

1 MARTIN: Hey Guys! Martin here from the Ad Council. Welcome to our
2 second podcast. Today we're going to do something a bit different from the last one.
3 We're going to be giving you an audio version of our latest presentation, My
4 Differently-Abled Life. That's what it's called, right?

5 KAREN: Yes.

6 MARTIN: I think that's what it's called. Today we have me, and Emma.
7 Emma, say hi.

8 EMMA; Hi.

9 MARTIN: And we also have someone new to you, not - well maybe, not to
10 us. This is Karen Harvey-Ohlson, who is our Youth Coordinator. She kind of makes
11 sure we're on track and such. She's going to present the questions that we're going to
12 be discussing. Would you like to introduce yourself?

13 KAREN: Hi, I'm Karen. I will be facilitating this podcast today, giving the
14 topics that the youth will be discussing. This topic came about at one of our meetings
15 when the youth were discussing kind of life as a youth with special healthcare needs or
16 disabilities, and how they wish their parents understood such and such, or how they
17 wish their teachers knew what it was like to, you know, have to be dealing with chronic
18 pain and also have to study for this exam.

19 So the youth got together and came up with a series of topics that they felt kind
20 of were the main points around that discussion. And we've gone around this year and
21 presented at various family support councils for an organization in our state called
22 Partners in Health, which provides support to families who have a youth under the age
23 of twenty-one with a special healthcare need. So our Council has gone around and

1 presented to these families and kind of just giving them some insight into what it means
2 to try and be a “typical youth” dealing with youth things like relationships, and wanting
3 to go to the basketball game, or tryout for the play, but also living with chronic pain or
4 chronic illness. Are we ready to start with our topics?

5 MARTIN: I believe so, Ms. Karen.

6 KAREN: All right. So our first topic is Parents. And you could sort of
7 frame this topic as in what do you wish your parents knew, or what do you wish that
8 they could understand, or what do you wish you could tell them about your life as a
9 youth living with chronic pain or chronic illness?

10 MARTIN: So parents are tricky, because they’re kind of who we rely on,
11 who everyone relies on, whether you have a special healthcare need, or disability, or
12 not. But when you have a special healthcare need or disability that kind of amplifies
13 times ten, because they’re your advocate, they’re the person you rely on to remind you
14 to do your meds, and like there’s a lot of things that a parent is responsible for, but the
15 typical parent/child situations that present themselves still exist and it’s still not
16 particularly easy to get along with your parent all the time. That can be difficult if you
17 are somebody who has a serious illness that needs attending to.

18 EMMA: So when you’re a teenager your relationship with your parent is
19 complicated, but if you have a special healthcare need or disability, now your parent’s
20 not just your mom, they’re now your caregiver, and they drive you to your doctors
21 appointments, and do all this stuff you can’t yet. So it gets really complicated because
22 now you and your parents are now doing kind of a shuffling game of parental
23 responsibility, then caregiver, then back to parent type of thing, so it gets really messy

1 sometimes and it's hard to like be able to parent smoothly. Like no, you can't stay up
2 till midnight, or you can't do this or that, and you have to then be well, if you do this
3 then you'll get really sick, but you can do it type of thing.

4 So what gets really tricky with me and my mother is I have a chronic pain
5 condition, so because of this I don't look like I'm in pain anymore really, unless it gets
6 really bad and then I'll be looking pretty bad, but so it gets complicated because I don't
7 tell people if something hurts really bad a lot, unless I need medication, so then usually
8 like my mom is like do homework, or get off your phone it's midnight type of thing, but
9 I'm in too much pain to go to sleep. So that ends up sometimes with me being a little
10 snappy because I'm annoyed that she's not recognizing this because it's been five years
11 when, you know, I do look like a normal person a lot of times so it's hard.

12 So you have to remember a lot of the time that even though they're with you
13 every single time you're in the hospital, or you're at a doctors appointment, and you
14 spend way too much time with your parents now, to the point where you think they
15 understand everything without you having to say it, they don't. They can probably
16 understand about half the stuff without you having to say it, but there are always going
17 to be moments where you have to remember that they don't live inside your head. You
18 have a chronic medical condition so you get good at hiding it. So I look like I'm fine
19 and I can go run around, but I actually can't, and if I stand up I'll fall over.

20 So it gets messy because then your parents, my mother, won't know that I'm
21 being snappy and angry because I'm in pain and I want to scream, but I don't. So she
22 thinks I'm just being a teenager, which ends up in arguments because she's like you
23 can't yell or swear, you know like a normal parent going to a teenager telling what's not

1 acceptable, and then it usually ends up with me saying my leg hurts. Then she's like
2 well why didn't you tell me in the first place, I would have left you alone? Which is
3 kind of my fault on that front.

4 MARTIN: Yeah, I think there's definitely - it's definitely hard as a child to
5 have something like that, and then not necessarily want to always have to tell your
6 parents, because like you want them to know on your own, but you also don't
7 necessarily want to burden them, because you know they can't make it better. So you
8 know it'll upset them so you don't want to tell them, but then you're snappy, and then
9 they're like well why are you snappy? And you don't tell them, and then it's just a fight,
10 and that's not fun for anymore. But for me, I have Lyme disease, and my biggest
11 symptoms with Lyme disease are anxiety, and then I get joint pain. But I have not had
12 as much joint pain recently as I used to.

13 But for me, my anxiety, it comes and goes. It's not a constant thing, and when I
14 do have it, it's usually pretty bad. And my mother also has anxiety, and at a certain
15 point I figured out well if I tell her I'm anxious, it's going to make her anxious, and then
16 I'm anxious, but now she's anxious, and no one is better. So what's the point in saying
17 it in the first place, and that's not super healthy. I think it has caused, I'll get to it later,
18 but it has caused situations that were not fun because of that, and I have gotten to the
19 point where I realize okay, now I do need to tell it, but there's different ways around it.

