

PAIN:

AN OWNER'S MANUAL

GEORGIA HUSTON

PAIN: An Owner's Manual

Georgia Huston Weston

First Edition

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This book is dedicated to those in
so much pain they don't see a way out.

A.A. – I will always love and respect you with all my heart.

Introduction

“If the people in your life don’t understand what you are going through (pain), ...find people who do.”

Pretty sage advice and wisdom from this young adult who has chronicled her inspiring life journey through the U.S. healthcare system, which failed to make a timely diagnosis to alleviate her painful symptoms, and in its way added to her suffering.

This book is the Owners Manual – a must read for anyone, child or adult, who has chronic pain. It is carefully organized with 37 stories from patients and professionals. Even the four-color cover quickly ushers the reader into this dissonant, blurry, confusing world of chronic pain. It may be uncomfortable for many professionals to read, but any physician who treats pain will suddenly learn a universe of information and perspective that has been missed while he/she was trying to help his/her patient.

These stories tell us what it is like on “the other side” of the desk...and it is sometimes discomfoting... e.g. doctors telling patients that “they hate them,” because they are not “behaving,” or responding to their therapy attempts...or “your pain is all in your head.”

As physicians, we are responsibly engaged in fitting patients’ symptoms and signs into categorical boxes to arrive at a diagnosis, and then plan therapy. We also do this because CPT reimbursement codes demand it. But underneath all this, what we often forget in our rushed day to document and bill, is that in the patient’s mind and body is the yearning to be understood, to have his/her symptom recitations heard, and the need to provide the narrative in how specific symptoms have affected his/her life.

Georgia has clearly identified many of the issues in the failures of chronic pain treatment from the patient’s perspective. But this book is so much more than that. It is real people giving voice to the personal journey that in many ways has elevated them and made them victors rather than victims.

In *PAIN: An Owners Manual*, through Georgia’s simple yet penetrating ques-

tions of both patient and healthcare provider, we learn of the common experience in the pursuit of help and in the eradication of pain. Nowhere is this more important than in caring for children, adolescents, and young adults with chronic pain.

Georgia’s perceptive questioning allows each of these individuals in the book to have a voice in how this personal journey affected them. It is inspirational and highly educational.

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Special thanks to Dr. Lonnie Zeltzer for believing in something that some doctors still don't think is real. You truly are a pioneer who has revolutionized medicine, not to mention many lives.

Dad – You've always believed in me enough for the both of us. Thank you for making me who I am. I know it hasn't been easy. I hope I can be as smart as you one day. You truly are the best.

Mom – You are the kindest person I know. You give your heart and soul to everyone. I am so lucky to have a mom who will always be there for me. I only wish you knew how special you are and what a big role you play in my life.

Nakks – I will always be grateful for how you handled yourself in middle school. You have always been too mature for your age. I hope one day the world catches up to you.

Zanie – I know I dump a lot on you. I know you don't always know what to do or say. I know it's hard. Just keep doing what you're doing and we'll learn together. I appreciate you.

Preface

When I was diagnosed with chronic pain six years ago, I had absolutely no idea what it was. I had never heard of it. When a doctor I'd just met diagnosed me with something I didn't know existed, and told me to throw everything I knew about Western medicine out the window, I had no idea what I had gotten myself into.

Fortunately, once I put all my faith in this relative stranger, things started getting better. As my health and strength improved, I noticed more and more people who were also living in pain. When I told my story, I heard from many who were either experiencing something similar or knew someone who was. That's when I started thinking about this secret community of people in pain, and wondered why we all feel so alone when there are so many people out there like us.

Pain is everywhere. I noticed it in commercials for medicine, billboards for clinics, stories in the media, and websites online. Everyone seemed to be looking for help.

I am in no way claiming this book will "cure" anyone. There is no simple fix to all this pain. This book is by no means medical or academic. It is merely an anecdotal collection of interviews about personal experiences with pain. To compile these stories, I simply reached out to people that I knew were having trouble and asked if they wanted to be a part of this. Some said yes, some said no – but the fact that so many people in my life are hurting showed me how much of a problem pain really is.

I also interviewed the wonderful pain professionals who helped me – and countless others – find relief after so many doctors had given up.

No matter how old we are, where we are from, or where our pain is, all our stories are astonishingly similar. We all go through the same emotions and ups and downs. We all have to deal with missing school or work. We have to cope with difficult family issues. We can't do all the activities our friends can. We can't do things the same way as others – but that doesn't mean we can't do what we want.

This book is full of special people who have shared their most intimate demons. No matter their situation, they don't let pain stop them from living their lives. I hope this may inspire others to do the same. Just keep going. Find a way. Know that – no matter what – we cannot give up.

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Randee

Age 53

Colorado Springs, CO

Could you give me some background about your pain experiences?

My pain issues started when I was fifteen and went tobogganing. We hit a bump and my older sister, who was about a hundred pounds heavier than me, landed on my leg and twisted my leg backwards and totally tore out my knee. I wound up having to go through thirteen very, very excruciatingly painful knee surgeries. That's where my pain experience got fun and going.

I'm allergic to opiates and codeine, so unfortunately I can't take anything for the pain. I just have to suck it up when I go through these surgeries. I don't get to take anything for the pain. My pain experience is one where I've learned to really suck up a lot of pain and deal with pain. So it's not too fun.

That started my experience with knowing about pain. When you can't take medication – and they're grafting muscles and all that stuff – you get horrible, horrible cramps in your legs, just awful double-up-in-pain-screaming cramps. And you can't do a damn thing about it.

You can't take the pain meds, so you just try and deal with it as much as you can. A lot of people self-medicate. They use drugs and alcohol and stuff, but because of the work I did for the government, I was drug tested all the time, so I didn't have that pleasure.

Did the pain continue?

I still, to this day, have pain that happens in my knees when it gets cold, when it gets damp, or going up and down stairs. I'll have pain where it still rubs. The knee was basically torn off and everything had to be grafted – the muscles, the tendons, everything. Then I got a post-op infection after one of the surgeries, so they had to split the bone and put an artificial bone in, and it's really horribly painful when it's cold. But you learn that there are people a lot worse off than you, so you just don't worry about it and you just keep moving on.

I guess the biggest thing was two years ago. I had to go through a double

mastectomy for stage three breast cancer, and I had to do all that with no pain medication.

Oh, that was awful, because they put expanders in your chest. I'm a small woman. I'm only five-four, a hundred and twenty pounds, and they had to put these expanders in to stretch the muscle, so they could put the breast implants under the muscles to hold them in place.

I swear the expanders were more painful than the surgery, and they expand each one every three weeks. They inject more fluid into the expanders to expand out that muscle, so basically you're five months with a muscle pull across your whole chest. I swear the surgery was easier than the damn expanders.

I would take the surgery again any day over having those expanders back. Those were awful. You have basically five months sleeping upright – five months – anytime you moved your arms above waist high, just hurting like you want to cry. Anybody bumps into you, you wanted to cry, it was just so painful.

The cancer treatment, I actually took pretty well. I didn't lose my hair or anything. I lost a lot of weight, but it was the expanders – the daily pain. You're sleeping maybe two to three hours at a time, then you roll over, you move, and the expanders wake you right up.

You spend five months without a good night's sleep while going through chemo. You spend five months just absolutely horribly miserable. Especially driving in a car. Oh my gosh, seat belts!

Seat belts are evil! Anytime somebody would hit the brake and the seat belt would tighten, you'd be just screaming. Seat belts were so evil. It was the worst part of those things.

And putting on bras. You had to have help, because you couldn't reach over your head to put them on. You couldn't reach behind you to put them on. You had to have somebody help you the whole way. That wasn't fun.

How are you doing now?

I'm doing really, really awesome. The cancer is one hundred percent gone. If I could quit eating rotten food and getting multiple organs shut down from e. coli, I would be really healthy right now.

What do you mean?

In March, I went to our rabbi's house to eat Shabbat dinner and I got e. coli from the fish. I walked around for a couple of months feeling like hell. Everyone kept telling me it was just the flu, and part of the cancer treatment, and this and that. Finally, on June 23, I went into multiple organ failure.

My heart, my lungs, and my kidneys shut down. I was in the emergency hospital with my poor little twelve-year-old as they cut open my chest to put a main-line in, a central line to try and get me blood, because my heart shut down. And

it was crazy, all in front of my little guy.

Yeah, that was painful. That hurt, man. That central line, they shoot you with a numb-er just for the skin, so when the scalpel hits your skin you don't scream, but getting it in – oh my gosh, that was brutal, but you just live with it. You've got to move on. I understand chronic pain. I have it. I have it with my leg every single day I wake up and put it on the ground – “Ah, this hurts!” But you can't let it dominate your life. You can't give up your life.

We do a lot with wounded warriors, where we work with a lot of military guys who have crushed or lost limbs and stuff like that – and have multiple surgeries and are living in chronic pain – and to see them not give up on life makes you just go, “Oh, this is nothing. I can deal with this.” And that's the attitude I take – the healthiest attitude I can take.

How long did it take you to get to that mindset?

It really had to do with my mom. My mom is one of those people – if she gets a paper cut it's a tragedy and she has to take a Vicodin. Her whole world falls apart if she gets a little “owie,” so I always thought of her as weak. She's one of those people who whines when she gets a cold.

Right before you called, she called and said, “I have a cold. I have to see a doctor,” and I walked around with e. coli for two months and didn't take a day off work. So it's in reaction – some people say it's an overreaction – to her being such a hypochondriac. She really had a serious Vicodin addiction. She was taking ten a day. It was ridiculous.

I think a lot of it had to do with that, just my not wanting to be weak like her, so I learned how to suck it up a lot more. It tends to be a problem.

I actually went back to work ten days after the double mastectomy. I still had blood packs hanging and the drains in me, and I still went back to work because I didn't want to be seen as weak. I didn't want to be a weak leader, so I actually went back to work like that, which wasn't the brightest idea in the world.

Since you are allergic to pain meds, what is your coping mechanism?

