

Autism. Science. Hope.

Introduction to the Sandwich Generation Survival Guide

Candace Dellacona: Welcome to the Sandwich Generation Survival Guide. I am your host, Candace Dellacona. Our goal, with this podcast is to provide resources to those of us in the middle trying to advocate for our aging loved ones and supporting the next generation, launching our children or our nieces or our nephews, or those who we love into life.

And many of us out there are advocating for our children and our younger loved ones with different and or special needs. And to answer that segment of our listeners, I am so honored today to have Dr. Theresa Lyons.

Meet Dr. Theresa Lyons: A Yale-Trained Scientist and Autism Advocate

Candace Dellacona: Dr. Lyons is a Yale trained scientist. She's a medical strategist. She is most importantly the parent of an amazing daughter who also happens to be autistic.

Dr. Lyons is also the founder of an organization called Navigating AWEtism, where she provides insight and coaching and quarterbacking to the parents in this segment of the population. So Dr. Lyons welcome.

Dr. Theresa Lyons: Thank you. I'm very excited to be here.

Candace Dellacona: It's quite an introduction for, quite a person. I just wanna say thank you so much for being here. As I mentioned, our goal is to provide resources, so you are here for that. We have never been lucky enough to have someone speak to the segment of the population, and so we're really happy to have you here.

I know that so many of our listeners are looking for resources, and that is really what you are. So why don't we start at the beginning.

Dr. Lyons' Personal Journey with Autism

Candace Dellacona: Dr. Lyons, can you tell us a little bit about your background and how you got here?

Dr. Theresa Lyons: Sure. So this was not planned at all whatsoever for me to be where I am right now, but that really is life. I have a PhD in computational chemistry from Yale University. My research then was focused on drug discovery, and so after my PhD I worked in big pharma and worked on optimizing drugs and then switched over to the business side and created an understanding of how doctors practice medicine and how pharmaceutical companies increase their revenue in the sense of doctors practicing in medicine. So I was a strategist. I worked in many different therapeutic areas. It was definitely high paced and high pressure.

And then my daughter was diagnosed with autism. And I said, all right, what's standard of care? Gimme the options. And there really was none. And that was really unacceptable. And that's what started me on this path.

Navigating the Emotional and Scientific Challenges of Autism

Candace Dellacona: And so as a scientist, you approach probably a diagnosis like this different than the average person. Also someone who's had exposure to big pharma and looking for pharmaceuticals as the solution to many of the things that sort of ail us as a society. So taking your perspective, maybe as a parent, I would imagine that most parents, when they learn of their child's diagnosis, they go through a plethora of emotions, probably shock and confusion.

For those of us who are not familiar with autism and the broad spectrum that it presents in terms of possibilities and what their child's future must look like and probably grief. So can you speak to how you dealt with it at first as a mom to your daughter, and then what sort of kicked you into gear, taking on that scientific approach to find the protocols and the treatments that you didn't see as being available?

Dr. Theresa Lyons: Sure. So I had two basically almost personas back then.

Candace Dellacona: Right, right. I can see that.

Dr. Theresa Lyons: Dr. Lyons, and then I had mom, right? So it was, it was me switching back and forth between those roles. And as I assembled a healthcare team for my daughter, I was really in Dr. Lyons mode. So when I would go and meet the doctors, when I would even make appointments and start to get to know the office staff, it was all in the role of Dr. Lyons. So that emotional side of me was put to the side, because once I started getting emotional, I couldn't focus, I couldn't come up with a good plan. You know, it's a totally different part of my brain. So there really was those two personas. But I definitely felt those emotions.

So, after my daughter was diagnosed, it was in a large hospital. We get into the parking lot and you know, I get her strapped into her car seat and of I just start crying. Even though it wasn't a surprise, but it's still, it's, it was a change in the future of what I ever thought. When I was pregnant, this was not what I imagined.

I had all these, fairytale kind of versions of what motherhood was, and this was just about entirely opposite to everything I was expecting.

Candace Dellacona: And how old was your daughter when she was diagnosed?

Dr. Theresa Lyons: She was three and a half. And I will say that is on the later side. If parents are listening to this and they're thinking you can get a diagnosis later and still have a favorable outcome. So the average age of a diagnosis is around five, but a reasonable and accurate diagnosis can be made at 18 months.

Candace Dellacona: Oh wow. So significantly.

