

Can Oversharing Information Be the Best Medicine?

A candid discussion about balancing privacy online with a patient's vital need to share.

Michelle Dennedy: We're in a new age of digital medicine and almost universal availability of information, leading to better diagnoses and more successful treatments, with the potential to reduce suffering and extend lives. But with this great opportunity comes new risks, and we all need to be conscious, well sometimes I'm not conscious but that's a different story, about how we use new technology and share information. My guest today has unique insights to share on this front both as a security and privacy professional and as a patient himself. As you'll hear in a moment.

Cybersecurity, data protection, privacy. You like to stay ahead of the curve and listen to experts who are leading the way in deriving greater value from data with a more organized approach to data privacy. You're like us just a few deviations past the norm. You are a Privacy Sigma Rider.

Hey Riders, Michelle Dennedy, vice president and chief privacy officer at Cisco, here with you again. Happy Tuesday. Jay Libove is a friend of mine that goes way back. He's a former security and privacy advisor with Delta Airlines, helping to formulate corporate info sec policies. He's a world traveler. He is a multilinguist now living and working in Barcelona Spain. Jay, give us a little bit of background, why Spain? What are you doing? And then we'll get into, of all things for privacy professionals, what's going on with your medical situation?

Jay Libove: Sure thing. Hi Michelle. And thank you so much for having me on the podcast. This is going to be fun.

Michelle Dennedy: I'm so happy you're here.

Jay Libove: I'd actually like to shortcut and I'll get back to what you asked me in a minute. But in your opening, you talked about people being more conscious about how they use the technology, but exactly in medical situations, and you were joking about sometimes you're not conscious, but in medical, sometimes we're really not conscious.

Michelle Dennedy: Exactly.

Jay Libove: We really cannot put the thought into anything other than right now my life is terrifying me. My friends are afraid. I don't know what's going on and maybe I don't want to but I need to share, and we'll go into some of what recently happened to me. Because as odd as it may seem to, to people who aren't us, who aren't privacy professionals, we sometimes share way more than other people do, even while our job is to help that not happen except when it ought to.

Michelle Dennedy: Yeah. It's funny because I often get that commentary of like, you know, aren't you a hypocrite because you use every single social network platform and you talk about all sorts of crazy stuff. And my answer's always of course, no, part of experiencing the networks and experiencing data

is part of my work life. If I'm not in it then how can I make it better or is sort of my perspective on that. And then I think the other thing is, you know, you and I have seen each other in person like maybe three times and yet we've been able to maintain a friendship that goes decades.

Jay Libove: Yep.

Michelle Dennedy: So—

Jay Libove: And has been invaluable to me, and you and I, we're not the only couple where that's been the case for me. I don't know if I can mention names ... Hugo Teufel who had been the chief privacy officer at the Department of Homeland Security at one point.

Michelle Dennedy: We're going to make Hugo come on and maybe you can co-host it with me that day.

Jay Libove: I would love that. He and I had never met in person, yet we had held a friendship for over a decade up to and including late-night how-do-you-deal-with-the-frustrations-of calls. Once, I was just having a bad time of it and he was there, and Hugo never sleeps. You post something on Facebook, and he answers at every hour of the day. I don't know how he does it.

You made a comment a moment ago about, oh, Michelle, you're a hypocrite because you use all these social media platforms. I created my Facebook profile because I got into privacy.

Michelle Dennedy: Yes, me too

Jay Libove: If I wasn't going to use the tools, how could I possibly help other people secure them or helped my employer at the time that was Delta, use it in a way that didn't negatively surprise somebody around their privacy.

Michelle Dennedy: Yeah, absolutely. So, let's talk a little bit about your background, Jay. I mean, tell us a little bit of kind of, how you approach privacy and security. You're coming more from a technical angle than I am, right?

Jay Libove: Absolutely. I came from, you know, super, uber Geek. Oh my God, you're scary smart. Kind of, that's what people used to say to me.