I try and sleep. Believe it or not, I'll take Nyquil. Whatever will put me to sleep. I can't drink wine because they put sulfites in it, and sulfites are one of the things I'm allergic to – so I'll take two Nyquil tabs to put me to sleep. I can't take Motrin because my gut won't hold it down, so I'll take those nighttime Tylenols or I'll take melatonin. Anything that will make me go to sleep so I can just sleep through the pain. That's what I try to do. I try to sleep through the pain as much as I can.

Does that make you miss out on things?

Sometimes the exhaustion will hit me, like yesterday. I'm still recovering from the e. coli and I've been working for five days straight, even though I'm not supposed to go back to work until – well, today is the first day I'm supposed to be back at work. Yesterday, I had to leave work early and just go to sleep. I slept from two in the afternoon until nine at night, because I just get exhausted – I've got such an active household.

I've got three Special Needs kids that are adults that always need me, plus I have a twelve-year-old, plus my niece and nephew and their two little ones live at home, plus I have a business with a staff of twenty. Between all that, I'm constantly moving. I've constantly got people who need my time, so I just suck it up. I just do that. Suck it up and keep moving kind of philosophy.

How do your kids react to everything that's going on?

My husband and I have been really good about keeping them isolated from it until this last – until the cancer. They never knew mommy's knee hurts, or mommy has this, or that mommy has problems, or anything. We never talked to them about that.

When the cancer hit, there was no getting around it. They've had to start dealing with it, because my bones started breaking from the treatment. I kept breaking ribs and things like that while going through the treatment, because it would decalcify my bones.

They would do something simple, like my son would hug me too tight – my twelve-year-old – and crack two of my ribs, so we joked, “Don't hug mom too hard, she breaks. Don't grab mommy's wrist, she'll break.” Things like that. So they've gotten used to it that way. The big joke is mommy's breakable, mommy's made of glass. So they take it not as mommy's going to die.

Now with this stupid e. coli thing, and them being at the hospital, we're dealing with that, but they never had known mommy to be sick. No matter how sick I was, I was up and going. It's really funny, because the first couple of months with the cancer, I actually kept baggies on my side door in my car so I could drive and vomit. I used to do that all the time. “Oh, mommy's okay... (Bleh.) It's just something she ate.... (Bleh.)”

It wasn't until I started breaking – and then with this e. coli – that they've actually found out how sick I got. Until then, they never knew how sick I was.

Why did you keep it from them?

Well, from the Special Needs ones, because they couldn't deal with it. They really couldn't. Their concept of life and death was very limited, like a seven-year-old's concept of life and death – way too hard on them to understand. So the first time they've ever had to deal with – oh, mommy might die – was a month ago when my heart stopped and I was in the ICU. And I mean – it just wiped

them out.

In fact, my twelve-year-old is still sleeping on a cot in my room and a couple of times a night, poking me – “You still okay? You still okay?”

My twenty-four-year-old Special Needs one, he's calling me every hour to hour-and-a-half when I'm away from him. “Are you okay? Do I need to bring you anything? Are you okay?”

That's why I've always kept it from them – because it's such a hard thing for a Special Needs kid to have such security issues, too, because they're all adopted. Except the twelve-year-old. For them to have that sense – oh my gosh, I might lose my mommy – so you just suck it up and you don't let your kids know.

That's why I was a lousy psychologist. When people would come in front of me and start whining, it took all my power not to say, “Shut up! Quit whining and get over it.” That's why I went into neuro-psych and neuroscience. Because I sucked at it.

Does that put more pressure on you and your husband to try to protect them?

It puts more pressure on me. I have to be really sick before I tell my husband. We always joke that my husband's worst fear in life is that I die and leave him with all the kids. That's always been the running joke in our family, because that is his worst fear in life. He wouldn't know what to do. He was always gone with the military 250 days a year, so he didn't even know where our kids went to school or where our bank was.

I took care of everything for twenty-four years. I would be at the point of collapse before I'd even tell him I was ill. Now that he's known that I'm sick and everything, it causes him a lot more worry.

It's neat, because he's a lot more attentive than he's ever been. He's actually realizing – hey, I might lose you – so he's being a lot more attentive. That's kind of cool.

But at the same time it bugs me, because I'm not dependent. I can open a damn door – “No, you might break” – “I can open a door!” That kind of stuff. I'm not used to people trying to take care of me. I'm always the caregiver. I'm always the strong one.

What's the first thing that comes to your mind when you think of doctors?

Ugh, yuck. You know that old saying? “Doctor, heal thyself.” Doctors are the worst patients in the world. I finished up college – my degree was nuclear medicine, and I got my masters and PhD in neuro-psych – and I'm the worst. And I hate doctors. When I have a doctor's appointment, I'm the worst. My husband will call my doctors now to verify I have an appointment upcoming, because he knows I won't tell him. So I hate doctors.

Do you have any advice for doctors?

Oh, my gosh. I don't even know. They hate me. I'm the worst patient in the world. My doctor – my general practitioner from the military – he hates me. He's never had such a hard patient in his life. Absolutely despises me.

Do they tell you that they hate you?

Oh gosh, yeah.

They say that to you?!

He says he's never had a patient who would not listen to one word he said. "I'm sorry," he goes, "I told you, you couldn't leave the hospital and you check yourself out." Yeah, I've had two doctors tell me they hated me as a patient, because I won't listen to a word they say.

Then I have other doctors who absolutely love me, because I'm one of the best diagnosticians from my medical background. I can diagnose better than most doctors can. I can pick up atypical lupus in a patient. I've picked up amazing things – that doctors were not able to find – that I've picked up on patients where I have been correct. Really great diagnostician, so I usually know what's going on, which means I avoid them even more. (Laughs.)

I've got a couple that really love me. I've got two doctors that just absolutely despise me. They say I'm their hardest patient ever, I'm the most bullheaded woman they've ever met in their lives, and they're going to have my husband duct-tape me to a bed. (Laughs.) Things like that.

What do you do with your dark emotions?

I try and deny it. I try and deny that I'm in pain. I believe denial's not just a river, and you jump around it being sick or in pain. I do my best – and some of it is just psycho stuff. Like I said, my mom was such a hypochondriac. I'll be sucking air through one lung – because I had pneumonia one time and my husband had to call 911 – and I'm like, (gasping for air) "Honey (breath) I'm fine. (breath) Let me (breath) go to (breath) dinner. There's (breath) nothing (breath) wrong with me. (breath) You're making it up." (Laughs.)

I just don't want to be that weak, sick person and it really sucks, because I am. It drives me crazy. I'll get up – like on Friday, I got up and went to work, but Thursday I was knocked out and had a tube shoved down my throat into my stomach to do biopsies. They said, "Lie in bed until Tuesday. You can go back to work Tuesday." By Friday morning at eight a.m., I was at my desk. So it's just total denial of being human. It's like, dammit, this body is pissing me off!

Does it ever catch up to you? Do you ever have moments to cry?

Every once in a while. Like yesterday, I came home from work early. I couldn't hold my head up anymore. It caught up to me, and I just went to bed. Every once in a while, I still have to be human – like once a month I'll take a day and just sleep. And I'm not a big sleeper. I'm very hyperactive, so I only sleep six hours in a day anyway, but every once in a while I'll just go to bed for twelve hours straight and just sleep, because I just get worn out.

What's next in your future?

I want to stay alive until my kid graduates high school. If I can make it that long, I am going to be so freaking happy. If I can just make it that long. I want to see him graduate. I want to stay alive, not do anything stupid. No more e. coli, ebola, whatever else is out there that I can catch, because I have a weak immune system. I just want to stay healthy enough to get my kid through school. If I can do that, I will be a very happy woman.

That's my next goal. He just started seventh grade this year. I can make it until he graduates high school. Then I'll set the goal on him graduating college, but I just want to make it until he graduates high school. Stay alive that long and then I'll be happy.

Who or what in your life gives you hope to keep going?

Oh, my kids. My kids. I don't know how much you know about my kids, but when we adopted my oldest son he was six years old. He couldn't read. He couldn't write. He was so tiny and so skinny, because his foster family wasn't feeding him. They said he was retarded. He wasn't. They just weren't feeding him or taking him to school.

My other son was born at 28 weeks gestation, with a .28 blood alcohol level. His mother stole him from the hospital. No one saw him again until he was four and a half years old, and he weighed fifteen pounds. His skull – he had footprints where she had kicked in his skull – and massive brain injuries, fetal alcohol syndrome, couldn't walk or talk, and now he is the happiest, healthiest kid. He's married to a woman who is also Special Needs. We also have custody of her. He came back and played high school football. He did wrestling. This is a kid who could not walk or talk, or wasn't potty trained at age five, when we adopted him.

And then my other son, who has done just so great, does have his issues with the emotional part, but when he was a month old, his mom caved in his skull. He went on to play two instruments, to go to normal high school and everything.

Those guys overcame a lot. I'm just overcoming little things. They're the ones I'm proud of. We worked really hard to get 'em past where they could be functioning adults, and they are. They still need assisted help at home, as far as living

independently, but they hold jobs, they pay taxes, they have friends, they go to dances. They have a great life. They are who motivate me.

Do you believe this all happened for a reason?

You know, it's really funny. I think it did happen for a reason. I'm a pretty woman. I am. I'm fifty-three, I'm very good looking, I have a lot of guys still hit on me – very much younger than me – and I'm extremely smart. And I think it humbled me.

I could be very conceited if this hadn't brought me down to earth, because growing up, I was always smarter than everybody else. I skipped second grade. I was the smart one and the pretty one with big blue eyes. All these injuries, and having to deal with the pain, has kept me humble. You can't get too full of yourself when you're dealing with chronic pain. You can't.

I think it's taught me humility and it teaches me to be able to sympathize with other people. The problem, when you think ten steps ahead of everybody else, is – “Well, why can't you do that? I can do long division in my head, why can't you? I knew the whole periodic chart by the time I was five. Why don't you?” So it humbles you. It teaches you humility. So definitely – it taught me humility.

Do you have any last words of wisdom?

