Naomi

Mother of Noah (age 14). Noah was born very premature and lives with multiple complex medical conditions.

1	<i>Title: A traumatic beginning at 26 weeks. Mom: "As long as you're willing to fight, I'm here to fight with you."</i>
	Link: https://youtu.be/kbDO1bhKEkY
	Description: The mother of a medically complex 14-year-old talks about the first few months with her son and the complications that arose during that time as well as the moment she and her son decided to fight.
	Transcript: Naomi Williams: So, Noah is born, and he had to be revived, so he was born dead, was revived and I'm very thankful they worked on him for a little while. His Apgar scores remained very low, like 001 or somewhere in that vicinity. And it was it was touch and go, I didn't see him for, I don't know, probably 36 hours because I was really sick. So I had very late diagnosed preeclampsia. And when he was delivered, I was in HELLP Syndrome. My body was shutting down. So he fought for his life while he was in the womb.
	He was two weeks old, the very first time I got to hold him. And they were pushing it, like they really didn't want to, but I was, you know, you want to hold your baby. And he's this itty bitty, he weighed one pound, one pound 10 ounces. So he was he was the size of a 24-weeker at 26 weeks. So he had a lot of trauma going on inside, while I was pregnant. But that being able to hold was just life, it was life-giving for both of us. And Noah has been he's been marching to his own tune since he got here.
	So of course, he was intubated. And about a month old, and earlier in the week, he just started declining and I could see this decline. And the doctor and I ended up having a conversation because he was on CPAP and then went to BiPAP, he was coming down but then started getting worse. And I remember pulling the doctor that was on at that time and having a conversation like okay, what so what happens, what's next. And I was trying to get him to have that hard conversation with me, and we were right at the edge, but he didn't go over, right. And I left the hospital, thankfully that I live locally. So Noah was only two, I live 20 minutes away from the hospital. So I was able to come home and take a nap which I didn't do often. But I did that. And I missed the phone call and I'm listening to the voicemail. I was like please never, nobody ever do this. Leave a message, you know, Miss Williams, you might want to consider signing a DNR because Noah's not doing well.
	So I rush to the hospital. I am eventually allowed back to see Noah, and he and I had a very straightforward, poignant conversation. And Noah's looking at

	me. And that was the most present he had been all week. And I just said, you know, if you are ready to go, I don't want you to go, but if you're ready, I will let you go, just give me the sign. And we were all there. We were saying our goodbyes and nurses and all this. My mom, my dad, I stayed that night, they created a space for me to sleep, and he had no problems through the night, you know, his oxygen, his sign would have been coding again or having, you know, having to need a lot of support. Nothing, nothing. And so the next morning, it was just like, okay, well, as long as you're willing to fight, I'm here to fight with you.
2	Title: "Noah is a trainwreck on paper but he is so much more than that." A mother's high alert vigilance and advocacy for 14 years
	Link: <u>https://youtu.be/7TOEHhm2WkE</u>
	Description: The mother of a 14-year-old boy with medical complexity talks about the frustrations that sometimes arise when working with new clinicians who make assumptions about what her son needs before consulting her.
	Transcript: Naomi Williams: Noah is 14, and some of the physicians that we had, so some of these physicians, they're not, some are at retirement point, but they haven't retired yet. It's not even that part. When we have emergencies, we used to know the teams in the emergency department in the PICU. In those settings, they knew me, they knew Noah. And they knew Noah is not Noah is a train wreck on paper . We don't discount that, Noah and I have this, baby this, you have these diagnoses, right? These are all the things and you are not that paper. So yes, you have these things. Yes, they create limitations and disabilities. And you are more than that. And it shows up now where all people see is when they get his chart, they expect a vegetative person. And no, that's not who he is. Listen to me. Let me show you.
	So I've started I have videos and I have pictures. We went in once. It was about 10 o'clock, and by the time we got to the floor and the doctor came in, he said okay, so this is his baseline. And he was asleep. I said no, it's 10 o'clock, it's bedtime, it's called sleep. That's not his baseline. And he adds, he was super sick. And I said this is not my child, something is really, really wrong, he doesn't just sleep, that's not him. And thankfully one of his physicians who one of the specialists that knew him came in to see him. He's like yeah, no, this isn't Noah, this isn't the Noah that I know. So it shows up now with new physicians who don't trust that I know what I'm talking about, who rely solely on what they learned in a book, and/or potentially from what they've seen from other families. I mean, who am I, just again, I don't know. But I'm not them, I'm not them and Noah is not them.
	We recently just had a major medical error with a new physician. Who changed a medication without telling me and enabled him to get generic. And

