

Episode 168: Julie is a hospice nurse

This episode is a little different from the norm.

Usually we talk to someone who has experienced something really unusual. But every once in a while, I like to have a guest on who has an unusual job – a job that I find really interesting and have lots of questions about.

So that's what we're doing here today. My guest is Julie – and she works as a hospice nurse. She's been doing this for many years, so she has lots of information, and lots of stories.

Every one of us is unique as an individual, but we all have something in common – we are all going to die eventually. And in some cases, we might get a medical diagnosis that says we have a certain number of weeks or months left before that happens. Of course, it's usually just a rough guess and not always accurate. But still, it's a sobering thing to have a medical professional tell you that there are no more treatment options, and you're probably approaching the end of your life.

That's often when hospice care enters the picture. So Julie told me all about that and what she does as a hospice nurse.

And there was something I also found very interesting that Julie told me, about herself. She has a very specific fear – and it's not one that I would have guessed, based on the type of work she does.

Julie has a fear of dead people.

Scott

It's been said - or at least I've heard it said - that people who are in a coma or they're unconscious, they're still able to hear everything that's being said in the room. Do you have any evidence of this or have you experienced something that might confirm that?

Julie

I do. I've seen it many times. I've been a hospice nurse for about 18 years and one of the common things I see a lot is, well, I'll give you a good example. I would have a patient who is bedridden. We call it non-responsive as opposed to comatose, meaning that no matter what you do, you can't wake them up. So they're non-responsive because they are near death.

I've had families– like one, in particular, there were four adult children. They were all in their 40s and 50s. It was the first time I visited and most hospice patients were at home. When I walked in, she was in a very small bedroom and it had two single beds. The mom was non-responsive in one bed and all four kids were lined up sitting on the other bed. So I went in, did my nursing assessment, had all my questions and I would answer. I was about ready to leave and I said, "Does anybody have any other questions?" The one daughter said, "Yes." And the brother said, "Ask her." She said, "No, nobody can tell me." And I said, "Go ahead and try me." She said, "When is she going to die?" Which is a very common question. I think we all get that question in hospice hundreds of times.

She said, "We've been sitting here for four days round the clock and everybody said she's going to die any minute and she just hasn't died." I said, "So you've literally been sitting in the room for four days." She said, "Yeah, we're taking turns. We haven't left her side." I said, "Try this. Tell her you're going to go to dinner, lean over one at a time, say, 'we're going to go out to dinner, mom. We'll be back in an hour.' Give her a kiss, draw the shades, shut the door, and see what happens." I usually clock out at 5 and that was about 4.45 in the afternoon. The next day, I looked at the overnight report and her time of death was 5.45. In order to put a time of death, the nurse has to go get the call, drive out there, and do the formal pronouncement. So what that meant to me was she had died minutes after they walked out of the room. The big question is, can they hear us? Absolutely. I know that, and I could tell you 10 more very similar stories. I've heard many doctors say the last sense— out of sight, touch, taste, feel, and all of that, hearing is the last sense to go.

Scott

I'm kind of saddened to hear that story because, if she was hearing everything, the impression that I got is that, "Wow, I'm inconveniencing my family by taking so long to die." Is that what the daughter was actually saying?

Julie

No, I don't think so. At least I don't perceive it that way. Usually, at the end of life, especially if it's been a long drawn-out decline, everybody's ready including the patient, but the family just wanted them to be at peace. It's not like I'm inconvenienced. It's more, like, "Geez, she hasn't had food or water or conversation in days." Nobody wants anybody to linger in what I call limbo, where they're just non-responsive, but people can for many days.

I think one of the kind of coolest stories - not cool, but it was interesting - very similar happening— the lady was in her bed. She had 2 hired round-the-clock caregivers because the family was very wealthy. The married couple— the wife was the patient, the husband was there and they were about 60-ish, so not really old and the kids were in their twenties. Same thing. They asked me, "Why is she hanging on? She had been nonresponsive for a whole week and I gave him the same spiel and he shot daggers at me." He said, "Absolutely not. We would never leave her alone " and acted like what I was asking him to do was a terrible thing.

I said, "I'm just talking about five minutes, 10 minutes." Anyway, he was very upset that I asked that, and he thought I was a horrible nurse, and his daughter was standing next to him. I very kindly tried to say to him, "Let me rephrase this, if you had a choice to die in front of your child or not, what would your choice be?" I saw this whole expression change. Nobody wants to die in front of their kid. I mean, I wouldn't, if you gave me a choice. The cool part was he realized that it was worth a try and that it wasn't cruel. That lady died five minutes after we left the room.

Scott

That's amazing to me. But on the other hand, you don't want to have somebody die alone. I mean, really, if the family's there around the clock practically and they just leave for five minutes, it's not, like, a big sense of loneliness. It's just that they felt okay to go at that time. Let's back up a little bit and define— can you give us the actual definition of what specifically is hospice care?

Julie

To kind of go back to the beginning, just give you a little background, a nurse, Cicely Saunders founded it. She started working on it in the 50s because what she saw was a lot of people would

have some kind of illness that they perceived to be terminal and their care stopped. But as we all know, at the very end of life, you have a lot of symptoms. You have pain, breathing issues, skin issues, all kinds, and emotional. To feel like someone is not caring for you is very difficult. So, in the 50s, she started to push towards opening a place to bring patients that were no longer cared for at the hospital, and it took her quite a while. She was actually told by a doctor that if she became a doctor, people would take her more seriously. That was in 1960-ish. So she did become a doctor and she went to the first hospice in 1967.

It is worldwide. Over 80 countries have adopted some form of hospice in one capacity or another like Japan. They do it just for cancer and AIDS patients. Across the US, it's very similar, and what it is is for people that have been told they have a disease that will take their life within six months, which is a very good educated guess by a doctor, and it has to be by a doctor. That patient is referred to hospice. The big thing about hospice is that patients have agreed not to get curative care, meaning if they have a tumor from cancer and a doctor says, "Well, if we keep giving you radiation and chemo, it'll shrink it down and it might take it away," that would be more of a curative. But they can get palliative treatment which people can— they mix up palliative and hospice a lot. They're very similar words. If somebody has a tumor in their neck and it's pushing and growing and, now, they can't swallow, if they're told that they get radiation, it'll shrink the tumor enough to let them continue to swallow for many more weeks, that would be a palliative chemo, and we do take patients like that, but it's on a case by case basis.

What hospice is is a patient chooses to live at home, and they choose to have hospice take care of them. So what they get is a nurse who comes out to see them once or twice a week. We do a visit, full head-to-toe assessment, readjust medications, and all of that. You have a doctor or a nurse practitioner who oversees the care. Then, we have a whole bunch of other people. We have social workers who come out once or twice a month and help them navigate any kind of social issue they have. When somebody gets a terminal diagnosis, the family often goes into a tailspin. So there's a lot of social issues that they come up with. Then, there are the nursing assistants who are one of the biggest help any hospice patient will tell you because they help with personal care, they bathe them, help them dress, change the sheets. They're a huge help to the family. There's a chaplain service. They're non-denominational. A lot of people are religious or they just want someone spiritual to come out and speak with them.

