

Project Sleep Narcolepsy Nerd Alert
Navigating School with Narcolepsy (Season 1, Episode 8)
Transcribed by Mirela Starlight

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Kenya Gradnigo of Opelousas, Louisiana, was diagnosed with type 1 narcolepsy with cataplexy when she was eight years old. In 2015, she received Project Sleep's Jack and Julie Narcolepsy Scholarship as she began her undergraduate degree at Northwestern State University. Recently, Kenya received a Master of Social Work degree from Louisiana College.

Danielle Brooks of Dacula, Georgia, was diagnosed with type 1 narcolepsy with cataplexy during her freshman year of high school. She was awarded a Jack and Julie Narcolepsy Scholarship from Project Sleep as she started her undergrad degree at the University of Georgia in 2015. Danielle recently graduated from Georgia State University with a Master of Science in communication sciences and disorders, and is now working as a school speech language pathologist.

In today's episode, Julie talks with Kenya and Danielle about how to get through school with narcolepsy, including high school, college and graduate degree studies. Having been diagnosed at eight years old and in high school respectively, Kenya and Danielle have many helpful tips to share with others about navigating school with narcolepsy, including how to advocate for yourself, doctors letters and getting accommodations, class scheduling and more.

The Narcolepsy Nerd Alert series invites listeners to dive deeper into specific topics relevant to living with Narcolepsy. This is a written transcription of the podcast "Navigating School with Narcolepsy" (Season 1, Episode 8) from Project Sleep.

Project Sleep is a 501(c)3 Nonprofit Organization, dedicated to raising awareness and advocating for sleep health, sleep equity and sleep disorders.

All guests and speakers express their own opinions. While medical diagnoses and treatment options are discussed for educational purposes, this information should not be taken as medical advice. Each person's experience is so unique, which is why it's so important to always consult your own medical team when making decisions about your own health.

Julie in intro: Students with sleep disorders have the right to an equitable education, but how do you work with your school and doctor to get educational accommodations? And what accommodations should you ask for? Today I'm joined by two amazing women who have both received Jack and Julie Narcolepsy Scholarships back in 2015, Kenya Gradnigo and Danielle Brooks, to discuss navigating school with narcolepsy. Danielle Brooks was diagnosed with type 1 narcolepsy with cataplexy during her freshman year of high school. Most recently, Danielle graduated with a Masters of Science in Communication Sciences and Disorders and is now working as a school speech language pathologist. Kenya Gradnigo was diagnosed with type 1 narcolepsy with cataplexy when she was eight years old. Kenya recently secured her Master of Social Work Degree and is now working in the mental health social work space. She is also a member of Project Sleep's board of directors.

Julie: Hello everybody! We're so excited for this, I just to— just go over what we're going to talk about— I think this topic is super important, you probably can't talk about it too much. People with narcolepsy not only face like, the symptoms of narcolepsy— taking treatments, side effects, and other complications of the disorder, but often— they're also facing misunderstanding, at school and work places and even at home. And so this is just the first of our nerd alerts to kind of tackle, at least the school aspect. And there's so many different parts of this experience, but we just thought for today we're going to go over some key tips. A little tiny bit about the legal framework for the American with Disabilities Act and how narcolepsy fits into that— a little bit about your advocacy team who should be on your side in dealing with this process— some different ideas for accommodations, and high school versus college versus grad school— the different phases of education, and of course some resources. But just to start, I think this is probably obvious what we think, but I think it's worth taking a second to say, is it worth it to get accommodations, or— should you even get accommodations? And, I know part of my own journey was— at first, when I was in law school, I didn't want accommodations right away. And then I came back a few months later and I said, maybe I will take some accommodations. So, I was curious from Danielle and Kenya's perspective, did you embrace accommodations right away, or did you have any of this struggle, and how you thought that might impact your sense of your self in any way.

Kenya: Yeah, for me it kind of was no choice to take accommodations because I had them so young, like when I first was diagnosed. So when I was pretty much, during grade school up into college, up until now I had them and at first when I got older I thought it was going to be a crutch for me but it actually turned out to be— very helpful, and I was very appreciative of my accommodations, so. It's definitely a strength right now for me.

Danielle: So I was diagnosed at the age of 14 and it was over Christmas break so we had some time to talk with my family and find some research and find Julie— that's when I found Julie's blog, right after I was diagnosed. And so that was one thing that— I was struggling in school to stay awake and everything, so we— my parents and I decided to talk with the teachers, and the meetings were, you know— hard at some points, because sometime— the teachers, they— they may not have understood what was going on. But that's when my parents and I talked about like, how we need to advocate for what my worst days— and I am so thankful that we got accommodations like from that, because I was able to do well in school and with those accommodations— 'cause, you know, it's not always easy when you have narcolepsy and are trying to figure out medication and all that. Especially towards the beginning, but I definitely couldn't have done as well in school without my accommodations.

