

# When it Mattered

## Episode 12: Caroline Catlin

Chitra Ragavan: Hello and welcome to When it Mattered, a podcast on how leaders are forged in critical moments and how they deal with and learn from adversity. This episode is brought to you by Goodstory, an advisory firm helping technology startups find their narrative. My guest today is Caroline Catlin. She's a writer and photographer, and a brain cancer patient and survivor. Caroline's research and work in behavioral health and developmental trauma has inspired her to incorporate art into the process of caregiving and therapy, and reforming the way health, illness and disability are portrayed in the media. Her work has been featured in the New York Times, Boston Globe, Huffington Post, and other media outlets. Caroline, welcome to the podcast.

Caroline Catlin: Thank you. I'm so glad to be here.

Chitra Ragavan: Tell us a little bit about yourself and when and how you first realized that you had cancer.

Caroline Catlin: So I graduated from college in 2015, and by that August, I was very sick. I woke up with fevers every day for two weeks. I had joint pain, and muscle pain, and intense fatigue, and that sort of started the process of trying to figure out what was going on for me. I went to urgent care, I went to local doctors, and everyone dismissed me and said, "We think you have a mild cold." I eventually was diagnosed with acute Lyme disease and pneumonia and began treatment for Lyme disease that we believed had continued and kind of become chronic. And that continued for three years, of trying to figure out what was wrong and treating me with antibiotics and different things, until my cognitive symptoms, so memory loss and word finding issues, became worse. And I asked multiple doctors and finally got one to agree to do an MRI, and that was when they found the tumor.

Chitra Ragavan: And how old were you then?

Caroline Catlin: I was 27, and I am 27. It was right after my 27th birthday actually, that the first doctor agreed to do an MRI.

Chitra Ragavan: And what was the tumor and where was it?

Caroline Catlin: So the tumor was in my right parietal lobe. It was about golf ball sized, and it is an anaplastic astrocytoma, a grade three out of four. It's in the same class as glioblastomas, which quite a few people that have been in the news have passed away from, and it is the type of cancer that will likely return as a glioblastoma.

Chitra Ragavan: Glioblastoma is the same cancer that killed Senator Edward Kennedy, Senator John McCain, and also Beau Biden, son of former Vice President and now presidential candidate Joseph Biden.

Caroline Catlin: Yeah, that's correct.

Chitra Ragavan: The right parietal lobe is one of the four major lobes in the human brain, and it regulates sensory processing and language among other things, which probably explains why you were having difficulty finding words and things like that.

Caroline Catlin: Yeah, exactly. And they didn't exactly know ... A lot of my symptoms were nontraditional with the type of cancer I have, and the area of the brain it was in. But when I started having more word finding issues and a few headaches, they started to be concerned. Most people who are diagnosed with my type of cancer, and in this part of the brain, have seizures, and for some reason I never had a seizure. So that kind of made it more difficult to diagnose.

Chitra Ragavan: And what was that moment like for you, when you were told that you had cancer, given that you'd had quite a bit of difficulty getting people to take you seriously?

Caroline Catlin: Yeah. You know, it was both incredibly crushing and ultimately relieving. I think I had felt like I was crazy and that I was making up all these things, because there wasn't any clear indication of what was going on. I had had my blood work done many times, and because brain cancer doesn't often show up on your blood work, there was nothing. There was nothing that was indicating how sick I was. And so when I learned, I was devastated, and I also was really grateful that I now knew what was going on.

Chitra Ragavan: To have something this serious at so young an age, you said it was crushing. How did you wrap your head around something like this, and your heart?

Caroline Catlin: Yeah. You know, I don't think I did at first. I think I really grieved. I remember leaving the hospital and just being absolutely devastated. I would wake up every morning with panic attacks, just trying to feel out how to live with this diagnosis that would never go away. And the fact that I will never be free from cancer. It's very possible I can live a full life, but a life, as long as I'm alive, I am going to live as fully as I can. But having this diagnosis that it will come back and it will come back at some point more serious than it is now, I wasn't sure how to live with that. And I think it's still something I'm figuring out, but I'm learning to be really present in the moment and focus on what's happening in front of me.

Chitra Ragavan: And what has your treatment been like so far?

Caroline Catlin: My treatment so far, I've done six weeks of radiation, so I did every day for six weeks, I went to radiation. And then I've just started chemo, so I've done three rounds of chemo. It's about once a month. It's an oral type of chemo, so I do five days of chemo and then I have like three weeks off. And I had surgery to remove the tumor back in January,

Chitra Ragavan: And I assume that was successful.

Caroline Catlin: It was. They actually got the majority of the tumor. This type of cancer tends to kind of have microscopic cells that invade other areas of your brain, which is why it's so serious. But they did get a lot of it, which is really good for me.

Chitra Ragavan: And in order to undergo radiation, you had to prepare yourself in other ways too.