Scott

You wrote that you have a fear of dead people. I mean, usually, when you think of hospice, you think of impending death. How does that fear manifest itself or what do you think brought that on?

Julie

I really don't know why I have a fear of dead people. It's not just dead people, it's dead anything. You could put snakes, rats, and spiders on me but, as soon as they're dead, it's irrational. I mean, I did have a couple of unusual encounters with death kind of earlier on. The first one that I can remember is when I was probably 12 years old and we had a new kitten and my mom said, "Put that kitten on the ground" because it was up on the counter. She said, "Can you take the kitten off the counter so it doesn't drink my drink?" So I picked it up, set it on the ground, and I had my feet tied together because I was just hopping around the house just being a kid. When I took off to hop away, I stepped on him and I killed it and that memory has never left me. Not that I dwell or think about it often at all, but I know that was, like, my first real memory of anything dying.

Then, I had a good friend of my husband's when I was very pregnant and I was 30 years old. He was in our woods chopping down firewood and he split his whole head in half with a chainsaw. So we lived and breathed that nightmare for days. It was just horrible. He was a young guy. It was a freak accident. Then, probably not even 3-4 years after that, I was remarried. At the end of our wedding, one of the guys - another good friend of that husband - was leaving our wedding on a motorcycle and got hit by a car and we were the second person to find him. The police were there and then we heard of it and went out. I kept trying to say, "Does he have a long beard?" to see if it was our friend or not because it was dark and foggy. Finally, the cop turned around and she said, "Honey, he doesn't have a face." And that never will leave you.

The only other fear in all of my life I have are frogs and that's irrational too because I've never had an issue with a frog.

Scott

They say these phobias or fears are irrational, but they're not irrational to the person experiencing them. It seems like a real thing. What caused you to get into hospice nursing?

Julie

I couldn't find a job. I was a new nurse. I was an LPN first - licensed practical nurse - and I wanted a job in shock trauma, something huge. The only place they would hire me is a nursing home and I had to get a year's experience. After three months in a nursing home, I sent out a whole bunch of applications because it just happened to be— it was '05 to '06, so I wrote on my application that I'd been a nurse from '05 to '06 and I didn't put the month, so I was hoping somebody would notice, thinking I worked there—

Scott

—two years of experience,

Julie

Yeah. I got a phone call out of the 20-some applications I sent, and they said it was Gulfside Regional and, if they said hospice, I didn't hear it. I showed up for the interview and she had started talking about money and that she wanted to hire me. Then, she said, "I have one more question. What makes you feel you'd be a good hospice nurse?" And I thought, "Hospice, what is that?" Remember, I was a brand new nurse and, in my mind, I went, "That's dead people." But I wanted out of the nursing home. It was \$4 more an hour, no nights, no weekends. My daughter was only 10. I was a single mom and I took it. I thought, "Well, the first time I have touched a dead person and I faint on top of them, they'll fire me, but maybe that'll buy me a couple of months and I'll be halfway to my year between the nursing home and the hospice." Cause I knew the minute I even maybe got close to a person who had passed, I would faint, but I didn't. Here I am 18 years later.

Scott

Tell me about, like, when you first get a new patient - someone who's just gone on to hospice - and you get there for the first time, let's say you go to their home, what's the process? What do you do to get them on board?

Julie

Yeah. As I said, at some point, a lot of patients come out of the hospital. Let's say, Tom goes to the hospital because he's had a bad cough. After 2-3 weeks, they diagnosed him with end-stage lung cancer and they said, "How about hospice?" And he and the family decide that's what they

want. So he comes home and he's on hospice, but it's difficult for most families and patients because this is usually a new diagnosis but it's still a difficult decision to say, "I'm done," almost like you're giving up any hope of a cure. The admission nurse, which is usually one and the same as the nurse that'll take care of them the whole time, we go in and we sit down with the patient and we go over all that a hospice has to offer. That's when they make their final decision to come on board or not, and they fill out a bunch of paperwork. We do a whole head-to-toe assessment.

I have a great story about— I walked into a house and there were probably— often, there are 5-20 family members because, again, if it's a new diagnosis, it's a big deal. They call everybody and say, "Hey, mom's going on hospice," and everybody shows up. So there were a whole lot of people there. When I walked through the door, the patient was in another part of the house. All the adult children surrounded me and they said, "We just want to ask you if you can take off your badge. We don't want mom to know that you're a hospice nurse," which I've had. All of us have been asked to do that, and my stock answer is, "Yes, I can. But if she asks me, I have to tell her." And they said, "That's okay. She won't ask. Just say you're the nurse." And I said, "That's fine." It was not just hospice. It was hospice and the fact that she had cancer. They didn't want her to know she had cancer. I went back into the room with the mom. The family followed me in and it's a long process. We can be there for an hour to three hours, depending.

At one point it was just her and I, the little old lady that was the patient. She leaned in and she said, "Honey, I want to tell you something." I said, "Okay." And she said, "I have cancer." I said, "You do?" And she said, "Yes, but please don't tell my family." So the family didn't want her to know but she knew, and she didn't know her family knew, so they were all keeping it a secret from each other. Anyhow, we get them all on board and then we kind of set up a schedule of how we're going to see them and we let them know that the social worker, the chaplain, and the nursing assistant, if they choose to have one, will be out that week to introduce themselves and get on a schedule with them too.

Scott

Once that's all done, you said you come out once or twice a week to see them, what do you do when you go there? I mean, I would imagine you take their vital signs, and make sure they're clean and comfortable and fed. If they're eating, do you just sit with them and talk or what else?

Julie

A nursing visit is usually an hour. Like you said, we do a head-to-toe assessment. We check their feet and their bottoms and their skin integrity. We take their vitals, which are blood pressure and pulse, and listen to their lungs, and that's the same as a nurse does in any hospital. Anytime a nurse does an assessment on the patient, they're all just about the same. But with a hospice patient, I often say anywhere from 50% to 80% of it is emotional. You sit and you talk to the patient. Sometimes, I do a quick assessment. The patient has end-stage dementia. She can't communicate even though they can live like that for years. It's mostly talking to the family, helping them navigate, listening to their feelings, and letting them talk, helping them with problems.

There are many complicated patients that have in-depth wounds. They've been in a nursing home for years and their skin is just not in good shape. They come home to stay with cousin Billy because now she's dying and they want her to have better care. That happens a lot. People will take them out of the nursing home at the end of life. There's that. Another big part of

a nursing job is medication management. There are so many people out there that have five different doctors. You have your general practitioner and then you have all your specialists.