Michelle Dennedy: Now they just say I'm scary.

Jay Libove: Yeah, well I am scary. I interviewed once for a job as a relatively senior privacy person for a really giant US-based corporation that I won't mention names, and they knew I wasn't a lawyer and usually they interviewed only lawyers for these roles because of the kinds of things that people had to do. And the person said, are you comfortable playing a lawyer on TV? And I said yes, absolutely. Because although I came from tech, I read so much privacy law and case argument and theory. Okay, I go back to uber geek, scary, whatever, I was.

Where did I come from? I started playing with computers in 1976 when I was eight years old. And this idea of being able to put my fingers on a keyboard and make it do something with so cool. And over the years I made it do a lot of things for a lot of companies, smaller and then larger, and somewhere along the way around the very late 1990s, very early 2000s when I had

done software engineering and I had done system engineering and I had done network and I had done pre-, post-sales tech stuff, Digital Equipment Corporation for the rest of us out there old enough to remember what that was.

Michelle Dennedy: Yeah DEC was a great company.

Jay Libove: It was, miss it, kind of. I, by the weirdest path possible, got offered a job as an information security engineer at Delta Airlines. My, then wife, my former wife was working in the human resources department at Delta. And this was before everybody in the world had high-speed Internet and people still had dial-up. And literally, I mean the company would pay for a phone line and a modem and you would literally dial in to the company. We don't mean dial-up Internet here.

Michelle Dennedy: Right.

Jay Libove: I had dial-up Internet. I was one of the beta test users of Mindspring enterprises that became Earthlink.

Michelle Dennedy: Oh god. Yes, yes.

Jay Libove: And so I actually had a pegged-up Internet connection, which meant if my wife needed to dial into her office, I had to lose my Internet so she could go to work. And so I asked her to ask the tech department at Delta if they could give us a VPN. And I think it was a field service engineer kind of back and forth and back and forth between me and her and the IT department and security team and back. And at one point the tech support person, the field service person, said to her, "You know, I think you guys should stop. I think you're really annoying them." I was really annoying them because the next thing I got was an unsolicited email: Are you looking for a job?

Michelle Dennedy: Good.

Jay Libove: And I said yes. And I became the third info sec engineer at Delta Airlines in 1998.

Michelle Dennedy: I love it. And when you say you got an email in 1998 it was like chain letters, cat videos, and maybe one or two a day that were relevant business emails. I remember that time and very fondly.

Jay Libove: I'm going to one-up you. I've actually owned my own personal domain since before then.

Michelle Dennedy: I love it.

Jay Libove: Told you, uber geek.

Michelle Dennedy: I love it. Well, I mean that's an important thing, right? So, and I think it is consistent across people who are Sigma people and deviate from the norm in that way is you follow your curiosity, wherever it goes and you have an infinite level of curiosity. So, let's talk a little bit about, so you're in Barcelona, Spain, which is like a dream situation for a lot of folks. Tell us a little bit about how you got there and how that's relevant to your thinking about privacy and security and where you're at today?

Jay Libove: It almost came chicken and egg, out of order. My wife who happens to be Japanese lived and worked in Japan until she was about 30 and then left because she wanted a freer culture. Had originally wanted to move to Europe but it just turned out to be a whole lot more practical to move to the US, and I'm glad that happened because that's how I met her. And many years later when I left Delta after doing security and five years in, getting an offer from the chief security officer/chief privacy officer, that role at Delta was one of the first companies that joined the security and the data protection or privacy leadership functions in a single person.

Michelle Dennedy: Yep.

Jay Libove: I moved over from the security team to the privacy team and I took on, by the time I left, I didn't have the title of deputy chief privacy officer but it's kind of what I was doing for the last year or two that I was at Delta. And when I left Delta, I sent my résumé, or my CV as we say here in Europe, to well, my entire professional network and that included companies that had been providing or were still providing services to Delta. Part of my role at Delta in those last years was overseeing security, privacy, and business continuity compliance in our supply chain. And one of these companies which happened to have its operations center in Barcelona, it was a call center company and it took English-language phone calls from Delta's customers, knew me because I showed up on site a couple of times every year to kind of audit their compliance with all those things. They went, "You come here, move to Spain, be our chief security officer." And I went, "sure."