I've kept the same philosophy since I was eighteen and heard that Albert Schweitzer once said, “Be ashamed to die until you've won one small victory for mankind.”

And every day I'm alive, pain or not, I'm winning a small victory for mankind with my kids, with the volunteer work I do with others, helping others get their lives on track, helping other people in need. So yeah, I might be in pain, but I'm winning my small victories every day. I'm not letting the pain take away my small victories.

My kids are my victories, my charity work – those are my victories.

Haley E.

Age 21

Walnut, CA

Thanks for taking part in this. I appreciate it.

I've personally wanted to write a book for a long time – and I don't know if you went through this – but I think it's one of the hardest things to write about for me. I love to write a lot of stuff. I love writing fictional stories and just writing about my day, and I stop and think, “Well, I'm going to write about my pain,” and it just feels impossible. But I think that's why it's so awesome. I would love to be a part of this.

Thank you. I appreciate that. Could you give me your background story? I know you've probably said it a million times.

No, no, I'm good. Fibromyalgia is one of my main ones, and then I was recently diagnosed with ankylosing spondylitis. That's a form of arthritis where your back basically fuses together – your spine – so it's just all the pain throughout that. A lot of hip pain, lower back pain, because it starts there. I also have something called POTS, and that stands for Postural Orthostatic Tachycardia Syndrome, and that's dysregulation of the autonomic nervous system. That can cause pain and discomfort. Those are my main ones.

Okay. Are there other ones?

Well, I do have chronic migraine syndrome.

How old were you when all this happened?

I was thirteen. I was in eighth grade, halfway through, in January. It started with a cold, and me and my brother both got the same three-day-long cold, flu. After the three days, he got better and I didn't. I had a headache, and it just never went away. We went to the doctors and they did all those tests and MRI's, and

they found a cyst in my head that they figured must've been the migraine. I was very dizzy. I passed out a couple of times, just not feeling like myself.

And this whole time I didn't go back to school. So they were doing these tests. They did a surgery on the cyst, removed it, and then a month later they found that it wasn't actually the problem, because I still had the headaches.

I went to a neurologist, and he diagnosed me with POTS. This was probably the summer between eighth grade and high school.

So you had – was it brain surgery or head surgery?

They actually go through the nose. They go in and remove the cyst through the nose. I had no idea how dangerous it was as a kid, but after – I heard there were a lot of issues. I could've gone blind. I could've had all these issues, but luckily everything went fine.

Wow, that's a really young age to have such a traumatic surgery.

It was definitely crazy, because my brother had been sick as well, and it's not really something you can identify. It's, "Oh, I have a headache," and everyone thinks you're lying. Everyone thinks you just don't want to go back to school. "No, I have a headache and I'm very lightheaded."

I went back to school one day in eighth grade, because I still tried to go here and there. I was a straight-A student, so none of my teachers really cared. They sent my homework home and I did it, but basically, for that second semester of eighth grade, I didn't do much work. They all passed me, but it was really crazy. I went back to school one day and someone came up to me and said, "Haley, I thought you died."

I don't know why it really struck me, because that's kind of how everyone felt. Everyone heard that I had cancer. There were all these lies, and my best friend was having to deal with a lot of the lies – because kids that age don't know – they don't know what to do when their peer...

It was a lot for me to deal with, but I felt like I was always pretty mature. All the other kids didn't know how to deal with it.

Was that weird, going back to school? Were they staring at you or were they comforting? How did they react when you popped back into their lives?

It was very strange and you don't feel the same, because people are talking about little gossip and you're thinking – "Okay, that's cool. Sally wore that shirt, but I have to go to the hospital after school."

They were talking about putting a pacemaker in my heart, so that really scared me. I was really scared of that. I was a kid and I had surgery on my brain – and I was freaking out – and that's all they talked about. When I stopped going to

school, I was so sick I couldn't get out of bed. I couldn't stand, I was so dizzy. I lost all my friends. One of my best friends to this day was my neighbor, and we stayed very close and we still are, but everyone else that I talked to in eighth grade, I probably never talked to again. They send you flowers, and then after a while they just disappear. You're last week's news. It was hard, and I was very upset for a while.

I remember going to Disneyland that summer with my family, and seeing all my old friends there for a birthday party, and it was just something that I was left out of. But I look back on it, and it was not just traumatic, but it was very traumatic for them as well – to see someone just like them all of a sudden get put in the hospital. It's like when we see someone our age get shot or something, it stirs up something in you. That could've happened to me.

Do you resent how they treated you and weren't there for you, because they were uncomfortable and were backing off? Do you wish they were acting differently?

I did for a while. I really resented them. I was really angry about it, but recently it's just been my gift. I've been really grateful for my one friend that was really there for me. I know she went through a lot. She lost her best friend who went to school with her. We ate lunch together every day, and then all of a sudden I was gone – and I'm really grateful for her.

It also was a lesson for me. I'm still young, and when someone goes through something that is traumatic, I don't shy away from it. I don't not talk about it. I will call that person and say I heard that this horrible thing happened. I'm not gonna be awkward about it, because I've been there.

Yeah, sounds like it. Are you on pain medication currently?

Yeah, a lot.

How much? Could you tell me a little bit about that?

Yeah, I'm down to tell you my whole medication list if you want.

Do it.

Okay, let's see if I can remember them all. I am on Lexapro, I think ten milligrams. I'll probably get all the milligrams wrong. I am on Humira – I inject myself with that every other week. I am on a B12 injection that I have to give myself every other week as well, because my body doesn't process B12 correctly. I am on, let's see, clonazepam for muscle spasms. Amirax. I have a sleeping pill. I have Topamax, trazodone, and then I have a couple of other ones that

I can't really think of right now.

I also have Vicodin, but it doesn't work for me. I'm sure you've gone through the same thing. It's so funny because I'm in college now and you hear the frat boys – "Oh my God, I took a Vicodin last night," and I'm just – "Bro, I can take three Vicodin and I don't even feel it." And I have a prescription for Dilaudid.

How often do you take all of this, because that's a long list and you're a young girl? How does that work?

My doctors get really mad at me because I don't really like to take ones that are for pain. I don't take Vicodin a lot. I rarely take Dilaudid. They have it so I don't have to go to the emergency room and wait in line. And I don't like to take actual pain pills, so I take stuff for the muscle spasms to be preventive, but my doctors get mad. I've had it for so long, I have learned ways to tune out the pain.

Sometimes it gets to the point where it's so much, and it's built up, and I can't move. They tell me – "You can't do that. You have to actually treat it while it's little enough to knock it down."

They tried to give me a couple of pain patches, like Butrans, and a couple of other ones that constantly distribute – like a narcotics patch – but I kept falling asleep all the time, because with fibromyalgia there is a huge chronic fatigue factor, so I am always tired. And the pain meds mess up your system. I can't handle it, with the constipation. You take a pain med, you're also gonna have to take a laxative, and I'd rather just take as little as I could. We have a huge drawer of medication, and it's just a constant thing.

Luckily, my mom really helps, because just refilling them – I have it on mail order – but the constant refilling is a twenty-four hour job.

So wait – your doctors were mad at you for not wanting to take these heavy pain medications?

They would get mad because – not really the heavy ones – more of the non-narcotic pain pills, just pills in general, but then the pain builds up. I won't deal with it when it's just a little bit of pain. That's the best way to deal with the pain cycle, is when it's little – to have one of those pain-soothing patches, not the narcotic ones, but just like a Salonpas patch – and then I just block it out. I'm twenty-one years old, and I'm in bed every night at ten o'clock. I need twelve hours of sleep – and basically I act more like a forty-year-old person – but I ride horses, and I do a lot.

When I'm talking to new doctors, they ask me, "How often do you get out of bed? Every day?" And I say, "No, I'm never in bed." It's not like that.

Sometimes I can ignore the pain. I go out and I do so much that at the end of the day, I'll be shaking in pain because it just overrides your system and you just can't move. I'll be crying, and I hate for my parents to see that. So, it's hard. It's

hard to find the balance, knowing when to deal with the pain, because I don't like dealing with it where it's overwhelming, and then I have to be on bed rest for a week. And stress definitely exacerbates it, so classes and college are hard to do.

How do you do that? How do you keep up? I'm in college, too, and it's hard sometimes to keep up – they go out partying three nights in a row, and then they wake up the next morning and go to class for five days in a row. How do you keep up with that?

I definitely don't party. Alcohol doesn't mix well with me. One time I was somewhere and I passed out and they had to call an ambulance. I'm always like – "Please don't call an ambulance. I pass out all the time," and everyone thinks I'm crazy, and I'm insisting – "No, this happens all the time."

The ambulance came and they asked, "Did you drink any alcohol?" I'm like – "I can't have alcohol because it dehydrates me. I drink three gallons of water a day. I know my health." They were very nice about it.

I do hear people talking about abuse of pain prescriptions and talk of alcohol and all that type of stuff. "Oh, you're hungover? That's how I feel all the time and I didn't even drink any alcohol."

So it's hard, and class is impossible, because sometimes I'm sick, or I've started doing surgeries to block the pain in my back, so they actually go in and kill the nerves and burn them off.

Wow. How many surgeries have you had like that?

They're called radio frequency ablations. I call them surgeries, because technically they are. They have to put me out for it, and I have to go to a surgical center. I've had four.

They burn off your nerves? How does that work?

Yeah, they burn them off. They go into your spine – not your full spinal nerves – but there's a tiny little microscopic nerve in between the joints, that feels the pain when your joints rub together. They go in and they burn it off with radio frequencies.

That must be terrifying.

Yeah, it was really scary for me a couple of times. First, they had to go in and do injections into them. They do these injections of cortisone, and I don't react well to steroids, but they have to, for insurance. It's annoying that I have to go in and have the injection done. It's like – "Oh, here's the injection, now let's do the radio frequency ablation."

My last one, I had a really bad reaction. They thought that my spinal column had possibly been torn open and had some leakage, so that was really scary.

But that wasn't the case?

