Welcome back. This is Jen Lee, the creator and host of I Need Blue. If this is your first time joining us, we are happy you are here. If you would like to hear other stories, or you have a story to submit, visit www.ineedblue.net Please note I Need Blue does contain stories which feature graphic content and could be triggering. Please seek help if needed. Remember, you always come first.

“My friends thought I would give them cancer. I wore gloves when I changed my 2-year-old sisters’ diaper because the waste was radioactive.” This is Maya’s story.

She was 13 when her sister was diagnosed with ALL: Acute Lymphoblastic Leukemia. She remembers the moment, the pandemonium, surrounding the announcement her sister had cancer. As a teenage sibling, Maya was thrust into a journey which left her confused, fearful, lonely, and feeling deprived. And those are just a few of the many emotion’s siblings feel when they cope with a sister or brother who has cancer.

Maya is now 21 and her sister is 9. She is going to share her story to help comfort others. When I first met with Maya, I was drawn to the emotional details she shared. She has beautiful eyes and as she spoke, she let me into the world she witnessed, watching this younger life and, almost death, of her sister.

I know your story is going to resonate with many families and provide a lot of helpful information. Let's take a minute to talk about your childhood and what it was like before your sister's diagnosis. That way the audience can understand how things were before and after the diagnosis.

Maya

It was kind of a normal childhood; one of those where you have a big family and always hanging out and spending time with each other. I was close with my extended family. Luckily, we all lived in a relatively close area; within an hour of each other. We lived in the Orlando area. There were many trips to Disney, going to water parks, going to different pools and such. It was nice, you know, calm. My mother just married my stepdad so that was an adjustment period, but it was relatively quick and went relatively smoothly.

My family came from Puerto Rico, and they all lived in New York. When my grandparents moved down to Florida, everybody eventually moved down to Florida too. We've always had kind of, I guess you could say, a clan mentality. We're here for each other. It's not “Oh, I haven't talked to my cousin in months. It's, I talked to my cousin on the phone last week.” We were lucky for that.

Jen

What was it like with your friends in school?

Maya

Honestly, I was awkward. I didn't have a ton of friends in school; a few close and I had my best friend. My other best friend moved away around that time, so it was adjustment. I was going to a new middle school and trying to figure out who I was, and what I liked to do. My friends were academically inclined; we would talk about school, different things we learned outside of school, it was very nerdy.

Jen

Hobbies?

Maya

I drew a lot. I was into sketching. During the time, I really got into anime; my art style changed completely. I was obsessed, always sitting in front of the computer, trying to find different references to draw. I was an avid reader then. I still am, but during that time, I was falling off the reading, and more into the arts, painting, and drawing, etc.

Jen

Did you use art to cope with your “awkwardness” during that time?

Maya

Honestly, not at all. Art kids were more unpopular, but I didn't really care about that. Kids would be like, “that's what I draw. You can't draw that.” It was awkward.

Jen

I have a younger sister and we're two years apart. You and your sister, Elizabeth are 11 years apart. For me, me and my sister had some of the same friends. We play Barbies. We played with the neighborhood kids. Is it safe to assume, with an 11-year difference, you didn't connect on that level?

Maya

 I was excited for her to get older so we could play. I did like taking care of her, watching movies with her, and I would play with her while in the baby bouncer. There was some playing, but it wasn't on the same level.

Jen

What is your favorite childhood memory?

Maya

For my eighth birthday, we went to Disney's Wilderness Lodge camping. I think that was my first-time camping? I'm very big on Disney. I was gifted a hidden Mickey guidebook when Disney used to highlight Hidden Mickey's. That was probably one of my favorite memories.

Jen

Let’s talk about your sister. Can you describe the moment you knew something was wrong? Were you told right away about your sister's cancer?

Maya

I knew something was wrong with her health. She was constantly at the doctor's. Almost every day, we thought it was a bad cold, fever, asthma, etc. She was on a nebulizer for a few days. They were running many tests. I was always close with my stepdad, my mom, and my sister so I went with them to those appointments.

I didn't go with them to the Children's Hospital in Orlando when they found out. That day, I wanted to stay home with my grandmother and spend some time with her. Before they left the hospital, they gave my grandmother a call, and told her the news so she would be aware before they told me. I remember her handing me the phone, crying, sobbing, and then running down the hallway to go to her room. I was really confused. They told me right away she had cancer.

