

# Raising Me to be a Good Person

## Young Adults with Complex Conditions Transitioning from Pediatric to Adult Medicine

04/28/2019

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### Cold open

**Morgan:** It wasn't until recently like maybe the past two years that I realized how hard that must have been for her. And I don't think I completely understood it until a couple of months ago. We actually talked about what it was like for her. I never really asked about what the whole process had been like caring for me and trying to raise me to be a good person and taking care of all of my medical issues and things like that.

**Amy:** When you love somebody you just do it. I would do it all over again a hundred times over.

### Episode intro 01:53

**Health Hats:** Welcome to episode six of the series about Young Adults with Complex Conditions Transitioning from Pediatric to Adult Medicine with Morgan and Amy Gleason. I interviewed Morgan and Amy in the previous two episodes. Morgan and Amy sound like pretty normal daughter and mom growing out of the self-centered teen years into mutually appreciative adults. In this episode we'll hear about that journey toward respect and shared support leavened with humor about the ridiculousness of some of that journey.

**Health Hats:** So, thank you guys for taking the time. I don't want to hurt your feelings Amy, but I got a ton more hits on Morgan's interview than yours.

**Amy:** I'm not surprised.

**Health Hats:** It is funny. You know I can't predict when people are going to be interested. How about we get started since everybody's got busy lives. I want to thank you, Morgan and Amy, for joining me again. We spoke individually before. I wanted to follow up with some questions.

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Push-me, pull-me. Our changing relationship. 02:33

From 11 to 20-years-old your relationship has really changed. Which, of course, it would 11 to 20 it just like everyday life. But how has it changed in relationship to, Morgan, managing your health.

**Morgan:** Obviously like you said 11 to 20 is such a huge jump. In the very beginning I didn't even understand that like what a chronic illness was. I thought that you took some medicine and then like a week later you feel better and you're perfectly fine good to go. So, my mom had to do a lot of the caring at the beginning. She obviously managed everything and made sure I took my meds and took me to doctors' appointments and things like that. As I got older, she actually started pushing me too. What age would you say Mom that you started?

**Amy:** Thirteen or fourteen? Probably yeah and then more 15 to 16 but you were already kind of there by this time.

**Morgan:** Yeah, some like somewhere around then and so I really started to learn how to take care of my own health from the very beginning are not the very beginning but when I when I was able to and understood what was going on. So, she started passing a little bit more responsibility over to like over to me and I just kind of had to learn how to do things and she always has been helpful and helped me along the way and things like that.

**Health Hats:** Was it your mom pushing you or you grabbing for control, or was it both?

**Morgan:** I think in the beginning it was my mom pushing. But not in a bad way. Like she just wanted whenever we go to doctors' appointments. She would make me rehearse over and over in the car. What things I need I wanted to go over and things like that. So in the beginning it was pushing and I hated that because you know, every teenager doesn't want to do what they're told obviously, But you know as I grow like as I got older I started to realize how important it was and then once I hit like 15, that's when my video came out and everything. So, I got a lot more involved. I think that was really kind of like a big push to get me into taking care of my own health. Although I was doing some but beforehand, I think once I got towards the end of high school, I was kind of like, "oh, well, I'm going to be going to college in a couple months. I better know what I'm doing." That was scary at first. But I always know that I can call my mom and ask her questions if I ever need to.

**Health Hats:** Do you concur? Amy?

**Amy:** Yeah, I think in the beginning from my perspective I had to actually not give too much information in the beginning. I had to kind of dole it out in pieces because it would scare her.

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You know, like when she was saying she didn't know that it wasn't going to be so bad. She took and it was going to be all cured. That was a huge shock to her. And that was when I realized oh, I need to be much more careful how I word things. I can't just say, "no, you're going to have this for the rest of your life." You have to be kind of like, this is something as we go along, you'll have ups and downs and explain it more in a way that she could understand it. I had to deal more I think in the beginning she kind of trusted me with the medical part. But more her mental health I think I had to focus on in the beginning. Her friend group changed because she wasn't doing gymnastics and cheerleading anymore. I had to kind of more help her with life coping and mental health I think than actually the physical. Then as we went along, we developed a way to talk about all that stuff and that wasn't such an issue anymore. And I had to focus more on we go to the doctor and they'd say well, how are you doing? "Fine!" So, then the doctor thinks oh she's doing well when the last two weeks she's been in horrible pain, but that one day she was having a good day. So, it's hard to remember.