The amount of drugs that people are on is mind-boggling. Often, especially the older population, they have no idea what kind of medicines they are. I've walked into homes and they're on 40 different medicines that they take every day and sometimes multiple times a day. When you put them all together, you're on a medication that helps lower the blood pressure and then you're on a medication that helps bring your blood pressure up because this doctor didn't know. Because when you go to a doctor, they say, "What meds are you taking?" It's just what you verbally tell a doctor. People have a little scrap of paper in their purse but, most of the time, patients don't know what they're on. A big part of it is medication management but you can't go in and say, "Holy heck! You're on 20 drugs you don't need" because to a patient, they think they're keeping them alive or helping them. So, little by little, maybe you could subtract one this week and subtract one that week.

Scott

And you're the one that makes the decision on medication like taking some away? Or do you have to get a doctor to do that?

Julie

Nurses technically can't put a band-aid on a cut without a doctor's order. What we do is we assess and we recommend. So if I saw a patient had too many medications or something, I'd just call the doctor and say, "This is where I am" and he's able to pull up their whole medical file, he can pull up their medlet and I make suggestions. And most of the time, they go with it. Sometimes, they say, "No, I like this" or "Let's do that differently." But anything, again, wound care, ordering oxygen for a patient, we always have to clear it with the doctor or nurse practitioner.

My favorite story about too many medications is when I had a little man in Atlanta. He lived with his mother his whole life and never married. I don't think he ever even had a girlfriend. He was a mama's boy. When I met him, his mother had just passed away at age, I think, 90. She was cutting the grass and she had a AAA burst, so he had been taking care of her his whole life. So, he was very lonely and very lost. Very low education level. He was so sick, he could barely walk and breathe. He was on continuous oxygen. His feet were so blown up. He couldn't put shoes on. They were just tremendous. He had cardiac issues. We started seeing him twice a week and set up his medications. He was another patient who had 30-40 medicines and had no idea when to take them. He just said, I just take them every day. I'm like, "Well, how many of each?" "I don't know. I just take some. We line up seven days a week. They're little pill boxes." So I set two of them up and he knew every morning to take this one and every evening take that one.

Anyhow, after weeks and weeks of helping him and then tweaking his meds, the swelling started going down. So, we lowered or took away the diuretic or whatever it was. After 4-5 months, we actually discharged him, which is interesting because most people think, once you're on hospice, you never leave, and that's not true. We discharged people often and he got better. He got better. He stopped using oxygen and he was able to cut his grass. I love this guy. We called him "chicken man" because he would ask me to bring him chicken every time I visited him.

I think 3 or 4 of the times I went to visit him, he didn't answer his door, and this was early on when he was very sick. So, I had to call the social worker. It was a guy I worked with and I'd

say, "Can you come to the chicken man's house?" Because he would ask everybody to bring him chicken. It wasn't just me. We all brought him chicken and we didn't know that, for a while, he was triple-dipping. Anyhow, because I was afraid he would be dead— because that's happened to me. You show up and they don't answer the door, and it's because they have passed away. His door would be wide open. So, I would make the social worker come and walk through the house and find him. But each time, he was somewhere in the bathroom or he couldn't hear me, but he had a happy ending.

Scott

To me, it seems so ironic that when a patient has a disease and they're seeing a doctor, that doctor might be seeing 500 other patients, so he can't really focus on any one really closely. I mean, obviously, they do their best, but then when they go into hospice, there's a lot more focused treatment. You can observe how medications help or hinder their progress and people actually get better because of going into hospice. You see that fairly often?

Julie

Absolutely. That's just amazing. The one I remember the most— she had a terrible cough and couldn't get better. They thought she had the flu. She was probably in her late 70s and had a really good family and a lot of support. When I met her, she was in a hospital bed. I walked in. She had gotten home from the hospital that day. She was in a hospital bed, laying flat, head barely elevated. She's got oxygen on, afraid to death to move. The backstory was they thought she had the flu. It didn't get better. They brought her to the hospital. They diagnosed her with end-stage lung cancer and had her own oxygen for the entire three weeks she was in the hospital and didn't let her out of bed. The biggest reason for that was, because she walked into the hospital— she was actually shopping for a car when she got what they thought was the flu. It was the first time in her whole life she was going to own a car, so she was so excited, but it got cut short. So, after three weeks of not being let out of bed, she comes home.

When I heard the whole story, I said, "So you never wore oxygen before you got to the hospital?" She said, "No, I breathe fine. I just had a cough." And I realized she had walked into the hospital. So the bottom line is— I said, "I'm going to take off your oxygen and see how you breathe." And she was fine. And then I said, "Let's get up and walk." Her whole family threw their arms up. They kept her in bed. And I said, "Why did they keep her in bed?" Her legs were... you know. The bottom line is she was able to not use her oxygen except now and again for the next couple of months. She used it sporadically when she needed it. I encourage people to use oxygen - it helps them.

For the next two or three months, she had a really good life. She got her car. She drove her car. She was walking and doing the dishes and participated with the family. I do believe if the right hospice care didn't come in there, she would have stayed in that bed strapped to oxygen because they all believed that she shouldn't get out of bed and she couldn't take the oxygen off. So, mentally, she would've let go. I've seen that with patients too. When they're ready, they let go and they're gone. We bought her another 3-4 good months, and then she slowly declined like they said she would.

Scott

Yeah. They had that extra time with her. How often do you see a patient that has no family or friends?

Julie

They're just alone in the world too often. When I have a caseload of patients— I usually have about 15 to 20 patients that are mine that I see consistently, and two to three will be living alone from the day that we identify they have no caregiver or no live-in partner or child. When we realize that, the social worker's job task is to start working on, "What are we going to do when you get to the point that you can't take care of yourself?", we try to put something into place. We solicit family members to step up, and it doesn't always happen. Most of the time, we find something or they end up going into a nursing home. Or if they have VA benefits, they'll go to a VA nursing home. Sometimes, people will not leave their house and it's very difficult to get the police involved. When a patient can no longer get out of the house alone, it's still not illegal to stay home. There's a lot of gray area on that and we've had some patients that just say, "I don't care, I'm not leaving." And they stay there.

Scott

Well, yeah, and if that's their decision, they're the ones to make that decision. Have you ever had a hospice patient that surprised you by how young they were?

Julie

We have a pediatric division and we have an adult division. I've never worked in pediatrics, nor could I. So, our population goes from 18— I had a guy in his 20s. I've had people in their 30s, plenty in their 40s. Oh, I think there are maybe just one or two in their twenties, maybe three, not too much. Most people that are young, they don't throw in the towel - well, that's a terrible phrase. They fight the fight until the end and that's their option. They don't ever want to say, "I don't want any more treatment." They usually die in a hospital being treated.