I didn't know what cancer entailed. I only was exposed to cancer in TV shows and stuff. I was very shocked. I was also very confused. In my brain, I'm like, it could be worse. Worse meaning dying. I didn't fully realize that cancer slowly kills you. I was just like, “they know what she has. And now they can help her.” Then I went back to playing video games.

My mom was asking, “how are you feeling?” And I was like, “I'm fine.” Again, I didn't really know what cancer entailed. I figured now that they know what it is, they can fix it.

Jen

When was the next time you saw your sister, after you got the news from your parents?

Maya

It all happened in kind of a rush. I don't remember if she stayed at the hospital with one of my parents and then my other parent came down and got me, or they might have all come home just to get what we needed, clothes and pack a bag. They weren't sure whether they wanted me there the first night, but they gave me the choice. They always gave me a choice. “Well, I want to go and see exactly what's going on?” I went up there. I think it was that night or the next morning.

Jen

So you went to the Children's Hospital? Is there a place where families can live there so they can be near their child who is going through cancer treatment? How does that work?

Maya

It depended. Most of the time, you can stay in the hospital room with the child. If it's a smaller hospital room, you’d typically only be there for maybe two to three days. They do have extended-stay hospital rooms where the patient is there for an extended amount of time, weeks, or months. During that time, I believe we were in a short stay, because nobody was sure what the next steps were. Eventually, we were moved to an extended stay where we had a futon and enough room on the floor for an air mattress.

Jen

So that became home?

Maya

It was odd. It became home more so for my parents, than me. During that time, my sister was in and out of the hospital either for short or long periods of time. I would stay with them if it was a short visit, however if it were extended amounts of time, I might stay a few days with other family; my aunt, my grandparents, my friend, my best friend. My mom was a teacher during all of this. She taught at the same school I attended. There was a time where we were commuting from the hospital to school.

Jen

Your sister is 2. What was it like to see her?

Maya

At that point, she didn't look different physically. Once I learned what cancer meant, I felt like she was dainty. I was always very careful with her with her. She was small and I was scared to move her in case it hurt her. She could feel hurt even from being touched.

Jen

That had to be hard. How was your sister during this because you don't really know anything at age two, right?

Maya

We were lucky she was so young because she didn't know any different. Her mind was strong, which is half the battle. When you have a strong mind, you can pretty much get through anything. She adjusted quickly. She didn't know any different. She was still strong. She was still peppy. She talked she tried and move a lot. She was fighting it and giving it a good fight.

Jen

Yes. Sometimes not knowing creates strength. In the beginning, who was there for you? Who was there when you needed someone?

Maya

I would say my mom and my stepdad were there for me; my whole family was. However, I think they didn't help me as much as I needed, because I didn't allow them to help me as much as I needed. For example, I didn't want any distraction from my sister so in my mind, I was perfectly healthy. Why do I need any extra help? Why do I need any extra attention when they should just be thinking about my sister? Everybody tried to help me and would ask, “how are you feeling? How are you doing?” I didn't let them help. I was blowing them off like, “Oh, I’m fine. Everything's fine here. I'm doing good at school. I'm healthy, and I'm fed. I'm good.”

Jen

Thank you for sharing. I think many people feel the same way you did during that time. I'm curious to see, when looking back, do you wish you would have accepted help? Outside of the family, who was the first person you talk to, and it was it right away?

Maya

I feel like I blocked it off as everything moved so quickly. It was kind of a whirlwind. I feel like knowing who I am now and who I was back then, I told my best friend and her parents. They were close to my mom, they worked together. So they were aware of the situation and for me, not having to explain the situation to someone else, made it easier for me. It was more of the gritty details of what I was going through, and what my sister was going through, that we talked about. She was very caring a good listener. I vented to her and shared what was on my mind. She would ask, “What would make you feel better? Would you like to come here?”

Jen

That is great you had the support. What do you wish you could do to help during that time, but you couldn’t?

Maya

I wished many things. Honestly, I think my most consistent wish was my sister wasn't sick and if someone in my family had to be sick, I wished I was the one. I'm not sure why, but I was a big hypochondriac leading up to this. Once I was introduced to cancer, I felt well, there's nothing for me to be scared anymore.

I wished I could take the pain, or that she wouldn’t have pain. As a child, I wished I could help financially because whether my parents told me or not, I could see it was hard on us. Having to eat out while we were in the hospital, hospital bills, or insurance, etc. I wished I could help out whenever I could. I stopped wanting to ask for things, but then I also asked for things because I wanted to feel normal.