### The big reveal. How much? To whom? 06:22

**Morgan:** Can I add to that? When I was, I think around that age I was very shy and the beginning I always have been very shy, so I think part of it was that I didn't want to just talk very openly with a complete stranger. I mean not a complete stranger. I've been seeing my doctor for like especially in the beginning it when it was brand-new. I didn't want to talk at all because I was very shy you know, so I think that was part of it for sure and then as I got older and I tended to get right I did get more extroverted and able to talk to strangers.

**Health Hats:** I know you're shocked to know this but I'm an extrovert myself. And I know that when there's a new doc in the mix, I feel like I'm 16 again. What do you mean you want to know about everything? Even though with my primary care doc I'll tell her anything, the good the bad the ugly. I don't care. I just lay it out.

**Morgan:** One thing I really, really struggle with is when I go to the hospital and I go get my infusions and treatments and things over the weekend. Because with an overnight stay I like to do it over the weekend. So, I don't miss too much class or things along those lines. A lot of times my doctor isn't on-call, so they have a hospitalist come in. I hate sharing information with them because it's just to me it seems completely pointless. I think the same hospitalist comes in every time, but I don't particularly like her that much. I don't really like to talk to her at all or share anything. So that's kind of like a new thing because I know that she's not going to be the one that's changing my medicine or any like she's not going to be the one changing my doses or tracking my symptoms. She's just kind of there because she has to be. So that's my perspective on it.

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**Amy:** I think she was kind of judgy with you and you didn't like that. She made judgments about you without knowing you. Why should I trust her? I'm not going to talk to her anymore. Because she's not going to do anything anyway, right?

**Morgan:** Yeah, I kind of just whenever she walks in. I'm kind of like she's like, so how are you doing and I'm like fine. So just like when I was 11, and it's just because I don't like her, and I don't get along with her very well. And I think it's pointless.

Clinical trials and data sharing. Deciding for your child. 08:46

**Health Hats:** Amy, you talked some about your concerns about clinical trials and data. About Morgan's privacy and her rights when she was a child. You were making decisions and you were thinking about what we're going to be the long-term implications of decisions. You are making on her behalf. Morgan, now that you're 20 and you're making your own decisions, are you feeling any implications of decisions that your mom made, that you're glad she made it didn't matter you wish she hadn't made?

**Morgan:** When it comes to my health care, I am pretty odd in this way. I genuinely don't care who has access to my data, I wouldn't say not care at all. But I'm very open with it. Like I share like I post pictures of my medical records online on my blog and stuff. So, I really don't care so much about privacy. I haven't noticed anything that from when my mom made a decision that has followed me. I can't really think of anything or at least if there is something it doesn't bother me. Exactly.

**Amy:** I always tried to have a conversation with Morgan about it whenever anything was happening like, "Hey, I'm about to share this are you okay with that?" Then once that was kinda out, then I didn't really worry about it the second time, because we already kind of talked about it. Clinical trials, Morgan is always said "I will do anything that I can do to make this disease better and to find a better treatment or a cure." She's raised money. She's talked. She's you know helped other teams that were newly diagnosed. So, she's always said, you know clinical research. I'll do it, but actually the very first visit they took 21 tubes of bloods from her and she was 11.

**Morgan:** And they lied to me and told me it was only like three or something. That's true. They're like, oh, it's just taking a really long time and I'm like and I never gotten my blood drawn before.

**Health Hats:** Amy, you spoke about that when we talked. I thought that like this was an area that I had never really thought about. It opened my eyes and my mind and I'm wondering in your guys community, Cure JM is this a topic of conversation that other people have? Amy,

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when we are in the Society of Participatory Medicine or that crowd that we hang with, this is a big topic of conversation. I just don't know if it translates beyond crazy advocates like us.

