

Nicky



Nicky Casty, mother of Janessa (age 15), Isaiah (13) and Avery (9).
Isaiah and Avery have mitochondrial disease.



A Long Indefinite Timeline

I had to learn to live in the moment and not look at the future

Nikki: -- when Isaiah was first diagnosed, I had googled at the time, mitochondrial disease and the things that you google are horrific because you only hear the horrible stories. When Isaiah was a year old, his first birthday I'll never forget, I just look back at some pictures from his first birthday, he was just released from Children's Hospital and I had about 50 people come in to our house and I just didn't even want to celebrate his birthday because I just didn't know what his future would be and Children's released me at 5:30, that Saturday morning and they said you're going to go and celebrate his birthday and we did. He still had IV marks, he still had the tape from him and we -- I -- I'll never forget the drive to Spencer and back from Children's and it rained and rained that day but we had 50 people show up at my house, and this incredible birthday party where people -- you know, saying happy birthday to him in sign language and it was just -- and I think -

Nikki -- having that support, you know was just huge for us and then you start to think about the future like, how long is Isaiah going to live, maybe he'll live till five, and then -- things get better and they get better, then Avery comes along and you say well maybe Avery's -- he seems much more mild than Isaiah, so maybe he won't -- maybe he won't walk but maybe he will be able to talk or maybe he'll be able to do some things. And so it's just living -- I had to learn to kind of live in the moment and not look at what the future holds because if I did that as a Virgo, I wouldn't be able to get out of bed so I'm just living for the moment and just being positive because really this is what's got me through.

I'm feeling trapped. We're getting closer to that future.

Nikki: So, me and my husband talk about our boys and what our future holds for our family, it's an ongoing discussion, we've had it from the day Isaiah was born and we still have it, it's ever changing. We've had so many obstacles and so many decisions and how we thought our future, is it going to go this way? Is it going to go that way? And you know my husband, you know it's taken him some time to open up, because he just -- I don't want to think about that right now, I

don't want to think about that. I need to have a plan, I'm a Virgo, I need to know what my plan is going to be for the future, so I can sort of ease my mind, and like I said the plan's ever changing, it now is a little bit more solid because I know Avery, my nine year old who's disease has progressed so far and Isaiah is much more stable, so I know Isaiah is going to be with us for a very long time. We just say Isaiah will probably outlive most of us, he'll be -- and we know Avery is -- you know Avery, and could get a very ill and a central line infection and be gone --

Nikki: -- Janessa is going to be graduating from high school in four years, I -- starting a new career and my husband is just at the prime of his career, so we're at the point now that we do have to start talking about when Avery is not here. We have this discussions as a family, what is four years going to look like for us? Janessa will be off in California for college somewhere, likely Avery will not be here, and Isaiah -- what do we do with Isaiah because I don't want to change diapers for the rest of my life, I love my Isaiah to death and I feel like he's been held back for a lot of years because Avery is so sickly and to manage the two kids, I think it -- I'm doing him a disservice and myself. You know, because it's that I'm feeling trapped in, I feel like, you know Isaiah, we're both being held back and I need to have a plan for my family for -- a five-year plan and so we're just at the stages of doing that but it's been ongoing all these years like I said it's changed and we're opening up more and more and more as we see that we're getting closer to that future.

Something always comes up. You do it again and again and again.

Nikki: So this crazy life, does it ever stabilize, does it -- it doesn't. Every time something new comes up, you know whether it'd be the decision to not do a trach for Avery, was that going to benefit his life, did I finally make that decision back then? That was a huge decision for us and once I make that decision, it's set in stone, it's in his hospital records, you've bypass that --then you know, life sets in again, then another decision comes up, he's got the scoliosis that's 90 percent then if you do back surgery, will he even survive the surgery and because he's only nine years old, every six months, you have to do the surgery and so then you have to make a decision -- is it worth the rest of his life, what little life he has left to keep on putting him through this so then you make that decision. You feel like that was another hurdle that you've gotten over and then you've got Isaiah, Isaiah had a severe bus accident over the summer, he was on this bus and they didn't strap him down and he flipped over on his head and broke a hip and knocked unconscious and he had a step back from that so then you have to now deal with that and so there is always -- between one kid and the other, there is always a setback, and you just -- you get through that hurdle and you just do it again and you do it again.

It's a suffocating feeling.

