

Finding the Style that Works Transitioning from Pediatric to Adult Medical Care

04/14/2019

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Introducing Morgan Gleason

Morgan: I can make change happen. Like I could do one small thing. It can start with my doctor. Because if I tell my doctor, "Hey, I don't like how you're doing this." They might get a little bit offended at first, but they might take what you said into consideration when they see their next patient. It keeps like spiraling down. It doesn't take some big system-wide changed to change anything.

Health Hats: That's Morgan Gleason, a 20-year-old student at Auburn University. Welcome to the fifth podcast in my series, Young Adults Transitioning from Pediatric to Adult Medical Care. You're gonna love hearing from Morgan Gleason, already a veteran advocate after making a YouTube video when she was 15 that went viral about her frustrations as a patient in the hospital. Let's jump right in!

I went viral 01:41

Health Hats: Morgan Gleason. Hello. Please tell us a little bit about yourself

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Morgan: I'm a 20-year-old college student, but my main job is patient advocate. I speak at healthcare conferences. I have a website and things like that. I was diagnosed with a rare autoimmune disease when I was 11, about nine years ago. So, I have quite a bit of experience in the health care world. And yeah, so I just I'm just trying to make the Health Care system better for patients.

Health Hats: Okay, so you have the advantage in a way. That you've been struggling fighting the fight, whatever for quite a while. I'm trying to remember the first time I knew of you and I think it was your viral video. I already knew your mom, but I didn't know you. And I think I didn't put the two together. Tell us a little bit about that.

Morgan: Yeah, so when I was 15, I would go into the hospital once a month for infusions. So, I'm pretty used to being in the hospital. But at the point when I made the viral video, I had been in the hospital with meningitis for five days. I was on really high dose steroids. I wasn't feeling well, obviously. My head was killing me, and I was just getting really, really frustrated how I was being treated. I would come in and doctors and nurses and pretty much anyone under the sun would come into my room at 5 a.m. And I wasn't able to sleep from getting steroids. I was so frustrated. I just started venting to my mom. She was already involved in the healthcare community and everything, so she had a lot of connections. I guess I had picked up on some of the words that she had been using throughout the years and I started saying things like 'patient advocacy' and 'patient experience' which most 15-year-olds don't really know about and she thought it was funny. She videoed it just to send to a couple of her friends and it actually ended up getting published on Forbes, which is how it really got kicked off. And then the New York Times picked it up, the Washington Post. And so, then I got asked to speak at the Cleveland Clinic in front of 2,100 people for the first time. That was like the most people I had never spoken in front of before. That's kind of how it all started off.

Flying. Out from under a wing. 04:26

Health Hats: Wow. One of the things that interests me is that you've spent these years with your mom who's already an advocate and who's been running point for you, trying to deal with the medical system. Now you're off to college and your mom's there but not as much. What have you been dealing with as you've left home? Your more autonomous now, which is probably a mixed bag. But you're in college now. You've had health issues over the last week and ended up in the hospital and now you're fending for yourself. So how is that transition from pediatric to adult care happened for you?

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Morgan: In the beginning it was really difficult. But it was probably less difficult for me than most people, because I had started learning how to go to doctors' appointments and how to talk to doctors and how to make my own appointments and everything when I was young. My mom started doing that before any doctor's visit. She would sit there and grill me in the car and be like, "so what symptoms are you having?" "What are the specific things that you want to tell them about?" So, I got really used to doing that on my own which was extremely helpful when I did have to transition, finally. But I'm not going to lie. When I got to college, it was very overwhelming, and I went to school seven hours away from home. It's not like I can just drive home really quickly, or my mom can come up and help me. I kind of had to figure it out all on my own. I didn't know anybody going into college, so I didn't have anybody there with me. So, it was really overwhelming at first. My mom actually came out for a lot of the beginning appointments. Like first time I went to my new rheumatologist. She came out just to get introduced and meet him and everything and make sure I was comfortable with it. Like I said, I get the infusions once a month. So, I'm admitted to the hospital monthly. I think it's extremely important to have somebody there with you in the hospital. Even if it is like a routine sort of thing. So, she comes up a lot to help out with those. But it was definitely a big big shock when I came to college because I had to start doing everything on my own. I mean my mom still helps a lot. But now pretty much the only thing she really helps with is the billing side of it - the insurance and all of that because I'm still learning but that's a whole other issue. And yeah, so I guess just whenever I'm having like a rough patch my mom comes up, but I'm pretty capable of doing it on my own when I got here.