Caroline Catlin: Yeah. I mean, I had to set up care so that I could get back and forth to radiation. I had to shave my head. Well, I didn't ... It was one of those things where I knew the spot where radiation was hitting, I would lose all my hair there, and so I decided to shave my head independently, and yeah, that was really hard and really emotional for me.

Chitra Ragavan: And you also had to have fertility preservation.

Caroline Catlin: Right. Yes, and I had to do that pretty quickly. I had about maybe a few days to decide, and then like three weeks to do kind of the first half of IVF where I basically preserved my eggs, because chemo will destroy most of my chances of getting pregnant naturally.

Chitra Ragavan: And what do they say is your prognosis?

Caroline Catlin: My prognosis is kind of across the board. It really depends on the case. It's kind of random, but the first statistic said the average survival rate was three to five years. With advances, they're seeing people live longer, but it's really kind of new that all these new treatments and the surgeries are getting better. So it's really unclear, but I do know that the tumor will return at some point in my life and it will likely return as a grade four.

Chitra Ragavan: Do you have insurance to cover these costs? How are you managing?

Caroline Catlin: Really, really good question. I'm on Medicaid because I'm not working, so the state insurance, and since being diagnosed with cancer, it's been very helpful. But before that, when we didn't know what was going on and we were trying to figure it out, a lot of what I was doing, I had to figure out how to pay out of pocket or some other way because they were seeing nothing wrong, so all the kind of traditional and standard tests people wouldn't do.

Chitra Ragavan: And you talked about how you were initially not diagnosed correctly and not taken seriously, and you've done some research since you were diagnosed to see whether this is actually a trend when it comes to women and diagnosis, and how people with traditionally less authority fare in the healthcare system.

Caroline Catlin: Yeah. One thing that I learned is that young adults who have cancer are often diagnosed at much later stages for a variety of reasons, but one of those is that they're often not believed as much as other people, and they also don't tend to have consistent health coverage or health insurance coverage and the same doctors. So they end up being diagnosed at much more intense and on dangerous stages of cancer, and also women, people of color, queer folks, anyone who is marginalized or kind of in a less state of authority tend to be less believed about their pain and their needs within the healthcare system. And that means that they aren't taken as seriously and can be diagnosed or misdiagnosed later on, and really not treated the way they should be often.

Chitra Ragavan: And so what advice would you give people who are in situations like yours? I imagine you're constantly advocating for yourself, even today.

Caroline Catlin: I am. The reason that I had an MRI, and the reason that further testing happened on my tumor, because at first they thought it was benign and didn't want to do further tests. I think advocating for yourself is the most important thing you can do. As someone who has a body and is experiencing any kind of symptoms, I think you have to make sure you trust yourself, and you know your body best, and whatever you can do to make sure you're heard and listened to, even if that's pulling in extra support in some way, you know your body and you should advocate for it.

Chitra Ragavan: What has been your mental and emotional state since then, and sort of the things that you are learning about yourself since your diagnosis, and in coping with this very, very serious situation?

Caroline Catlin: I think I have to take it day by day. I mean, I know everyone kind of says that and suggests that, but when I try to look towards the future and plan, I can't really do that anymore, and I've always wanted to plan my whole future out, from a five year plan or whatever, and I can't do that. I kind of have to be where I am. And you know, I think my life has sort of become lived in three month chunks, because every three months I get a new scan to say whether the cancer's returned, and so I plan that far ahead and I enjoy my moments in every day. I think it's really important to let yourself grieve, and I don't think the grieving process stops shortly after diagnosis, I think at least once a week, I'm kind of really feeling that hurt, and I let that happen and then I get up and I move on, and I have fun with the people I love, and that's how I'm getting through.

Chitra Ragavan: And one of the things that's really evolved as a result of this is your own writing, and your art, and your creativity, and your photography, and talk a little bit about that, and then we'll talk about some of this photography that you've been doing.

Caroline Catlin: I think that returning to art, I always have been an artist and I've always looked to art and photography and writing as a way of translating the world around me into something I understand better, but I think having the opportunity to really throw myself into it since my diagnosis has been very helpful. I've been writing a lot about my own experiences, and some of that I've published, and some of that I haven't, and I've been working as a photographer

for an organization called Soulumination. I've been volunteering, and they provide free photo shoots for families with critically ill children, and I've been able to be a part of that, and that's been really incredible.

Chitra Ragavan: What has that process been like for you, to photograph these moments with very young children, even babies who are about to take their last breath, and you are in the room taking these photographs? Tell me the process of what happens, how you are invited to observe these moments and and how you go about doing it with your camera.

Caroline Catlin: You know, I think I'm figuring it out. Every time I go in the room it's different. What happens is I'm on call, and so if there's a photo shoot that comes up that they think I'm a good match for, or just one that ... I have agreed to do end of life sessions, and a lot of the photo shoots aren't end of life. Some of them are just families with kids that are sick and they really want to document their family, but I've agreed to do these end of life sessions, and so I think when that comes up, I'm often contacted, and sometimes it's an hour's notice, and I'll go to the hospital and I'll find out what room they're in, and kind of just step in.