No. They thought I had a spinal fluid headache, but actually ended up diagnosing it as something else. So yeah, just dealing with that – “Oh, I'm sorry you have a midterm on Thursday. I have a midterm, too, but I also have a surgery that day, and I can't do anything, so that's gonna be hard.”

I've had professors that have been absolutely amazing about it, that have said, “Do not come to class for a week, we will do whatever you need us to do,” – and that's just amazing – but I've also had professors that are the worst. Like complete assholes. I'm registered with Disabled Student Services, but it's hard, and people don't understand. I have letters that I'd give, supplementary to what Student Disability says to all my professors, and it explains that I don't have ADD, I don't have some other learning disability. I have a chronic pain disorder and I feel pain twenty-four/seven. It's intense.

Wow. Do you go to school locally?

Yeah, I go to school at Cal Poly Pomona, so I live in the city next to it. I grew up in the town over, called Walnut. Definitely wasn't my first choice for school, but it's one of those things that just kind of plays away and I could not imagine going to school anywhere else. My horse lives on campus, and it's just perfect.

Do you live away from home during the school year?

No, I live at home during the school year. Last school year, I lived on campus and that was really hard.

What was that like, being independent with all this going on?

I liked it a lot. It definitely made me do a lot more. When I'm at home, I get very dependent on my parents. They wash my dishes and everything. I lived on campus and then I moved to a house off campus, and both were great experiences, but for me, it's really stressful having to deal with other people that don't understand the illness.

When it comes to living – they're partying until three a.m., and you're just, “Oh my God, I have this illness.” You know, just things that people can do. If you're so tired, and you're dying, and you're having a bad day, and you can't really walk – and they're bothering you, or they're yelling at you to wash your one dish, which definitely has happened. And you're going – “I have a dish, I just had breakfast, and you really need to calm down. I am so sick today, I'm going

to have to go to the ER.”

My first two roommates, I did try to keep it a secret from, but then they saw all the syringes, they saw all the pills, and they were like, “What the hell?” I remember once it came out because there was a blood drive on campus and my roommate said, “Oh, look – I have these track marks and everyone's going to think I'm a heroin addict,” because she had these bruises on her veins. I said, “Oh, we match. Me, too.”

I'd just had ten blood tests and they can never find a good spot on me – because my veins know when a needle's coming. She was like – “Oh, cool. Did you give blood, too?” It was just awkward. Then she asks – “Do you do drugs?” And I was – “No, I have a chronic pain thing.”

I laugh at it a lot, to be honest. I try to have fun. I try to make the best of it. I try to help other people that I know have it, and I try to survive the best that I can.

Why did you try to keep it a secret from your roommates?

Because people definitely treat you differently. They don't know how to act, so at first I thought – “I'll try to keep it a secret and we'll see how that goes. I'm not going to make a big deal out of it.” Usually, I'll tell people right away – “I have arthritis.” I have this, and I never had not told anyone right away. And so there were these new roommates in college, trying to see how it goes.

It didn't last that long because it is everywhere, and I have a lot of special accommodations from the housing department. I didn't have a food plan because I'm gluten intolerant. I needed to have a special refrigerator in my room, because I needed to keep my Humira cold and I didn't want it in the group refrigerator. People would ask – “You don't have a meal plan?” – because it was required to get a meal plan, and so I'm okay with telling everyone. Sometimes I think it gets misinterpreted and people think you want that attention.

And people try to compete for the worst life – I hate that. Okay, everyone has their struggles. Stop trying to have a crappier life than me.

You said you pass out? How often does that happen?

That's my Postural Orthostatic Tachycardia Syndrome. It happens a lot during weather changes, so summer is hell.

Some weeks, when it goes from being sixty to being ninety degrees, I've had doctors say, “You need to stay inside,” and it's true, because my body can't handle the change in barometric pressure. I just pass out and I get short of breath. My heart races and it's – a few weeks ago I was in Dollar Tree and all of a sudden I just got so lightheaded. I haven't passed out in a while because I can feel it. Everything kind of goes black, but I'm still conscious. I just can't see anything, and so I just lie down on the floor.

I don't care where I am. I've done it in the middle of class. I did it in an alley

behind Jimmy Kimmel. I just lie down and everyone's asking – "What the hell is going on?" I'm like – "Nope, sorry. I'm about to pass out. I'm gonna lie down, so I don't pass out."

That's one of the most dangerous things, because if I fell down and didn't listen to my body, then I could really hurt myself. The people in Dollar Tree freaked out and I just left – "I'm leaving. It's fine."

That's really brave of you, to know what's going on with your body and to not care about what people think.

Yeah, I try to listen to it a lot. I was always afraid that people thought I was searching for attention. I don't know why. I think it was significant for me that my illness struck me in eighth grade. That's the time in your life when you don't know who you are. Everyone's trying to find who they are. You're just unsure of yourself, and that became something that really defined me. I don't want it to define me in any way, but I do definitely always want to acknowledge that it's part of me. I'm happy for what it has made me. It's made me a very strong person and a very compassionate person I think.

When stuff happens, I used to – well, I still do it now. I will take pictures of me in a hospital gown and just be like – whatever – hospital swag. And my mom is always asking, "Why are you doing that? You're going to scare people." And I'm just – "But that's me, that's my life. I don't want to have to hide it."

I spend a lot of time in the hospital and yeah, my doctors are some of my best friends. Is that weird? Yeah, but that's my life.

Wow, that's a very nice outlook on it.

I made this video about me doing my B12 injection, and whenever I do it, I play the song "Shots" by LMFAO, and I'm just singing – "Shots, shots, shots, shots, shots..." All my friends think I'm so weird, but they love me still.

I have a handicap placard because of my tachycardia and all my passing out. Because of my spine fusing, I am legally handicapped, so I get that a lot – "Wow, is that your grandma's handicapped placard?" And I say – "No it's mine, I'm legally handicapped." And then there's a lot of – "Why?"

I've gotten yelled at for it. I've gotten kicked out of places because I'm in the handicapped section. They yell at me and I say, "Okay, I'm going to sue you."

Really? They yell at you because you don't seem to have any problems?

Oh, I've been screamed at. My first year in college, I was backing out of my parking space and this car backed up into me. I said, "It's fine. I don't really see a scratch on my car," and the driver asked, "Are you okay?" And his girlfriend started screaming at me about having a handicapped placard – "You're

not even handicapped!" And I said, "Actually, I am," and that's my first mistake. You should never engage with anyone like that. Like my mom says, "They are blessed not to know about hidden disabilities."

She was saying, "Well, if you're handicapped, you shouldn't be driving," and basically tore me a new one about that, and I just cried so much. I've cried a lot.

I used to work in the music industry, and I still kind of do, here and there, but it's not as much a part of my life. I was at a concert once, and I sit in the handicapped section because I can't go into the mosh pit. It's too dangerous for me and I might pass out. My doctors have made that clear. I was in the handicapped section, and the security guard yelled at me and kicked me out, and I just cried.

I went to the owner – "I can sue you, but I'm not going to, but you need to retrain your entire staff." And they did. That's all I want. I don't want money. I just want this to never happen to anyone else.

I've had a lot of those types of things. My mom gets really defensive whenever we use my handicapped placard and someone looks at me. I just roll my eyes at it now. I just smile at people. I'll say, "Hi," if they are staring.

There are a lot of cops at my school, and they check everyone's handicapped placard. I always thank them for their service, because I know there are a lot of people who fake the usage – but I'm not one of them. I have my permit for my placard and I have my license, so I will give it to them and they're always like – "Great. Have a good day," and then it's fine.

What do you do to cope with your pain?

I've done a lot over the years, and different things have helped me through different times. I did yoga for a long time, and it was absolutely amazing, but then you get busy and it's hard, because I can't go to a regular yoga class. I did specialized Iyengar yoga, and I'd go to private teachings, but I just couldn't go to a regular class.

My horse is my best friend and he has been there through everything. I got him very shortly after I got sick, because we thought that I wasn't going to be sick for long – that I was just going to have the surgery and be done with it.

I had always wanted a horse. I'd had a pony and had ridden my horse, my current horse, and I had always wanted my own horse. I have him now and he's my best friend and I'm with him all the time.

It's really ironic – well, not ironic – it's creepy, how horses can mimic you. I have ankylosing spondylitis, which causes fusing in the SI joint. It starts in the SI joint and it will go all the way up your back and fuse your entire spine together.

I have a lot of pain in my SI joint, and my horse has been kind of off in his knee and hip, and I'm thinking – "Oh my God, I need to get the vet out here. His hip is all messed up and his knee is all messed up. Oh my gosh, I'm gonna have to...."

So the vet comes out and says, "I don't know what you're talking about. His knee's fine. His hip's fine. It's his SI joint that hurts." I just screamed – "You're

kidding me!” And he’s like – “What?” I said – “I’m having surgery on my SI joint tomorrow.” So he likes to copy me a lot. But he’s my little angel.

Is riding him and taking care of him therapeutic for you?

It’s a huge therapy. It’s a lot to ride. It takes a lot of muscle. I know riders who have ruined their back from riding. Recently, I’ve been really training properly to strengthen my back, to strengthen my body through riding. Just being around him is therapy. I’ll get really sad some days, and my mom will basically kick me out of the house. The only place I have to go is the barn and she knows that, so she’ll say, “Go to the barn and see your horse.”

I see him every day, but when I get sad, I don’t want to go anywhere. She’s just, “Go see your horse.” And of course I come back from the barn super-happy – “My horse, he’s so perfect!” And she laughs – “Yep, that’s all you need to go do.” He’s the best therapy ever. I’m looking into starting to work with equine therapy, because I really do believe in it. Not only physically, but mentally.

They’re such intuitive animals and they reflect back to you. If you’re anxious, they’ll be anxious, but if you’re calm, they’re gonna be super-calm with you.

And then I have my dog. I adopt Special Needs animals. So my horse was a rescue off the track, and my dog was a rescue pit bull, and he’s deaf, and he’s just the cutest thing in the world, and I love him. He’s with me all the time, and he’s the one who actually gets me outside to run around in our backyard. I love him so much. Definitely, a lot of animals help me through my pain. My mom, too. My mom’s amazing.