Nikki: So, how do I deal with the burden -- knowing that I'm trapped sometimes by having my boys and the burden of it and how that affects me, well I'll start with -- we've lost a lot of friends. For mitochondrial disease, every year one of the best posts that I had made said, "you know this is mito in my house, if you make plans with me, do know that those plans are probably going to get canceled because I might be going off to Children's Hospital with one of my kids, if you can't deal with it then you probably shouldn't be my friend." It's just that realization that there is nothing ever set in stone, we can plan, I can plan trips and likely I need to buy that insurance because I may not be able to go on that trip, I want to be able to do a seven-day trip with my daughter and my husband but we don't have enough nursing and we can't -- we can't do a normal seven-day vacation, it's just that trapped feeling and I have days that I just think why me? Why me? This isn't right, I see other people's lives and they are not trapped and they complain about things that I say really, I would just like to do a normal thing like take a normal vacation, we work hard, I work full time, we should -- financially we're able to do it but I can't because I have 24 hour care for my boys that in any minute, they could be whisked to the hospital, I could be on life flight and so that really is just a -- it's a suffocating feeling, it really is and I have days that I question how much longer can I do this. I feel like that superwoman role and I'm not superwoman, I'm just -- I'm a mom, I'm a wife, I'm a woman, I have my own things, I like to go to the gym and I feel like I need to still be me, and sometimes I don't feel like that because I just feel like a nurse, a doctor, a caseworker for my nurses, transportation, I just feel like I have to give, give, give. And it's just -- I struggle with that a lot.



DECISION-MAKING AND PALLIATIVE CARE

Medical Orders: Making the Decision Together

Nikki: So I was at the hospital, I brought Avery and I usually always bring Avery in and you know my husband will relieve me and I had told them that I was doing this form, and he knew what it meant and he didn't -- he knew I was doing it at the hospital and I even brought the form home and he didn't participate in it and so my husband, you know he has a good relationship with Marsha at palliative care team and she's a social worker. And it takes a lot for him to open up and I was just upset, I said, why is this my decision only? He's your son too and I know why he was doing it because he didn't want to have to deal with it, denial is best place to be, right? But you can't, you have to -- this is -- and I came home that day and I said this is not fair, this is our son, we need to make these decisions together, I don't want you to have any regrets and he understood and we sat down with that form and we redid -the form, and he went in that next day, sat with Marsha, because it had to be an original copy and he went in, I went to work and he sat with Marsha and they did that form together.



SELF CARE

I saw a counselor.

Nikki: So have I got any counseling? I did for a year and that was about two or three years ago, I had an incident where -- I like wine, and it was just a little too much for me and Rick, we were fighting and I just -- I got to the point that I knew I was destructive. If anybody knows me, I don't ask for help and I was at Children's Hospital and I just knew things were just bad, I was, going down a bad path and I just -- I knew I needed to fix myself because if I didn't, the family would -- it wouldn't be a good situation, and I had ask one of the social workers at Children's Hospital, and I said I need the number to a counselor --

Nikki: -- I work with her quite a while and she got me a list, I called the first one and stopped in the next day, it just worked out for a year, I work through a lot of my issues and I was done after a year./

I've learned to take the breaks I need.

Nikki: : I've learned slowly I'm a control freak - Initially when I had nursing for Isaiah, I would hover there and I think because slowly over time, I knew I needed a break that self awareness, if I don't get a break right now, this is not going to be good. I knew when to step away and I have moments when I say to my husband, I'm just going to lose it and I probably say that a lot and I don't even really know what losing it is, but I just tell him I can only take so much, I am only one person. There's not a day that goes by that I don't have to make a phone call, to a doctor, a nurse, a home care company, a supply ordering company for these boys and if I could clone myself I would, but it's just not possible and so those were the days that I just feel like I just can't do this. Do I ever get a moment that I don't have to make a phone call? And so I think there were times that I let it go, if I go on vacation, once I get on that plane, I may not call home for three days because they'll call me when there's something wrong, and I've learn how to do that. You know, so I'm on vacation, the minute I hit that airport, the flip-flops come on and I'd have a glass of wine. I know how to check it, because I've had to learn to do that because I know the minute I get back on that plane, the anxiety starts because I know I am checking right back into that life. So I've learn to take the breaks that I need and for me, I found this gym two years ago, life changing for me, it's people that know me as Nikki Nolt not Nikki mom or special need kids.



SPIRITUALITY

It's not fair and I'm at that point where I'm not sure I believe.