New cronies as partners 07:19

Health Hats: You were saying that you realize that it's important to bring somebody with you. That it's been your mom all these years. But now you're in a new situation. Have you been able to find cronies that can sometimes fill that role? Go with you?

Morgan: Yeah, my boyfriend now comes with me a lot. It's really helpful. We've been dating for two and a half years. He got initiated pretty quickly. But that was really helpful to have him there. I'm able to have him there when my mom can't make it. Because she has a job, she's a wife, she's working all the time. She can't just come up all the time and help me out. So, it's really important. I was in a car accident last fall, in September, and that was another huge thing. My mom came up and stayed with me a lot in the beginning because I have memory issues now. I'm scared of driving - being in the car. She came up to take me to all my appointments. I was seeing all these new doctors. I was seeing a neurologist that I hadn't seen before. So, she came

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up for that and then after the first couple months - once I started to recover a little bit more - my boyfriend started to help out a lot more.

New clinicians as partners 08:42

Health Hats: You're just now saying about a new neurologist, new rheumatologist. I know for myself - I have MS. When my first neurologist - who was a young curmudgeon, but I really, really liked him - he moved. It was really a big deal to go audition a new neurologist and you're dealing with a whole slew. You had a whole stable of pediatric specialists that you were comfortable with and now you're dealing with this in spades. So, how have you been managing that?

Morgan: It's always tough when you go to see a new doctor. Because when I first came to college, we were planning on me still being in Pediatrics for a little bit. I was still 18. They would still let me come for a little bit. We had actually plan on doing that. That kind of got thrown off the rails when they realized that they couldn't admit me to the hospital for my monthly infusions. So, we had this idea of she'll still be in Pediatrics for a little bit and then we could transfer because I go to a small college town. There aren't really many rheumatologists to choose from. We have one adult rheumatologist I was going to see in the beginning. I don't even think she was a rheumatologist. I think she's a primary care doctor. But she was one of our family friends. So, I was going to go see her and then that didn't work out. That was really stressful because I didn't know anything about this new doctor that I was now being forced to go see and that was my only option. If that didn't work out, then I was going to have to drive to Atlanta two and a half hours away to go see my doctor. Instead of being able to just drive 20 minutes. So, it's really stressful. Because of the car accident and everything, I had to actually see the new neurologist for the first time. It was it was a very strange situation. It was probably one of the weirdest doctor's appointments I've ever been to. She, for some reason, was trying to diagnose me with my disease that I have already been diagnosed with. She didn't really understand what was happening. She just didn't really seem like she cared that much. She's the only neurologist in Auburn, Alabama. So I'm now having to go to Atlanta for all of my health issues after the car accident and everything. So honestly, it's really just hit or miss but you got to hope for the best.

Health Hats: Yeah. One of the things that I find helpful is that I have a very strong primary care physician who I really trust and who hooks me up with specialists as I need them. She knows my style and what would work for me. So how do you handle that? Like having a primary medical partner whether it's a primary care physician or not. For some people it's their neurologist or

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their rheumatologist or whatever. But so how are you trying to set yourself up so that there's one doc who will fend for you, be your partner?

Morgan: Right. For me, that's my rheumatologist. He's an amazing doctor. Right from the very beginning he always treated me as like even though I was young and was my first time being an adult care. He always treated me like an adult which I really appreciated. So, he's always been that person for me for the past. Okay, and so that's amazing. I got really, really lucky with that. Because he's very hands-on and he knows that I know a lot about my health condition. He knows that he always takes my opinion into consideration before actually doing anything or occasionally even asked me, "What do you want to do? I'll prescribe it for you". So that's kind of my style. I like to play a very active role in my healthcare and finding a doctor who's okay with that and being able to accommodate you for that. I think that's an extremely important thing to have that partnership.