What else do you do?

I do physical therapy. I am way too close to everyone in that office. We literally talk like we are best friends, because I’ve been there for so long and I go there so often. I used to have to go three times a week and now I am down to two times a week, but I love physical therapy.

And I definitely do art therapy, but I wouldn’t say I ever went to an art therapist for it, or any program, but I paint a lot. I do it just to get that extra energy out. I think sometimes that when you have chronic pain, your body isn’t always allowed to do as much as your head can do, so you’re just kind of everywhere, but then your body’s tired and in pain, so the painting really helps.

I do a lot of crafts and really love to make stuff with my hands. I’ve been really getting into woodcrafting, so that makes me actually do stuff with my hands and my body. I cut lots of wood, and sand it, and drill it – all that type of stuff. I just really love making anything, so it’s a lot of fun.

Does it help with your pain or does it just help you relax and get your mind off it?

I’d say it helps me relax and get my mind off it. Most things are distractors for pain. When I’m doing something else, I’m not thinking about the pain, so I’m pretty good at getting away from it. I have a regular therapist that deals with me. She puts up with me, and I’m always afraid that she’s gonna say, “Yeah, get out of my office,” because I can be a pain sometimes. But she’s really good.

My mom’s a psychotherapist, so I’ve always been very used to talking about my feelings and thinking about everything, so therapy’s always been a normal thing for me, in terms of psychotherapy.

I’m trying to think what else. School doesn’t help. I notice when I want to do something, I can get my pain to go away, but when I don’t want to do something – like sit in a two hour lecture – my pain is right there on the top of my head. So that sucks.

Does that ever make people feel skeptical?

Very. One hundred percent.

I know for me it’s, “Oh, you’re too sick to do your chores, but you’re not too sick when your friend invites you over?”

One hundred percent. And it was like that a lot when I first got ill. I think my parents really didn’t get it. Wash the dishes, do your chores, clean your room – and I was like – “I’m in so much pain.” Then it was – “Oh, you want to go to a riding lesson.” Or – “Oh, do you want to go over here?” And I was – “Oh, I’m good now. I’m going to go hang out with my friend.”

My brother would be very mean about it. My dad did not understand in any way. Same with my mom, and then eventually – I think doctors are very aware of that. The docs that I was dealing with have been very aware of adrenaline and the energy that you get when you want to do something, so they’ve always been telling my parents, “That is normal. She’s not making it up.” So my mom understood, eventually. Now my dad finally gets it. I don’t think he’s ever questioned my pain in the past couple of years. Everyone else, I just don’t care about.

It’s very confusing to people how little I care about what other people think, but when you have people constantly talking about you, constantly saying that you’re lying about your pain, that you’ve died, that you had cancer, all these things – and people would say it to my face – that I was lying. Then you start thinking, “Oh, my God – am I lying? It’s in my head.” You literally go crazy. And so it took me a long time to get that confidence in myself – to stand up for what I honestly feel on the inside.

When I have to take a test or when I have to study – studying doesn’t work for me. I don’t study because it hurts. I’ve wanted to drop out of college multiple times because I’ll just sit there and cry, and say – “Mom, it’s not fair. I’m in so much pain and I have to go through this and these other kids are healthy.”

I feel like I am asked to run a marathon and carry a five hundred pound weight, and everyone else doesn't have to carry it. And we're being judged on the same thing and we both are competing on running a marathon and I'm carrying all this extra baggage. But that's life.

That's life, that everyone has their stuff, and it's not going to be fair. My parents have been very supportive. You want to drop out of college? You can drop out of college tomorrow. Or today, whenever. Whatever you want to do, but I think that it's not about the degree. I'm sure I'll be successful doing whatever. I'm sure I'll be happy in the end. It's about finishing something.

I tested out of high school. I didn't graduate normally. When I was sixteen, I took the California High School Proficiency Exam, which is the legal equivalent of a high school degree. It's not the GED, it's harder. Then I was done.

Now I'm in college and I don't like it. It's hard, but things are always going to be harder when you have pain, and people aren't going to understand it, and people aren't going to want to understand it. But when other people go through their stuff, then they'll stop and see. A lot of people my age don't really get it yet.

What's the first thing that comes to mind when you think of doctors? I know that you have a ton of experience with them.

I want their cell phone number. If they don't give me their cell phone number, I get very upset. I don't ask them for it, but in my head I'm like, "You're going to give me your cell phone number, right?"

Do they give it to you?

My primary care doctor, I have her cell phone number. And I've had to call her a couple of times.

Everything is complicated when you have a chronic issue. When you have an illness, everything is complicated. I recently got bit by a dog. It was an attack, and my leg got torn up. It was on a holiday weekend and I'm on Humira, and that severely lowers your immune system, and it's weird about dog bites. They don't stitch them up because of the risk for infection, and so I called a couple of Nurse Help Lines.

They said – "Call your primary care doctor," and I'm saying – "He's not gonna be back for two days, and my leg's all bloody." That was my prescribing doctor, my rheumatologist, but then I call my primary care doctor. "Do you want me to go to the emergency room so I can get some shots?" And she goes, "Please, you're not going to the emergency room. I will prescribe the medication in pill form and you can go pick it up from a twenty-four-hour pharmacy."

She's amazing and I love her. She's not specialized in fibro or any pain thing. She's just a primary physician, but she's been with me since before I got sick. She's the first doctor I went to go see, just saying, "Oh, I have a headache," and

she's been with me through it all. She has a couple of other patients with about the same illnesses I have. When I have to get vaccines, everything needs to be watched a little bit better.

If I get sick with my Humira, I have her cell phone number, and I use it. I feel so bad when I use it. I'm always – "I'm sorry," and she's like – "It's okay, that's why I gave it to you." She's kind of like a grandma to me, like a second mom.

I'm very mean to my doctors until they're in the inner circle. I have a circle of doctors that I trust, and getting there isn't easy. Like – I don't think that you're good enough, I don't think you know enough. Then, once you've proven that you know enough, I'll trust you. I've become very picky about who I see.

I have amazing insurance, which I've been blessed with, because I know a lot of people have the same illnesses as me and they struggle with that type of stuff. I'm lucky on that perspective, and I get to see all my doctors. I know that a lot of them see people with chronic pain, so I try to lighten up their days if I can.

My mom has always educated me on the fact that it must be pretty depressing to have to deal with people and see all the pain. My main rheumatologist sees kids that are two-years-old and up, all the way to eighty-year-old people. And to see a two-year-old with arthritis must be very depressing, so I try to cheer them up a little and just joke with them. But if my medication makes me gain weight, I will yell at them, and then they get very scared.

I have a couple – I cry in their office. They know me well, and it's scary sometimes how well your doctors know you. My physical therapist and me are really close friends because I had to see him three times a week for months. Now we're down to two times a week, and I just ask – "Did you watch the new 'Game of Thrones?' What'd you think?" He's like – "Oh my God, you're crazy."

If you could give doctors advice on how to improve their practice, what would that advice be?

The main advice I would give is to look at the whole picture. To know that these are people's lives and to take that seriously. I've had doctors that don't take that seriously. They think they're the rock stars and you're not. You are not important. If they all took a bite of humble pie, I think that would be amazing.

I have a doctor – he is recognized by the arthritis foundation – and he is the most amazing doctor, because he doesn't just see you, he sees your entire life. He looks at you, and because with POTS there's a whole dysregulation of your system, I was telling him, "Oh my God, I've gained weight. For that last month I've gained a pound every week, and here is my weight."

He just gives me a hug, turns to my mom and says, "Take the scale out of her room." And I'm like – "What? You can't take the scale out of my room." And he says – "Listen, you're having a flare-up. Your body's in super dysregulation. You're going to gain weight, you're going to lose it. It's fine. It's not real weight, it's just the dysregulation thing. You're just holding onto a lot of water. Don't

worry.” He doesn’t just go – “Oh, it’s okay that you’re gaining the weight.” He goes all the way to say, “Okay, I see that you are going crazy about this. Stop being crazy.”

He asks how I am doing in college. He cares about my grades. He’s the first person I consulted when I thought I was going to drop out, and he was – “Absolutely not.” He makes me schedule my appointments two weeks before my finals, because he wants to make sure that all my health is in line when I take my finals. It’s just that extra care, and he is so humble about it all. I have other doctors that can come in late, they are late for surgery, they think the world revolves around them. He just knows it doesn’t, and I really like that.

Wow, you’re really lucky. That sounds great.

Yeah, I have some amazing doctors. I can’t move out of California because they’re all so great.

In general, do you hide or embrace your pain?

I think I embrace it. Sometimes I’ve had guys walk me to my car and they’re like – “Oh, cool. Is that your grandma’s disabled placard?” People will ask my friends – “Why does she have a disabled placard?”

When I had pain patches – you have to wear them on your arms – and everyone, every single person that I met was like – “Oh, is that a nicotine patch?” And I’m just – “No, it’s a pain patch for my arthritis.”

I think a lot of people suffer from chronic pain more than you can know. I’m on Twitter a lot, and sometimes I see people post about it. They just feel so lonely, because people don’t talk about it. People hide it, and I tried hiding it.

I tried hiding it from my roommates and it lasted a month tops, because I love to joke about it too much. I love to play “Shots” while I give myself actual shots. I just think it’s funny. Some people don’t, and are like – “That’s really not funny,” and I say – “Yeah, but this is how I deal with it, because I need to laugh about it, and I need to talk about it, and if you can’t handle that, then don’t be in my life.”

My mom is the same way. We always make jokes about giving blood – “Yeah, we are vampires. We’re always at the blood bank.”

I have to get so many blood tests because of the Humira, to make sure I don’t get sick. Everyone at the blood place knows me and I always joke with any nurses – “Oh yeah, you stick that needle like it’s nobody’s business.” I walk in there and I’m like – “Okay, I need a butterfly needle, I need to lie down, and I need this.” And they are – “Who are you?” And I’m just – “Sorry. I do this a lot.”