Dr. Theresa Lyons: yeah. Yes, yes, yes. So, back when my daughter was diagnosed, I worked with the team that we were assembling really to make sure we eliminated any other possibility because an autism diagnosis is based on observation. So, you have an observation and an evaluation from speech therapy and occupational therapy and physical therapy and some type of psychology or learning aspect. And then all of those reports get sent to a developmental pediatrician or pediatric neurologist, and they look at those observations. They see your child, the appointment might be 30 minutes or 45 minutes, and they see your child and after 20 minutes or so, they make a diagnosis.

Short observations and we really spent time making sure it wasn't anything else. And it wasn't.

Candace Dellacona: And so ruling out the possibilities was part of your exercise and I assume part of others exercise when coming to this diagnosis. Here you are as a scientist and like you say, wearing these two hats as a mom and as somebody who is experienced with data.

Building the Right Healthcare Team

Candace Dellacona: And you receive this diagnosis and when you get over the sort of blow of thinking about what her life may have in store, which is perhaps different than what you first thought, what was your next first step in finding and assembling the right team?

Dr. Theresa Lyons: Okay. So the emotional aspect I don't think has ever stopped and I definitely oscillate.

Candace Dellacona: Fair. Fair.

Dr. Theresa Lyons: Yeah. I just put it on pause and I switch into Dr. Lyons mode. And then certainly go back. So when I would have doctor's appointments, I would go in with an agenda. And these are the talking points that I have, and this is the research either that I've done or that I wanna discuss.

And these are the tests I wanna either go over for their expertise or these are the tests that I want ordered. And so it would all be summarized in a one pager I'd sent to the doctor the day before. And so they, they definitely came into the appointment prepared. I don't like to surprise people with my level of organization or questions.

And I, I really invite that dialogue and that partnership. So that was something that really had to be cultivated and I learned that from my medical strategist days of, okay, you have a key opinion leader, right? So we want the best doctors and we really wanna tap into that knowledge. So you wanna go in there prepared.

Otherwise, the worst thing that happens is you leave your doctor's appointments and then you're like, ah. I forgot to ask. And that's just, and the way it was back then was, we weren't sleeping, so it really took me a lot of effort to be organized just because when someone doesn't sleep, cognition starts to go a little bit for sure.

Candace Dellacona: And as a parent too, like you said, the emotional piece never turns off

Dr. Theresa Lyons: oh no.

Candace Dellacona: I think it's so important to keep in mind that you're not going about this in a clinical fashion as much as you would like to, as a clinician as someone who holds her PhD in chemistry.

Having your daughter's diagnosis be the subject of the appointment, obviously makes you incredibly vested. And so it's really easy to lose sight of those questions. I think that's fantastic advice.

Telling a parent to set the agenda and send that information in advance so that the physician and the care providers have some time to understand what your question will be so that they're prepared with answers and they make the appointment as useful for everyone as possible, so in terms of, assembling the right team, can you kind of give us the inside scoop on when a family comes to you having just received this diagnosis, what is the protocol that you help families set up when taking the next step after a diagnosis?

Dr. Theresa Lyons: Sure.

Conventional vs. Functional Medicine

Dr. Theresa Lyons: So you wanna use both sides of medicine. So there's conventional medicine and then there's functional or integrative medicine. And so conventional medicine is, let's just use the example of constipation. 'cause constipation occurs often in autism, and it is not just autism. So some doctors and people just think, oh, if you have autism, then more than likely you're gonna have some GI issues.

There's no reason for a person with autism to go through life with GI issues. So I'm gonna use a basic example of constipation. So conventional medicine, you might go to a general pediatrician or maybe a GI specialist and maybe their first piece of advice would be, all right, let's give the child some MiraLax, right?

Get things moving. So that's a short-term solution. But if you stop the MiraLax, are you gonna be exactly where you were before? More than likely, yeah. So conventional medicine has more of a short-term focus of let's resolve the problem. Very important. If someone's constipated, that can create issues in learning and sleep and being comfortable and eating, so many things that are important.

So it is good to resolve that. But then functional medicine, a different aspect of medicine is looking at what's the root cause. So a doctor that practices functional medicine or integrated medicine might say, okay, the child's constipated. What would be causing that? So is it improper diet? Is there not enough fiber? Is there not enough hydration? How much are they drinking? Is there some type of gut infection? So you can start then asking the why, and those solutions will really impact things long term. You really wanna start to build a team that has different perspectives and you'll have to have different specialists so that every aspect of health is covered.

'cause there's no reason whatsoever for someone with autism to live, a life of GI problems or anxiety or OCD or sleep problems or picky eating, right? There's so many things that we just assume, oh, that's just autism, but it's not. And these things certainly can be resolved and should have attention on them from a healthcare standpoint.