20 So in the past I would have been like "I'm anxious," and then she's like "Oh my
21 God, what do we do?" And then everyone is anxious and nothing is getting better. So
22 now instead of doing that I'll be like "this is bothering me," and kind of focusing on the
23 specifics of what is, rather than saying "I'm anxious," it's kind of like a general thing, I

1 will say “I’m nervous for this.” And then my mom can be like “yo, okay. Feel better.”
2 Which is more constructive than if I’m just like “I’m anxious” and then she freaks out,
3 because then we’re both freaked out.

4 So I feel like, for me, focusing on better communication skills is helpful. And I
5 think the other thing is my dad is not an anxious person at all, in fact he’s very not
6 anxious. He tends to be a good bridge of anxiety, because like if I’m anxious and I don’t
7 know how to tell my mom, I can tell my dad and my dad can be like “okay, I’ll help you
8 like tell her, or I’ll just listen because it doesn’t bother me.” So that, I’m really fortunate
9 to have that.

10 But at this point, I think, looking back I really see that communication is the
11 easiest way to fix it, because there are ways you can communicate what you’re feeling
12 to your parent that won’t upset them. Or if it does upset them, you can communicate to
13 them please don’t show me you’re upset, because I can’t tell you if you show me you’re
14 upset. So if you have a reaction can you do, like I know it sounds selfish, but can you do
15 it somewhere else, because like if you want me to tell you I can’t see that, because it’s
16 very hard to see your parent emotionally distraught or upset, especially if you
17 internalize a sense of this is my fault because it’s my disability that’s causing it.

18 EMMA: Yeah.

19 KAREN: Yeah, we had had a story related to us on the Ad Council where
20 there was a young adult with diabetes whose mother would get so upset when he was
21 having issues with his health condition that he stopped telling her, stopped talking about
22 it, and so he ended up in a pretty serious health situation because of that. And
23 everything did resolve itself and turned out okay, but his message was just to kind of

1 talk to your parents about you know, it's okay if you're freaked out. Like you're scared
2 about your child's health, that's great, but go be scared. I think I said this the other day,
3 like go pick another place to have your freak out. Don't do it in front of me, because
4 then you're now making me, you know, responsible for that, and then I'm not going to
5 tell you things that maybe I need to tell you because maybe we should be going to the
6 doctor instead of, you know, sitting on the couch, but I'm not going to say it, so.

7 EMMA: Yeah, going after that, my mother is a very emotional person, and
8 I am not. So, that alone already isn't a good combination when we're locked in a room
9 together because I'm sick and she has to take care of me. So what would happen was
10 you can't fix my condition, and the medication I have helps me very little, and
11 sometimes it doesn't do anything at all.

12 So, I got sick very fast and no one really knew what was happening. So my
13 parents and me both realized at the same time that you couldn't fix me, which of course
14 made them upset, and me upset, but what started happening was when I told my mom I
15 had pain, or it was getting worse, or it was spreading to a different part of my body, she
16 would get upset, and you know sometimes maybe cry. She knew it was a normal
17 reaction, but if your parents are now upset because of you, and what happens is you
18 realize that okay, well this is happening to me and I know no one can do anything about
19 it, and if I tell anyone it's not going to change it, so I'm just going to keep this to myself
20 and suffer alone, because you know then that's only one person that gets to be upset
21 about it.

22 So what happened was I ended up in a couple kind of dangerous situations
23 because things were happening, and I didn't tell my mom until I told the doctor, and

1 then you know took me off to some tests, and it turned out that there were some bad
2 things happening that shouldn't have been.

3 So really me and my mother came up with a deal after one of these incidents
4 was that okay, I will tell you something, and I'll tell you any medication, but you can't
5 react at all. Like don't be upset, don't be indifferent, just say okay, what can I do to help
6 you. And then she would go like outside or in the hallway and have her own reaction, or
7 cry, or whatever she did. I think she probably cried, knowing my mother, and that
8 worked.

9 So really, like Martin's saying, communication is really important. So if you're
10 not telling your parents something because you know that they can't do anything, and
11 it's just going to make them upset, talk to them about this. Maybe say work out a
12 system where you say something, or you write it down, or you send them an email, or
13 something like that that tells them what's going on so they know, because what's
14 happening might not just be related to your disability. It might not be harmless, it could
15 be something pretty dangerous or some reaction wrong and they might need to know so
16 they can go help you. So it is important not to keep everything bottled up in yourself
17 just to keep other people from getting hurt.

18 KAREN: Are we ready to move on to the next topic?

19 EMMA: Yeah.

20 MARTIN: Yeah.

21 KAREN: All right. So our next topic is relationships, and that could be
22 family members. It could still include your parents if you think of something else you

1 wanted to add. But it could be other family members, friends, or a boyfriend, or a
2 girlfriend, so relationships.

3 MARTIN: So relationships are tricky because that is your relation to every
4 other human that isn't you on the whole planet, and when you have special healthcare
5 needs or disabilities it's already complicated, like girlfriends, boyfriends, friends,
6 acquaintances, mothers -

7 EMMA: Cousins.

8 MARTIN: - fathers, cousins, grandparents, all of that stuff is already pretty
9 complicated on its own. I mean you've seen the 90s sitcoms, family gatherings are
10 always awkward, but that can have a whole new level of just complicatedness if you
11 add in special healthcare needs and disabilities.