Nikki: First let's start with one of the worst lines I cannot stand is what doesn't kill you makes you -- no, not that one. That's not the one, I do believe that one is God doesn't give you more than you can handle, my saying to that and somebody said that on Facebook, is God must have thought I was a badass then, because I mean I really just don't -- I say that I just -- what God? And that makes me questions my spirituality. I think really -- I'm a spiritual person, I do, I but this has made question whether I believe in God because I just think, you know what God would want us to go through this, what God would want my daughter to have a future that she's going to lose both of her brothers? What God would want us to bury both of our children? And so it does that, I go back and forth over the years, I think my husband did that really early on, you know why us, why us? I was the person back then to say babe, this is what we got, we have to deal with it, let's not question it, it is just for us not to question and while I'm blessed and I feel like if I didn't have my boys, I wouldn't, I have such value of life and living life to the fullest, I'm -- it just really truly made me the core of who I am, it will make my daughter an incredible person in the future and I'm just so proud of the girl she's -- woman she's blossoming to be --

Nikki: Even my husband, I feel like we're such an incredible family because of my boys, but it's not fair and I feel finally okay with saying our life is not fair, and so I am at that point now that I'm not sure I believe in God, and my daughter, she goes to a catholic school, my husband works at central catholic at a catholic school and I think that she's going to find her way and I think he's finding his way with it.



MARRIAGE

Isaiah's illness almost got us divorced.

Nikki: If I go back, I had a period of our -- me and Rick's relationship after I had Isaiah, we were nearly divorcing. Isaiah was a year old, having this child that needed me 24 hours a day, having Janessa who is, you know still a baby herself, full time job for me, my husband working two jobs, -- they were away from home, I was on my own in the middle of a farm town, it just really got to our head and me and my husband were on that path of -- going to get a divorce, this is not going to work. Ironically, I -- you know I'm a little bit impulsive -- he didn't plough the driveway one day and I said that's it -- I'm done, I'm not doing this, I called the realtor and said, we're selling the house. This realtor (and I believe in signs), had said -- I said I'm getting divorce and that is it, and she said "honey, I'm going through a divorce, if this is something that you can really work through, there is a number of this counseling program that they have a two weekend course, why don't you give them a call," and I did, and it was five years of counseling in two weekends and it was all about your inner being and who you really are. You have to sit in a room for all weekend, eight to five with seven other random people, you had to meditate, journal, they would ask you a question, you would write it down and then you would have to sit

in this room with people that you didn't know and really say what you wrote, you can't -- you got to say it verbatim what you wrote and one of the biggest things that came out was --Isaiah was a burden to me, and as a mom to say that it was really hard, really, really hard. I now have this child that I -- he -- I am responsible for him 24 hours a day for the rest of his life, it was really life changing for me. And so I really learned a lot about myself with this, it really help with my marriage, and Rick actually, took the course as well and that got us on the path of -- okay, we can do this, so that by the time Avery came, we were like we're good, we are good.



ANTICIPATORY BEREAVEMENT

I try to prepare but there's just not going to be any preparation.

Nikki: So, how do I deal with the fact that I know I'm going to bury Avery, he's going to die. I'm a very verbal person, I mean I say it out loud all the time, you know, if I need somebody and they just find out my story and they'll say well, you know, is he -- how -- what's his progress. I'll say, well, he's terminal, so I say these in a very matter of fact way.

Nikki: I don't think about it every day but there'll be times in the car, you know, live in my car, driving my car all day every day, you know, there'll be just a thought that comes to my mind and I just get very overwhelmed then I'll start tearing up like what will -- how will I be okay, am I going to just drink myself into a stupor when Avery's gone, am I going to be able to get out of bed the next day, I mean, I know that this is coming but how -- you know, and I can -- in my head, I have a way and one of the things that I hit on with my counsellor, he said Nikki, you're trying to prepare yourself for something that there is no preparation for, you can't do it, you can't protect your heart. And some people may think it's a little easier for me because Avery's been sick from the beginning but there's no preparation of your heart for losing a child, there is not.

One of the most profound things, this is what makes my daughter so incredible, she said mom the thing is when Avery dies, who's going to take me to high school, she said because you and dad won't be able to get out of bed, I said Janessa, we will because you know what, we have you and Isaiah, so we will. I said it will be very hard but we will get out of bed, you know and she said, well, I can just find a ride from somebody else if you can't do that. So it's something that pops up, not frequently but when it pops up, it's just overwhelming to think, you know, the nurses will leave our lives and you know, where do I go, how do I get up, so I go back to the gym, do I -- I don't know where that's going to be. And sometimes, I get a little overwhelmed to think of all the steps because this little guy with that smile, with those crooked teeth and Janessa says, this big head, he just has, made such an impact in our life that I don't know, so I think about, I try not to delve in it and let it run my life but it's there, because I know it's going to happen. You know, so I try to prepare but there's just going to be no preparation.