**Amy:** I think the moms talk about it more than probably other people. But it's more for fear of us doing something that they're going to regret us doing later. I don't know that I would expect Morgan to say anything different than I'm fine with it now. Because she's been involved in making that decision. It's more 10 years from now, 20 years from now, 30 years from now who even knows what our Healthcare System will be like. And what decisions will happen from data that was shared and most likely it'll be fine. But you have to make that decision, right? The only time I remember two things is we do a lot of fundraising for Cure JM which when you do fundraising you tell your story and explain rare disease and why there's no treatments and why we have to raise money to do research and all that stuff. I invited a bunch of people from Morgan school to a fundraiser like her teachers and stuff and she was mortified like off the charts. Like I can't believe you invited my English teacher to this evening, and I don't know that it was so much about the healthcare data as it was - it was some kind of an invasion of privacy. I'm not exactly sure.

**Morgan:** I think one thing is that if you had asked me before the video came out and I started speaking. So, when I was younger, I guess in middle school, I would have been like absolutely don't share anything. But my answer from that to now is very, very different. It took me a long time to open up about it with people that I cared about and people that I knew and friends. But that was really that was really hard at first to because it's very hard to hide an illness that causes so much like. I don't know the right word but

**Health Hats:** Disruption?

**Morgan:** Yes. Yeah, that would work. And also when I was in Middle School I started getting I started prednisone and I got the big puffy face and I've always been a very small person and then I leave sixth grade and I come back for seventh in August and it looks like I've gained like 80 pounds like so. I still tried to hide it at that point though. I still tried to kind of act like it wasn't that big of a deal or nobody really need to know or things like that. But then I really think the turning point was kind of when the video happened. Or maybe even the months leading up to that. I was getting much more comfortable with talking to strangers and things like that.

**Amy:** I would say in the beginning you don't want anybody to know and then actually it was fundraising that you said. Okay? Yeah, there's like three months in or four months in and there was this big contest and you said okay, you can tell the story and you can use this one picture. So, I sent it out and then you kind of got more comfortable but then there were still boundaries

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which is why I raised the English teacher like I kind of thought, “Okay. Well if we're going to talk... she was like interviewed by the news and she was in the newspaper. So, I was kind of like, okay well, it's out now. Well, then I found out like that's not really true. You still have like the English teacher off-limits.

**Social media. Different than real life. 14:43**

**Morgan:** I think that it's very different because I still kind of see my public like social media post it online me like as a different version than with people that I actually see in like real life and face-to-face. I was fine with it being posted on Facebook because I think I wasn't going to have to have that conversation with anyone at that time. And I didn't I think I didn't want the pity or the sympathy or the “oh you poor thing” like that kind of that kind of deal. Even now I've kind of with my friends now I kind of whenever I tell someone about it, I do it in a joking way like, oh I have this really rare autoimmune disease and I feel really horrible most of the time but you know, it's really great I love it and like sarcastically so I've kind of developed coping mechanisms and ways to break the ice that I had to develop over time and I didn't know how to deal with it because people...

**Health Hats:** You may feel awkward about it, but I'll bet other people feel even more awkward about it.

**Morgan:** I agree but I think they do feel more awkward because, especially people my age and in there and in high school like in teens and early twenties, you don't often meet a person who has at 20 years old that has a chronic lifelong autoimmune disease and I think the word disease really freaks people out. I think that's the one thing that. I don't even know but definitely when I say that I can kind of just tell by people's expressions. They first looked surprised and they kind of look like they got more guarded. I don't want to say they get more guarded and more reserved, but they just they don't know what to say to that like when you say, oh I have autoimmune disease and I look nor like pretty normal healthy, like I have an invisible illness like you would never really be able to tell based on looking at me unless you looked at the very close details like the rash on my hands and things like that. So, I think that people just their can they're shocked and they don't know what to say it first. So, I've kind of made it into a humorous like light-hearted sarcastic kind of thing.