Julie: So we're going to go over some key tips in the beginning and the end, but— you know, one thing that was important I thought as a key tip for anyone is, to really know what accommodations you want, before starting the process with the school. And I know that's difficult when you're newly diagnosed, you might not know what you want, or need— and we hope that the toolkit will be a resource that will have lots of different ideas for you to think about what would be helpful for you. I don't think that now or any time in the near future that we can expect a school to be able to know what the right accommodations are. In part because narcolepsy is pretty rare but also everyone's different with narcolepsy, so, what might work for me might be different than what works for Kenya which might be different from Danielle, so. Figuring out really what would you want is a good starting place.

Danielle: Whenever I go about making accommodations or writing down what I'm going to ask for, I would think back to my worst days, is that, without medication, is that— those days that I can't take my certain medications, what is that day going to look like, and what am I going to need, to succeed in school. So that is what I look at, I mean, I don't like to think about my bad days, 'cause they're not super fun— but it's one of those things that when they happen you

want to be prepared, so even if something may only happen like once or twice throughout the year, it's better to have that as a safety net. And hopefully you don't have to use it. But you know, having the safety nets in place is really important.

Julie: I love that so much. It reminds me of one of the exams I took in a really, really hot room.

Danielle: Ooh.

Julie: [laughs] So, plan to have an exam in a sauna— what kind of accommodations might you need? [laughing] Kenya, do you want to share this quote and where the story behind it—?

Kenya: “It’s okay to be delayed, just not denied.” It was from my mom, it's one of my biggest supporters for me, she really took the initiative to really— do the research, since I was diagnosed at such a young age and I didn't really understand but— in my undergraduate, just really trying to adjust to the new environment and medication and being on my own for the first time, it was a lot of days that I really struggled. And I actually was held back a semester, I called my mom and I was just crying and just needed someone to talk to and she was like, “Kenya, it’s okay to be delayed, you’re just not denied.” And, ever since then, I really just thought about that saying, “It’s okay to be delayed, just not denied.” Some of us do have to take an extra semester, some of us do have to take that break. To just step back and to breathe and just to tell ourselves, it's okay, you know. You focusing on your abilities and not your disabilities.

Julie: I love that quote so much. It just is one of those mantras now for me that I just love so, so much. Okay! I don't want to go too far into it but a little bit of the legal framework, to understand, does narcolepsy qualify as a disability? Because you might not be entirely sure and you might be talking to people that don't understand narcolepsy at all. Don't understand how severe of a condition, or— how individual of a process it is to figure out, you know, whether your medications are working, how you're going to accommodate everything. So! Just to go over a little bit about this. It's always an individualized process, so there's not like a list of conditions that are qualified as a disability in general, or for academic accommodations. It's always based on the individual, case by case basis. So how do that determination get made? Federal law defines for academic accommodations that an individual with a disability as, any person who has mental or physical impairment that substantially limits one or more major life activity. And so what are these major life activities? That, you know, have to be impaired, there are a ton. You know, there's a long list of them— and originally in the law it had examples such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working.

Julie: Those are activities that probably do get disrupted by narcolepsy, but I just wanted to share that in 2008 when some new activities were added to the list it included eating, sleeping, standing, lifting, bending, reading, concentrating, thinking and communicating. So, even if someone doesn't really understand narcolepsy and how it affects different parts of life, pretty easy to understand that narcolepsy would impact one's ability to sleep. That was a really helpful addition to the law in 2008 that made it more— more and more clear that people with sleep disorders, would be able to be considered— have a disability.

Julie: In addition in 2008 they added some interesting language that said that, you cannot make this determination in thinking about whether someone is feeling better with medication. So it's kind of almost like, taking you on your worst days, you know. You can't think, well this person has narcolepsy, but— they're taking drugs and so are they really— you know, impaired? No. The determination has to be made without thinking about any sort of mitigating measures such as medication. Which is also helpful. If we want to make sure that as many people as

possible should be able to access accommodation. And there's also a special pamphlet from the office of civil rights that talks about hidden disabilities— and how, there are disabilities that you cannot see— and that they still can very much impact, and impair life. And I think that's extra helpful for people with narcolepsy, to arm themselves with some of that language as well.

Julie: If you think about approaching this process, which is, you know, very different depending on where you are, but just some basic things to have ready, I'd say some basic narcolepsy facts, how narcolepsy affects the student or the individual and some accommodation suggestions. And— your advocacy team, so who you know should you think of having on your team, as you're approaching getting accommodations— should definitely be student, parents and your sleep specialist. Here's kind of like what the doctor should provide, as part of that process, and then I can't wait to hear from Danielle and Kenya about their advocacy team and how that's been. But a doctor school report should include like, the basic symptoms of narcolepsy, the current treatment options, impact on quality of life, and then things about what the individual is, you know, unique challenges for each— that individual. And then they should also include the specific accommodation suggestions, that are consistent with what the student wants. So, their letter can be consistent with what you're saying, as far as, whether that's getting a nap during the day or you know, needing someone to take notes for you, or something like that. That should be consistent with what you're suggesting. So, Danielle and Kenya, have you felt like this was a team effort in your experience?