Candace Dellacona: And how does a family go about finding integrative medicine specialist or a functional medicine doctor? Particularly, in light of what many have called the healthcare crisis now, making sure that their doctors are accessible and even more rural areas. I'm fortunate enough to be here in New York City and probably there are more of those physicians available to families.

But how do you guide your families and finding the right functional medicine doctor to help with an autism diagnosis?

Dr. Theresa Lyons: So functional medicine doctors, typically you have to pay out of pocket so they don't participate with insurance plans. And I got very knowledgeable on functional medicine because I really wanted to, to pick the right doctors for my daughter. So I studied all of them in the US that focus on autism. And then as I started working with parents and helping them assemble their team, I got to know many of these doctors. And then I did write a book in 2020. It's called The Lyon's Report. And so it explained what functional medicine is, explained different science based information that parents should know or grandparents should know about autism. And then it also had a directory of the top functional medicine doctors in the US that focus on autism. So these were like the key opinion leaders. And in 2026, we will release a updated version of that book as well. So it really depends on where someone is in the States. Certain states you don't ever have to visit the doctor in person, so it could be entirely virtual, which is a real benefit.

So like the state of Oregon, if there's a functional medicine doctor in Oregon, they can actually see any patient in the US and you don't have to visit them once a month. Whereas in New York State the law is that the person has to have at least one in-person visit per year. So different states have different requirements.

And so it's just important to figure out what works best for the family.

Candace Dellacona: Yeah, I think, and we will obviously have a link to your book in the show notes, and I think, part of the Sandwich Generation Survival Guide's goal is to provide resources like this and people like you so that families do know where to begin. But, going to The Lyon's report, you put so much work into providing the sky for families and parents, grandparents, even as you mentioned.

What would you say are the few facts that many families come to you that are not aware of from a scientific perspective and how that can impact both the child with autism and be a guide for the families?

Scientific Insights and Hopeful Research

Candace Dellacona: Are there sort of, lesser known scientific facts as it relates to those who have the autism diagnosis?

Dr. Theresa Lyons: Yes, there certainly is. So one of the reasons why I went all in and really wanted to understand more and more of the science was when I first started there were publications, just

occasional ones sprinkled over the decades of autism showing that a diagnosis is not lifelong for everyone who's diagnosed with autism.

So when my daughter was diagnosed, it was about 10% of kids diagnosed with autism lost their diagnosis. And when I say lost it, it means, right again, it's observation. The researchers called that an optimal outcome. So it was 10% optimal outcome. The research back then was within about two years of there being a diagnosis, then about 10% lost.

So for me, I thought, whoa this is a huge divergence of possible outcomes, right? So in one hand, I'm told there's nothing you can do. Autism typically gets worse, it doesn't get better. And you just kind of like accept how things are. You could do maybe some ABA, which is applied behavioral analysis but it doesn't work for everyone.

And that's pretty much it. Whereas I'm reading this research and it's saying, wait a second, 10% lose the diagnosis. How is that possible? Right? So that, that's what got me really interested in knowing the details, knowing the science. And then now in 2023, new research was published, and this was from Boston Children's Hospital up in Massachusetts, very reputable hospital. And their research, they followed a little over 200 kids. And when they were diagnosed, average two years of age, they did analysis at follow up age, somewhere between five and seven. And they found 37% of kids with autism lost their diagnosis. So they've actually now in the scientific literature, they're calling autism, there's a non-persistent autism and then there still is autism as it's generally been defined. But there's so much change that is going on that they've had to reclassify. And the thing is, information like this is not known to the general public.

Candace Dellacona: Well, for sure. And when you think of a lost diagnosis, it almost sounds negative, but I think what you're saying. Is the opposite, right?

Dr. Theresa Lyons: Yeah, this is, yes. Yeah. So that means that child doesn't need speech therapy anymore. It doesn't need occupational therapy or physical therapy or TA at school or, all these other additional supports. It's, they're off doing life, right?

Not having any of those barriers, whereas parents whose kids have autism, a lot of times we see our kids want to do something, but they're inhibited in some way. Either they can't speak or, they have motor control issues, or maybe anxiety is too high in order to participate in some social things. So it's really important for parents to know this information and then use it to, to help them follow their intuition. 'cause a lot of times parents have that little knowing voice. It's like something could be different.