Michelle Dennedy: Cool.

Jay Libove: And that's how I got here. It wasn't really that I sought it out specifically, although we had wanted to move to Europe. It sought me out and the first opportunity was Barcelona. We were thrilled.

And then a year later the global recession happened and the job disappeared and you know, everything got really complicated and we stayed despite it all. We stuck out some hard times and it worked.

Michelle Dennedy: So, when we were talking about doing the show today, what we were talking about is context and time and patients changing context. So, let's talk a little bit about your current situation if you're comfortable doing that. And what you were talking about is how you were becoming informed.

Jay Libove: Absolutely. So, for anybody who's seen the Arnold Schwarzenegger movie, Kindergarten Cop, one of the little kids in this class kept saying, "It's a tumor," and Arnold would go, "It's not a tumor." In my case, it's a tumor.

Michelle Dennedy: It's a tumor.

Jay Libove: Yeah. A little more than a month ago, I took a nap in the afternoon and woke up with earth-shattering headaches, headaches of a magnitude I had never experienced or dreamed of in my life. They were more or less the same as a month earlier when I had broken a tooth in half at dinner and had to seek an emergency dentist at ten o'clock on a Saturday night. And after pumping my mouth full of Novocaine, she started to drill out the damaged tooth. And I went

through the roof, and she said, “Oh wow, the nerve is already inflamed.” She said, “This is going to hurt a bit” and stuck the needle with the Novocaine right into the center of the tooth. And I swear my hand left a dent on the steel arm of the chair. It was three seconds of the worst pain ever. And she's looking down at me and I'm white and sweating and she goes, “It's okay. Now it's over.” And she was right. But I now know what post-traumatic stress disorder is. I really do.

Michelle Dennedy: I'm having it right now. I'm not going to lie.

Jay Libove: And these headaches, they were, in a different way, that kind of pain. They were something is so wrong, get medical treatment right now. I called my neighbor. I was up at our house in this beautiful little mountain town. Fortunately, he was there. He drove me to the nearest hospital. They did a CT scan and it was, “You have a pituitary tumor.” And a few days later as the headaches gradually were subsiding with rolling series of potent meds of every sort, I started reading about this and I learned far more than I ever wanted to. And partly that's because we have the Internet and lots of medical journals and articles are out there, and the big medical centers put data out there so that we can learn and we can understand our own medical status. And partly it's because people share their experiences.

Michelle Dennedy: Yeah.

Jay Libove: And so I have a pituitary macro adenoma that produces insulinoid growth factor one that provokes the body to produce excessive amounts of growth hormone. At one point, the endocrinologists in the hospital where I finally ended up, the one where you met me, which is the reference place in Catalonia where I live and one of the reference hospitals in all of Spain for this sort of thing, they said, “You know, the reason that you had all these nice muscles the last couple of years is basically you've been naturally doping. You didn't know it.”

Michelle Dennedy: Oh gosh.

Jay Libove: It's true. My body was producing excess amounts of growth hormone, which is one of the things that athletes dope with. And I'm like, aw, I miss my muscles. I liked those. I'm going to have to work a lot harder to get them back after this is all over and they allow me back into the gym. It won't be so easy the next time

Michelle Dennedy: My doctor says the same thing just being over 50.

Jay Libove: Yeah, well, I'm just over 50, and so thanks for reminding me I have this double whammy going against me now. Wow.

Michelle Dennedy: It's all right. We're looking good, Jay. We're looking good.