12 For me personally, both of us actually, both me and Emma have issues that are
13 not super well-recognized in the medical community currently. They're getting better,
14 they're getting there, but they're still not quite there. When I was first diagnosed with
15 Lyme disease a good amount of my family basically just did not think it was real, like
16 because one of the things my doctor told me I needed to do was be gluten-free. And I
17 have multiple family members that believe being gluten-free is just a stupid fad diet,
18 and despite knowing that I cannot eat gluten when I would see them they would only
19 ever have options that were like pasta, or sandwiches, or things like that, and every
20 single time they would offer it to me and I would say no, they'd say oh, that's right
21 you're gluten-free in a very snide way. So that's just one small example of that.

22 And then for friends and stuff it's also difficult because you can't do
23 everything your friends can do, like just making friends in general can be difficult

1 sometimes if you're seen as like, I'm using quotation marks, "the sick kid." And I think
2 that makes it really hard personally because then you feel isolated. I'm thankful enough
3 that I've been able to find friends who understand me and such, and my friends know
4 me well enough to know like when I'm anxious, or when I'm in pain, and like
5 understand that there's reasons for that and I'm not just like being difficult for no
6 reason.

7 It was not exactly easy to get to that point, because I think a lot of people don't
8 really know how to deal with people who are different or have new things. I think that's
9 when you really find out who is the most - like who really cares about being your friend
10 because you will - there will be people that don't want to be, or don't understand
11 enough to be able to be your friend anymore, and that can be tough, but that's when you
12 also find out like your best friends and who means the most.

13 EMMA: Yeah, so definitely when you have something different or when
14 you're chronically ill or have a disability you definitely find out who actually cares
15 about you in your family and your friend group, and who are just really, you know,
16 pretending. So my medical issues, I have a couple.

17 MARTIN: A brief intermission brought to you by (LAUGHTER).

18 EMMA: Hello? So my - I have multiple medical conditions. It turned out I
19 had a genetic disorder called EDS, that no one knew about until I was 11 and I
20 developed my pain disorder. So that's another thing, but that always - we always kind
21 of knew there was something a little off with me. So when I got sick my illness is really
22 controversial almost, in certain aspects of the medical field, as in literally almost every
23 doctor I've ever met had never even heard about it, and usually the ones that do treat it

1 in a very damaging way that is not helpful at all, and end up hurting you more, and
2 making you worse. So it was very complicated, because it's pain, and you know,
3 everyone reacts to pain differently. When you have it for a long time you stop looking
4 like you're in pain. You can feel like you're getting stabbed all over and I'll still be
5 smiling, because you know, it's just my life now and I've adapted to it.

6 I'm in a wheelchair now, but I wasn't when I was eleven. So what happened was
7 it was very hard for a lot of my family members to understand. So my sister is a lot
8 older than me, so she already moved out so I saw her rarely. But when I got sick she
9 found it very hard to understand the fact that I actually was, and that I couldn't just push
10 past it, and there was nothing that they could do, and the doctors that I was seeing at the
11 time were actually wrong. So what happened was she would refuse to like - wouldn't
12 refuse, but she would talk me out and a kind of belittle me down until I said okay, I
13 don't need crutches, and I can get on the bike, and I can ride a mile, when if I do I might
14 pass out, which my family knew but she didn't really understand. So that was really
15 dangerous, and my mother and her ended up having arguments, because I couldn't stand
16 up for myself with her.

17 And then my father's side of the family I don't talk to anymore, because they do
18 not believe I am ill. They believe that my mother made it all up, no matter what we say,
19 and they are very mean people. So relationships can be very difficult and tricky, and
20 they can make you feel crappy, and that everything is your fault, and maybe they're
21 right and you really aren't just trying hard enough, which is the truth.

22 So the - and then of course I lost all my friends that I had, except for one. So that
23 was another thing. So when you're sick, you know that you're sick. Whoever really

1 matters, let's say your mother or your father, they know you're sick. The biggest thing
2 to take away when you have a special healthcare need or disability, if someone doesn't
3 believe you're ill or that you are not trying hard enough, and they are toxic, they no
4 longer matter in your life. It doesn't matter who they are. It doesn't matter if they're
5 your sister, it doesn't matter if they're your father, or an entire side of your family, they
6 are now gone because you are dealing with enough, and you are ill. You know you're
7 ill, and you know your limits, so you've got to listen to your body and not let other
8 people tell you what you can and cannot do, and what your limits are when they don't
9 understand it. So toxic people need to be cut out, because they will do more damage
10 than any good that they ever could.

11 So just believe in your diagnosis because that is what happened to you. You
12 have something that isn't totally correct. That's not necessarily a bad thing, but is now
13 part of your life, and you must change to adapt to it, and you can't listen to anyone else
14 that is trying to tell you otherwise that are wrong.

15 MARTIN: Yeah, I think it's - it becomes a point where it's very emotionally
16 damaging to have someone tell you try harder, because when you have special
17 healthcare needs, like we touched a bit on parents, you already internalize a sense of
18 guilt, and a sense of this is my fault, for what your issues might change about your life
19 and your family's life, and it's really not good to have people in your life that are also
20 saying this is your fault, like it's adding on to the guilt that that part of you has already
21 created.

22 I think it's very important to reach a sense of comfort in being who you are,
23 because once you get to a point where you're confident enough in who you are, not only

1 will it be easier to cut other people out, but you'll start attracting the people that you
2 want to be attracting as friends if you have the confidence to say like this is who I am, I
3 have this, and this, and this, that's me. If you can get to that point the right people will
4 be like awesome, let's hang out on Tuesday, let's go see the new Avengers movie, and
5 if they're not, then they're going to be immediately weeded out of your friend group,
6 and as they should be, because if they're not going to accept you for who you are, then
7 they have no place hanging out with you, or being around you, or any of that.

