Nadine: It's not shocking to me but it's fun. This is so much fun it's crazy.

Robb: Yeah. And it's funny, you hear story after story and it can be crazy stuff but you're never, you can never hear it enough. The next story is never not a little bit surprising and, yeah, yeah.

Nadine: Neither one of us do this necessarily for our own health although that is a benefit and a bonus. Because I climb mountains now and whatnot. It's just that for the next several generations this is going to be crucial. This is not about our

generation or even our kids' generation to some degree. This is changing the epigenetics for future generations. That's going to be the big thing.

Robb: Right. I couldn't agree more. Well, Nadine, I'm super excited for your next project. Hugely honored to have you on the show. I hope you have a great rest of your day.

Nadine: Thanks, Robb. It's been a pleasure.

Robb: Okay. We'll talk to you soon.

Nadine: Bye.

Robb: Bye.

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