Jay Libove: We are, up until very recently and the beard started going a bit white and nobody ever knew my age. Now they kind of do. So yeah, I was diagnosed with a tumor and I needed to understand it and a lot of it was just reading. But then I needed to get feedback and bounce ideas off people and see if my understanding of stuff was realistic and matched the actual experiences of other people who had been through it before had had. And so, on Facebook, I found a number of private Facebook groups. These are groups you have to ask to join. The people who run the groups ask you questions, they check your answers. And they only let people who really have

the issue and who are going to follow the group rules join the group. So, I joined up with four or five of these groups. Amongst those groups, they count maybe 15,000 people, every one of whom has one or another variant of the pituitary tumor and endocrine insufficiency. Something about their body not working right and relating to these things. The pituitary gland, the adrenal glands, or the hypothalamus.

Michelle Dennedy: So, but right now you're in the earliest stage of learning about your condition. So, I think what you're illustrating here, Jay, is the hunger for knowledge when you're in panic mode and when you're not sure what's going to happen. The appetite for you to share and the willingness and the excitement actually of coming together with groups is really at its zenith, right?

Jay Libove: Yes, and if you'd like, I can send you offline, copies, actually you've seen because you're my friend on Facebook and you've seen this stuff. I posted detailed medical records and reports and interpretations. Literally not just to these private Facebook groups but to my, well, my feed isn't public but I have lots of friends and lots of friends of friends. I mean lots of people in the world could find every detail about what I've been going through. I didn't have time to consider how good an idea is that because I had to deal with, I may be very, very sick and I need to be able to manage it and putting it out there will help me do so.

And I commented earlier that a long time ago, 25 years ago pre-Facebook, pre-privacy officers, I had another medical condition, and there was this thing called the Usenet.

Michelle Dennedy: Yep.

Jay Libove: Which was an online distributed bulletin board system all over the world. And the whole idea of privacy was much, much less mature, but it was the same deal. Something scary medical happened to me and I needed to share and get feedback and I did. And back then I didn't even know to think about privacy. And today I certainly do, but it's what you said, we're in this emergency situation. And the last thing we can do is worry if we're oversharing cause we need to save our lives.

Michelle Dennedy: And that's a really important thing because I think the, the privacy nihilism of the past has said, look, kids are willing to share online and these patients are sharing their conditions online. Isn't privacy a degraded ethic? And I think what you're talking about is not that you've given up on privacy or even that you'd suspended privacy. It's that you actively chose to share. And the return on that sharing investment was building community comfort, knowledge, a way of going forward, right, in that context of time. That doesn't mean that every piece of information and all of your blood work should now be publicized. Right? That doesn't seem to be a good expectation.

Jay Libove: Very true. And also a little bit idealistic and which is why people like me and above all, people like you, that's not why we exist, but it's why we do the stuff that we do. Sure, my goal in sharing wasn't giving up my privacy. Did I choose, okay, I'm a certified privacy professional, even in that emergent situation, I was making something of a choice and maybe I had more ability to make the choice than the normal person does. When I say normal, there is nothing pejorative about it. If you know—

Michelle Dennedy: Like they're normal, we're not. Yeah.

Jay Libove: And we're not. And that's a good thing. We do the stuff that we do so that everybody else doesn't have to be a privacy expert and especially when something bad is going on with them and they need to share and they need to get that feedback that the world in which they do it, hopefully by design and by default, will be a little bit more privacy protective.

Michelle Dennedy: Yeah. And so you're touching on something. Oftentimes, and for years and years, the analogy has been made or the metaphor has been used that a patient in an ambulance should be forced to or should have taken from them all of their information. You know, you don't want to be in an ambulance unconscious and be allergic to penicillin and have an IV needle of penicillin stuck in your body. And so that's like people say, oh, well it's better to share because this outlier case, and my argument to that has always been, this is the case to me, not for oversharing or permanent sharing, but instead for privacy and ethics engineering. This is where I want to think about these cases because you're not the first person to be diagnosed with something that's very unusual that you can't go to WebMD or some of these other online sites and get a perfect answer.