Danielle: For sure. I was diagnosed at 14 so my parents were a big part of that, going in to my first few accommodation meetings and we had talks about what we were going to talk about and as I got older, I started taking over the conversation while my parents were still present, so I could learn those advocacy skills. If you don't have supportive parents, or they're not there, having someone like a friend, or another advocate in there with you in the meeting would be highly recommended, just to have another set of ears— but also to make sure that, you're being heard— and you have someone on your team. The doctors report is really important as well. I— in like, fluid communication with my doctor, if I need an accommodation letter I'll send something in the portal to her and— listing what I would like, and I'll send the forms and she'll have it back within the week— which is really helpful and that's the only way like I've been able to get my accommodations for high school, college, grad school.

Kenya: Yeah, I'm pretty much the same. My parents, my sister and of course my doctor and his whole team. I was lucky enough 'cause I know some people aren't that lucky enough to have the same doctor throughout their journey, so. I am very lucky to have my same sleep specialist and his team. And also it was a good thing for me to have that one roommate as well, that was a part of my team, that I could, uh, be appreciative of. Because she knew my condition and understood that, and anything I needed she was right there to help me along the journey, and she's still here for me so I could appreciate that. Accommodation wise, like you mentioned Danielle, like doctors notes, very very important. So, it was easier for me to transition to, uh, college. So I had certain things such as making sure I stayed on the bottom floor, just for safety measures. And extended time, and really communicating with my doctor like you'd said and also the school, what I wanted. And also, they helped me as well, they told me like, okay— you need to do this, this and this. Like my doctor was like, okay. You need to request for this, I'll sign off on it if you agree with it, just go to your school and have a talk with them and report back to me and— he was like, on it. He was like if you have any issues you make sure they call me.

Danielle: Yeah.

Kenya: So I'm very appreciative of that.

Julie: That's awesome. I feel like we need awards for both of your doctors, and that roommate Kenya, like, that is so cool—

Danielle: Yeah.

Julie: I don't know if she's like, taking applications for new friends, but— [laughing]

[Kenya laughing]

Julie: —send her my way. [laughing]

Julie: Let's go to some of these accommodation ideas! Kick this off with— managing sleepiness. Some of the different things people have shared with me and with Project Sleep is having a place or a time to nap. Or both. Do you guys have experience in, in that area?

Kenya: Yeah, not me so much. It wasn't in paper— that I had to like, be in a specific place or a time, it was on an as needed basis, so if I did feel tired during school or class hours I had a place that I liked to go that I was invited to by the school nurse. She always said hey, if you need a place to lay your head, you know you can always come to my office. And I had a teacher as well that was the same. She also offered her office for me to take a nap if I needed to. That was one of those accommodations for me during grade school, not so much for college.

Danielle: So for high school I— had a shortened day at school, so I didn't have to have all the classes in order to graduate. So that was how I mitigated that, and my mom would pick me up and then I would sleep on the way to swim practice in the car, but for college I lived on campus and close to campus so I didn't have accommodations then, but in grad school I asked the director of my program if I could, you know, use her office 'cause she had a couch— and she said, well if you need an accommodation for that like, we've got open rooms. And she got me a couch and a nap room. Which I was— blown away, and I was so thankful for it. So we had classes from 7 a.m. to 7 p.m. our first semester, with breaks— but it wasn't enough time to go home, so— and then I used that also in my internships with the schools and everything. I was able to have a separate room, I brought a yoga mat and a pillow and a blanket, and put it in a bag. And had that time designated. And I would leave that time flexible, and like one to two naps, during the day— you know, so that you're not— in, with like a time frame of like, you know, a variety of time frame including your set up and take down time so you're not like pinpointed on that, so they don't think you're like taking advantage of your naps. 'Cause you— I need them throughout the day in order to be able to— finish strong and be clear. Those have been very helpful for reducing that brain fog by the end of the day.

Julie: Yeah, that's a really good point, you know that, the time it takes to set up and break down, but also sometimes I often wake up not— feeling myself. And being able to have some time to just kind of process, where I am— come back to reality— [laughs] uh, before moving on. Alright! Did you guys have any support with note taking? Some people had described that they were able to have a classmate assigned to take notes, or they were allowed to get the teachers' notes.

Danielle: All of the above? [laughs]

Kenya: Yeah— I had, in grade school, I did use a recorder. So I would just place it on the teachers desk, up closer to them. When I got more into high school, I did have note taking, all my friends— we pretty much had the same classes so um, they— helped me take notes, 'cause there was times where I'd be dozing off and I'd go back and look at notes and I'm like,

okay I started writing this sentence and it just— turns into scribbles, so I can call them like, hey — what was this part of the notes? What did it say? And also when I got to college, they offered it— but I didn't really need it because I pretty much disciplined myself to stay awake and take my own notes, I just used colored pens 'cause that's what really helped me. And it really made me more engaging into what I was writing.