Do most people in your life know about your pain, or have you managed to keep it a secret?

I would say that everyone knows. The people who don’t know are just people that it hasn’t come up with yet. I’m pretty open about it, and I’m always happy to talk about it. If anyone ever has any questions – “Why are you taking those pills? Why do you have that?” – I’m happy to talk about it. It bothers me when people don’t ask, because that’s how rumors get started. That’s how people start talking about other things. People think I have cancer. People think I’m dying. People think I’m lying. People think that, so I’m always happy to talk about it.

I tell a lot of people, especially when I have riding and I have commitments. I was president of my equestrian team, and am now the captain of our equestrian drill team on campus, and I tell people straight up, “I have back problems. I have issues. I have illnesses. I have doctors that I’m on a four-month waiting list for, so whenever that appointment is, I go. And that’s that.”

Were you always that way when you were younger?

When I was younger, I didn’t really know what to say. I wasn’t always confident when people would ask questions. With chronic pain, especially living in California, everyone has a cure for you, right? Everyone – they know the answer. I had a five-year headache so it was always, “Oh my God, I have this migraine.” It literally lasted five years, so everyone was telling me how to get rid of it.

It was just, “Oh, well you haven’t tried this, this is exactly what we’ll do,” and it used to really bother me when everyone would tell me what to do with my illness. It made me feel like I wasn’t doing enough.

Me and my mom have literally tried every backdoor alley, every snake oil – we’ve done everything. And she really does think that one day I’m not going to have any pain – and that would be great if that happens – but I’m okay with living my life with it. It’s kind of a best-worst-case-scenario thing.

My old roommate’s mom is this really loud woman from the Bronx, and she’s got a thick Bronx accent. Me and my roommate were really close. I just assumed she told her mom about it, but she was like – “What illnesses?” I was – “I have fibromyalgia and ankylosing spondylitis,” and she goes – “What’s ankylosing spondylitis?” And I go – “Well, my spine fuses together.” She didn’t even know what it was and she’s – “Oh, well that all can be cured.” I literally said – “I know. I just haven’t done it yet, I just haven’t cured it yet. Yeah, it can totally be cured.”

I get so snippy with it – it’s just those people, they think you can totally cure that. You just have to drink all vegetables, and it’ll just go away, and I’m like – “Yeah, totally. One hundred percent. I just don’t do that because I want to be sick.” I’m just sarcastic.

You get all different types of reactions to it. I had a friend once, when I told her she started crying. “You’re going to die?” And I’m like – “We’re all going to die, but I don’t think this is going to kill me.” And she says – “Okay, never mind.”

When you’re in pain are you the kind of person who finds yourself calling

a friend or trying to fix it yourself?

Myself. If I call anyone, I call my mom. I don't talk about it with friends. I use friends more as a distraction. I am definitely working with my therapist more about talking about my pain with friends. When I talk about it, I present it that I'm this strong person, I've overcome this, and the truth is, it's a chronic thing and you are always gonna deal with it.

I've had days where I just go home and cry and say, "Oh my God, I'm in so much pain." I don't like to present it that way. I like to present it as a strength and not a weakness.

But my mom is the person who knows everything and she knows how bad it can get. I'll call her if it's that bad. Sometimes I have to call her and she'll say, "Okay, do you want to take this medication?" A lot of the time I'll just be – "No, I'm just gonna try to sleep it off." And sometimes it is a lot, and it can be hard.

I turn to my friends more when I need a distraction, because I do think it's impossible to comprehend chronic pain unless you directly know someone that has it – or you have it yourself. A lot of people can't wrap their minds around it.

Do you think you've missed out on anything because of your pain?

I missed out on a lot of stuff, for sure. I didn't have high school. I went to high school for about four months. I tried to do it. I would go to class, and I was only going once a week. None of my teachers actually knew why I was only coming once a week. One of them called me out on it. He goes – "Oh, you decided to join us today," and I was like – "Why would you say that?" And then it became a thing. In the end, he was the best teacher I've ever had. He was great. That became the thing that opened me up.

I told the school to send out a memo, but they never sent out the memo, so none of my teachers knew. I was actually failing all my classes because I never got any of the attendance points. I was really lucky that he did say that in the end, but you miss out on a lot.

My high school was absolutely awesome. Because I was such a good student, they told me that I could walk with the class the year that I had graduated, and most of my friends were in that year, but by the end I graduated in November. In January, I'd started taking classes at the local community college and so I was already in college.

I learned a lot, but you always have this distance. I missed out on the regular college parties. I miss out on boys. (Giggles.) I've never had a boyfriend and I'm attractive. I'm hot! I never had a boyfriend. I just think that it's opened my eyes to a lot of other things. All my friends are like, "Oh my God – boys!"

Well, I'm ready to take over the world, start my own company and all this. I'm always cheery. I always want to help other people, and I think that I gave up a lot. Not of my choice. I didn't decide to give up – it's just my life, it's the cards that

I was dealt. I lost a lot, but I also gained a lot of other things. I've gained insight. I've gained a special view on the world, and the ability to help other kids who go through a lot of the same things.

Do you feel that boys are intimidated by your illness?

I think boys are very intimidated by my strength that I've had from my illness. I am an intimidating person. Everyone tells me that. I'll go to my physical therapy office and I'm so used to being there that I make aides cry. They have aides that help you with your exercises before you see the physical therapist. I tell them, "Get away from me. Are you a physical therapist? No? So don't talk to me."

When you get in that mood, when you have the pain, I get into that – don't talk to me. Why are you alive? Even right now, I'm sitting here and – "Oh my God, it hurts so bad." I can smile through a lot of pain, but then it gets to that point where I can't really deal with stupid questions.

One guy at my physical therapist asked – "Oh, what'd you do to hurt it?" And I was just – "I have fibromyalgia," and he kept asking – "Yeah, but what did you do to strain it?" And I was like – "I have fibromyalgia," and then I just made him walk away.

Now I'm allowed to hold my own chart, so the aides at physical therapy don't have to talk to me. They all know. My physical therapist has told them, "Don't take it personally. She just doesn't like people." When I go there, it's painful. You're doing all these exercises that don't always feel good, but they're strengthening your back, and I don't want to have to smile at people while I do this painful exercise. They're used to sports injuries – either sixteen-year-old people who are in soccer, or ninety-year-old people who have arthritis – and then there's me.

If you could have one day without pain – you wouldn't have repercussions – you just had one day to do whatever you wanted, what would you do?

Oh, wow! I'm just trying to think about it. It's funny, because when you have pain for so long, you forget what it's like to not have pain. I used to go to Disneyland all the time, even when I started having pain, but all the walking and everything – I just feel like I'm a fifty-year-old woman going through menopause, and I just get tired. I'm just – "Oooh, I don't like all these people." I think I would just be happy. I would just be like – "Oh guys, look – no pain."

That makes sense. Do you have any regrets of missed opportunities, or experiences that you missed because of your pain?

I think if I did drop out of college, it would be a huge regret, but you know I'm trying, I'm trying to deal with it. The first summer I got sick, I went to Hawaii

with my parents. I was in the hotel room the whole time because the flight was too much on my body. I was in so much pain. I was so sick and I was so dizzy. The change in barometric pressure and everything was just too much for my body. I remember being in the hotel room and I felt like that trip, I didn't try to make the best of it.

I was okay with just being in the hotel room, and when I first got sick I just laid in bed. For the first six months of being ill, I was just in bed every day. I would watch movies. That's what I thought I could do, and I was just waiting to get better. Even though I was young, I felt like I put life off.

I don't regret it, because every step I took brought me to where I am today, and I'm happy about that, but I would never want to do it over. I would never want to put life off ever again. I would never want to be in that place.

I come out and everyone thinks I'm crazy. I ride horses and I have a back that's fusing together, but I don't look at it like, "Oh my God, I'm so depressed, I'll wait until I feel better tomorrow." No, I have to live today for everything it is. That doesn't mean I'm going to go sky diving. I'm gonna do what I love. I'm not gonna drop out of college, because I still do plan for the future. I still plan to be here, but I'm just going to enjoy today, and I want to do as much as I can.

And keep that mobility. It really is a "use it or lose it" type of thing. My horse has been off for a month, so I'm finally getting back in the saddle, and it's really hard, and oh my God, it hurts everywhere. I used to be super in shape and I gained ten pounds from not riding, because I eat like a monster. When I used to ride every day, I would come home and eat everything in the fridge, because you're so used to that. You're like a football player. But then, not riding, I still would eat the fridge and I just didn't have the exercise. Now I'm getting back to it, and I'm like – "Oh wow, this is me and my horse getting back into shape" – and it's just hard.

These next questions are kind of intimate but....

I'm down.

Okay. Has your pain ever caused you to be depressed?

Yes. Anyone who says "no" is a liar. How can you not? Because it's so lonely. It's one of the most lonely feelings, because only you can feel that pain. You can't describe it to someone else. No one else can feel it with you. People can't even sympathize, because it's impossible to describe. It's impossible to understand unless you've gone through it yourself.

I think that's why it's so important when you can have relationships with other kids and other people, when you can talk to other people with chronic pain – it's very important that they are only uplifting conversations, because it's very easy to go in a dark place with those.

I think that it's so depressing because I could tell someone about it and they could be watching me. And even my friends and my mom – you know she wants me to get better – but there's nothing she can do and there's nothing I can do. I don't like sitting around being depressed about it, but I also get depressed by all the things you miss out on – like wow, I really wish I could go to that party tonight, but oh my God, my back hurts, and I know that I'm going to fall asleep at ten o'clock.

Do you feel you can share those dark emotions with people in your life?

Yeah, I feel like I'm a pretty open book. I'm not really ashamed of anything at this point. I think that a lot of that is just because I know how far I've come, and I know that everyone goes through it, even if they haven't had it yet. I really strongly believe that everyone has their shit. You know?

I think that one of the things that everyone goes through is the fact that they're depressed or they're sad or they struggle, but at the same time, that's what we hide from everyone else in the world. It's ironic that the one thing that unites us is what we hide from everyone else – that emotional pain.