8 I think there are probably some people out there that it's just completely better
9 off that they don't accept you, because anyone who doesn't accept a child for their
10 disability is probably not worth keeping around.

11 KAREN: I know you had mentioned something about communication in
12 relationships and how if you're not honest about that reason that you can't do whatever,
13 like not being honest about it actually becomes a bigger issue, a bigger barrier. Do you
14 know if you would share that?

15 MARTIN: Uh-huh.

16 EMMA: Yeah.

17 KAREN: So do you know the story I'm talking about? A dance?

18 MARTIN: Oh, yeah. So, real quick, the person that is our Coordinator is
19 actually my mom. So that whole thing when I was talking about parents as in the third
20 party, she was sitting right there. So, haha. Anyways, once a couple years ago, a girl
21 asked me to a dance, and because of my anxieties and my Lyme disease that was kind
22 of the first thing that really broke down the barrier for me of being able to talk about
23 what I have, because I was like very panicked. Like I was having like full blown panic

1 attacks. Like I was scared to leave my house, like I was laying in bed all day, and I was
2 not able to make it to the dance. I know that I had to tell her why, because it wasn't
3 about her. Like I didn't want her to feel like I'm just trying to get out of going to the
4 dance with her.

5 So that was really the first time that I think I was able to fully accept who I was
6 in order to - like 'cuz I knew if I didn't I was going to hurt her, because it's rude to just
7 kind of back out of something like that. In doing that she was very accepting. She was
8 like oh yeah, okay, I understand, maybe next time. And I think that really broke a
9 barrier down for me where I was like okay, so I can talk about it. Like I'm not
10 incapable, I can advocate for myself, because before then I had a really hard time
11 expressing that I had anxieties, because growing up until I was like eleven I didn't
12 experience that, like it was not something that was in my everyday life. So when it hit
13 me, it hit me like a truck. Like it was very different and I wasn't super comfortable with
14 it. So I think being able to get past that barrier was really good for me, because since
15 then I've been able to be much more forward about my setbacks.

16 EMMA: Yeah, if you have someone that might be having a hard time
17 understanding what your disability is, or what your health issue is, if you start lying
18 about what the reason is it's going to make it a lot harder to understand, which is what
19 happened with my sister. So it's still an issue, but it's getting better.

20 So when I was younger what would happen was she would be like well, why
21 can't we go out to dinner? And I'm like because I don't feel good, and she's like well
22 what do you mean you don't feel good? And I'm like uh, and I would like then
23 shutdown, and my mother would have to handle it, which then in turn made it a lot

1 harder. So the biggest thing was when I started telling her in my everyday life that
2 actually older sibling person -

3 MARTIN: Older sibling that shall not be named for copyright reasons and
4 legal reasons.

5 EMMA: Yes. Yes, that I'm actually home from school today because my
6 leg hurts too much, or I actually missed that party or that dance because I'm too ill, and
7 that may be easier for her to understand that okay, this isn't just when I see you, this
8 isn't just this, this is every single day this is happening, which made it easier. And, of
9 course, my - I have anxiety as well, so my ability to handle it better got better so then I
10 could stand up for myself more.

11 So same as Martin, I was fine until like one day, and then all of a sudden boom,
12 I can't walk, and I'm too nauseous to eat, and I'm passing out when I stand up. So all
13 this stuff happened really fast, really quick, and no one knew what was going on. So
14 then everyone in my life had to immediately do a 160 to try to adapt to it, and take me
15 to specialists, and the specialist didn't know what was going on.

16 So, of course, a bunch of 11-year-old children obviously do not understand the
17 whole complicity of that, so that made that very difficult when all of a sudden I couldn't
18 go to school, and I said I would go to this party but I can't go know, and I know we
19 have plans. So that made them a little angry at certain moments, which then of course
20 turned into, you know, children get angry they tend to pick on people if they're not
21 totally great bright people to begin with.

22 MARTIN: I think because - I think there's a very big level of this is
23 something we shouldn't talk about, and we shouldn't ask this question, and I think

1 something that we, as a society, kind of drills into childrens brains that it's not okay to
2 ask, I think you're supposed to ask when you're told to ask, and you're supposed to care
3 when you're told to care. I think that makes it really hard for understanding to happen. I
4 think that's why there's so many issues of children INAUDIBLE children that are
5 different, because I think they were raised thinking well if I ask this it's going to upset
6 them, and then that internalizes as oh, they're weird, and I don't - like they never ask
7 the questions so now children are not - like if children aren't told what's - like what
8 something is they're naturally going to fear it, because that's human nature, and human
9 nature is amplified when you're a kid because that's pretty much all you have to go off
10 of is your human nature.

11 I think something that could fix that would be teaching kids it's okay to ask
12 questions, like teaching your five-year-old that it's okay to ask questions, as long as
13 their questions aren't like very rude, like if you go up to ask someone and be like why
14 do you walk funny? That's not - maybe not to the most constructive way, but just
15 asking questions because then when you're older it's not such a weird thing to see
16 someone who is different, because then it's just like oh yeah, that's just someone who is
17 different.

18 EMMA: Yeah, there is the invisible wall with people with special
19 healthcare needs and disabilities that are when you're younger, like if you see someone
20 in a wheelchair your parents are like don't stare at them that's rude, and you're like
21 okay, but I don't understand what's going on, which of course, I probably did because,
22 you know, I didn't know any of this stuff until I got sick, and I was at the other side of
23 that wall and I didn't know what to ask, and it was awkward.