Even your own doctors may not have the right kind of information that you want to share, but people who are living with this sort of thing in their own heads, in your case and in my case, you want to have that conversation with them and it suits a certain purpose. Right? And it's risky because you don't want to get medical advice from other patients necessarily because what works for them may not be right for you. But at the same time, I think this goes to the structure of various things. Can you have a private sharing group on a social platform? You absolutely, I think, should be able to expect that you do have that and you're not going to be constantly inundated with marketing for that condition. I have multiple sclerosis and I can't tell you what, when I first got online and started sharing and, this is 20 years ago now, in the panic of thinking, oh my god, I'm going to be in a wheelchair like tomorrow.

You know, I shared a lot of things and the worst was this constant marketing of stuff back to me. And the worst of it was, and I actually shared this with the pharmaceutical that did this, when my daughter had a condition and she received in her own name, and now when you're eight years old and you get a big manila envelope with your name on it, that's exciting. That's exciting. That's like grandma letter exciting. And so she got this letter and she opened it up and because the pharmaceuticals have to give the side effects, I found her under her bed, literally under her bed, curled up in a ball crying because one of the complications of this experimental medication that was sent to my daughter from a pharmaceutical company, because we had shared her diagnosis with some other families going through situation, was death. And she's like, "Mommy, you've been lying to me. I'm going to die."

Michelle Dennedy: And I was like, oh my god. And so of course, you know, the blessing and the curse of being a privacy officer is that we are a bit of a rare creature. And I was able to call the cell phone of the CPO of that pharma and my voice was heard, you might say. So, let's wrap this up so that we're not leaving on overly optimistic or overly pessimistic. Where does context and sharing of condition, and also your condition has vastly, like the prognosis has vastly improved from those first dark days, right?

Jay Libove: Yes. So, the private Facebook groups, if you said those words, private Facebook group, I would wager that—

Michelle Dennedy: And for the future, Jay, in case someone plays this in a year or two, Facebook was the social networking company that was really important. Just in case they don't fix their bits.

Jay Libove: Ooh, sharp end of the stick Michelle.

Michelle Dennedy: I love them too. But get your acts together, people. Come on now.

Jay Libove: Yep.

Michelle Dennedy: Anyway, sorry.

Jay Libove: Absolutely. So, if we say that phrase, private Facebook groups, I would wager that more than half of the users of Facebook today, they would recoil and they would think it can't be, it doesn't matter what the settings are. It doesn't matter what you do that there's no such thing. There's no privacy on Facebook. They're going to violate it. Yeah and no. I actually am not particularly concerned that Facebook would violate the privacy of these private Facebook groups and share the identities and the contents of the posts beyond the members of the groups.

Michelle Dennedy: Yeah.

Jay Libove: There's lots of things that Facebook does very wrong. Something like that, I don't think, I'm not particularly worried about. Now a member of any of these groups could violate the privacy. There's no way to stop that.

Michelle Dennedy: Yeah.

Jay Libove: Somebody could lie to become a member of the group. There's no meaningful way for the people who host these groups and they're all very well intentioned or they all have very good rules for their private groups, but there's no real way to stop somebody who's lying and cheating to get in and then do whatever they would want to do. But we have to take a degree of that chance because of the value. And you made a comment about maybe your doctors, the first ones that you, for any particular value of you, somewhere in the world that isn't Barcelona that has a leading medical center or New York or Boston. Maybe you're in a little town somewhere and your doctors don't know this stuff. What I see from the 15,000 other people in these private groups talking about their medical journey is that an awful lot of them, they get seen by doctors who don't understand their conditions as well as they do.

Michelle Dennedy: Right.

Jay Libove: Because of what they've been able to get by researching online and by talking with other people in the groups. So, this stuff literally is life-saving. We are making a choice to expand what is our privacy circle at a time when we need that sharing and that feedback because our professional medical circle, the one we have easy access to, they might not be good enough.