What has your darkest thought been regarding pain or your life?

I wanna kill myself. And I think that most people that have pain have thought about it. You consider it, you weigh it. You think – "If I kill myself, I can end this." Or – "I'm going to live with the pain. Is it worth it?" Because you balance it. I'm a business major, so it's like opportunity, costs, pros, cons, everything like that. Everything is measured and measurable, and is it worth it to live with this pain? The answer's always been, "Yes."

Why do you think that is?

Because I absolutely never know what tomorrow holds. I never thought that I would be here like this. Some days I'm really happy, and I never thought I would feel that way, just being happy to be happy. And other days, I'm really sad, but it's not a type of sad that's not gonna get better. I went through that a lot when I got sick. I listened to a lot of emo music and I wore black or whatever. I was really sad a lot. And now you know that it's gonna get better.

I've gone through it enough to know that there are some things – I see it a lot when I am with my horse, I feel it when I'm at a concert – you just feel like it's worth it. Like this feeling, this moment – I feel it every time I look at my horse – this moment in time is worth all the pain. And if just that one moment is worth it, I'm sure there are many more moments to come.

Wow, what do you hate most about your pain experience?

The burden it's put on my parents. I wasn't really able to fully understand that until my horse got his pain issues. To watch someone, to watch something go through pain – and it's the one thing you love more than anything – and you have absolutely no control.

My mom will be there and she'll hold my hand through it all, and she never cries. She's never weak. She's always strong, and I don't know how she does it. My dad gets frustrated a lot because he is six-foot-two and he's this gigantic ex-LAPD cop, retired, and he's got all this muscle. He used to be a bodyguard for celebrities, and he's huge. When I first got ill, he was so upset about it, because he couldn't wrap his brain around the fact that he could do nothing.

He was ready. He was saying, "We have money, we have everything. We can do whatever's necessary," and it was just – you can't. You can't just pay for it to go away. You can't change it. That's how it is.

What do you think got him off that mindset?

When he was able to see – I talked to him a lot and I tell him – I used to try to hide my pain from him, because I didn't want him to be sad. Now I tell him, and he sees my attitude about it, and I think he's really proud of it. How I'm just kind of – whatever. I live with it, I laugh at it, and he sees that.

When it comes down to it, he's accepted that he can't do anything. It's hard when you don't accept it. And when you try to fight it, it's just impossible. But now he's accepted, "Well, I can't do anything about it." But he can support me through other things. He can't change my pain, but he can change the oil in my car, and that helps.

Do you feel guilty about how your friends and family feel seeing you in pain?

I don't feel guilty. It's not my fault and it's not their fault. There's no fault. I think that for a lot of people, like my dad, it's hard to get the concept of there being no one to blame. It's like you're taught when you're little – there's a good guy, there's a bad guy – it's the bad guy's fault. This is why something happened. The fault.

And to understand that – wait, something bad happened and it's not the consequence of something else – it's just something happened and there's no one to blame. It's no one's fault. It just happened. And you have to accept that and to look at your life and try to find the good in everything – try to look at it in a positive light, or the best light you can look at it in. And be accepting. I think my dad's coming around and looking at it that way.

I don't feel guilty, but at the same time, it's not something I like to focus on with them, because there is such an amount of hopelessness. I'm hopeless to fix it, they're hopeless to fix it. So I don't feel the need to sit there and cry about it.

I want to go on. I want to live my life and I want to find out the best ways to do that. That's what I like to focus on.

How can I still live a normal life? That's what my parents focus on. That's how they help me a lot. When I had moved out – grocery shopping is really boring, and it's really hard because you have to lift all these groceries. Everything I eat is from Costco, so my mom said, "Give me a grocery list and I'll bring it to you," and that was really helpful. They still did my laundry, and I'm not ashamed of that, because Lord knows if I did my own laundry, it would be a mess.

I upgraded to doing my horse's laundry now, so I'll wash his blankets and polo wraps, and luckily I haven't burned anything, but it could happen.

You mentioned people doubting your pain. How does that make you feel when other people don't believe you?

It used to make me really mad, but there's no hard evidence. Doctors will do x-rays and MRI's and when it was just fibro there was nothing, absolutely nothing, that shows it. You can have an inflammation test and maybe that will show it, but maybe not. And with the ankylosing spondylitis, you almost want the ability to look at a scan, look at an MRI, and say – "Look. Here's proof that this would cause me to hurt." And having nothing wrong is really frustrating.

When I got diagnosed with ankylosing spondylitis, in a way I was happy because it was finally something to look at, something we could measure. I had the gene marker for it, which is rare in women. That was big. And now my most recent x-ray shows shrinkage in my SI joints, and that's what they do. The space starts shrinking and then they'll start fusing, but I'm on the Humira to prevent it.

You want to be able to see something, because that's how humans work. We are used to the proof, the hard facts, and being able to have tangible evidence. Then when you see it, you think, "I don't want to see it anymore. Please go away."

With my first MRI, it was – "Oh, here's a cyst. It's pushed up against your brain. Of course this is why you have headaches." And the cyst got removed and everything looked normal and I still had pain. I remember I had days where I felt like my back was broken. We would go in, and luckily my primary care physician dealt with me, because I would say, "My back's broken," and then she would take an x-ray and – "Nope, your back is in perfect alignment. None of your ribs are broken. Everything looks amazing." I'm like – "No, it's broken. I am in so much pain." And then you see, and you just feel crazy, because everything on the scan is fine, but you're in crazy pain. It drives you insane. It's insanity.

How has this impacted your relationship with your brother? How do you guys deal with it?

Me and my brother didn't get along much as kids. He's three years older than

me, so he's about to turn twenty-five. He is severely bipolar. He's diagnosed bipolar, and up until recently he was taking his meds. He had a lot of anger issues growing up, and he was one of the people that always told me that I was faking it.

He was young, and he saw the difference between when I wanted to do something and I didn't. And the difference between – "I want to go outside and play with my friends," and – "Oh, I have to clean my room? I'm sick." Or – "I have to go to school? I can't get up."

Mornings are really hard for me, so I could never get up at six in the morning, and that's the time when I had to get up for school. It was really hard because I always heard him telling my mom that I was faking it. It was terrible, and my relationship with him is weird.

We fought a lot as kids – bickering is what my parents called it. He couldn't always contain his anger. He yelled a lot. He called me a lot of names. It just was never good with him. Then when he moved out, it got better, but he's a very high-stress person and one of us always looked at the other like – Gabe got this, Haley got this. If your sibling got something, you wanted it.

My parents trusted me a lot more than they trusted him. I was always the good kid, so when I was fourteen, I would have a later curfew than he had when he was fourteen. He dated a couple of my friends, which was horrible. He always had sex in the room right next door. That was horrible.

He didn't respect me. He also didn't respect my parents, so a lot of the stuff he didn't do, I tried to overcompensate on. The illness does mess with that because – I don't know if he even believes that my pain is a hundred percent real now, because for a long time he would say not nice things like, "Yeah, Haley's faking it."

He would have his music up so loud at night, and my sleep was really precious when I first got sick. I was getting one hour a day. It was impossible to sleep because I was in pain, and I wasn't used to going to sleep in pain. So our relationship isn't great. It's not even good, I would say. It's tolerable.

He always joked about my medication. "Oh, can you give me one of those meds? Oh, I'll take a Vicodin." And if anyone ever joked about that, it really upset me – and he did. I would tell my mom, "I don't think he should have access to my medication."

I don't know how different our relationship would be if I was healthy. Probably very different. But he's always been the immature one. Everyone always thinks I'm the older one, because I act like I'm fifty. I get along with my mom's friends better than I get along with people my own age. Everyone just thinks I'm the older sister.

Okay. Does your pain make you feel alone at times?

Yeah, I think pain is very lonely in its nature. Only you can experience it. It's not like a movie you can go and watch, or a song you can listen to, or a book you can read. Someone else can read the exact same book or watch the exact same

movie the same way. No one can experience that pain the way you experience it. I can meet someone with fibromyalgia and they won't have the same pain as me.

I always have to fill out these questionnaires whenever I go to a doctor's office. Is it itching? Is it burning? Is it stabbing? And none of those words is right. It feels the way it feels. There's no word for it. It just feels this way and I can't describe it, and it just hurts, and make it stop.

So it's very lonely. It is. You say, "I have back pain," and everyone else in the room will say, "Oh my God, my back hurts. Oh my God, you don't even know." I love that. "You don't even know." No I don't, you're so right. Your back pain is so much worse. You don't even know.

I just keep my mouth shut whenever it comes up and someone asks me about it. I'll go into detail, but I try to be compassionate to other people about it, because usually, if they haven't dealt with it for very long, they don't know how to deal with it.

They're trying to reach out to other people – "You don't even know. My back is horrible. It's so much worse than your back," and I just say – "Okay, you win." What did you win? What was the contest? Oh, nothing? Okay.

What's next in your future? What's your dream?

I want to take over the world. I worked for Live Nation for a while. It was awesome. Absolutely loved it. Then I realized I didn't really like having a boss. I didn't really like someone above me, even though I had the best boss in the world. I will say that – best boss in the entire world. And if I didn't have the best boss, I probably wouldn't have stayed there as long as I did.

I'm very creative. I have a lot of ideas. I think all the time, so I'm constantly thinking of things. How can we improve something? Very entrepreneurial spirit. I came to the conclusion that I need to start my own business, so this summer I didn't go back to Live Nation. I've been there for three summers and they have given me some of the best memories of my life.

One of my main supervisors actually had fibromyalgia, and it was just crazy. It was amazing that I could go through all that and have someone understand. I could say, "I'm in so much pain today."

So that was amazing, but I'm ready to start my own business. I'm still trying to decide. Probably my first business will be an equestrian apparel company, hopefully called "Bitches in Britches." I'm working on the trademark. It's not as easy as I wish it was. But just doing a bunch of sassy things.