1 So obviously if you're a child and all of a sudden there's something that you
2 don't understand and everyone your whole life is telling you don't bother them, don't
3 look at them, don't ask them because that's rude, then obviously you're internalizing
4 oh, this is bad, avoid it, or like fight against it, because that's the type of thing that kids
5 do. It's pretty simple, you tell them something they're going to start acting that way. So
6 asking questions is a big deal, and you know, how you answer them too.

7 So like if someone asked me when I was younger what was wrong with my leg,
8 I would give them the answer. Then as time went on I'd be like my nerves are messed
9 up, which isn't the truth, but was easier to understand. Then it's just the answers change
10 because you get more comfortable, and you learn what to say and what not to say.

11 MARTIN: Yeah. So I think the next thing we're going to is?

12 KAREN: Balancing act.

13 MARTIN: That's what I thought, but I wanted to make sure, because I know
14 we switched them before. Anyways, balancing act: So we've touched on this briefly
15 throughout both, because it's something that comes up. I think it's a daily thing for
16 everyone who has special healthcare needs and disabilities is trying to balance your
17 health, your social life, your work life, whatever different aspects of your personality
18 there are, trying to make sure they are cohesively working together and not just like a
19 mess of destruction and pain, because that's not fun, no one likes that.

20 I think it's very hard because kids have a lot on their plate from the time you're
21 like six to when you're like twenty-two, like you have a lot to do. There's school,
22 there's work, learning about how school and work works, and then there's also like
23 social time, and there's extracurricular activities, and just your life's very, very busy. If

1 you're like suddenly, or maybe you've grown up with it your whole life, I'm going to
2 speak from the suddenly part because that's what applies to me, and like you suddenly
3 have something that might limit that, it's hard to know how to balance that from the rest
4 of everything.

5 So I touched briefly on the fact that I have had joint issues in the past. Currently
6 I don't have a ton of joint issues, although as we speak my knee's actually not doing so
7 great, but when I was younger, around the time I was first diagnosed, every morning
8 when I would wake up my kneecaps would pop. That's not a particularly pleasant
9 experience for an 11-year-old boy to have to have every morning. I did gymnastics, and
10 parkour, and martial arts. That was a very big part of like who I was, and having my
11 knees being in a position to pop so often made that scary, because I didn't want to stop
12 doing what I was doing, but I was scared that I was going to injure myself. But being
13 11, and 12, and 13, I did not necessarily have the thought to be like maybe I should sit
14 this out. So I was really lucky I didn't permanently injure myself, because I continued
15 going to do those things, even on days when I could have been like oh, my leg's
16 bothering me, maybe I should stay home. But I did it, and thankfully nothing came of
17 that, but looking back on it, it probably would have been better to sit out on those things
18 because I could've hurt myself, or hurt myself more. I actually did hurt my knee pretty
19 badly once when I did parkour, and thankfully it was at a time when my knee was past
20 the popping. I had been on medication, and antibiotics, and my Lyme disease was not -
21 my knee was not popping every day, but I was climbing something and I actually fell
22 off on a part that didn't have a mat knee first, on the same knee that used to pop, and it
23 didn't pop, but it was very painful and I had to miss the next two weeks, and wear a

1 brace, and just it was not a fun time. So thankfully it was like a year past that whole
2 knee popping thing so it was not an issue, but like looking back I've always been like
3 wow, that could have been really, really bad if I had - if that had happened just a year, a
4 month, or sooner, I could be like very permanently injured.

5 So it's definitely hard to find the balance, because you don't want to commit to
6 things that you can't do, and you don't want to hurt yourself. Because, like I said, with
7 the dance thing, like I committed to that, probably against my better judgment, knowing
8 that I could have a panic attack, and then I did, and then I had to miss out, and that girl
9 could've found a better date in someone that wasn't dealing with my issues. That's hard
10 looking back on. I think, thankfully, I've gotten to a point where I know my limits a lot
11 better than I did, but there was definitely a learning curve to be able to figure out okay,
12 this is something I can't do, and this is something I can do. This is what I need to know,
13 this is what I need to not know, this is what everyone around me needs to know in case
14 something does happen.

15 EMMA: Yeah, balancing acts are difficult and are tricky. In normal life
16 just balancing high school, or you know, being a little kid, or soccer, and social life, but
17 when you add a special healthcare need that adds a whole other level of trippiness. So
18 it's very difficult when all of a sudden you're - again, I got suddenly ill, just like Martin,
19 so I'm going off of that, but I had also had a genetic disorder my whole life, which we
20 didn't know, but I was having issues.

21 So basically the short thing is that my body can't hold itself together, so I
22 dislocate everything all the time, like I literally just dislocated my wrist. So my whole
23 life it's kind of been okay, don't push yourself. I'm always getting hurt, something

1 always hurts, the doctors say it's nothing type of thing. So I always knew I needed to be
2 more careful with stuff, we just never knew what it was. So that was really difficult. So
3 I did - what am I saying? I'm so tired.

4 MARTIN: Want to pause and reset?

5 EMMA: No, I just need to think for a second.

6 MARTIN: So, how is your day listener? How have you been doing? I hope
7 you're doing good. I hope we're not bothering you. I hope you're enjoying this.

8 EMMA: I hope you're not forced to do this. So balancing acts are really
9 hard, especially if you're a teenager. So all of a sudden you have all these
10 responsibilities, but now you have a special healthcare need and you've got to figure out
11 how to deal with that at the same time. So because I have chronic pain, that means that
12 any given notice I can be in so much pain that I'll start going into shock, at basically
13 random flip of a switch type stuff. Like I could be asleep and I wake up, or I could be at
14 a party and it's like that. So that's very difficult. So my balancing acts include trying to
15 figure out how to get to school without dying, and you know, getting dressed, and
16 taking medication, and then, you know, interacting with everyone.