FEAR OF REGRETS

I will have peace knowing I've done everything as his mom.

Nikki: I think the one thing that gives me solace is that it's going to be huge for me, I know Avery would not be here if it wasn't for me and I finally own that, Avery shouldn't be alive. Avery has had so many chances that he should've been gone, and the decisions that I've made for Avery, I think, have kept him where he is and so I've done right by him, I've made decisions that are right for him and I know that when he leaves me and us as a family, I feel like he's going to be like -- mom, thank you. His body won't work, he's done, I don't know how he stays alive now but I know it's the love that he gets, it's a higher level, it's not anything mechanical. I think it's really just out of love and he will leave me and us, Janessa, Isaiah, Rick, even the dog, when it is time, when he feels like he has completed his mission, I guess and I will have peace knowing that I've done everything that I can as his mom, so there won't be any guilt, it will just be pure sadness, just pure sadness and missing him, and trying to lead a life with that hole, missing.

One of the best things that a mom said, she had a son that died of mito -- I said, how do you go on, and she said, you know, I did this -- my son for all those years and I'm okay, we miss him but I'm okay and I feel like that -- I hoped to be me, that I just know that I will be okay in terms of, there will be no regrets, it will be just be sadness and just my heart broken and missing, you know, him, dearly.



WORKING WITH THE MEDICAL TEAM

I want providers to know that there needs to be some flexibility.

Nikki: So, what I want providers to know, doctors, nurses and you know, I've got these two boys -- who obviously are very medical, who needs lots of doctors' appointments. I could literally spend the whole month, I could not work and spend the whole month at Children's Hospital, going there three times a week to bring the boys for all the appointments that they need, not realistic. I need to work in order for me to maintain a house, I have to work, so I'm a mom of two very sickly kids yet I have to work fulltime to provide my family. My husband works two jobs to provide for our family so that the boys can get all the care that they need and the quality of life that they need. So I very well cannot spend three days a week at Children's Hospital, so I think it's important for providers to know that, you know, I've got two children and so, if I don't go every month or maybe it might be every six months or maybe you might need to do some home visits, there needs to be some flexibility and while it, you know, it helps with their care you can't do it all unless I hired somebody to bring both boys and I think that it causes me huge anxieties. I think that is the lesson I've learned with Avery because he's homebound. I bring in Avery for an appointment and if we're not on that road by two o'clock, he is in all out respiratory distress, by the time I get him home, I might as well drive him back to go in the ER because he would be in the ICU, that's how respiratory it is. So, the anxiety that I feel, to get him in for an appointment because they haven't seen him in six months a year, to bring him in it takes a lot, it's easier for them to say, oh, you know, just come in at this time or whatever, but now I had taken a day off

of work. I've got work demands and to do this times two boys, it's just too much, so I think just having some understanding from the providers that, you know, how can we tailor it for this family.

Now they say, "Whatever you say, Mom."

Nicky: Usually when I walk into the ER, a new situation I will say this is Avery and I give them the whole rundown which that's why I think I've built such a rapport with Children's Hospital because they appreciate me saying -- you know, when sometimes the doctors will say like, you know. I'll say, listen, you cannot give him anymore fluids, if you do this, XYZ is going to happen and they have their own way of doing things and guess what, they've done what they wanted and they saw the XYZ. And I then just have to stand back so then the next comes around, they're listening, it's all ears, so now I've perfected this over the years, that I do know my child and if I say he's going to do this, he typically does and it's gotten to the point that they now have a trusting, they say whatever you say, mom, you know him better but it took a long time to build that up, that they would trust what I was saying because I'm -- you know, the kind of medications Avery's on, are not typical for the homebound child -but because they trust that I can keep Avery at home for nine months a year, they're going to trust what I'm saying because you know, I've been able to keep him healthy at home. So, it's just building that rapport that -- I don't know that there's ever been, you know -- I've always guessed that there has been some situations but not really anything that I can stand though. I think that it's just -- I've got a great personality being able to communicate with them, that -- listen, you only see him for this very short period of time, I live with him at home, I know if -- I wouldn't have brought him in unless I knew he needed to be here kind of situation. So, I think that, you know, it's been a work in progress over the few years but it's perfected, now they say, whatever you say, mom, you've got it, you know and it really is nice to have that relationship because it's going to be a better situation for the doctors and for Avery, you know and Isaiah as well, so I think once you have that open line to communication, it benefits everybody.