I've gotten involved with the Arthritis Foundation. I want to be an advocate for people with arthritis, with chronic pain. I don't want people to think that they have to stop, because doctors do tell you that. A couple of doctors were, "What are you talking about? You can't ride horses anymore." All my doctors now say, "You can ride horses, and we one hundred percent think that's great for you."

I can't ride horses the day after a surgery. I tried that once. They got pretty

upset and it hurt very bad, so they're saying, "You can't do that – but we want you to ride."

I want to have a life that's flexible. I think that's very important when you have illnesses. When you have chronic pain, you need to have a life that's calm, that is flexible, so that you can control your own schedule.

The music industry is the most amazing industry in the world, but it's also 24/7, 365 days a year. You will never stop. If you get an email at twelve in the morning, you'd better answer it at twelve in the morning. And if someone calls you to come in on your day off, you'd better come in on your day off. "We don't care if you are in the hospital, come in."

Luckily, I had a boss that didn't care, but that was the idea. I have a lot of friends who are still in it, and they work seventy hours a week, and I think that they are absolutely insane. I had a fun period in my life and I'm done. If I went back, it would be in a very different way.

I'm very happy with what I do. Being in school, I've done some private work for bands, and it's a lot more calm on the band side. Much more chill than being on the venue side. That's all crazy.

Is your pain permanent?

My mom would kill me if I said yes, but 99.9%. I'm not holding my breath. You have doctors who say – "We are going to get this under control," and – "You're fine," and it's like – well, it's not. I get very upset.

I went to a couple of doctors who were herbalists, and I just went to every different type of person. I went to an herbalist that would tell me, "Oh, you're going to be fine in eight weeks. You're going to be a hundred percent done." And I would yell at people – "You have no right to say that. You have no right to say that in front of my mother because she's done so much. You have no right to tell her that my pain is going to be gone."

So I don't know if it's going to be gone. I am happy. I can live with the worst case scenario, which is that it won't be gone. I don't think I will let it get to a point where it's keeping me in bed, because I tell my mom, "I would rather ride and be in pain, ride and shorten my back's lifespan, than have a longer life just living in bed like a vegetable."

I want to have a life. I want to go out and do stuff. I want to have fun, and there are always restrictions to that with chronic pain, but you try to do as much as you can.

I think for the future, I don't personally want kids right now. Everyone tells you when you say that, "Oh wait. Wait a couple of years, you're going to want kids," and I just say, "No, I'm really good with being the cool aunt." I'm really good with that. I'm really good with having horse children. I would much rather spend money on building a barn than sending children to college.

I like myself. I don't know if I would like kids. I would happily take my friends'

kids or my brother's kids, if he has kids, and put them in horse shows and have fun. Then when they start crying, give them back to their parents. I'm not really a kid person, because I think that if I did have kids, they'd just be like miniature adults, because I would talk to them like full adults.

I can't handle it when people say the word "potty." – "I'm going to the potty." It is a restroom. Don't call it a potty. You are a full grown adult. You have children. It's a restroom. And my mom says the word potty, and I'm going – "I am an adult. Don't call it a potty."

I don't know, but at the same time I don't really think it's possible. If I ever did make that choice, it would definitely be through adoption, because my back is already messed up and anything can send me – one of my surgeries sent me into a bad flare-up. Anything with a dysregulation can make me pass out. I just don't think it's safe.

And I have a gene marker that's passed on hereditarily for ankylosing spondylitis. I don't know if I'd want to pass that on. I don't know if I could run the risk of a kid having this. I don't know – and luckily, I don't have to know – but it's something that I think about. A lot of my cousins are having kids now, and I just hate dealing with infants. It's like – "Eeeew, get it away from me." But I get that feeling with horses, so maybe I'll just be a dog person.

Who in your life gives you hope? I know that's a loaded question.

A lot of people do, but I'm trying to think who really does. I have a couple of friends that give me hope. I have a couple of friends that pull me out. Obviously, my mother, but she doesn't count in this question, because she obviously gives me hope. I have a couple of friends that have been very strong, have faced a lot of adversity.

One of my friends was a diabetic when she was eight months old. She became a Type-A diabetic, and she is amazingly strong, and she gives me a lot of hope and strength. She's the type of person that laughs at it. She just laughs all the time because she can't have alcohol, so she just goes and watches people get drunk, and she just laughs, "Ha ha. I'm a diabetic."

I can't do that. I grew up with her and when she would get shaky – when she needs sugar, her hands would start shaking – so I'd be like, "I'm shaky, too. I want a cookie." And I would pretend that I was shaking, and everyone thought I was crazy.

One of my cousins has had severe illness issues from when he was young. I couldn't even tell you all that he's had. He's had surgery on everything, and I mean on his brain. He's just an amazing, amazing kid and he's very strong and he's definitely developmentally delayed, but whenever we're with the family he's always, "Haley, Haley, Haley." He always wants to hang out with me.

I used to go visit him in the hospital and he'd be smiling, playing around, making fun of the nurses, giving them hell. Him and his parents are some of the

strongest people I know. I've had times when I'm depressed and I look at them, and they have their kid in the hospital, getting all this crazy stuff. It gives you that check. That reminds you that if they can get through it, so can I. If that is life, I can do it, too. So they definitely give me a lot of hope. My horse, too.

Do you feel like you inspire people?

I hope so. I think that's one of the most important things to me in life, to create change, to leave the world a little bit better than you found it. It's really important that everyone has their own meaning to what they want out of life, and mine – it's not as easy as having a husband and a house with kids and a front porch. It's not that. That's not my meaning to life. Mine is, I want to change the world, and I think that if you can inspire one kid, if you can inspire one person, help one – that's enough. And I hope that I've helped someone. I know I've tried.

Sometimes you try and sometimes it ends up really bad. You just look at your intentions and you want to outweigh the bad with the good, and that's what I do. Every person I meet, I try to say – even if it's someone ringing me up at Vons – “How's your day going?” Be happy, it's cool.

This guy at the Dollar Store was helping me out and I was talking to him, “Thank you, so much.” He was amazing with customer service. Every person you meet, you could change their day. And I think that if people understood that, and opened their eyes to that, the world would be a better place.

Do you think that this whole thing happened to you for a reason, or do you just resent the whole thing in general?

A hundred and ten percent, this happened to me for a reason. My grandma was always the person that'd say, “Oh, why me? Why this? Why Haley?” And I was like – “I know why me. Isn't this awesome? Isn't it awesome? There's something in this.” And she never got that.

She'd always get so sad, I remember, and she'd always be – “Why you? You're so beautiful. You're so smart. Why did you have to get sick?” And even if it's like – “Grandma, if I got ill so I could help one person or I could educate one doctor or do something, maybe there's a reason.”

And if there's no reason – even if there's no reason at all – I want to think there is. I want to be positive about it. I don't want to have that negative outlook about this whole thing, because you can find the positive in everything and you can find the negative in everything. You just have to decide what you want to look at.

Do you think that you're a better and stronger person now because of your pain and because of your experiences?

I'm definitely a stronger person. I don't know if that makes me a better person.

I've gotten this suit of armor around me due to the things I've had to go through. I lost a lot of friends when I was in eighth grade. That gives you trust issues. And having illnesses, having to be with doctors all the time, driving to L.A. all the time because you need to see a doctor, getting blood taken out of you all the time, having surgeries – that becomes your normal. That's my version of normal. They'll ask me, “Are you nervous?” Why would I be nervous to get an MRI? I've gotten a bunch of these things. I'm definitely stronger, but I don't know – it's just who I am. I'm a really tough girl. I can deal with a lot and I don't get overwhelmed when it comes to health stuff.

I have definitely an interesting view on life. Everyone has their stuff. My grandparents both passed away a couple of years ago, back to back, from cancer. I wasn't really upset when they passed. No one knew why. They just watched me and – “Well, this is how it goes. This is life.”

And it wasn't in a depressed way. It was that I've seen it, from always being in the hospital as a kid. That was my biggest fear when I got sick. I had an MRI and then I had this whole weekend. On Monday, they called me. Everyone thought I had brain cancer because I had all the check marks for it. You know how precious life is and what a balance it is. And it's not something that you're entitled to. It's a gift.

Every day is a gift, and then when it's gone, it's not something that was taken away from you. You don't get that gift anymore. Some people look at that like – “Oh my God, you're so cynical. You don't have feelings. You're not crying. Your grandparents are dead.” And I'm like – “No, I have a lot of peace with a lot of things.”

And also, just physically, things don't hurt. I'm sorry, when people say, “That really hurt,” I answer – “No, it didn't. I know real pain.” I'm not gonna get into you on our different pain tolerances, but I just got laser hair removal and I said, “I don't need numbing cream,” and the lady says – “Oh my God, you need numbing cream.” And I'm insisting – “I don't need numbing cream.” And everyone's saying – “You're so tough,” and I'm just – “No, I've just experienced pain that's much worse.”

So I'm fine.

Franz

Age 56
Alpine, TX

Do you know what this project is about?

As I understand it, this is the second in your series of books about pain. And this is not about your pain, this is about pain that other people have.

Yeah, I'm interviewing different people and trying to get a grasp of ways people deal with it, and how they're living their lives with different types of pain.

Well, it's going to be a very eye-opening experience for you, because I know what you suffered through. Mine is a totally different animal. Mine is not of my own making. Mine is because of external things that have happened to me.

I guess the way to start this is to give you a history. In 2004, my daughter had a friend over to our house and that friend needed to go home, so she and I got in the car with her friend and we took her home. On the way back to our house, we approached an intersection and there were two turn lanes in both directions on the street we were on.

A young man ran a red light going about sixty miles an hour, and I was going about forty miles an hour in the opposite direction. We hit head on. Totaled my car, his car, he ricocheted off me and hit another car in the intersection, and totaled that car.

So, here's what happened to cause this. My daughter was in the back seat. She was a swimmer, and basically it threw her shoulder out. It ripped muscles and cartilage in her shoulder and ended her swimming career.

Wow, I'm sorry.

Yeah, well it happens. It's just that this is why parents are deathly scared when their kids get a car. Just so you understand the other side of this – just for you to understand the magnitude of this, it would be like getting in your car and going

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