Danielle: I did not have a note taker in high school which would've been helpful. I did talk to friends and get notes if I needed them. Or my dad would re-teach me biology, uh, at the kitchen table every night. [laughing] For college and grad school I did have note takers, as well as— in grad school it was more along the lines of, they gave me a software that I could use, that I could download on my computer and, you could upload the Powerpoints, record the session— and then take notes, as the Powerpoint is going on, or as the teacher's speaking. But we shared our notes in grad school— we had the work smarter, not harder mentality, and— so everyone shared notes. That was helpful. But the note takers, I highly would recommend. Also like at some schools they get an incentive, so the notes sometimes are really good! Like whether that's like scheduling early, or—

[Julie laughing]

Danielle: —getting some money, so.

Julie: And I used a smart pen at work. And we just had them because I was a writer at my job and I was trying to write down stuff that doctors were saying, and they spoke very quickly. Everything they said was super smart and eloquent but it was hard to keep track between anyone, you know, just not even with the sleep attack or anything, it was just really hard to keep track of everything they were saying, so the smart pens were really useful, 'cause you could take notes— and then you could go back and I could like press the pen to the paper where I was— couldn't really remember what they said and it would go right back to that point of the audio and replay it for me. And also just— it felt very, it didn't feel too— invasive, or— I did have to ask them permission if I could record it, but. Yeah. It was kind of cool. Alright, in the classroom. Seating, placement, or ability to stand— some people I've even read, the ability to snack in class. So how about, you know, day to day in the classroom? Are there any sort of accommodations for that?

Danielle: Well I could— I could sit where ever I wanted in the classroom, but it was more along the lines of like, who ever I sat next to I would tell them, if I'm falling asleep, please elbow me— and nudge me. And I would ask the teacher not to make it known if I'm falling asleep or not, you know make a scene. The other thing is, I when I would talk to my teachers at the beginning of the semester, they would offer, if you need to get up and walk around or pace the back of the classroom, you are more than welcome to do it. Most professors it didn't really bother. If I needed to do that. Or get up and go get some water. So that was helpful for me, to kind of refresh myself or if I was falling asleep in class like to get up and kind of walk around a little bit. The other one thing for testing— I took, took all my tests standing up at a standing desk. And I had a chair there if I wanted to sit, and I know some people say their cataplexy would kick in too much, but I would still have a chair there if I needed it. But that helped me stay alert and then I could be moving, and active, to keep more fresh.

Kenya: Same— I had, um, assigned seating, in classrooms. Particularly in the front, that way I could stay awake 'cause if you in the back, then you the most likely to fall asleep. I know I was. And especially not against the wall because I had a tendency to lean on it and then, next thing you know my eyes start to close— particularly like an aisle seat if it was one of those classes that had tables and they had like, two people to a table against the wall or an aisle chair, I would usually get like an aisle seat. Also, um, closer to the door, in case I needed to stand up

and walk out because I would get restless legs. Or just to get like a drink of water. And I always did keep snacks, to snack on. And something with caffeine in it, not so much uh, coffee, or tea — it was most likely a Dr. Pepper or something. I would go to the nurses office, I remember being in grade school going to the nurses office and she used to keep those little cans of Dr. Pepper. Just for me. Those really came in handy, the caffeine.

Julie: Yeah. I just love hearing your perspectives. I know you already know that, but— it's just really cool to hear, to me, the different things. And now I'm just wondering about how many nurses are going to be stocking little cans of Dr. Pepper. [laughing]

[Kenya laughing]

Julie: There's a lot of absenteeism we often hear from the Rising Voices speakers, about— before their diagnosis, you know, or— often, when you're just new to being diagnosed. And so one of the ideas I thought was really neat, is that— you know, someone said, providing a doctors note for the whole semester or year as the kid was newly diagnosed and trying new medications so they didn't need a doctors note every single time, they had kind of a blanket one that the— they were able to use for the semester or the year. And yeah! I don't know if you guys had any sort of— there are often sort of very strict rules around absenteeism for, probably like grade school, so. I don't know if you guys had any experience in that area.

Kenya: No, I didn't have that. I was one of those students that I always wanted to be at school, I love school. So I tried my hardest not to miss school, I already felt like I was behind, because narcolepsy and when you're tired and you don't want to do anything. So I already felt like I was playing catch up, even though I really wasn't. But in order to prevent that, I really tried to make sure I had to go to school. That way I wouldn't get behind. But when I got to college that's when I really started missing classes 'cause there were days where I had an eight o'clock class and I would wake up and I'm like, *I don't feel like going to class*. I'm really debating if I want to go to class, or not go to class. So I really did just think about my doctor saying, it's okay to take those days— to take those extra 30 minute naps, or whatever you need. So, I didn't have like a— excuse, from the doctor, but teachers they really understood, you know, I had narcolepsy and they respected that, and— they always did give me the resources to— catch up, what I missed that day in class.