Scott

Can you talk about the use of morphine? For some patients or even family members, is there a wrong concern or misplaced concern about the use of morphine?

Julie

I have found that often. A lot of times when someone gets to know me and finds out that I'm in hospice, they often say, "Oh, yeah, hospice killed my mom with morphine," which is a terrible misconception. I love when I'm able to kind of explain to them that's probably not what killed them. It was the dying process because, a lot of times, at the very end, we do use morphine because morphine is an excellent drug. It helps with breathing, it helps with pain, and it's super easy to administer because it comes in a liquid form. The other thing is it's readily available - hardly ever do they run out - whereas a lot of other narcotics or opiates run out at pharmacies. There are shortages, they're backlogged in production. So it's readily available. But it's an excellent med.

One of the men I had, he lived with his daughter and her family and his wife and he had end-stage dementia and something else on top of it because he was still walking and talking. In order to qualify for dementia, you have to be almost non-verbal and bed-bound. Because dementia is a very long process, from diagnosis to death can be 20 years— he had something else too, I think it was cancer. On my first or second visit, I was sitting at the table doing my assessment, everything was peaceful, and all of a sudden, there was this tremendous bang on the door, and in came this guy. He was the patient's son. He looked at me and he said, "Are you hospice?!" And I said, "I am." And he said, "Get out of here. You're nothing but a fucking murderer with morphine!" and just screamed in my face. He was so angry because he just found out that his sister put the dad on hospice and he was sure I was going to kill him because that's

a big misconception people have - that hospice waltzes in and we dope them up with morphine and they're dead in three days. That's so not the case, but.

This was kind of a neat story because it took me a long time to win him over and make him understand that he wasn't on morphine and we didn't use that until we needed it and, sometimes, we often never pull out morphine. But then, just as many times, I can have people on morphine for two years and it's just part of their pain regimen. Like I said, it's a good drug. It works well and it manages pain well, but he ended up. After a couple of months and his father's decline, the sister couldn't handle him. So, he moved in with the son and I then started making visits at the son's house and we became BFFs throughout the journey because he realized how helpful hospice was. I can't remember if we ever used morphine or not, but I know that he was very grateful. Along with a lot of misconceptions about hospice, that's a big one.

I think the one I'm the most passionate about as far as misconceptions - and this is an important one - when you come to hospice, we know that you have a terminal disease, on the first day of admission, they ask you if you want the patient to be a DNR or a DNRO, which is a "Do Not Resuscitate Order" versus a full code. It's really quite simple but people don't understand it and make it much more complicated. All that question is, "If you stop breathing, do you want me to try to resuscitate you?" Period. Has nothing to do with feeding tubes, respirators, none of that. It's one question. "Do you want me to try to bring you back?"

Hospice - a lot of people believe that you have to be a DNR. That is not true. It's illegal to force somebody to do that. There are private hospices that can kind of tweak their own rules and maybe they handpick people that aren't DNR, but the thing about it is— I'll use my mom as an example. She was perfectly healthy, I mean, she appeared to be perfectly healthy. She was 80 years old. She was walking, talking, driving, and eating. She was going to her happy hour every night, having her two beers, and she had a lot of pain, thought it was her damn arthritis. She finally went to the doctor and he said, "Let's just run a bunch of tests." Within three days, the test came back and my mom had bone, lymph, lung, and liver cancer, and this was just three years ago. So, as a hospice nurse, I said, "Ma, you have a triple metastasis. You don't want treatment."

So, a lot of people, if your wife was 45 years old and, again, she has a bad cough and they say, "Oh, she has lung cancer and it's spread everywhere." And then my next question is at that same hour. So here, sign this, "Do not resuscitate." You're like, "What??" It takes a lot of time for people to wrap their heads around, "Okay, we're not going to get her treatment anymore" or "We're not going to pursue treatment." But for me to say to you, "If she stops breathing, we're going to let her die," that's a whole nother question. And it takes days. months.

But, again, in my 18 years, I've had many people come on as a full code. In the end, only one patient scared me and it was the wife, because that's another thing about it. if I have a husband and he says, "These are my wishes. If I get bad, don't resuscitate me." You should honor that. But as the wife or the next of kin, whoever's next in line, as soon as that patient can't speak anymore, you now have the right to rescind that, which I don't think is right. It doesn't make any sense to me. Most people honor what their loved one wants, but we had a whole family of grown children.

Dad was dying and the stepmom had them as a full code. Even hospice, doctors, and social workers, everybody encourages the nurse to get them to sign that DNR, which I don't. I bring it up. I explain it to him. Then, if things really start going down, I might mention it again, "Hey, do

you want to think about this? No? Okay.” But it was the hour before his death because she didn't want to give up. No matter what, she wanted him resuscitated. She wanted him put on a ventilator and all of that. But at the very, the hour before he died, she finally said, “Okay, now I see that he is dying and there's nothing we could probably do.”

The other thing about a DNR is people misconstrue that a DNR is a respirator. So I'll say to people, “Would you like to be a DNR or do you want to remain a full code?” They say, “Oh, honey, DNR? I don't want to be put on machines.” And I'm like, “Well, that's the second part of the question. If we resuscitate you and you come back and you can't breathe on your own, then the next question is, if you can't breathe on your own, you can't eat on your own, what kind of life-sustaining support do you want?” A lot of people say, “Bring me back.” If you find out that I can't live off of a machine, then extubate. So it's a kind thing.

I go over it so lightly in the beginning because I don't think it's right to ask a patient to make that decision on the heels of getting this catastrophic news. It's like, “Okay, he has this big problem. If we don't do anything about it, he stops breathing.”

Scott

It seems like this whole thing is a very - it can be, anyway - emotionally intense experience. When you're there with the patient, especially when there are family members involved, how do you maintain professional boundaries? I mean, you're a human. A family is about to lose their father or their mother or a loved one. Everybody cries at that.

Julie

And we do. It's all the real highs and the real good part of hospice and the connections with people. I mean, it's pretty darn heady when you can walk into a pancreatic cancer patient who's been literally suffering for 6-8 months because they haven't been able to have their pain managed and, within 24 or 48 hours, I can get uncomfortable. I mean, it's almost godlike, you feel. The reason I'd do it— again, when I say “I”, I mean me under the guidance of a doctor, of course. Hospice is super generous with medication.

There are medications that work well together and help fight pain. So a lot of, we'll say, practitioners, they just keep increasing the opioid. And what happens? We fight the pain, but you knock the patient out. We're all about quality and quantity of life. We want to give them the longest, best life we can and the quality of it. So if you add steroids, you add nerve pills for the nervous system that help block pain receptors for the nerves, there are tons of medications. Another one is mental. If you're anxious, your muscles are tight, so you also need something to relax the mind because pain is always worse if you're tense. Even Tylenol— I'd say, if there's only one drug in the whole world for pain, I would choose Tylenol. It's great. To be able to take somebody out of pain and walk in two days later, and they go, “This is the first time in six months. I haven't had pain or my pain is so little. I can tolerate it now. I feel good” because when you're in pain, you can't, you don't want to eat. You don't want to talk. You don't want to smile. So that's part of it.