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It's messed up. What's the fix? 13:27

Health Hats: So, you and I are both in the situation that we drive our own train, whether we're able to or not. But everybody's not like that. In your advocacy work as you're thinking about other young adults that are facing a transition to adult care, what would you like to see happen so that was more routine? But it's never routine. What do you think? What are the key features for going out there and advocate for something or try to make change happen system-wide? What do you think are the keys are?

Morgan: That's a big question. The healthcare system is obviously so messed up at this point that you could change about anything and it would change healthcare significantly.

Health Hats: So, anything. [laughter] Pick one thing. But well, that's terrible.

Morgan: Yeah, it's pretty bad.

Health Hats: [Laughing] It's true. It's just I'm sorry. No so funny, but it's hysterical.

Morgan: Yeah, so I honestly think that the biggest thing that I've noticed really helps is to... That's why I adopted my style of driving my own train. That's what I found works best for me. But I really think that for all the other patients out there. You can't just copy what someone else

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does. You have to figure out what relationship works best for you and how you'd like to handle certain situations. Even when I was younger, I always I always would get very offended when my doctors would talk to my mom and not to me. But some young adults, some teenagers actually like that. They don't want anything to do with it. They'd rather not acknowledge that they have anything wrong with them. I'm generalizing a little bit. But there's so many different situations. So, I think just really finding the personal style that works for you. That has to come first.

Learning/listening to advocate better 15:58

Health Hats: You've been an advocate since you're 15. Thinking about more than just yourself. I don't mean just yourself. You put yourself out there. How do you see yourself doing that as you get older? You're in college which is one place where you can learn new skills. Certainly not by any means, the only place to learn new skills. But what is it that you're seeing for yourself? Because I think one of the things you want to do as you get older and get out of college is to continue to be an advocate and to grow and season as an advocate. So, what are the skills that you're looking for yourself, to make that more possible?

Morgan: Being a patient advocate is something that's very passionate to me. Through the huge exposure that I had when I was 15 from that video, I encountered so many different situations of people who had all these different problems. At that time, I was really only focused on myself. I hadn't really figured out how to – I'm not exactly sure how to phrase this - but how to help others. I guess, I don't know. That was a really big that's really helps me. It's just talking to other patients and talking to doctors and hospital administrators and nurses and getting all sides of the story. I find that that is probably the biggest way to make the most changes. To try to find a compromise between all of the different parties because, I mean, obviously there are some things that I want that just aren't possible with how the healthcare system works. There are certain things that are just not going to be able to happen. I just think that hearing all different experiences is just incredibly valuable to me. I'll always love listening to other people's stories because it always gives me some new insight into the healthcare system that maybe I hadn't thought about before.

Health Hats: What are you studying?

Morgan: I'm doing psychology and Health Services Administration right now. I definitely want to do something in healthcare administration. Being on the inside. Preferably I'd like to continue speaking and doing almost consulting. I think that's something that's really interesting to me or healthcare design, for sure.

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Health Hats: So, building your healthcare business skills is one of the things you have in mind. Is that what I'm hearing?

Morgan: Yes, for sure

Everyday kids my age need advocates, too 18:54

Morgan: I really want to be able to expand this. I just want to be able to reach as many people as possible because it's something I'm really passionate about. Everyone has an encounter with healthcare some point in their life. Like everyone. So, I'm not even focused on just the chronic illness, the people who have chronic illnesses, but I'm focused on kids my age because that was one thing that really. It doesn't surprise me. When I first met my boyfriend, he had no idea about anything with the health care system. He went to his annual checkup, maybe every 2-3 years he'd go see a doctor. If he had a cold, he'd go see a doctor. But he's never dealt with anything long-term and dealing with specialists and things like that. So, I'm also advocating for those people. Because he didn't know that he could stand up to a doctor and be like, 'hey, that's not what I want'. So, I'm advocating for people with chronic illnesses and the just everyday average people. Dealing with the health care system is a very valuable skill that everyone needs to everyone is going to need to figure out at some point.