	it was more so to get a capsule, Noah is solely G-tube fed. And so everything has to be able to go through the G-Tube without clogging it. They changed the prescription and said it was okay for him to get this. Not only was it almost life-threatening for him, in the sense of clogging the tube. I fought years, years with insurance to get this medication covered, because it's considered over the it is an over-the-counter medication, but he can't take it by mouth. And so fighting with insurance finally getting it cleared for this person in a matter of five minutes to potentially up and all of that. So it is and as a continual, I have to be on my P's and Q's.
3	Title: The mother of a medically complex child's advice to clinicians: Don't call me 'mom' Don't ask me questions you can find answers to in the chart and then some.
	Link: https://youtu.be/AOGmplq5Uok Description: The mother of a 14-year-old with chronic medical complexity shares some advice that she has for clinicians about engaging with patients and their families. She explains how she wants to communicate with her son's medical team and what she expects from them.
	Transcript: Naomi Williams: My advice is because at times I do have the opportunity to do this, it's when you come into the room, acknowledge everyone in the room, acknowledge Noah, say hello to Noah, tell him who you are. And if you're about to do anything to him, to tell him because he's a person. He can hear you and just because he can't give it back to you, in the same way that you give does not mean that he doesn't understand, that's my first and foremost, acknowledge him because he is a person and a person of value. Right. Who deserves and I will require that you give dignity and respect to him. Acknowledging me and being able to say, you know, ask the question, Miss Williams, or Naomi, I am big on and I will tell them don't call me mom, don't call me mom, I'm not your mom. And mom is not a word that I've heard from Noah yet. So you can call me Miss Williams or you can call me Naomi.
	But, you know, tell me about Noah, what is his baseline? What are your concerns right now and why? What's different? So he's 14, and, you know, we see all of the things that he has going on and the diagnoses, so what are your concerns because you're with him all the time. And so, level setting, if you will, and respecting me as the person who is with him day in and day out and knows him. think about the questions that you're asking a parent of a medically complex child. Don't just ask, well, has he been coughing lately? Well, he has respiratory issues. He has chronic bronchial dysplasia, he has challenges swallowing. So all of that would kind of tell you he's going to be coughing anyway, right? So what do you really want to know?

If you've done your part in looking at his chart, and you don't even have to do the whole history, what I'm not going to do is give you 14 years of history, when you have it in a chart, that's unfair to me, you're asking me, so I would want them to understand when you encounter Noah's mom is very different from Naomi. And I'm very upfront with that, and I don't apologize for that. I am not going to do the work for you, it is unfair to ask me to relive trauma to catch you up.

I understand when students come in, if I say please come in with the attending -- come back with the attending and I will answer any questions then that you have. Because I don't have the capacity, if there's something that is concerning me. And I tell you then I have to trust that you're going to relay that to the attending, and how I say it and how you interpret it, and how then you relay it may not be the same. I'm not doing that. Because I don't have the time, I don't have the capacity. So if you're a student, an intern, and sometimes even the resident, come in with the attending and we can have the conversation. But understand I'm tired. The hospital is not where I want to be, I'm concerned for my child, his life and his safety. And I want us to get it right. Let's be a team, I'm not being adversarial. And to that point, I would say get out of your feelings, it's not about you, it's about my son that is laying in his bed. Right. And I have gotten... I am direct, one of my colleagues will say Naomi let's round the edges. Okay. In some instances, I can round the edges and in others, it is what it is, and to be able to know that it's not personal, it's not personal against you, it's not. It's 14 years of being a nurse who didn't go to nursing school, who is sleep-deprived, trying to make things work and get the team to partner. I write questions on the board, or on the window. I think the last time he was hospitalized because they were asking me questions that didn't make sense to me, based on a child who has looked at the laundry list of diagnoses, and then what are the symptoms that come along with those, all the questions that you're asking me, he would do, coughing at night, not sleeping well, constipation, you know, all the things. So what is it that you really want to know? And let's think about what are those questions to get to that answer. So I will sit and I will think about okay, this is the question that you should ask me to get to the answer that you want to know.

We now have palliative care involved, and I'll just tell her, I need you to relay if you're not here, when we have these conversations, I need you to relate this to them, because I get labeled the angry black woman. And I am black, I am a woman and when you're not listening to me, I do get angry.

Title: A Complex Care Parent: *I love palliative care*. Link: https://youtu.be/LD-Vc7e6FF0

4

Description: The mother of a medically complex 14-year-old talks about how important palliative care has been for her son's medical care since they began

receiving it. She speaks to the support they have been able to give to both her and her son as they navigate his medical journey.