Danielle: For me it was a little different. After I started the night time medication— are we allowed to name medications on here, Julie?

Julie: Yeah, that's good.

Danielle: So I started Xyrem right off the bat and after I started that— finding out that if I wasn't able to take it, due to like getting a chest cold or something like that— then my day would not be so great. And so that's when I added accommodation in, saying if I'm not able to take my night time medication I may— be absent to class or— may need another nap— so that was something that I put in place at the end of high school. And throughout college and grad school. So that was something that was really important because like, the few times or maybe I — was only able to take one dose, and have to drive to campus. Or I've taken the second dose and I wake up, my alarm's going off, but I still feel the Xyrem and it hasn't been long enough to drive. You know I have to make that educated decision and I would email my professor— or ask, you know, for the notes, or just be late to class. That didn't happen too often, which is good, so.

Julie: And I just also think some of it's, it's— I don't know if you guys feel this but just listening to you I feel like it's sometimes also permission for ourself— that this is part of our situation, you know—

Danielle: Yes.

Julie: That's just like that, it's okay— to take that time. Because sometimes I think with narcolepsy it's not— black and white, it's a grey area. Could I drive? I guess technically I could, but— do I fully feel there, am I— you know, it's just sometimes a little bit tough to know. So maybe even just having some of that built in permission—

Danielle: Yeah.

Julie: —could be even helpful for ourselves, so. Alright. Homework! With extended time, anything I guess that one's kind of basic. I'm not sure if you guys had any specific thing that you wanted to mention. Oh there was one interesting thing that someone said about— that they did homework assignments, but they actually had ability to go back and make some corrections later, or something— if they hadn't had a good night the night that they were doing the home work— [laughs]

[Kenya and Danielle laughing]

Julie: So, I don't know if there's anything there?

Danielle: I did have one accommodation like, in high school I'm pretty sure, and— and maybe in grad school, because it's just grad school [laughs] it's a lot. I could ask for an extension— for me, then I would just get even more behind, so I would just try to get it done. But sometimes life happens and you have a brain fog and you need to go to bed. For me that was like, if I was doing homework, if I wasn't able to finish it I would just— and my brain was not working— you gotta go to bed. The sleep is important.

Kenya: I had extended time on tests and assignments. So, for me it was— an hour and a half extra time on tests. And with homework if it was— or projects, it was more so if it was— not if I missed it, due to like, an absent day— I really didn't use it then, it was more on the basis of, I was really struggling to finish the project— and I knew I needed more time and I— that's when I used that more time. But I never extended that more time, if that makes sense— like I never tried to take two or three weeks, knowing it was due like, a week. So I would try to have it like the next day or two days after.

Danielle: I also got extended time in coll— in high school it was like, time and a half, and then — that was same for college. Grad school I got double time. Which the classes are three hours long, so some times the tests would, they were, I would have like— basically it would take six hours to take the test. Which I let my max at like, three. And then I was able to take like I had rest breaks during my tests so I could go and I could lay down and take a nap, like would tell someone, hey, I'm taking a break. And then they could pause my time. That was excellent for accommodations for the GRE and my Praxis test— that was, very useful for those, 'cause I'm — very slow when it comes to reading and taking tests. And also sometimes I'll be looking at a problem or a question for 10 minutes and my brain is just not working and I need like, just—

Kenya: Mm-hmm.

Danielle: —shake it out, eat something, reset my brain. Get things flowing again. [laughing]

Julie: Class scheduling and priority registration. So, I know for me in law school um, I was able to get priority registration which helped to get in to some of the classes that the dean recommended as more engaging. More conversational, as opposed to lecture-based classes. Some of the more exciting teachers that you know, people were all trying to get into the class and— I did feel a little bit, badly, but— [laughs] I'm really, really grateful that I was able to get into some of those classes. And that priority registration could also help, if timing of the day with classes is an important thing, so. Is there anything about class scheduling that you guys experienced?

Danielle: I was the same way, I got the priority scheduling, it was excellent. Class scheduling I like to do blocks, like— three hours in a row and then take a two hour break for my nap and eating and then— if I had anything else. Later in the day is harder for me, so. The other thing is, if you're in college or anything, rate my professor, you'll be able to see which are the good teachers. That's so helpful. Then you can pick out who you want to have and even if the time might not be the best, if you have a really good teacher— then maybe you can find a way to work that in your schedule.

Kenya: Yeah. I had priority scheduling as well. For my undergraduate, it was freshman year when we didn't have like, the opportunity to pick the times, like— everybody had an eight o'clock class, and it was always those— English classes, or those math classes. So um, those was always eight o'clock. Which I actually really enjoyed because I got it over with and I had the rest of the day to do whatever, so I didn't have a problem with the early courses— but during the rest of undergraduate it was— a little mixed, um, sometimes I would have morning classes, sometimes afternoon with a big gap in between, so it really worked out. And then for graduate school, it's more— evening, three o'clock, 'till like nine at night. And that's like, all the time, so. You really can't pick what time.