And then, developing relationships. I've had patients on hospice services for five years, and people— it is for six months or less but, like, you have a COPD patient. They have a chronic lung disease and they're not being medicated properly, they don't have the right oxygen or whatever it is that makes them look as if they're on the way out with somebody taking care of them and visiting them once or twice a week and changing and tweaking and helping. They can live for a lot longer than the doctor expected. You develop relationships, but I always say, like, “You and

your job, how many times this week has somebody hugged you and said, 'I love you. Thank you.?'” Probably not.

Scott

Nope. Nobody hugs podcasters.

Julie

That's right. And in most professions. I get that almost every day. I have heartfelt thank yous and hugs all the time. So it definitely outweighs those moments of sadness because they are just moments. When somebody passes, again, most people are ready. I mean, I had a guy who was 6'7 and he was in tremendous shape. He got pancreatic cancer, but the whole rest of him was healthy as an ox, and he was in his 60s, so he wasn't that old. When he finally became bedbound, he said, "I'm done. I want to go." And he stopped eating and drinking. It always gets to the point where they can't eat and drink. So it started out that he mentally let go probably long before his body would have shut down, but he became weaker. And, I think the three days before he passed away, I went to hug him goodbye. He grabbed me by my scrub shirt, and pulled me back down - he was a big guy - we were face-to-face, and he said, "Why can't I die?" I said, "I don't know, I'm so sorry." He just wanted to die so badly. He went 42 days with no food or water, and no IVs. He had ice chips. That was it, which a lot of people, unless you're in the industry, find that very hard to believe. He had nothing. Those moments are very sad, but the highs way outweigh the lows.

Scott

You just mentioned pancreatic cancer. What do you see as the cruelest disease?

Julie

There are several answers to that. Brain cancer is the most unpredictable that I see. If you have end-stage cardiac, lung cancer, or liver cancer, I can almost, and I do predict all the time. This patient's going to die in three days, a week. I can see it coming weeks ahead of time and I can almost tell you step by step what's going to happen, how it's going to happen, what's going to happen to their appetite, their bowels, their urine, all the different systems. They systematically shut down, usually in a pretty common order. But with brain cancer, it's totally unpredictable.

I had a guy who was out at the neighborhood barbecue, and he was in his 40s. He had a wife and some young kids. He was having a beer with the neighbors and, the next morning, I got a call that something was wrong, and I walked out, and he was dying, and he died that day. Thinking about how the brain works, when you have a tumor in there, it's a dead spot that doesn't function, and it can grow up a millimeter overnight and hit an area that controls your vital signs and it interrupts something and you have a very quick death. But also, the really sad part of brain cancer is it changes personalities. You can have just crazy, wacky, unpredictable behavior with brain cancers. So to me, that's probably one of the saddest.

Emotionally, pancreatic cancer, absolutely, because it's common knowledge. If somebody has more than a stage one or two of pancreatic cancer, there is no cure. It's a death sentence. So people with pancreatic cancer emotionally— they don't even have a chance to think they have a shot. It's just immediately like, "I'm going to die." It also has a lot of symptoms with it when the pancreas doesn't function.

What I see - the biggest fear - is people that are afraid of pain, and that is the hardest thing to make somebody understand that we can control your pain, and I am 0 and thousands. I've never had a patient dying in pain - a little bit maybe, but a lot? No. We have such great ways to help control it. I think one of my craziest stories is, at one point in the county where I lived, they decided that people in jail were entitled to hospice care, which was really strange because they have a whole infirmary, they have a ward where they put them, and my boss chose me to be the jail hospice nurse because she thought I was thick-skinned, I don't know. It was scary. I met two patients in there - actually I had three. After a month of me going to the jail twice a week, which was not nice because I always said, "If you work at jail, it's kind of like you are in jail. It's not a very fun atmosphere." But two of the patients got sent home on compassionate release and that's when they know that the patient has a slim chance to do anything but just go home and die, and they put ankle bracelets on them.

But the one patient I had - one of the people in the jail asked me if I wanted to know what his charges were, and I said, "I don't think I'm supposed to know that and I really don't want to know." I don't know if he was allowed to tell me. Anyway, whatever it was, he was in there for a very long time. He was actually a really neat guy. He was in his 70s. He lived with us. He went home to his sister's house and I got to be friends with him and all his family. I'd see him all twice a week and, every time, he was happy joking around - he'd always joke.

When I got to the part of the assessment, I said, "Well, how's your pain?" He'd go, "Oh, it's terrible. It's an eight." Well, we ask on a pain scale, 0-10. In the hospital, if you say your pain's an eight, you get narcotics - most people who are frequent flyers know that, and I'm like, "Ugh." But what we're taught in school and part of your job is you don't doubt people but I did, in my own mind, but I kept every- we send meds out every two weeks and I refilled - he was on OxyContin and oxycodone, so long-acting and short-acting, and he got lots of it. He had, like, the max for whatever it was. Hundreds of pills every two weeks would come to his house. I want to make it clear that I never saw him in pain. He never acted like he had pain.

Anyhow, in the end, part of our job is we have to count all the drugs or all the narcotics that are left over in the home after a patient passes, and then we have to dispose of them. I was up to about 280 OxyContin and, all of a sudden, the sister said, "Oh, honey, I got more." She went in and got a whole nother huge box of drugs, and I was up to over 700 or 800 OxyContin that we had given him. I thought, for sure, that this guy was selling them. It was terrible and it was one of my big learning experiences because I thought, "Come on, he was not-" when somebody's on that much narcotics, you can see it in their eyes. He never took one of his pain pills. But he believed with all his heart that there was going to come a time when he would be in so much pain and he wouldn't have enough medicine that he stockpiled it. All the while, I thought that he was- I mean, he was a jailbird, right? He's a bad guy. That's what I thought. I thought he was peddling them on the side because, believe me, that happens, but it was so not true, and it was pretty eye-opening.

Anyway, my other jail guy, he had an ankle bracelet on. He had an Italian mama that was awesome, but he had a lot of swelling because he had liver cancer. One day - it was a Friday - I went to visit and he got to the point within the last week of life. His leg was so swollen. His mom called and said, "You got to come over here quick. His ankle bracelet was cutting into his skin." I called the jail and I said, "You guys got to come over, send a cop over here to take it off." And they said, "Oh, we can't do that. It's the end of day Friday. We'll be there Monday." And I said, "No, it's got to come off today. It's compromising his circulation," and they didn't care. So I told the brother who was a bad guy too. They were Italian brothers and both had very long rap

sheets - They were very proud to tell me about them as I got to know them. I said, "I know you have a bolt cutter." He goes, "Man, I got six or seven." "Go get it."