**Health Hats:** You want to say something, Amy.

**Amy:** When you first went to college you were pretty open talking to people about it. And then I think you realized it was awkward because you had kind of stepped into a different audience. Then you stop talking to people about it as much until you know, you really need them. And

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even your roommate didn't know until she was tracking your location one day and she saw she was at the hospital and she's like hey, are you okay? I see you're at the hospital...

**Morgan:** Like oh, yeah, it's fine. I'll tell you later. And then I had to explain it to her and everything. Just because I don't know I found that it's easier to tell people about it once they... Because I think I think just a lot of young people they don't deal with disease frequently. Like that's just not something that is very common. So, I try to I try to make sure that they know me well enough to see that I'm normal and I try to make sure that they see that I'm normal and then I'm not like

**Health Hats:** So, you're normal and you've got these you're dealing with instead of you're not normal.

**Morgan:** Yeah, if I come right out of the gate saying, oh, I have this autoimmune disease, people are gonna be like, oh, okay like that's a little bit too much information for the first-time meeting. But it's also really difficult when people ask me what I want to do, like what I want to do in life and I say I want to do a public speaking and health care and they're like, oh. How did you get into that and you know, it's kind of an awkward situation?

**Amy:** Yeah, so I guess my point to that just to sum that up is, I think. And different audiences the amount of data that you share is different and different points in your life it changes and even when you think you have it figured out and don't always the one here and I think she's never wavered is on research data.

**Health Hats:** Yeah. Yeah, so you probably both know that you know, I lost a son and I think it is way more awkward. for people. That it is for me. Yeah, and I forget because I'm just I wear my life on my sleeve. You know, I blog about it. I podcast about it I talk about it. It's just you know, it's my life and I can just see oh whoops too much information. Better backup. I get all this sympathy which, you know, I just don't want.

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It's not just about me anymore 19:36

**Health Hats:** Let me ask a different thing. One of the things Morgan I heard you talking about when we spoke was your growing awareness of your mother taking care of herself while she's taking care of you. Can you talk a little bit more about how you became aware of...? I mean part of that is just growing out of your teen years where your life isn't just all about you.

**Morgan:** When I was first diagnosed, I was 11 years old. I mean I had no idea was going on like it was just a complete whirlwind and I didn't think about anybody but myself. I think I was on a lot of steroids which made me very angry and very upset. So, I would get very agitated and irritated. Yeah, it was the worst. That definitely helped it. I would my mom would try to do one thing and I would just snap I would start yelling and crying and like throwing a temper tantrum at like 12 years old like the and I but I mean it was just the steroids like I couldn't do anything about it. It wasn't until recently like maybe the past two years that I realized how hard that must have been for her. And I don't think I completely understood it until a couple of months ago. Maybe I don't remember if it was right after the accident or maybe right before but we actually talked about like what it was like for her and I for some reason I had never really thought to ask that before to ask like, I mean, I had a little bit like that must have been like really scared. Like I mainly meant just like the diagnosis, but I never really asked about what the whole process had been. And like caring for me and trying to raise me to be a good person and you know taking care of all of my medical issues and things like that. So it wasn't until we sat down and talked about that that I really understood and then as I got older and moved out and I realized I and I took on a lot more responsibility for my own like I had already taken on a lot of it in high school, but when you move out and you're living in an apartment like and like two states away, like, you know, you kind of have to take on a whole lot more responsibility and I go to the doctor's appointments on my own and things like that and then so I would sit there and think about oh, well, I'm doing all this and I only have to care about myself and my mom had to worry about me herself. My dad, my siblings like everything like that as well as balancing work and you know, just taking care of herself and like I. That's like a lot that's a lot to ask for and oh and all during this time as if she's not amazing enough. She was like starting a company and like building it from the ground up.

**Health Hats:** That's how you introduced it to me, my mom is an entrepreneur my mom, you know is she's got a life. She's got more than more than just me. I mean, that's how you yeah you broached that when we spoke and so, how's that from your angle Amy seeing? Was it like welcome that you know Morgan was beginning to or understanding the fullness of your commitment? Was that weird?