Julie: Mm-hmm. It was funny actually, a friend from law school said to me, that— later, after she read my book— [laughs] she then admitted that she had known I'd had priority registration 'cause I'd gotten into this really popular class, I was the only second year student that had gotten into a class that mostly only third year students made it into. And at the time she didn't understand. And then after she read my book she was like, Oh. I get it now. And I feel really badly that I kind of, silently judged you, I guess? You know. So, it is what it is. People can't always understand, um— unless you want to write a full memoir about it and then— [laughs]

[Danielle laughing]

Julie: —try to get people to try and understand what you're going through. [laughs] Um, but she was a really good friend, she always has been. And I always felt she was a supporter, and always has really supported me, so you know even people that are kind of close to you and that generally seem supportive might not quite fully understand. Just a little tidbit! [laughs]

Danielle: Oh! One other thing, is reduce class load. I know I have several friends who have narcolepsy, that helped them able to stay in school. As well as, also sometimes like, you can switch out like, internships or do like an in-person internship instead of take a certain class, or what not. Depending on your program. So don't be afraid to ask, you know—

Julie: Yeah.

Danielle: —if there's something more engaging you want to do.

Julie: For a few more ideas I know, um— so cataplexy considerations— I know for me I felt okay at school. I think if I had a day where I was going to have severe cataplexy I probably

would've stayed home, sort of. You know, I don't know if you guys had any experiences around consideration for cataplexy.

Danielle: To let your teachers know, or your— a friend, if you have a close friend, know what to do in that circumstance. Because you can talk about it, but when it happens like, it's— scary to watch sometimes? I didn't realize that and my mom would explain that to me but when I saw my brother's first really bad cataplexy attack it was hard to watch 'cause I knew exactly what he was feeling. So just tell them what to do and make sure they like, for me like I didn't want anyone to call an ambulance. Because it— I'm not having a seizure, like I'll be up in a few minutes. I just need some space, and my— well now my service dog would be on me. But, just like, telling someone what to do— in that circumstance. If you have a full on cataplexy attack, I know cataplexy could be anything from just feeling it inside to facial tremor.

Kenya: Thankfully I never had a cataplectic episode in public on a campus or anything— I did have one in my dorm. Which that's why my roommate was very, very helpful. She knew what was happening and right away she called the ambulance and called my mom— and it was, like you said Danielle, very heartbreaking to hear— for me when I had a cataplectic episode I can hear what's going on around me but I'm—

Danielle: Yeah.

Kenya: —kind of blacked out at the same time, and I could hear my dad like, crying. And for me that what broke me. You know, just talking about it, afterwards like what happened— what the experience was like.

Danielle: Yeah.

Kenya: So yeah. It is a lot to take in, so— for our undergrad and the office of disability when they sent out the accommodation letters to all my professors— they had specific instructions on there, on what to do. If I had a cataplectic episode in class, you know, I'd like— just try to wake me up. Or just let me lay there for like an hour. 'Cause usually it will take me about an hour before I get out of it.

Danielle: Yeah.

Kenya: And if not, call the ambulance and call my mom and then, uh— they'll take it from there. So, I'm thankful I didn't have any cataplectic episodes on campus or, uh, like— caught off guard by it. I tend to know when it's going to happen. So I pretty much like, let them know like, hey you know I'm feeling a little bad so, you know, just— watch me or catch me if I tend to buckle or fall, so.

Julie: Thank you guys so much for sharing all of that. It's just, I'm learning more about you guys too! And it's just, but it's kind of comforting, in a way, to hear, you know, stories of other people and— your experiences. Not that you had to go through it, but. I know other people will be relating, I guess, is what I mean to say. To what you're saying.

Danielle: You're not alone! Like Julie said—

Julie: Yeah! [laughing]

Danielle: —Narcolepsy Not Alone! That is so huge, and so important.

Julie: Yeah. Um, alternatives to standard classroom— so, you know, like virtual school programs. People have mentioned online classes to make up credits to graduate, or summer classes. That those could be helpful? Or— homeschooling, possibly. Stuff like that. So. Those are things I guess to consider. And— final papers, that we kind of talked about that. I found, once I started treatment— I think I got a little bit zoned in, on Provigil. I don't know how to describe this but I would like, rabbit hole down— research. I would research, research, research. So a 20 page paper for law school all at once became an 80 page paper. And I just felt sometimes almost like, I was still adjusting to medication, I felt kind of compelled to do this research— and then— after my medication would wear off I'd be like, oh my god! I didn't get anywhere. 'Cause I'd gone in too much depth on, you know, a part of it. So, extended time really, really helped me. And actually, for one paper just kind of even had a few months extra— to finish a paper. My big final paper for class. And was really grateful for that. Because ultimately the teacher said it was one of the best papers she'd ever received— in all of her time of—

Danielle: Wow!

Julie: —yeah. [laughing]

Danielle: That's awesome!