Scott

They're ready for that job.

Julie

And his brother's like, "Man, I'm not doing it. I'll go to jail." And I said, "I will." And I cut that ankle bracelet off with a big old bolt cutter and we set it on top of the little machine that was in the house. I asked them when I came back Monday and nobody ever did come. So, I don't know if it didn't work or if we cut it at the right spot, but it turned out that the state finally figured out that we were double dipping and cut out hospice at the jail.

Scott

People that are listening to this, some people might think, "Man, I would love to get involved with this, but I have no medical training. I'm not a nurse." I know there are hospice volunteers.

Julie

There are.

Scott

What would a non-medically trained person do as a volunteer?

Julie

Well, when we talked about all the different people in hospice, the last one I didn't get to was something that's also mandatory. The nursing assistant and the chaplain are volunteers, and every hospice has to have a percentage of volunteers that work there. The volunteers can actually go to the patient's homes. A lot of the families need just a break. Maybe just the husband and the wife need to get their hair done and the patient can't be left alone because everybody gets to the point where, morally, you should not leave people alone so they can sit with them. A lot of people develop relationships with the volunteers and they come every other week. Sometimes, they even come once a week.

It is very different through COVID. Now, in the last six months or so, everybody's trying to get volunteers to come back, but most places I've been are in sore need of them to go into the homes and all you do is hang out with them. You're not allowed to change a diaper. You can make them a sandwich and hand them a drink, but you can't do any personal care, you can't help them onto a commode, so you're just hanging out and being in the eyes. If something were to happen, you would just call me or the wife or whatever. Also, in the office, there are all kinds of duties - making new folders for admissions and helping with a lot of work in the office. A lot of volunteers do that.

The coolest program we have for volunteers is called— some call it the 13th hour, some call it the final hour. Wherever the patient is, to be with them in the final hour of life when we identify— again, usually, you can identify a patient in the last 24 hours of life and have them go out there. It's usually not because the patient's dying alone, but because the patient is dying and the wife has no support - or the husband or the child. More patients have just one person in the home with them than the patients who are lucky enough to have a group or a family and extended family hanging out. But I would say more than 50% of all my patients have just one caregiver and the caregiver doesn't want to be alone. They're scared to death. A lot of people are like me.

They don't like dead people. It's really cool because it gives support to that family member when they need it the most.

I've had a lot of people wrestle with the words, "I promised him that he could die at home, but I can't handle this." It's easy to make a promise like that. But when it's 3 o'clock in the morning and you can't sleep and you're listening to somebody in their final stages, it's scary. Most people have never seen somebody pass away and they don't know what to expect. I was on call one weekend. I was just picking up a shift and I got a call from the triage nurse and she said, so-and-so called and his mom's breathing four breaths a minute. Well, normal is 16-18. So we knew, at that respiration rate, she was close to the end. So I turned around and it probably took me half an hour to get there.

As soon as I pulled up - it was a single-wide trailer - the son threw the door open and he said, "Mama died about five minutes ago." I said, "Okay, I'm coming." Well, as soon as I walked in the door, again, it was single-wide. The room's 12-foot wide and she's in the living room in a hospital bed. From the second I saw her, she was long gone. The skin was gray, the mouth slack, eyes open, peacefully laying there. So I walked up. I went up to the bedside, the son came next to me, and his wife next to him. So all three of us were side by side. I have to actually put my stethoscope on their chest and listen for an apricot pulse to make sure. That's what we do. We hold it there for a minute and then we can pronounce that she is gone.

There was no heartbeat and I was 20 seconds in. All of a sudden this lady took the biggest gasp and she sat straight up, and it was instant. It was just this big, huge noise. She sprung straight up. Of course, me with my fear, right? Wasn't very professional. I screamed and threw my hands up and my stethoscope went flying over and hit me in the back, and the son screamed and the wife screamed. I turned and looked at him and my whole body was shaking. I've never seen anything like that. And I said, "I am so sorry. I'm so sorry." I had tears streaming down my face. Well, half of it was I was scared to death, but the other half was I was so horrible. I mean, what a nurse I was to scream like that. He looked at me - we're all crying - and he said, "It's alright. She scared the shit out of me too. It's okay." But, that set me back up until that point. That was maybe a year into my career. I've felt better and better with taking care of people who had passed, seeing death, and touching them, which was very difficult.

I did have a spiel that helped me out when I heard somebody pass and I had to go pronounce. I would walk into the house. Typically, I would know the people and already developed some kind of relationship. Whoever greeted me, I would always give them a hug. I mean, somebody just died. It's very sad. Then, I would not let go of them, kind of hold their hand, and I kind of pat them on the hand, and walk them back to where the patient was. That way, they were holding on to me. They thought I was comforting them. Really, as long as I have somebody holding on to me or next to me, I'm better. It's very difficult for me to go into a room with a person who passed away alone. It's almost impossible.

The first time I faced that, it was a patient I got to know very well. He had a big extended family and there were always 5-6 people there. They told me he passed. So I knocked on the door and they were like, "Hey, Julie, how are you doing?" We were chit-chatting. This was a long time coming, so it wasn't a terribly sad thing. He was kind of ready and they were ready and they said where he is, and pointed towards the back. I scanned the room and I was like, "Looks like everybody's out here." So I said, "Well, you want to walk back with me?" He went, "I don't know. I got to get a drink or something." And I was like, "Oh, shoot. I got to do this alone. Like, you're a big girl. You can do this." I felt good in their home. There was a nice family. So I'm like, "I can do

this.” So I went back to the bed. He was laying there with a sheet over him. I pulled it down and put my stethoscope on his heart and, all of a sudden, his whole body started jumping under the sheet - I mean, legs flailing, it's bouncing up and down - and there I go again.

I scream, actually, “Bloody murder!” Because I'm telling you, my life, I bet this guy had passed away. There's no way. The family came running in and I was just standing there. “I'm sorry. I'm sorry.” They whipped the sheet back and, of course, I screamed again when they did that. It was a greyhound. His greyhound was under the sheets and he knew me, so when he smelled me coming in, I guess, he got all excited and moved up and down. I thought the patient was having these spasms. That was even worse than the poor lady who sat up and screamed on me.

Scott

Honestly, that sounds like a YouTube prank, a cruel hospice prank.

Julie

The family loved it. It didn't make them laugh. I was a mess, but they were kind about it. There are crazy happenings in hospice because you're dealing with patients in their homes.