17 So when you constantly have to juggle everything it gets kind of stressful
18 obviously, and it gets very difficult. You've got to learn how to like balance but not
19 destroy yourself at the same time, because I am notorious for not pacing myself, or
20 taking breaks, or not doing things when I should be at home resting on medication. To
21 the point where I have permanent damaging in certain spots of my body because I've
22 injured them so much and didn't listen.

1 So balancing is hard. If your body is telling you not to do something you really
2 need to listen to it, and it could be anything from diabetes, to a genetic disorder, to a
3 pain condition, because you know you're going to do damage and your body has these
4 warning spots for a reason. So like going to school is very hard for me because it takes a
5 lot of energy out of me. So I would be going from doctors appointment, to doctors
6 appointments, and hospitalization, and then back to school, and homework, and all this
7 stuff, and I'd be killing myself to do it. And that's not exactly good balancing. I don't
8 know what I'm saying.

9 MARTIN: It makes sense. It's okay. Deep breaths.

10 EMMA: So when you're balancing all this stuff and then you're going to
11 add in your social life, that's another level of craziness. So people might not understand
12 what you're going through everyday just to, you know, exist. That can be difficult. So
13 when you have to take medication, wear braces, or be in a wheelchair, it's hard enough
14 as it is. Then you've got to add in like homework, and teachers, and teenage girls and
15 their stuff (LAUGHTER).

16 MARTIN: That's a good way of putting it.

17 EMMA: That's literally the only way you can explain that. It gets pretty
18 crazy, and you've got to be able to take a step back and say okay, this is what I need to
19 do, and none of this stuff matters until I take care of myself. Because, you know,
20 nothing is going to matter if you can make friends, or go to a party, if you can't stand
21 up, or you know, use your arm because you didn't listen when it was broken type of
22 thing.

1 MARTIN: Yeah, your body is your temple, and being able to like figure out
2 that you need to take care of it first, I think is hard especially because you don't want
3 people to just think you're trying to get out of things with your disability, or like trying
4 to make excuses. Because we presented this a few days ago and we had a question
5 saying "Well, what if you're just trying - like what about the days where kids are just
6 trying to get out of doing the thing?"

7 EMMA: That doesn't really gist for us.

8 MARTIN: Yeah.

9 EMMA: When you're forced to miss things like school, you want to go to
10 school.

11 MARTIN: Exactly. Like when you have experiences where you can't go to
12 the thing, you're not going to use your disability as an excuse, because that's just one
13 more thing that it's taken from you. Like you don't - like the parents seemed very
14 baffled by this answer because I think they were expecting a different answer, but like
15 neither of us know anyone who has special healthcare needs or disabilities -

16 EMMA: And we know a lot of people.

17 MARTIN: - yeah, that would like willingly miss something.

18 EMMA: Unless there's something deeper going on there.

19 MARTIN: Yeah, unless there's like maybe there's a bully incident, or like
20 there's something like really bad.

21 EMMA: Jerk teacher.

22 MARTIN: And then, even then, I think using the disability as an excuse
23 would be like one of the last things that they would do, because I think people don't

1 want to let their disability take more from them, and people don't want to miss out,
2 because they've missed out so much that they want to do the thing.

3 I think people don't want to lose that trust, because I know for me, I worry all
4 the time that people are going to say - like if I say I'm anxious well there's a good
5 chance someone in this room, like not this room specifically, but in the room where that
6 happens is probably thinking oh, he's making that up to get out of this. Like I think
7 that's something that a lot of us think and we don't want to like have a boy who cried
8 wolf situation where it's just not believed, because there are times where we do have to
9 miss things. So we don't want to miss things when we don't have to miss things. Does
10 that make sense? I think it makes sense.

11 EMMA: Yeah, I have people tell me to my face that well it's just because
12 you're a teenager, or you don't want to go to school, or that, and that, and that, when
13 I'm telling them well I'm on homebound now, or I missed the entire last week. So let's
14 once again round back to my sister and her husband, so like one of my medical
15 conditions gives me extreme exhaustion because my blood doesn't circulate correctly,
16 so I can't get up before a certain time because I actually will pass out because I'm too
17 tired. So I tell my sister's husband this, and her and his response immediately is well,
18 that's just because you're a teenager. I'm 13 at this point, and I'm like no, this is
19 because I'll actually pass out if I wake up before this point, which of course they
20 ignored.

21 So I think I had usually a pretty big deal, I think is what parents think a lot, like
22 well what if - how do you tell if you kid's just really ill when they have a special
23 healthcare need or they're just not trying to get out of school? Which I imagine parents

1 probably did, or if they had older kids did that, or younger kids, but we don't do that
2 because this - the fact that we're well enough to be able to leave the house, and go to
3 school, and talk to people, even if the people are annoying and the teacher is mean, well
4 now we get to harp about it to our friends at school because we have the ability to do
5 that. And by using something like that as an excuse you're now taking away - it's taking
6 away another part of your life that you want to do, even if it's bad.

7 MARTIN: Exactly. Like we want to still - like part of life is dealing with
8 annoying things.

9 EMMA: Yeah.

10 MARTIN: Like that's part of being a person and part of day to day activities.
11 Like there's nowhere in the world you can go where you won't have to occasionally do
12 things you don't want to do. When those things are constantly taken away from you,
13 when a lot of things are taken away from you, you're going to want to do the things that
14 might be harder, because it's something that you're doing with like your friends, or it's
15 just - it's normal. It's a sense of normalcy that a lot of people that have special
16 healthcare needs and disabilities lose. And while it seems strange to somebody who
17 might not have ever experienced it, it's true. Like you - if you miss out on every class
18 you want to go to the class, even if you don't enjoy the class. You might hate math, but
19 if you haven't done math in two months you'll want to go to do math.