Managing health as core curriculum 20:08

Health Hats: The silver lining in this for you is that your mother was skilled. You don't go to grade school or high school and learn about the healthcare system. That's always been sort of amazing to me. I'm a nurse and I've been a nurse for 45 years. I had been a nurse for 15 years and I realized I didn't know what I would do if an emergency happened to my family. I had gone to school for all these years and I'd practiced. So, then I became an EMT and then a paramedic and started working the emergency room because I didn't know what I would do if something emergent happened to my own family. And it still shocks me at how this is not like core curriculum.

Morgan: Right, I grew up around my mom. She was a nurse first. Then she worked at different EMR companies and she founded her own company - all based around the healthcare system. I grew up with it and my grandpa was a hospital administrator. I was raised on the healthcare system. So, I guess, like you said, that is kind of a silver lining. A lot of people I've talked to - a lot of kids my age who were diagnosed with the same disease as me - nobody in their family has any health care experience. You get this diagnosis of this incredibly long complex word to say

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and hear all the symptoms and things that you need to do and there's nobody to really help walk you through that and figure everything out. It is a very valuable thing that my mom was involved in the healthcare system.

You give me hope 22:09

Health Hats: I have a few degrees more hope with you out there. I guess I'm pessimistic about the healthcare system in general, but I'm very optimistic about what individuals and small groups of people can do in communities.

Morgan: I agree.

Health Hats: I'm glad you're out there and I'll keep following you.

Morgan: Of course. Yeah, thank you. I do think that it's very important. A lot of people look at the healthcare system and they see this big vast insanely complex thing. You look at it at first glance and you're like nobody can ever understand this. But I figure it out through being exposed to it - that I can make change happen. Like I could do one small thing. It can start with my doctor. Because if I tell my doctor, "Hey, I don't like how you're doing this." They might get a little bit offended at first, but they might take what you said into consideration when they see their next patient. It keeps like spiraling down. It doesn't take some big system-wide change to change anything.

Health Hats: Next week. I'm talking to your mom. I'm gonna talk to her about her view on this dilemma. I'd like to consider the possibility of chatting with the two of you together.

Morgan: Yeah, I think that would be great.

Health Hats: I guess I shouldn't be surprised but there's a lot of interest in this challenge of transition from young adulthood to adulthood and dealing with the medical system. I've been interviewing another young adult and mom. Also, a very active mother and a knowledgeable mother. I'm more challenge to look at the dilemma with people that don't have the cognitive abilities that you do. I did interview a mother on Monday who has three children with severe genetic challenges. And while on the one hand talking to her, I just wanted to cry. On the other hand, she's out there advocating. I mean she has the energy to ... She's built this whole advocacy of helping parents who have children with this rare genetic challenge that three of her kids have. She thinks about teenage, young adult autonomy. That transition you go through in this part of life. She has kids that have varying abilities to be autonomous. Right? And I'm like, whoa!

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Morgan: Yeah, I can't imagine having to go through the healthcare system without being able to advocate for myself because I'm just like that. I've always admired people who are able to do that because it's insane to me what people can accomplish.

Health Hats: Yeah. Thank you. I appreciate talking to you. I look forward to talking to you again, of course and take care of yourself.

Morgan: Thank you so much.

Health Hats: Okay. Bye.

Closing 26:14

I was right, wasn't I? Already a well-spoken, engaging veteran advocate. We heard from Sara Snyder, in high school. Now Morgan in college. Common underlying issues, different settings. Building a team - family, peers, a lead, coordinating clinician. A team that works for them. I meant it that they both give me hope. Lived experience firing their desire to give back. Ahhh. [Deep breath]