Michelle Dennedy: Yeah. Yeah. I think that's absolutely, and I think you've illustrated the balance beautifully. I think probably one of the most annoying things in the world for any doctor now is dealing with the Google doctors. You know, your Google search does not meet my seven years of preparation to be a specialist. I hear that from doctors all the time. And it's true for lawyers too. I love people

that are like, well, I read the GDPR and it says this, and I'm like, you are so cute. But it makes for a really good debate. You know, I often show up at my doctor's office and he gives me the hard eye roll. But he always listens. He may be rolling his eyes, but some stuff he's like, okay, snakebites nope, that doesn't work. That bee sting thing actually does. It's weird. Here's the chemical compound, blah, blah, blah.

And so I think it's not the worst thing in the world to challenge professionals and not have that wall. It's not the worst thing in the world to feel confident that you can change your outcomes with diet and meditation and yoga in addition to western medicine. And it sounds like what you're getting from your healthcare in Barcelona and your background in security and privacy is really getting the right medical treatment for you and your wife in this time, and the support that you need. And you know the blessing of Facebook that for Future Me, that was a social media company that existed and when it adopted privacy engineering it saved itself, that's how I knew that you were in the hospital and I sent you a note. I said, "Hey Jay, I'm going to be in Barcelona for Cisco Live if you want a visit." And that's the magic.

Jay Libove: Well to be fair. We had been in touch in advance because I'm a cyclist. You're a cyclist.

Michelle Dennedy: Yes.

Jay Libove: And it was, "Hey Michelle you're coming to Cisco Live. Let's go for a bike ride."

Michelle Dennedy: That was the plan. Yeah.

Jay Libove: And then I got sick. And it's like, "Hey Michelle, would you visit me in the hospital instead?" And world, Michelle rocks! Because she and her, I forget what Susan's title is, came and spent an hour and a half with me—

Michelle Dennedy: It was lovely.

Jay Libove: ... in the hospital. It was so good for me, and all of the friends and others who supported me through it.

Michelle Dennedy: And we're recording this on Valentine's Day so that makes my heart warm.

Jay Libove: That's true too.

Michelle Dennedy: Well thank you so much for your time and your candor and your relentless hunt for privacy and security. Before I let you go, can you give us the name of the group that you're working with right now? It's an exciting initiative so that people can check that out too?

Jay Libove: Do you mean the Information Security Forum? The Information Security Forum is a 30-year-old, originally European government-funded effort just to help the world, companies, and governments do better at managing information security and managing information risk. It's not something that we as individuals can join. The members are companies. It's a nonprofit private society. It no longer gets any government funding. It's completely independent, and I do consulting only to the member companies of the Information Security Forum, only on the research that we do, which is business methodologies for getting a handle on what risks our

businesses have because we have information and how to manage them. So, we don't do technology. We might tell you a firewall is a known control for this area. You should probably have one. We won't give you any opinion about which one. We might help you know what the features are, but then it's up to you to choose products and deployment. So, I have done consulting to banks, financial services industry, natural resources companies, shipping and logistics, and others on risk management practices where the risk goes to the business but comes from the information. And I love it. I love it.

Michelle Dennedy: Yeah, and I mean you can hear the excitement in your voice about it too. So, if you are in a company and you're listening, it's the Information Security Forum. It is a 30-year institution and you can actually get someone like Jay or even Jay himself to come and help you, whether you're an SMB or a larger company. So, check it out and see if your company is already a member and if they're not, consider some membership. And thank you Jay Libove. Thank you, thank you, thank you. And continued recovery and success my friend, and we will get that bike ride in one day.

Jay Libove: Wonderful. I'm looking forward to that very much. And, Michelle, thanks so much for having me on the podcast. This was a lot of fun and I'm looking forward to hearing it.

Michelle Dennedy: Excellent. Well, thank you so much, and hey Sigma Riders out there, it's a wrap.

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