Jen

You are around ages 13,14, and 15 years of age. That is a lot to have on your shoulders, knowing you couldn't do those things financially to help or take the cancer away from your sister. How did that leave you feeling?

Maya

I felt like I didn't have a place in the situation. At that point, going from wanting to be around my whole family all the time, I wanted to remove myself from my immediate family, and either spend time with my grandparents or with my aunt because I didn't want to get in the way. I didn't want to directly contribute to “another meal” “eating out” or “needing” something, etc. I tried to stay back as much as possible so I wouldn't feel like I was directly contributing to it.

Jen

You took on a mode of being unselfish so your parents could give their full emotional and mental attention to your sister. During that time, you still need emotional support as you are processing all of this. What did you do? How did you get through?

Maya

I didn't, honestly. My family was very close so I can't say my grandparents didn't want me because they did. My extended family was there emotionally, but I didn’t want them to feel burdened. I feel like many of us whenever we go through something hard, we don't talk about it. We don't think about it. At least we try not to think about it and then we just lock it away until it resurfaces like 10 years later.

Jen

Did this feeling grow more intense as time went on and your sister grew sicker?

Maya

Yes and no. I was adjusting to not explaining how I felt and not communicating; not communicating didn't become harder but trying to lock in those emotions did. When I saw my sister struggling it became harder and the immediate reactions became harder and harder to tone down.

When she was in the hospital, I would changer her diaper. I wanted to help. I had to wear a mask and gloves to change her diaper because of the chemo treatment making her pee radioactive and toxic. I thought I shouldn't have to wear gloves or put all this protective gear on just change a diaper. I remember as she was growing out of a crib and graduating to a bed, she was so small the bed swallowed her up.

She had an infection in her port, which is where they access for the chemo. This infection in her chest was so painful, she couldn't move to look at anyone. She was frozen and crying because of the pain. Even crying caused pain. I felt so bad for her. I didn't want to react, I wanted to hide that from my sister and parents. There was a cafe down the hall with chairs, big windows, free coffee, free snacks, and I started sitting over there.

Jen

I can't imagine. What was it like to witness this cancer take hold of your sister?

Maya

Acute Lymphocytic also known as lymphoblastic leukemia directly attacks the white blood cells. White blood cells protect us against sicknesses, colds, flus, they're kind of the attacker cells, right? With her having less white blood cells than what she needed she was constantly bruised. Even just helping her sit up could bruise her. She went from being healthy, and happy 2-year-old to crying all the time because of the pain. She was bruised and the chemo made her slowly lose her hair. I would help wash her hair. I remember putting shampoo in her hair and pulling my hand back and it would be covered with her hair. Slowly, stopping movement where she laid in her bed, or was hooked up to all these wires. When she did have good days, her immunities weren't good enough, that we couldn't take her outside to get some sun. She was becoming pale and weak from not being able to physically move.

Jen

As a mom, I remember by age 2, kids are running around. They're getting into stuff, driving you nuts. You've childproofed the whole house, right? And that's what your parents were expecting, but instead, they're having to help their child stay out of pain. I can't imagine what that's like for a family. I appreciate you sharing.

Your sister is brought home. Can you tell us at what age and at what point in this process?

Maya

I don't remember the increments of when she was well enough to go home. It always depended on what the doctors thought. Of course, my parents didn't want to be in the hospital when it could be avoided as overnights in hospitals can be very expensive and add up quick. However, no matter the cost, my parents wanted to make sure she was first and foremost fine to leave.

When she was coming home, I would stay home, or I would get picked up and driven home. I needed to sanitize everything and make the home sterile to prepare for her coming home. We had to mop the whole house, wipe all the doors, door handles, clean all surfaces, clean everything that she touched, do all the laundry, do all the sheets, the blankets, even we had a leather couch which we disinfected. I became a good cleaner, and kind of a germaphobe honestly. That’s one of my biggest things that has stuck with me. I just had to keep everything clean.

Jen

I was going to ask if the intense cleaning created anxiety, knowing that everything had to stay so clean all the time.

Maya

Yeah, for sure. It really did. It's one of those things where now I'll touch a handle and my skin burns because all I can think is the last time this was disinfected. It has laid long term effects on my family and my immediate family. My sister doesn't remember having to do that, so we had to tell her to stop with the germs.