Transcript:

Naomi Williams: I love palliative care. I love palliative, our palliative care physician and the principles around it. Palliative care has been involved with us, our program here at our hospital was very new. And we fought, we had to bite to get them here. And so I'm so thankful that they're here. So we've had palliative care for maybe two years. I don't understand why but it's a different skill set, right. And I say I don't understand why, because when you -medically complex children are not new. Learning about how to talk about the hard, how to have hard conversations is not new, people and children die every day. As unfair as that is it happens and in this profession, I was really surprised at how uncomfortable people are talking about death. And so palliative care for me and for Noah has just -- it has taken a weight off of my shoulders. The time that she spends with us outside of appointments like we can go through and we talk about, we do talk about what's going on with Noah, what my concerns are about him and forward-thinking. But we also talk about my needs and where I am and how I'm coping or not, how I'm sleeping or not, you know, what is the path. Being able to continue, they have been my person where, and I love my son's pediatrician.

She lives a similar life that I do. So she gets it, which has been phenomenal, phenomenal support. And now having our palliative care physician, if I'm having challenges whether it's getting prescriptions or if there's an issue with things, I can go to her and she can be that intermediary. When we've had challenges with communication with attendings, she's been able to help translate, if you will, what I'm saying as well as what they're saying. she'll meet us at Noah's specialty appointments which is fabulous, so then I won't have to make another appointment to meet her. But then at the same time, she's able to sit in and hear what they're saying and then okay, well how do you feel about that?

People think about palliative and hospice as the 'death people' because they typically get involved or they are invited in at the end, when with palliative you can really, the support that is provided along the process, just like with spiritual care, inviting them to come in at the beginning, as opposed to at the end and it helps everyone, to me, it helps the journey so much more, it helps the patient, it helps the family members and it truly does help providers, I think with the interaction, decreasing confrontations or conflicts, not having this us and them sort of dynamic, but it's a, you know, we're here for the betterment of your loved one.

Title: Decision-making about a trach for my son: palliative care appreciates that it can be a loving decision not to do everything.

Link: https://youtu.be/KiJhMRdss30

5

Description: The mother of a medically complex 14-year-old speaks to how the medical system can make caregivers feel as though the only correct answer is to say 'yes' to an intervention when in reality, saying 'no' might be what is best for that child and family. She shares that hearing the story of another family who looked like her and made the decision not to trach their child, meant so much to her when she was making the same decision for her son.

Transcript:

Naomi Williams: When Noah was three a physician walked into the room an ENT walked into the room, and heard him breathing, so he had a bad strider, he walked in, he said 'he needs a trach' and he walked out. I was like oh, whoa. Okay. And so I have started this conversation since Noah was three years old or thinking about 'what does this look like for us?' And then in 2020, right before everything shut down, we were working to get, I think CPAP or do something. And the respiratory therapist, well, all he needs is a trach. Oh, okay. Just. Okay, thank you. And then just some other things have progressed. But from that point, at three, we, he and I talked about it. And Noah doesn't use words to communicate, but he communicates, right? We talked about trach. And what does that mean? And what does that look like? And how will that impact our quality of life, yours as well as mine? And even before we got to this conversation there was I forget the family's name. But there was a mom, who was -- there's a clip and she was talking about their decision to not do a trach. And I think up until that point, before watching that video had kind of been brainwashed, I had been brainwashed, you know, there's a fix, you can do it, if you love your kid, this is what you'll do. And then watching that video was, even though I wasn't in that space, and I didn't need that at that time, it was such a light bulb moment for me. One that, no, you don't have to do this. And if you choose not to, you're still a loving parent. And giving yourself permission to know your children and what's best for them and knowing what your family life is like, and what's best for your family. And it is a loving decision to not do everything.

So having that in the back of my mind, as I've been presented through the years with this for my own family, it's been very helpful. And she looked like me. So having a black mom and dad make this decision and know it won't be criminalized. And to be able to say I love my child with all my heart. And as hard as a decision as it is, it is the best decision for them. So that's a space that I'm in now because he needs a trach. And we've made a decision that that's not something that we're going to do because it would totally alter his quality of life. And even our palliative care physician, excuse me, had said, you know, I'm like he's not going to keep it in. He's an active kid, train wreck on paper, he's not this paper. And he has a good life. And he's active, and it would so change him. And that's not fair. It's not fair to him, in my opinion, because there's a fix, and it's not a fix. It's a temporary prolonging, and for how my son is that would not be a good quality of life for him. And so, this was a very