**Amy:** Actually, I don't know that I've ever heard it said that clearly has right now. I'm about to cry

**Morgan:** but I'm about to cry your eyes are tearing.

**Amy:** I mean we've talked about it, but I've never heard you say it all together like that at one time. yeah, it is hard, but you don't really think about it while you're doing it. You just do it do

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it. You just put one foot in front of the other and somehow you make it all work, , I look back now sometimes and I don't know how we made it It's a family like in general. I mean it puts stress on your marriage. It puts stress on the other kids put stress on your job, you know all the while. I wanted to help find a cure and did research stuff and you know, like there's only so much of yourself you can give, and at different times you can give more in areas than others. But you know when you love somebody you just do it like I would do it all over again a hundred times over and you know, I think Morgan is so appreciative now when I'll say, oh I can I can do that for you or can I help with that and she'll say you know, no Mom, it's really okay. I can do this or I really, yes that would help me a lot, could you help, and she's learned to balance that and then I know okay. This is something important and I need to drop this and do it right now or she's got it. I'm okay and I can kind of step back.

**Morgan:** And I think I think when I was in high school and teenager and everything. Like I said, I was very self-centered and I thought the whole world like revolved around me and I thought that everyone needed to drop exactly what they were doing at the exact time that I needed them and I mean part of that she's growing up. I realized my mom has a life. I'm not her only commitment like she has so many other things and yeah, you're incredible. I don't know how you did it. Do it.

**Amy:** I feel the same about you.

[Finding humor in this s\\*\\*t show 24:54](#)

**Health Hats:** Last question. You know managing the medical community for anybody, but especially somebody with complex medical stuff going on and somebody who's supporting them. It's a shit show. It's amazing it works it's just nuts. How have you found humor for yourselves in this shitshow?

**Morgan:** I think all you can do is laugh about things like when they get so ridiculous with the healthcare system that you can't even try to rationalize it or work it out. You kind of have to laugh at it there are just some things in the healthcare system that are so ridiculous and wild and like why would it ever be like that? Who made this that I mean, like if you were going to get mad about every single thing like you'd be mad your entire life or at least I would say spend a lot of time in the health like in hospitals and doctors and things like that.

**Health Hats:** What do you think if you were to pick a couple like real absurdities that you guys have gotten a chuckle over after you're pissed off?

**Morgan:** Oh God, I think do. I don't know. Actually, here's a recent example, so my doctor just started me on a new medication and. It that was in the beginning or the middle of March. And I

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just got the medication last week. It was it was like over a month ago now and so I like he prescribed the medicine went to the pharmacy. I was in Florida where I live instead of at school because I was there specifically for that doctor's appointment. He prescribed me the medicine and I had to go to the pharmacy to fill it. They said no, requires prior authorization. You're gonna have to because it was a controlled substance. So, I had to take it. I can't have them transferred across state lines. So, I had to go back pick up the prescription. When I got to school I had to go drop it off in the pharmacy. And stays there for what around to one and a half two weeks the meantime, we're trying to contact the doctor's office, the insurance company, the pharmacy. We're just like trying to talk to someone to see how they can get it pre-authorized everything I called the doctor's office. They said that the insurance sent them a form they fill out the form and send it back, but I don't hear anything back. Then the insurance said they sent the form to the doctor, but the doctor didn't fill it out correctly and they send them another one and I'm like, okay, we all y'all are telling two different stories right now. So, which one is correct? So eventually we finally get it worked out and the doctor the insurance sent the right form. Doctor signed it sent it back the insurance denied it. They so we went through all of that and the pre-authorization was denied and so. They were like, here's another list of medications that you could use as some like that we will pay for as a substitute to this. I was like, okay great. Call the doctor back. He orders another prescription for a new medication. I was on their list I go to drop it off at the pharmacy.