Even now with my marriage, there's a lot of differences. I can be heard saying, ”no, please don't do that. You're dirty. That's gross. You must disinfect that or when's the last time you disinfected your phone? Or did you put on any hand sanitizer? Did you wash your hands before you ate that? Did you wipe the counters? “

Jen

Did Covid amplify your need to disinfect?

Maya

Honestly, it didn't because for once everybody's disinfecting. I already had hand sanitizer in the car. I already had disinfectant wipes. It was, “please put on hand sanitizer when you go out anywhere.” The second you get in the car, put on hand sanitizer. You get home, wash your hands. It helped a little with the germaphobe in me even with the masks. Now we're lucky COVID numbers aren't as high.

Now, as it’s calming down, it’s setting me back to the same degree where it was during the height of the cancer. Now I feel like, there’s too many people here. This is dirty. Nobody's sanitizing this. It's more of an issue now than it was even in the height of COVID.

Jen

How do you manage going to Disney and other theme parks?

Maya

The germs don't bother me just existing. It's the if it gets to me, or if I see anybody in my immediate family or whoever I'm with, if I see they touched something gross, it bothers me. I think, you’re going to get sick, and must take all this medicine. I've become the friend that always has hand sanitizer. We are on a ride, and I say, “here is some hand sanitizer.” Or “here put some on before you eat. Don’t touch your face. “

I feel like I carry a diaper bag for the theme parks just for me. Hand sanitizer, wipe, etc. Personal hygiene is the biggest thing for me. I can go into the New York City subways and not really care as long as I know my hands are clean.

Jen

Does part of you feel your sister's illness came from germs? Like maybe if she would have washed her hands more, maybe she wouldn’t have gotten sick?

Maya

No, with it being a blood attacking cancer, nobody can really say exactly where it came from. It wasn't like skin cancer where maybe you can claim sun exposure. It wasn't that as much as now it's more of a byproduct of cancer.

Jen

How old was your sister when she came home?

Maya

It really depends. Honestly, at age 2, she wasn't in the hospital for too long the first time. The number of times she was back and forth from the hospital to home varied by age. Between ages 2 and 4 were more significant amounts of times. The number of times started to lessen around age 5 and 6. 7 to 9 years of age was much calmer.

Jen

When she came home you had to do cleaning but was there anything else that had to change whether it be furniture moved, to make the home more comfortable and accommodating for her?

Maya

Not necessarily. My parents’ bedroom was also her bedroom. Making spaces wider to walk, bring in bags, and medicine helped to make easier. There was a time where she wasn't getting the nutrients she needed. She had to have a vitamin bag attached to her port. She gets all her medicine through the port in her chest. With the nutrients bag, it was hard connecting the port to the bag. There was a long cord attached to it and the bag had to be elevated. We didn't have one of those IV bag holders on the wheels which rolls around. I would carry the nutrients bag behind her and hold it above her head so gravity would allow her to get the nutrients. It was a lot of walking changes and personal changes rather than furniture and home changes.

Jen

What was hardest about being a caregiver?

Maya

You’re never taught how to do it. You go through school to learn how to be a nurse. As a caregiver there is no school; you just must do it. I would ask my parents for help. “You don't have to help us with this. “My parents always gave me a choice. I'm between 14 and 15 years old and a mature child. I didn't mind helping. I had to learn quickly and ask my parents for a lot of help at first to make sure I'm doing it right. The second guessing of, is this the right amount of medicine of this medicine? Is this the exact time?

 I learned not to care about blood. It never bothered me. At that point, I was used to seeing different IV’s and all of that. It was the lack of training and the force of training at the same time which was difficult.

Jen

How would you describe your new normal?

Maya

I was always “somewhere” if that makes sense. I always had an overnight bag. Even if I was staying with my aunts and my grandparents who live right next door to each other for weeks, I always had a backpack, just in case. I got good at packing quickly. The normal was going back and forth to hospitals or going to different houses, going to school, and trying to adjust to social life as a middle schooler. It was frantic, quick, and fast paced. Now everything's slowing down. I don't like slowing down. You know, I like to have my whole day booked out.

Jen

How is your sister?

Maya

She's a firecracker. With her being so young, she either doesn't remember much of the cancer or it’s the fact the chemotherapy affects her memory. She knows what happened, but as a nine-year-old now, she doesn't remember the pain much, which we're all glad for. It's hard to think about someone you love getting Phantom Pain, phantom procedures because it’s invasive. It’s invasive to your mind and your body when going through something like that. We're lucky in a way she doesn't remember.