20 EMMA: Pretty much. And then, of course, it's just the experience that
21 everyone has. Like everyone's gone to high school, or done some sort of high school
22 classes and with these people. Well actually I missed this entire section of my life
23 because I was stranded in a bed. Like I didn't go to school at all for eighth grade and my

1 class had all these bonding things, and they went to DC, and I didn't get to experience
2 that. Which is, of course, another thing that everyone got to do and was unfortunately
3 taken from me, no matter how much I didn't want to do it it's something that, you
4 know, I didn't get the choice in, because this is really - what it comes down to is we're
5 having the choice to experience something taken away because our bodies have decided
6 to go say no, not today, we're going to do something totally miserable.

7 MARTIN: Exactly. So I think we went into missing out already.

8 KAREN: You did. I didn't even have to introduce the topic of missing out.
9 You guys just went right there.

10 MARTIN: So pretend we said that a while back. Now on "Missing Out"
11 officially, I'm going to share, I think, the only consistent thing that I've shared
12 throughout every presentation is this story. For me, personally, missing out is something
13 I've had to do not a lot, but when this happened it's definitely impacted the people
14 around me, as much as it's impacted me, which definitely is hard because you never
15 want to be the person that prevents everyone else from doing the thing.

16 So for me the story that I always go to is last year me and my friends, we had
17 this big plan to go to New Jersey, so a six hour drive from where I live. So we drove a
18 six hour drive from where I live to go see this concert. When we got there, the whole
19 time I was a little bit anxious, but I didn't bring it up, which was not the smartest
20 decision I've ever made, because when we got there I had a panic attack, and went in,
21 and then immediately left. My friend was understandably like Dude, what are you
22 doing? And I was like I can't stay here, like I'm having a panic attack. Thankfully I
23 have a friend who understands me well enough to be like okay, I guess we'll leave.

1 So we left, and we stayed at a hotel overnight. But there was a lot of guilt on my
2 part for that because not only did I ruin the experience for myself, but I took away the
3 experience from everyone I was with. That was no fun for me, because I had to now
4 deal with like not only my own like upsetness (sic) for missing what I wanted to do, but
5 also the guilt of being the reason why my friends didn't, and the reason why I didn't.

6 So that was hard for me for sure, because there was - I managed to move on
7 because I think my friend moved on pretty quickly too. So like we had a six hour car
8 ride home the next day and it was not a fun six hour drive. I mean it got fun, but at first
9 I was pretty sure it was going to be miserable because I felt so bad. Thankfully I have
10 good friends who understand, and it was actually a really fun car ride once like we got
11 on the road, and it was not as bad. There was like no hard feelings. But that's my go-to
12 experience because not only was that something I had to miss, but my friend had to
13 miss it too.

14 I had experiences like that a lot. I feel like I accept more responsibility than I
15 necessarily should for it, because I know it wasn't my fault, but I always think well, I
16 should have planned this, or I should have done this. I think the biggest thing that
17 people have to do, as hard as it is, because it's impossible to do completely, but make
18 sure you silence like the what ifs, or I should have done this, or like I should be better,
19 because in the end it just matters that you're okay.

20 So if you're going to do something that's going to make you not okay, it's not
21 worth it, even if it might be hard, or just it might be upsetting, or you might be sad, it's
22 not worth dying or anything past that, because you're not going to enjoy it if you're
23 dead. That's just kind of the easiest way to put it is it's not worth it if you have to die just

1 to get there, because I mean what was that for? You did all that, but you can't even
2 enjoy it in either scenario.

3 EMMA: So as I mentioned before, my medical condition is completely
4 unpredictable and just kind of does whatever the hell it wants, whenever it wants to, and
5 this literally happened to me, and literally just has happened to me so many times I
6 cannot even tell you like in the hundreds of thousands basically. Like one time I was
7 supposed to go down and see my grandfather with my mother. My grandpa lives in DC
8 and we're in New Hampshire. So that means a plane, getting on a plane and going, and
9 all that stuff. I remember we had planned this and I was okay. Then all of a sudden that
10 week I just hit a corner so fast that I just - I could not get up, and I was almost throwing
11 up because my leg hurt so much. I was like basically crunched down on the floor almost
12 screaming and having to bite my hands because it hurt so much, which of course meant
13 that we had to cancel the trip because my pain flare wasn't ending, which made me feel
14 so bad. I was so upset because I wouldn't have been able to get on a plane because it
15 would have restarted it all over again.

16 My mom was like it's okay, you're really sick, it's fine. My mom was totally
17 understanding about it, but like I could almost hear my aunt in the text messages like
18 "What do you mean you're not coming down? Like, what's going on?" Which, of
19 course, my aunt understands this completely and accepts that I'm sick, it's just kind of
20 like you were supposed to get on a plane today, where are you type of moment. It's
21 happened so many times that it's just become so normal to me where I like literally
22 have to mentally think for about ten minutes before I agree to anything, and think about
23 how I feel today, what am I doing that week, what is this going to set off, what

1 medications do I have in my arsenal to be able to do before I go to this thing that I just
2 know is going to make me sick.