Julie: I don't know if I wrote it, or Provigil wrote it. [laughing]

[Danielle laughing]

Julie: And then testing, you guys did mention about testing— and I— just to go over again though, cause I think Danielle you mentioned that you have something like a three hour limit, could you just mention that—

Danielle: Yes. So I— for any testing— high school, college, graduate school— my limit was three hours. So for the ACT, I had one section of the test, a day. So it took me two weekends to take the test. But it was very helpful because by the time I was done with one section my brain is fried! And it's been several hours. And I also had my own room for any of the tests— that was something that helped me because I like to read aloud and stand up. The other thing I did that with— the GRE, I got accommodations and I got multi day testing. So because I had the 3 hour time limit, I was able to do the multi day testing, which definitely helped. The other thing is with the ACT accommodations my parents had to call two to three times. For them to actually accept my accommodation. So don't be disheartened if you're denied. Just keep fighting for what you need— and advocate for yourself.

Kenya: It's pretty much the same for me as well. I did have a special testing site that I went to — that was one of my accommodations, was to go to the office of disability, they had their own room. I did have accommodations for the ACT like you said— fight for it, cause sometimes it can be a time before them to approve the accommodations, so— I did have accommodations for the ACT as well. I did take it with everyone else, it was just I had— more time. So I started probably before everyone, that way when they finished I probably finished as well, during the same time.

Julie: I think, similar to what you guys said— when I was in law school and I was kind of— mentally wrestling with the idea of accommodations— at the beginning, my dean did tell me, said that if you want to take the Bar exam, that the Bar exam people are going to want to see a record of you receiving accommodations in law school. That really helped me to then accept accommodations for law school, which I'm ultimately happy I got, and I never took the Bar. But

— I think that's really interesting, is building up that track record of using accommodations over time— can be helpful.

Julie: High school versus college versus graduate school— Just want to ask these ladies who have made these transitions— how did those transitions go— and any specific advice that is more specific, college or grad school? And then one more question which is, do you feel like your career choices have been influenced by your journey— your personal experience living with narcolepsy.

Danielle: So for me, like high school to college— I got so many more accommodations in college. I actually dual enrolled, so I took college classes my senior year, and they were like, "Oh, you can have all of these things!" Like a note taker, someone to record the lectures— an audiobook, as well as a book online that can read aloud to you. I was like, I didn't get any of this in high school. And they were like, "You should have. You should have been offered it." But that wasn't offered to me, and I didn't know about that. So, anything that might spark your mind, just like— ask. And do the research and so you can be like, hey, I can get this according to the law. Right? And for college versus grad school— like Kenya mention earlier, the whole— you don't really have choices really when your grad school classes are, so— that's why I needed the additional accommodation of, of a safe place to take a nap. And— that time to take a nap during the day. But everything is like, communicate with your professors— and even if they don't understand, like— provide them information— and tell them, and— hopefully they will. Or compare it to something they might understand— maybe be like, so— my nap for me is like, or my medication is like— a person with diabetes. They need their insulin, I need my nap. To keep going. So then they might be able to relate, oh— wait. This is real, and— you're not just a college student who has a terrible sleep schedule. [laughing]

Kenya: Yeah— the transition, from high school to college was, a little rough for me in the beginning. Like I said, Louisiana we have parishes, so— I started off in one parish and certain accommodations that they had there, going to a different parish in a whole different setting from high school to college— they may not offer the same accommodations, or maybe even offer more accommodations, so it's kind of like Danielle said like, I know I can get that. With that just all dependent on like, where you were and if— they had the resources to be able to give you those accommodations. Also, like I mentioned earlier, having a new environment, new people— going between medicines, really made the transition a little harder, but once everything got on the right track it was easier for me. Graduate school pretty much the same. It's easier now 'cause I'm— older and I pretty much know how to maintain my narcolepsy. How to schedule my medications and how to time manage those with assignments and get those accommodations. So uh, the transition was— pretty smooth from undergraduate to graduate school.

Kenya: And it did alter— my first major was nursing and nursing is very— demanding and— hands on, so it was hard for me, very hard for me to keep up. And I did fail two classes in nursing and— it really discouraged me, and it caused me to actually sit out for— three years. And I was like, *why sit out three years when I could get another degree in something else*. So I had a lot of credits toward psychology and social work. So I switched my major to psychology and I graduated in that. That's pretty much how I ended up getting my— well getting my masters in social work. It's pretty much on the same basis, just more— very broad. And I feel I can get into more— so much more, with social work. So I'm very grateful about that, and it was a learning and humbling experience for me.