As a 9-year-old, not everything is good. Even though she doesn't remember her treatment, she still can't remember math that she learned yesterday. She can't remember words that she's seen a million times on paper. She has a lot of learning disabilities which we are working through. Other than that, emotionally, and mentally she's very active and excitable. She loves talking. She loves hanging out. She likes playing video games with everybody. She always wants to spend time with people which probably is a byproduct of the cancer treatment. She always wants to be around people, and she craves playing even though she was in the hospital inside and out and didn't really have a traditional childhood of making friends going through kindergarten, first and second grades. One of the biggest things we're navigating is giving her the social aspect without her being able to have the social aspect. Her immunities are so low, she still can't go to school without getting very, very sick. It's very dangerous, dangerous for her still out there.

Jen

I think that you're a very special lady. I was going to ask how you found ways to make Elizabeth’s childhood special?

Maya

 Disney as a company is, you know, like all companies, there's good and bad. One of the best things that Disney does is host cancer events for kids. We've been to many of the events in our time during her treatment, when she was able to, that were hosted by Disney and Mickey and Minnie Mouse. You take pictures, they'd have food, the princesses will be there and, they'll be performances. They always had a Christmas special where all the kids’ got bikes. Those events brought back magic, some normalcy, and more childhood things which she missed out on. For a while, when her immunity was well, we were able to bring her to Disney, Epcot and Magic Kingdom.

Make A Wish, we took her on a Disney cruise. She loves Disney Cruise’s with it being so immersive with the Disney experience; the pictures move in the hallways, Harry Potter characters walk around the ship, and they greet her. It's magical. Whenever someone is going through this, regardless of whether they're a child, adult, or teenager, you need to bring back the magic in their life to give them hope, and brightness to look to when everything's hurting. She loves the beach too.

Jen

I love how you use the word magic. It's not something we think about as adults too much. I think it's great she had those opportunities and was able to go have fun.

Maya

Runway For Hope, a charity auction. It is a fashion show where all the kids, would get a full outfit from Bloomingdale's, and they could dress up in whatever they want and walk the runway. All these kids are going through some sort of terminal illness and they're walking the runway with characters, models, and Miss universes. They get to dress up and be the stars. She loved that because she loved dressing up and was always wearing something fluffy and sparkly, or white or pink or whatever. They did her makeup, so she had fun, bright yellow, feather eyelashes.

Not only does it help the kids, but it also helps the families too. We were able to dress up and sit at nice tables outside of the runway during the auction. We wore fancy clothes, and you eat fancy food. It was nice. That was one of the biggest organizations that helped her mentality and us. It gave us time to get out and not just be at home or in the hospital.

Jen

What message would you like to share with the audience?

Maya

Thank you for this time honestly, one of the biggest things is everybody goes through something that is life changing. Cancer may sound big for someone listening or may sound minuscule for someone listening, but that doesn't make what anyone's going through less important. It's all about interpretation. If it is important in your life, then it is important. I want people to recognize that it is okay to go through something. It is okay to have a life changing event. It is okay that your normal is not what it used to be. You can do it. Another thing is for all the siblings of cancer patients, just because you're not in the frontlines doesn't mean your family doesn't care about you. I promise. They're worrying as much about you, but they don't want to scare you. They're worried about you. They want you to be happy. They love you. It's hard because whenever you have a sibling that is going through something difficult, it's kind of pulling your emotions because you're missing out on a lot of the love you feel. You feel like it's less than compared to someone who's going through a sickness, but you still care about them. I imagine many people feel guilt.

The least we can do I feel as a society is to be kind to each other. Everybody we meet, everybody we pass on the street is going through something. The world cannot be the best, it cannot be the kindest, but if we can at least be kind to each other, then hopefully it spreads.

Speaking about cancer is hard because a lot of people are like, well, why would you say that? People think it's insensitive to talk about how someone else feels when someone close to them is going through, “much worse.” I'm not downplaying my sister's sickness at all, it’s that everybody matters.

Thank you so much for having me honestly, this has been a great opportunity. It's not often I get to talk about cancer in a way where it's both educational, emotional, and inspiring. I want people to know they’re not alone regardless of their role, whether they are the patient, the parent, the sibling, even the cousin or the aunt. Everybody is affected by a sickness and it's not just the immediate people; everybody matters.

Jen

That is a beautiful message. Maya I want to thank you for being you. You have some special gifts, and I am thankful to have met you, thankful to have connected and really happy that you are here today. Everybody does matter. Thank you so much.

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