	long-winded answer to get to this, but our palliative care, when we are presented, when we are in meetings with new physicians, and they say, well, he just needs a trach, and she is in the room and she can back me up and say this is a decision that has been made and that's not an option that's on the table. And Naomi understands what that means.
6	Title: Parenting a medically-complex child: I tell him, 'This is between you and God. I'm just the one in charge of helping you become the best you can be.'
	Link: https://youtu.be/3WDKS1SiT-o
	Description: The mother of a 14-year-old boy with medical complexity talks about her perspective on life and how she has chosen to live each day with her son knowing that one day they will not be with each other.
	Transcript: Naomi Williams: I tell him, and I always tell him, since he got here, you know, this is between you and God. I'm just the one in charge of, you know, helping you become the best you that you can be. And that's all I can do. And so really paying attention to his cues. And even though Noah is completely dependent, there are things I can't make him do, which is really comical, and people don't understand that, I said, he has a lot of autonomy. And if he wants to do something, he finds a way. And so we talk openly. And he will, he will smile as part of his responses, he'll grimace, I mean his nonverbal, his facial expressions, his body language, his grunts or he's been vocalizing a lot more lately. And he'll repeat things. And so we continue to have the conversation.
	And one of the things that I do, and that I have done since he was little, I wanted to set him and I up for success. And to be able to set us up for a day when one of us were not here. And so I have worked to have other people, as I can, when he was younger it was a lot easier, now that he's bigger, it's a bit more challenging. But where he'll stay with others, whether it's family or friend and I'm gone. Like if I have to go away for business, and to know that you will be loved and you will be taken care of, if there's a day that mom doesn't come home. And I've had to set the same thing up for myself if there's the day comes, when he's not with me. So we live every day as it's our last, we make lots of memories, and we laugh a lot. And that's just how I have how I've chosen to do this life. It's hard, it is hard, it's challenging. And not the physicality of it is hard it's the systems that make it unbearable. But in wanting to make sure that Noah has a good life, and he has a good quality of life, and modeling what that looks like, and that I have a life too.
7	Title: The antidote to regret: the mantra – 'These are loving decisions.' Link: https://youtu.be/qCS3wkCiJks

	Description: A mom whose 14-year-old son has chronic medical complexity shares how she battles the regret and guilt that can sneak in when looking at the different decisions she has made for her son throughout his life. It comes down to reminding herself that love conquers guilt.
	Transcript: Naomi Williams: I don't have a fear of regret, because I've been very intentional about it and have had conversations. It would be very different, if I were faced with this, when Noah was an infant, or even a toddler like two, and if we had it then, you know, to now, but knowing, having confidence and knowing him, and how he is and the life that he lives, I don't. To also not be bullied into things, or in making that decision and I've had the privilege, this life is a life that not many get to experience. And for those who don't, I'm thankful to that they don't in a way, you know, but at the same time, I have had the honor of meeting some amazing parents and kids because of this journey. And I've had the privilege to support parents that have lost their children. And I have been able to learn from them.
	Some who've had they had time and had the opportunity to make decisions, and others who did not. I take lessons that I've learned from them. And I have been putting that into practice, and really thinking about, you know, we hear about doing advanced directives, as adults, we don't talk about that for children, because it's out of order, per se, but it happens. And so, learning from those who have gone before me, being able to create a plan. I don't have regrets.
	I do struggle with guilt at times. And that comes and goes. And the guilt is when Noah is having more challenges in pockets, and is like, okay, there's something that could be done to alleviate this. And I'm choosing or I've chosen not to do that. And the narrative that sneaks in is, there's something that you can do and you're being a bad parent by choosing not to do that. And I combat that with this is a loving decision. So having palliative is extremely helpful. And if that could be sprinkled into, you know, to the others, where it is the loving decision these are loving decisions. I think we get caught up where because there's a fix we should fix, but it's not truly fixing. It is not changing things. It's essentially prolonging some things, depending on, you know how you look at it.
8	Title: The Role of a Mother's Faith during her Son's 14 Years.
	Link: https://youtu.be/nrG-h2jFDiQ
	Description: The mother of a 14-year-old boy with medical complexity talks about how her relationship with her faith has changed over the years and what it means to her now as she looks into the future with her son.
	Transcript:

And there was my own regrets and how things have, it was not my plan let me say it that way. It was not my plan to be an unwed mom. And at the same time things happen, life happens and you move forward, right. I'm in a space now where I have faith and I have a relationship with God, with Christ. And that is something that is renewed, because for a while I was extremely angry, extremely angry, seeing other people and their children get miracles and trying to understand, you know, I think I asked God twice 'Why Noah?' Once he was in the NICU and the response I got was, well, 'why them?' and he was talking about the family next to us. Okay.There was this devotional called Unlocking the Treasure. And it took me two years to go through that devotional. Because as it brings up scripture, and it was a mom who had a child with disabilities, and, you know, going through and just as reading the scriptures, and I'm like, oh, no, you know, this isn't. And then how people how some church people are and can be. And really now as Noah is getting older I'm challenged. And I didn't expect I was hoping the world would be different at this point, right. I knew and I would say when he was little, he's a cute, sweet little boy that everybody wants to help with now. And as he does his part, he's going to grow and become a man. He's going to begrown, and he's going to need support. And so I'm working to build my physical community again, and asking God to help me.9Title: Isolation and Varying forms of Grief: Finding emotional support from with word. So it's a daily walk.		Naomi Williams: It's been an unexpected rollercoaster honestly. When I had Noah, and probably up until he was three, and in my book, it talks about, it's laced with scripture and journey and prayer. It was around the time when the doctor says, you know, at three or four, how ever he is, is how he's going to stay, and got to a place where, you know, God, I know you can because I believe in miracles, I see miracles every day. And even then, and, you know, I know you can heal Noah, I know you can take these afflictions from him. I believe that. I need your help if you choose not to do that. And so that was a big struggle. And coming from, you know, growing up in the church, being in the church, you know, people believing and praying and you have some, you know, feel that because I wasn't married, you know, this is the sin and this is the outcome of that sin, right. So, dealing with that part of people, which I don't believe that, but hearing that from others.
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Link: https://youtu.be/VQPij-NWd E	9	without in the community and from within

Description: The mother of a 14-year-old boy with medical complexity talks about where she looks for support and understanding that a single source can't provide all the different types of support you may need. She shares what she has done to build a community of external support for herself and how she supports herself from within.

Transcript:

Naomi Williams: So emotional support. My therapist is one. So learning who can support you where and when, so I have good girlfriends from high school that we don't live close, but we talk on a regular, and so being able to share, you know, where we are and so they are safe space. There are other parents locally, but everybody has their own stuff, right?

I work to check in with others, I have a dear friend in Colorado, we text every day. And we talk about all the things good, bad and ugly, you know, how are you doing and just being able to be really honest, which is, it's super helpful. I became a grief coach some years back because I realized that families like ours are not told about this type of grief, like it's not shared that, not only having a -- when it's a serious illness and a terminal illness, you know, you get kind of that support, but this prior to the medical complexity of it, and your world is flipped upside down. And the milestones that you miss, and not having the ease of moving through life as your friends. The grief that comes with that. But maybe others knew this, but for me, it was like, oh, my gosh, I'm grieving, I'm grieving. And it's a continual, a continuous type of grief.

And so learning that, and as becoming a coach in that, understanding where I am, and learning the people who can support me in different places of that. So, you know, my mom, or my girlfriends can't always support me in the way that I need in there. So finding different pockets of people. And then really working to not isolate, COVID wasn't hard until later on, because initially, for me, it was like, the world is getting a taste of what my life is like, welcome to the world, right? I probably shouldn't be like that, but it is what it is. Well, welcome to --

Blyth Lord: Everywhere family says that.

Naomi Williams: Because it was it was, now you have a taste and an understanding of what I live every day, and hoping that your experience will bring a bit more compassion and not pity, but sympathy and a taste of empathy, because you experienced that. And then they didn't. Right, it's like everything that you learned, you just threw out the window, and it's forget y'all, I can go back to my normal.

Learning how to be extremely intentional to not stay in the house, because I don't want to deal with other people's inconsiderateness. And in doing that, as I

show up for myself, I invite other families and other people to show up with me, whether they have children with different abilities or not, disabilities, medical complexity, everybody is going through something. And so working to create a space, creating the space that I need for me, like I've started a walking challenge, that's just how many miles can you get, I would need to reach 65 miles and I can't do that on my own anymore, even though I have used to run, I can't do that anymore. So can you help me reach the goal of 65 miles in a month, and the number of people who jumped in and it was virtually just, you know, tell me your miles. And we did over 1600 miles that month.

And we just did a glow, walk, and roll. So we did it at night. And it was like, you know, if you can come out, come walk with Noah and I, and the people that showed up, it was amazing. And the connections that are made. So believing, there are moments where I feel a lot of despair and hopelessness, especially when I think of the future of Noah as an adult. And to combat that, and to support my emotional wellness, I don't watch the news. I can't take it, I'm an empath too. And I hear about these but I'm not immersed in it. So I really have to watch what I listen to and what I see. But as I feel these things of hopelessness and despair, I will begin to list out what I feel that I can't do. And then look at, what do I want to do? and create gratitude lists and that helps to shift how I can begin to live the life that I want for he and I.