Candace Dellacona: Listening to that is really important. I think that leads to advocacy. To that point from Boston Children's, I think that bit of research seems pretty hopeful. And it also seems to me, and again, not a scientist, but having a number, like 37% of kids losing their diagnosis means that we're onto something and perhaps there are therapies that are working.

And so, for those parents who are out there who have just perhaps received the diagnosis or they have a, that feeling in their stomach saying something is wrong, knowledge is power, and there's so much hope in those numbers.

Dr. Theresa Lyons: Yes. And that number, as you can see, is just growing. And that's what I saw back even in 2013 when I was reading the research. It was like, whoa, this number is just 10%. Okay, a decade or so ago it was like five. Okay so there is knowledge there on, on what to do with autism, right? That's works for some people.

Obviously not for everyone, but as a parent you want to know these. Options and then really assess, okay, is that, does that make sense for my child? Does, is that relevant for my child? And is that something we wanna do?

Candace Dellacona: I love the fact too, that you're providing the guidance Dr. Lyons to these families. Because even with all of the hope what comes with hope and the possibilities are a lot of options. And options can feel really overwhelming and really noisy to those of us who don't have that background or don't have the ability to parse through the information.

So having someone like you as almost a care navigator seems like a smart thing to do for a lot of families. Are there, do you see an uptick with these families looking for people like you to help them as their guide to this, what seems to be a pretty confusing process?

Dr. Theresa Lyons: Yeah, parents are looking for quality information, for sure. So on, TikTok and a variety of different social media, there's snippets of parents showing, okay, this was my child and this is what we did, and this is what's changed, which is great. But the important part is to understand, is that to my child. So a lot of times parents see that and they're like, oh my gosh, okay, let me just try it. And if you just start trying things, that's when you don't put in full effort because you're like, I don't wanna get my hopes up because I don't know if this is gonna work for me. So the more you base your decisions in science, then the more, in many ways, hope you can have because there's logic wrapped around it, not just, random trying. So that's the really important part. There's a lot of different symptoms. There's a lot of different approaches that are really beneficial, but you've gotta align the approach and the therapy with the symptoms of the child. And that's why autism can seem so complex, because you can't do the same thing for one child to another child and get the exact same results because their body chemistry is different, right?

So some kids have huge problems with the guts. Many kids, right? But not all. Some kids have problems with autoimmune antibodies in the brain, but not all. So that's where the, in many ways, tricky part comes from really understanding the symptoms of your child, and then making sure whatever you do is addressing those symptoms.

Candace Dellacona: You speak to something that is so relevant, particularly now in the time that we are in. Trying to separate fact from fiction and the emphasis on science, which I so appreciate. You are one of the science warriors and you are out there making sure that the information that we receive is based on that science and to really follow the guide of professionals and not look to TikTok certainly for treatment options. I think that mediums like that are helpful maybe to get information out, but you do have to rely on the practitioners to advise you if this is relevant for your own child, because it's such a big body of research and it seems, from what I understand and how you've explained it, is that autism can manifest so differently, child to child.

Dr. Theresa Lyons: Yeah so you have level one and level three and just to talk about the two ends of the spectrum, right? So level one is what used to be called Asperger's. So Asperger's is no longer a diagnosis. It's been rolled under an autism diagnosis. So that might be a child or a teenager or a young adult who can dress themselves, who can cook breakfast, right? Can walk across the street and go to school. But they might have problems with executive functioning and some other areas, conversations. Then you would have level three, which is someone who is more profoundly autistic. So they might not be able to dress themselves. They might not be able to bathe themselves. They might not be able to speak at all, but yet this is the same diagnosis of autism. So you really wanna make sure you understand what are the priorities and what is, what are the health barriers that that child is facing so that you can get very specific. You wouldn't do the same thing for both those kids and expect the same result.

Candace Dellacona: Absolutely.

Balancing Care for Children with Autism and Aging Parents

Candace Dellacona: And sort of segueing into being a sandwich generation member, some of what you've shared with me so far is that your daughter has this autism diagnosis and you've made your way through and you're looking to the horizon and thinking about your own aging parents.

And so for those of us in the middle, how do you best navigate that piece when you have a differently needed child or children and your aging parents, what is your best advice for those of us who are dealing with both ends of the spectrum, if you will?

Dr. Theresa Lyons: I would say definitely to stay grounded with yourself first. You can't help either of them well if you're stressed out and you have emotional dysregulation, right? You have no patience. If there's a problem with either that, it's just, oh my goodness. And it feels the pressure and the overwhelm. So really having focus on yourself, and it sounds so cliché, self-care. It's not. I remember there were times when I was just exhausted and really at the end of my rope and, something great happened with my daughter and it was like, I couldn't even fully appreciate it, right? Because I was so drained.