Danielle: For the last question, did narcolepsy impact your career choice? I came into UGA wanting to do biological engineering and— with like, then go into PT school and work on— prosthetics. But first semester, bit ambitious, uh. And it was hard. I had like calc 3, chemistry, a

coding course and— P.E., and all the stuff. And it was just a lot of classes. I ended up going from 12 hours to dropping down to nine, I dropped out of calc 3— or, withdrew from it. And— chemistry was really hard for me. So I ended up making my first C ever— and [laughs] I made a C in chemistry and— so I decided to, I really loved science and learning, but I also really wanted to be in a helping profession, and I talked with my parents and some friends, and— found that my aunt is a speech language pathologist, and my dad was like, “Great flexible schedule. You get to work with people. It’s evidence based and science based. Why don’t you try it?” So that is why I chose to do speech therapy, and— I love it ‘cause my schedule is super flexible and also having something, and having a diagnosis really helps you to relate to people. And it helps them feel like, oh, wait— she’s done something, and is graduated from— grad school, or, like— I could do that too. So I love that advocacy part within my job.

Julie: Aw, man, I could listen to you guys talk about this all day, I think it’s a really cool and wonderful thing, that— some of your adversity I guess has, gone into helping other people through adversity.

Danielle: Yeah!

Julie: I did want to really quickly point out, you guys had talked about college accommodations around transportation, ‘cause the campuses are really big. And so if you could just share a little bit about that?

Danielle: My campus had a para-transit— bus, or system— it was actually a van. So, if you ask your, if you have a larger campus— not all of them have this, but, uh— UGA is quite large, so. I didn’t find out about it until I had foot surgery my junior year, and they pick you up from your class, drive you to your next class— and you just schedule it— it’s almost like an Uber. They had an app and everything. I had to do it, like a day in advance, but I knew my schedule. And also you could call, and schedule, basically like an Uber— you just might have to wait a little bit longer. So that was very helpful to help me save my energy, reduce fatigue, so definitely look into that. The other thing is I took busses, all the time. And I also had a parking— handicap parking sticker, and I know Kenya has one too. So you can touch on that.

Kenya: Our campus had a shuttle, as well. You just had to call them and they’ll come get you, bring you to class, where ever you needed to go. Thankfully, we also had the— campus police, so say you were at the library late at night and you probably walked there during the day, and it’s late and— you can always call campus police, they can come and pick you up and bring you to where ever you needed to go. So that was helpful as well. And, like you mentioned, the handicap sticker— which a lot of people didn’t know they can get— so, I would recommend that as well. I’ve used it very much a lot, for me— I was parking right next to the building that I had classes in. Not all the time that I use my handicap tag because some of those days when you really want to be awake or get some exercise or something, I did park like way across campus and walk. But it was really cold, or really hot, you know I didn’t— I didn’t walk. Mm-mm. It was, it was too hot. [laughs] But um, definitely talk to your sleep specialist or call your local DMV and ask them about those parking permits, handicap permit— ‘cause they can come in handy.

Julie: So I just love this quote, “I can do anything but I can’t do everything.” I think it’s true for — anybody, but probably for a little bit for narcolepsy, and I think prioritizing your time and— being a little bit more choosy about, what activities you get involved in, there’s always lots of activities on campus and everything, so. Just figuring out what is meaningful to you and still doing the most meaningful things. Just a few more tips, we have the tips that we already talked about— but then, you know, addressing concerns before problems arise— is always helpful, which I think is part of that whole process of the accommodations— it really helps to make

sure that you're talking to your teachers [laughs] before— there's an issue. And I think that can be very helpful. Putting everything in writing when interacting with the school district, making copies of everything, creating a folder. And really securing that full report from the doctor, that it's not just the parents' input, that the doctor also backs up— um, you know, about the condition and, and the students' experience with it.

Julie: So just a few resources to mention— disabilities.gov, [The Children's Law Center](http://TheChildrensLawCenter.org), [The College Board](http://TheCollegeBoard.org) is where you go about SAT accommodations, the [ACT website](http://ACT.org) for ACT. And I think, you know, [U.S. Department of Education](http://U.S.DepartmentofEducation.gov), [Office of Civil Rights](http://OfficeofCivilRights.gov), especially if you feel like you have been— denied accommodations, that you needed to succeed, with your education.

Julie: And then there are other great resources, from other great organizations in our space, uh, so just always want to mention [The Hypersomnia Foundation](http://TheHypersomniaFoundation.org), [Narcolepsy Network](http://NarcolepsyNetwork.org) and [Wake Up Narcolepsy](http://WakeUpNarcolepsy.org). Their websites probably have additional resources on these topics as well. And we're excited to add our [toolkit](#) to the list of resources available for people.

Julie: So, with that, do you guys have any final thoughts that you'd like to add, or— any final pieces of advice?

Danielle: You know yourself the best. Make sure you just advocate for what you need!

Kenya: I agree and, you know, focus on your abilities, and not your disability—

Danielle: Yep!

Kenya: —and turn your obstacles into opportunities!

Danielle: Excellent! Couldn't agree more!

Julie: Thank you to Danielle and Kenya for being here and taking this time and energy!

Danielle: Bye!

Kenya: Bye bye—

Julie: Bye!

Kenya: —thank you!

Access the toolkit for this episode [here](#).

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