Scott

That really gives us a good overview. I know there's more that I could have asked and there's most likely going to be questions that people listening to this want to ask as well. So we're going to have your email address in the episode notes for this show. You're also in the Facebook group. So, people in there can just look for this post and they can post questions right there. That way, maybe if, like, 10 people have the same question, you can answer it once instead of answering 10 emails.

Julie

Sure. I'd be happy to help if I can. One thing I just wanted to say as a footnote, and this goes out to everyone, has nothing to do with hospice, but I think all hospice nurses see what I touched on earlier about medications and how important it is to be on the right medicines. Everyone, no matter who they are or where they are in a disease process, if you're taking medication, you should know what the medicine is, what it does for you, and make sure that you're not taking another medicine that could either interact, because there is that, or when you have multiple doctors, a lot of doctors who'd say, “No, I just want to focus on this.” They don't want to hear the big picture. You should have one of your doctors or a friend who's a doctor or someone take a look at your meds and make sure that you're not on too much or sometimes you're not on enough and keep a running list. But it's super important because medications can give you an incredibly good normal life or they can kill you. So it's important.

Scott

There were so many more aspects of her job that Julie could have talked about, and so many more questions I could have asked – but I try to avoid creating an episode that's like 6 hours long. But you can contact her directly by email if you want. And as I mentioned in our conversation, she is in the podcast Facebook group so you can ask her questions there as well. And you can join in the amazing discussions we have there every day! And it's completely free of course. Join at [WhatWasThatLike.com/facebook](https://www.WhatWasThatLike.com/facebook).

And just as an aside, I used the Facebook group to decide whether or not to have Julie come on the show. I knew that I would be interested, but I wanted to make sure YOU as a listener would want to hear about this too. So I posted a poll in the FB group asking that question – and in the

end, 95% of the votes said yes, we want to hear about this. Some people also said, yeah, we're about to start thinking about maybe using hospice, so we need to get some of this inside information.

And you can see pictures of Julie and get the full transcript for this episode at WhatWasThatLike.com/168.

In an episode earlier this month, I introduced you to Meredith – my producer. And from the feedback I got, you guys really liked her. Actually, I knew you'd like her because she's a fun person and she's really smart.

So I thought – how about if I bring Meredith on sometimes to answer one of our Tuesday questions. If you're in the Facebook group, you know what I'm talking about. Every Tuesday I ask a question – sometimes really deep, sometimes just fun – but these questions always generate a ton of responses and some great discussions.

So I got Meredith to answer one of those questions, and I also asked her about a recent episode of HER podcast that just listened to, and I couldn't believe what her guest was saying. Check it out –

All right, Meredith, are you ready for a question?

Meredith

I'm ready.

Scott

What's a common smell that you can't stand?

Meredith

Candles.

Scott

Candles?

Meredith

I really dislike the smell of almost all candles. I know you would think that would be– especially as a 90s kid, Yankee candle, Bed Bath & Beyond, those are all things I'm supposed to be nostalgic about– the one time I went into the Yankee candle store - the Yankee candle store in Massachusetts, it's the big one - I ran out almost throwing up because I just cannot stand the smell of candles. I'm the worst 90s kid ever.

Scott

Yeah, but a candle has to be probably the most pleasant smell anyone could think of, I would think, but not you.

Meredith

No, not me.

Scott

Wow. Alright, that's weird. I'd have to look back at the Facebook group to see, but I don't remember anyone saying candles - maybe somebody did. There were a lot of smells in that answer, for sure. Okay, I wanted to ask you about a recent episode you did on your podcast called Meredith for Real. You had someone come on and talk about child marriage. When I first heard that, I knew a lot of people would hear that and say, "Yeah, the things they do in other countries..." It's pretty crazy, but we're talking about the US. What is that?

Julie

Yeah, isn't that funny how we tend to have this view of American exceptionalism that we think we're always number one in every category, including human rights, especially for children, but it's not the case. I can't quite remember how I came across this particular guest, but she tells the story of how she ended up in a forced marriage. She's from a Satmar Hasidic community - not Satmar, but something very similar to that. It was depicted in this Netflix documentary called "Unorthodox" for anyone who is curious. After she was able to escape from that marriage, she started a nonprofit to help other women escape. How she learned about child marriage is more and more women requested help from her to escape, but they were minors and therefore legally unable to sign their own legal documents. If they were to seek shelter anywhere except for the marital home, they were considered a runaway. So then, she realized that, at that time, 48 of the 50 states permitted child marriage, some with no minimum marrying age. You could betroth a baby to somebody else. Now, it's illegal in 40 of the 50 States, so she's making progress.

Scott

Man. I know what part of what she talked about marriage. It's now just used as a cover for pedophilia and sex trafficking. It's just mind-boggling how our government allows this.

Meredith

Isn't it? It is crazy. And it wasn't until after I had recorded this episode with her that I just knew what to listen for. I think that, after you hear it, you will realize when you're talking to someone, if they're in that situation- I've met four women since recording that in my own hometown who are in forced marriages and they were not from any sort of extreme religious community or anything like that. They were just run-of-the-mill folks who were forced to get married, some because of pregnancy, others for religious reasons, but they weren't, like, an extremely insular community. It was just like the church around the corner. It's wild. It's really wild. It really opens your eyes to not just the legal part, but also just the human rights part. Her story is incredible - how she escaped. She's such an incredible woman and she's doing really cool stuff.

Scott

Yeah. I was very impressed with her. So if you want to hear some stuff that's really going to piss you off but, more importantly, learn about the group that's actually working to end this, go and listen to episode 216 of Meredith for Real. And Meredith, thanks so much. We'll talk to you soon!

Meredith

Sounds good!

Scott

Meredith is one of my favorite people, and her podcast is full of stories like my own podcast.

Graphics for this episode were created by Bob Bretz. Full episode transcription was created by James Lai.

And now, one more story – it's this week's Listener Story. Since we all love stories, we always end the show this way – with a story that was sent in by a listener. And in case you didn't know it, YOU have a story. Probably several! But you can just pick one – something funny, sad, amazing, whatever, as long as it's not boring! Record it on your phone, like 5-10 minutes, and email it to me at Scott@WhatWasThatLike.com.

This week's story is from Jason – he's the editor in chief of a major magazine, and he talks about losing one of his five senses.

Stay safe, and I'll see you next time.

(Listener story)

Okay, picture it. I am in my twenties. I'm living in an apartment with my girlfriend. I'm in the kitchen washing dishes and she's in the bedroom and she yelled to me, "Hey, is something burning?" And I said, "No, nothing's burning." And she said, "Are you sure nothing's burning?" I said, "No, nothing's burning." Then, she walked from the bedroom to the kitchen where she found me washing dishes, standing literally next to a George Foreman grill - I mean, come on, we're in our twenties - on fire, pouring smoke, and I didn't know. You know why? Because I don't have a sense of smell and this is the story of how I discovered that and what it's been like.