**Amy:** It had to be mailed.

**Morgan:** Yeah, I forgot about that. They mailed me the prescription all the way from Florida to Alabama. I pick up the prescription I go to the pharmacy. I go to fill it and the ladies like okay great. It'll be about 15 minutes. Just come back whenever. I'm like great. So, I went ran a couple more errands like and while I'm in the middle of one of my errands I get a phone call: CVS Pharmacy. hi-yah. Your insurance will not cover. This and I'm like, what do you mean it won't cover it. That's the list that it was literally the list that it was on the list like how and so thankfully it was a pretty cheap medication compared to the one before which was like \$600 in this one was only \$22. So, I end up just paying for it out of pocket and the insurance don't cover it. So. I mean, it was really frustrating at the time, but when you think about it, that's just that's hilariously ridiculous.

**Health Hats:** It is a very nice and that's a good. Yeah, what were you going to say Amy?

**Amy:** Well originally, I was going to say when Morgan was in the hospital so much when she was younger, we would take turns doing skits, imitating to healthcare staff and their silly things. We'd laugh hysterically and so, you know, they come in and flip on all the lights you're sleeping

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get up. I have to do this blood pressure, even though your blood pressure has been normal the last 22 times we took it, we must take it right now. Give me your arm. Yeah, so we would just exaggerate it and be silly and shine a light in the face, you know.

**Morgan:** Yeah and it made it made the hospital visits a little bit more lighthearted, a little bit more fun.

**Amy:** So, the other favorite is when they make you drive like, you know, you live a long way away. You have a test and you drive for an hour, then you wait for an hour and you wait in the room for an hour. You talk to the doctor. All your test results are normal. Like okay. Thanks for wasting our time. We make fun of that one a lot: the wasted time - waiting for normal.

**Health Hats:** Waiting for normal. There must be a skit in that. Yeah, good screenplay waiting for normal. That's a good. We'll have to work on that one.

**Amy:** I do think we've used humor a lot and I can't remember if I told you this story last time. So, if I did just stop me, but one of my favorite stories about Morgan is I forgot how old she was maybe 13 or 14 and she got to see her medical record the first time. Morgan is a cheerful something 13-year-old or whatever some artists. Like why does it say that? And I was like, well, they're assessing you as a whole being and your demeanor and your personality on that is part of how you're handling things in your health. And so, they document like how your mood is and how you act and Morgan kind of before that we were constantly "put your phone down when the doctor comes in. Answer their questions, you don't get that much time with them. Tell them what's going on." So ever since she saw that in her note, as soon as the doctor would come in the room, she would put her phone down and the biggest smile you have ever seen. Hey. Yes, and it's like I'm gonna make damn sure it says I'm cheerful on that note. She was really concerned about that.

**Morgan:** You said in the beginning that it said cheerful, but it said that I was closed off. Reserved, or something like that. And then and then I was like no I'm going to make sure it's going to say cheerful and it was just purely out of spite.

**Amy:** But it's goes to show you that having your medical records can also change the way you look at the visit. So, she got better care, ironically, because she smiled and put her phone down and engage the conversation then she did when she was grumpy and didn't want to talk to them.

**Health Hats:** Thank you ladies. It's a pleasure talking to you. This has been a gift for me. Thank you.

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**Amy:** Thank you. Yeah, awesome. Yeah.

**Health Hats:** Good luck on your exams Amy. I'll see you around the block. Yeah. Take care. Have a good day.

**Morgan:** Bye. Bye.

Episode wrap up. Next few weeks in Spain. 32:17

Next Friday my wife and I are going to Spain. My wife and a couple of her friends are hiking the Camino de Santiago, maybe a hundred kilometers in two weeks. And since I'm an assistive device kind of guy two canes or wheelchair. I'm going to go along but I'm not hiking. I'm going to get probably get driven from town to town and hang out. I'm going to try to podcast from there and I'm bringing equipment and I'm learning to use sound equipment in a different situation and capture environmental sounds and just try to tell the story while I'm in Spain. So I'm going to take a break from the series on young adults and it'll be back in three weeks. But this should be fun though. I'm looking forward to sharing it with you.