And so if I can't appreciate the good things, then, I obviously was not handling the bad things as well as I could have. So really being able to check in with your own bias, okay, how am I sleeping? And I know sleeping may be difficult when there might be crisis during the night as to something's going on. But, really making sure you get sleep is important so that your brain can actually function and be able to make those decisions and quick decisions and see different angles and see different perspectives. So really starting there is the only way to do it so that you bring yourself like your best self to either of those situations.

The Importance of Self-Care and Delegation

Candace Dellacona: I think that's great advice and I think that, recognizing our own limits and as you point out. You can't be your best self if you're not running on sleep and you're being forced to make these decisions, that can be quite difficult. One of the things that I love that you mentioned too, is this identity shift.

And looking at a parent of a differently abled or differently needed child and the daughter of, or the child of aging parents and trying to toggle between those two. So obviously you want to take care of yourself, but trying to prioritize the two. Do you have any advice with respect to that other than the standard?

Where I say delegate, we have to ask for help and delegate.

Dr. Theresa Lyons: Definitely delegate, but I think it's forming those bonds right with, because I know many times with delegating, I feel like I should be there and then there ends up being like guilt feeling and I'm not doing a good job. Like you can really start to, to spin in a negative way in your own head when you start delegating, even when it's supposed to be helpful. So I always think it's good to have conversations with either as to what is really meaningful help for you. So I know with my parents you know what is really meaningful for them is, quality time with them. And so when I'm trying to prioritize what to do, when I get to spend time with them, and now we take vacations in the summer and the entire family gets together because we know this is important, right? So we all of us adult kids have busy lives and we all have so many things going on, but we do our best to prioritize that time so that we have those memories and those good places to, to make decisions. And same with our kids. Even though right, even a child with autism that's not speaking, we can really start to understand their love languages, right?

Believe it or not, kids have love languages. And if they're not talking, you can still figure out what's the best way to bond with them. So for a child who, let's say you know, gifts is something really important, that's good to know. So that maybe you can delegate a certain aspect of their care, but then, oh, they love gifts, so let me just go buy, a \$2 fidget toy or something that they like.

So that you still know that what you're doing is meaningful to them, and I think that's the really important way to help delegation feel like not like you don't care.

Candace Dellacona: Yeah. Yeah. And also giving other people the opportunity to love up your child, right?

Dr. Theresa Lyons: Definitely.

Candace Dellacona: And especially when you have a diagnosis of autism that can be complicated. And so perhaps what to do isn't intuitive. So bringing others into that world to share what might work best for your child, your empowering the grandparents, or the aunts and the uncles to have that bond and share that bond with your child.

Who, like any child, wants to be connected to their grandparents, their aunts, their uncles and cousins. So that opportunity I think is great.

Celebrating Small Victories and Building Support Systems

Candace Dellacona: I also love what you'd said in the past about, celebrating those victories that may not look like others victories and the small things, and not losing sight of progress that can be made along the way.

Dr. Theresa Lyons: Yeah, it's really important. Just for so many reasons, and especially with the people who have supported you along the way. So when you have a child with autism and they're developing differently, you want to have that supportive family so that you could go to your parents and say, oh, thanks for, taking John to school one day a week so that I could, do X, Y, Z, because now look, look, things are changing and you really start to build that support team around you. And hopefully you could have conversations with your parents as to, okay, I'm a little overwhelmed. It would be really helpful if you could do X, Y, Z. This way then the parent, the grandparent isn't trying to do something and be helpful and then you kind of resist that. Sometimes we, we love each other so much, we just get a little, a little tangled in, in what is helpful. So clear communication is really important when you're in this kind of stressful situation so that you can say, this will be helpful for me, or it won't be helpful for me, and then that person will wanna give you more 'cause then it's easier to receive help that really is worth it.

Conclusion and Resources

Candace Dellacona: It really is, and Dr. Lyons, I can't thank you enough for being here and sharing with us, Navigating AWEtism. And for those listeners it's spelled like awe in awe, awe, which I love. And I hope that those of you out there who have a special needs child or who loves someone who does, will look to Dr. Lyon's latest book that hopefully will come out soon, as you said, with updated resources. And we are grateful to have you here and to shed a little light on how best to navigate the in-between when you love someone with autism. So thank you so much Dr. Lyons, for being here.

Dr. Theresa Lyons: My pleasure. Thank you for having me.