But first, why don't I tell you about myself? My name is Jason Pfeiffer. I am the editor-in-chief of Entrepreneur Magazine, and I do a whole bunch of other things - write books, make podcasts, speak, startup advice - but one thing I would like you to know about is that I have a newsletter. It's called "One Thing Better". Each week, one way to be happier and more effective at work and build a career or company you love, you can find that at onethingbetter.email. That's a web address, just plug it into any browser - onethingbetter.email.

So how did I discover that I don't have a sense of smell? Goes back to that girlfriend, actually. I was in college and I was dating this girl and she had a great sense of smell and a great ability to taste food. She was, like, a supertaster, a super smeller, I don't know, whatever. She was the first person in my life who had ever pressed me on things - "What's that smell? What flower is that? Oh, what ingredient is in this food? Is that rosemary?" I eventually realized I did not know what she was talking about at all, so I told her that once. I was like, "You're picking up something that I'm not."

So we decided to do a taste test, a blindfolded taste test where I tied a shirt or something around my face and she had me taste different ice creams - I can't remember what they were, but let's just say vanilla and chocolate and strawberry. I tried these ice creams and they all tasted exactly the same, and our minds were blown. I didn't realize until that moment that I was experiencing the world differently than other people. Maybe you're thinking, "Well, how could you not have known? Isn't it obvious?" No, it's not obvious. You don't know if you experience the world differently than other people because all you have is your own senses. Maybe some people have gone through this. The first time that you ever put on glasses, like, as a kid, the first time you went to an eye doctor and they said, "Oh, your vision is not very good" and you put on glasses for the first time, that is when many people experience, like, a total shift in how they perceive the world. I remember putting on glasses for the first time and being shocked that I could see individual leaves on trees. I could see the fabric on the carpet. I didn't know other

people saw that stuff until that moment, and I didn't know that other people smelled things that I didn't either.

My parents were aware that even as a kid, I didn't care about food. I was not motivated by it. I didn't seem that interested in it, but they just thought, "Eh, kids don't like food." But then, in college, I dated this girl, did the test with the ice cream, and discovered, "No, there is something different about me and I didn't know what it was." But I'll be honest, I wasn't that concerned because I had gone through my entire life like that. So what was there to do? What was there to fix? It seemed fine.

Then, a couple of years later, the fire happened and I couldn't smell anything. That was when I thought, "Oh, I understand how this can be dangerous. If there's a way to fix this, I should fix this." So I went to a taste and smell clinic. There are a number of them around the country. I went to the one at the University of Connecticut and I saw every possible doctor. I saw a dentist. I saw a general practitioner. I had a CT scan of my brain. I saw an ENT who stuck a scope up my nose. Why were they all doing this? Well, it's because a loss of smell can come from anything. It can be an indicator of, like, anything. It can be nasal polyps which is a very simple, little inflammation in your nasal passage - not a big deal - or it could be a brain tumor or it could be anything in between. So they wanted to see if there was an active cause. After lots and lots of testing, the answer was no active cause. They couldn't find anything which means that it was probably one of three things that happened or, well, it could be four. One of them could be that it's called congenital anosmia, which means that I was just born that way. But in this case, that's not what it is because I actually get occasional whiffs of things. I can smell that a candle is different from the regular air. Like, I was picking up something, just not enough to identify the smell. So it's not congenital. And I have no memory of ever being able to taste and smell things.

So my doctor or person or whoever it was at the taste and smell clinic told me, "Look, there are three main causes of what was really olfactory nerve damage. The olfactory nerves are these tiny little nerves that control your sense of smell. They live basically right at the top of the bridge of your nose, almost between your eyes, and they're easily damaged. If they're damaged, then you lose your sense of smell. The three things that can do that the most are an upper respiratory infection - like a bad cold that happens to get in the wrong place and fry your olfactory nerves - chemical exposure, breathing in chemicals, or head trauma, which is the reason why a lot of people, when they have a car accident, lose their sense of smell.

I told my parents this and they said, "Head trauma." The answer is it was head trauma. I didn't know this but when I was a baby, a babysitter was strolling me down the street and I wasn't buckled in and she hit something and I fell out of the stroller and landed on my head and was in traction. So that was probably what happened. That was probably what did it. Now that I know that, there's nothing you can do about it. Your olfactory nerves can regenerate on their own, maybe. If you have a car accident and you lose your sense of smell, it could come back. But me, probably not because it's been so long and that's okay.

So what's life like? Well, first of all, here's the thing, you might be wondering— I've been talking this whole time about smell and olfactory senses, but the taste test was with the ice cream, which is really about tasting things. So what's the connection? The connection is what you think of as taste— if you taste a chocolate cupcake, you're actually doing two things at the same time. You're utilizing two different senses. So you are tasting, which is technically just sweet, salty, sour, bitter. It's from your tongue. But then odor molecules from this chocolate cupcake go to

the back of your throat and up and are read by your olfactory nerves, your sense of smell, and that is what creates the sensation of flavor. The chocolate that you taste is actually you smelling chocolate inside of your face. It's not a taste. It's a flavor. It's a combination of taste and smell. My tongue works just fine. So I get taste. If I eat chocolate, it's sweet. It's just not chocolate. That's why chocolate is vanilla, is strawberry, is everything.

When I was single, I did not marry that girl from college. Eventually, I moved to New York. When I was single, I was very afraid of buying things that would smell. I didn't buy milk, for example, because I didn't want it to go bad. I was afraid of not knowing. I was also obsessive about washing my sheets and my towel cause if I brought a girl over, and it smelled bad, I wouldn't know and that was scary. Now I'm married and it's actually pretty useful for my wife because she had me change all the diapers or a lot of the diapers when our kids were very little because I couldn't smell it. I take out the garbage. I walk down the street in New York City where I live in the summer. Garbage outside is smelly. It doesn't bother me. I and my wife, when we go out to eat, she tends to order two things and I'll just eat whichever one she likes less because it doesn't matter to me. I also don't crave food, so that's pretty useful. I don't know if I could fix this. If I could fix this, I would because I understand that I'm missing something, especially when you travel and so much of travel is about food and the sense of place and just ingesting that, and I miss some of that. I know. But on a day-to-day basis, I just don't think about it much.

The way I've just kind of come to understand this is we have these senses and it's how we understand the world. If you have to lose one of them, then I think I lost the right one. Sometimes, in life, that's as much as you can ask for. So that's what it's like to not have a sense of smell. If you have more questions, feel free to reach out. That newsletter that I told you, One Thing Better, you can get it at [onethingbetter.email](mailto:onethingbetter@email). If you reply to that email, any of the emails that come from that, it goes directly to my inbox. I'll read it. I'll get back to you. Go enjoy your chocolate and vanilla and strawberry ice cream and tell me how it is.