3 It takes a lot of planning, because like if I want to get in a car and go
4 somewhere, cars hurt me a lot. So if I go to a doctor's appointment in Boston I am out
5 for the entire next day. So then I have to be like well I can't go to the doctor today
6 because I have this party, but I can't go to this party because I have a doctor type of
7 thing. Missing out is really hard because you're getting something forcibly taken from
8 you, but also if you have people that are your friends, eventually, even if they're good
9 friends, sometimes they get really sick of being canceled on, or not having you be able
10 to come to things when you say you will. And it's complicated, because they might be a
11 really good friend, but you know, everyone has their limit of being canceled on and
12 feeling like -

13 MARTIN: Exactly.

14 EMMA: - you're ignoring them on purpose. And you know if they're good
15 friends they'll get over it, and then they'll move on from it and understand that it wasn't
16 your fault, and the bad ones will not, and then be mean about it. So it just really depends
17 on what your limit is. You know your limit. You know what's going to make you sick.
18 You know what's going to make you worse or what makes you feel better. You need to
19 listen to the fact that if something is going to push you past your limit, you can't do it,
20 and there's nothing wrong with that. It's good pacing yourself and listening to - you
21 know your limit and it's okay if you can't do something. There's nothing bad in it, like
22 being able to pace yourself and learning the skills to accept the fact that you can't do
23 these things is good, it's awesome, because frankly literally I almost couldn't come

1 here. And I was supposed to have PT today, but last night I was up until 2:00 in the
2 morning in a pain flare on medication that makes me loopy. I was like okay, well I can
3 only go to this one meeting and we have to cancel PT if I want to do this, which we did,
4 and I'm here on medication. Just ignore that last part.

5 KAREN: Well, thank you for being here.

6 EMMA: Yeah. So like really it's what you can do. And if people don't
7 accept the fact that you can't do something, even if it's last minute notice, like an hour
8 before something, than they really don't deserve to be around you because you can't
9 control it.

10 MARTIN: Yeah. Like everyone is human, everyone has like their limits.
11 Like obviously you will emotions even if you know it's not their fault. Like there's no
12 one in the world that can constantly be able to just accept that 100 percent, but that's not
13 an excuse to just completely be angry at them, because you can't - you can be upset in
14 the moment, but if you don't move on, and apologize, and continue on, that's no longer
15 well I'm human I make mistakes, that becomes well you're human, but you're also
16 mean.

17 EMMA: Yeah, like everyone is entitled to having one upset thing after
18 you've been canceled on so much. You can only take so much in your brain.

19 MARTIN: Yeah.

20 EMMA: But the -

21 MARTIN: Everyone has their own issues going on, their own lives to worry
22 about.

1 EMMA: Yeah, the deciding factor is whether they move past it and accept
2 it, or not.

3 MARTIN: Exactly.

4 EMMA: Because if they refuse to accept it and they keep acting like this
5 everytime you cancel, then really they really shouldn't be in your lives. I really don't
6 care who they care. I mean, as I've said, I've cut out an entire branch of my family.
7 That is painful, and it's messy, and it takes a lot of courage to do, and understand that
8 they're more damaging than they're worth, so.

9 KAREN: So our last topic is positive outcomes. So if we can end our
10 podcast on a positive note.

11 MARTIN: So we've just depressed you for about an hour, so let's - let's be
12 cheery.

13 KAREN: I think, based on as a listener to your podcast today, and having
14 heard you guys present.

15 MARTIN: Like seventy bazillion times.

16 KAREN: The communication skills that you have are, I would think -

17 MARTIN: Very developed.

18 KAREN: - very developed and superior to, you know, others your age, and
19 many adults that I know. You talked about needing to communicate your healthcare
20 needs to friends and things like that so that they can understand where you're coming
21 from. So I think I would give you a positive outcome in that you guys have great
22 communication skills.

23 MARTIN: Yee-haw.

1 EMMA: Thank you.

2 MARTIN: Yeah, I think the ultimate saving grace in life is communication. I
3 think there are entire world conflicts that could be solved with a conversation, and that's
4 a very powerful thing to think about. Like the fact that humans are able to communicate
5 on such a deep level is very important, and I think the fact that all I've been through
6 personally has made it so I'm able to communicate with other people well, is a gift that
7 I would not want to take away because I really like that I'm able to communicate with
8 people. I don't like passive aggression. It's not a fun scenario, and it's not healthy, and
9 it doesn't help anyone. So I like that I can settle things that need to be settled, and
10 communicate information that needs to be communicated when it needs to be
11 communicated.

12 EMMA: Really just I've met a lot of people, and made a lot of friends that
13 I would never have met if I didn't get sick. Being sick is awful, and it's awful that they
14 are also ill with this, but you know a different person that I would have been because of
15 this. So I guess that's okay because I like who I am now, and the fact that I know all this
16 stuff that I didn't know before.

17 KAREN: And I think, you know, you're both on the Ad Council, and you -

18 MARTIN: Get a sense of empathy towards everyone because you can feel a
19 sense of - because like if you've been through things that are really bad you can be
20 better at finding empathy sometimes.

21 KAREN: And I think your work here, you've created materials, and you've
22 done these podcasts, and you have a You-Tube series, and you know, created different
23 things that help kids who are, you know, growing up younger than you who are going to

1 face the same struggles that you faced. You know the hopes are that you will make their
2 lives a little bit easier by -

3 MARTIN: That's the goal.

4 KAREN: - informing them, helping with their advocacy skills, or giving
5 them information, or even just helping them know that other people understand.

6 MARTIN: The moral of the story is, young-uns, communicate with people,
7 talk to people, and make friends with nice people, and if they're not nice, don't be their
8 friend.

9 EMMA: Yup, even if they're you're family members.

10 MARTIN: Yeah. Goodbye.

11 EMMA: Bye.

12 KAREN: Bye.