Caroline Catlin: Sometimes I don't even introduce myself. If the opportunity comes up, I do, but often they are so wrapped up in what's going on for them that my job is to kind of just be a quiet presence, saving the moments that they will want to remember. So you know, holding their child's hand, or their siblings getting to hold the baby for the last time. And those things are really important, and in that space they can't capture them themselves, and so my job I think is to ... Almost if they don't know I'm there, that's almost better, because I want it to be just them focused on their family and then have these things to hold onto after.

Chitra Ragavan: The first time you went in and had to take a photograph like that must have been extremely challenging.

Caroline Catlin: It was. It was very difficult. I work in social work and crisis management, at least before I got sick, and so I have a little bit of that practice kind of putting my emotions on pause so I can do the job I need to do. But it's very hard. I mean, I watched a little boy say goodbye to his sister, and I was just ... It was just very painful and sad, and it takes strength to kind of notice, "Okay, what is the good that's happening here?" You know, "What parts of this grief can I find love within?" And that's what I really tried to focus on,

and I didn't know when to step out of the room and give them space, and I just had to trust my instinct and my own experience being in crisis situations in the hospital.

Chitra Ragavan: I know most of the work that you're doing is confidential. Are there any stories that you could share? And you also had this beautiful op ed page piece in the New York Times, What I Learned Photographing Death, in which you were able to talk a little bit about the family and the child and show a photograph. Can you describe that?

Caroline Catlin: Yeah. So the photograph is a picture of a baby who had kind of complications that were going to result in him passing away either a few hours, a few days. They weren't sure, but they knew he wasn't going to be able to survive long. So I was actually in the operating room when he was born, and I was able to take pictures of him and take pictures of him as they laid his body on his mom's chest, and his hand kind of was across his mom's face, and that moment of pure connection and love. I'm so grateful I got to be able to be there to witness it and also to photograph it, because to me it was such a expression of connection between these two people, and this baby that did not get to have the life and the length of life he deserved, and it was incredible to be there for that.

Chitra Ragavan: Are there any other stories like that that sort of stay in your mind and encourage you to do more of this work?

Caroline Catlin: The first one I did that I was talking about, the three year old who passed away, seeing the way her family was there, and the way, when her brother was saying goodbye to her, the way the mom handled that situation and how gently she explained what was happening to the little boy really inspired me and kind of altered the way I think about death, and think about these tragedies, because there was so much pain in that room, and there was also just the example or the evidence of how much they loved each other was really clear. I recently did a few NICU shoots and there was a family who took their baby outside, and that was really wonderful to see just so that the baby could experience being outside, and that was really lovely.

Chitra Ragavan: And how do the doctors and surgeons respond to having you in the room?

Caroline Catlin: I think that they've used the services of Soulumination enough and they know their mission, and so they kind of let me do my thing

and they're aware of my job, and I think Soulumination is very respected within the hospitals that I work in, and so they know when I come in and say, "You know, I'm working with Soul, and here's my name and here's who I'm here to photograph," and so they give me the space to do that. And all of these doctors and nurses that are in these rooms too, I have just experienced nothing but deep caring from them. I think often these children have been in the hospital for quite some time, or have been sick for quite some time, and so they've developed a relationship and they're just as grateful to have someone documenting as the families are.

Chitra Ragavan: For those of us who are photographers, the real joy of photographing people is the ability to share those images. But most of the photos that you're taking will never be released, and they're just handed over to the families for them to have and so that they can remember that moment. How does it feel to know that perhaps some of your best work will never be seen in public?

Caroline Catlin: You know, that's a great question, because it often is the case where I'm so proud of these images, and I know that they're not mine, you know? I think it's interesting. It really feels like I'm there as a tool of translation, as I've said, just to kind of transfer these moments for them to keep. And it's definitely hard. I think there's work I'd love to show, and I also know what my job is and what I'm there to do, and that is kind of always in my mind. And I think meeting the families, the priority that is giving them a gift is very clear to me when I'm there.

Chitra Ragavan: And how has this act of photographing end of life moments for others helped you deal with your own illness?

Caroline Catlin: I think it's made it less scary. I think all of a sudden ... I mean, it's still scary, but when I'm there, I can see the reality of what death looks like, and sometimes there's humor there, and great moments of people loving each other, and I think death is something that's inevitable for all of us, and so facing that and facing what it actually looks like makes this huge thing that I can see someday coming a lot less foreign and a lot less scary.

Chitra Ragavan: And it likely probably has changed how you view the grieving process, hasn't it?

Caroline Catlin: It has. I think it's connected me to my own grief and the grief of other people in a way that's really, really wonderful. I think I've been able to see how much grief is rooted in love, and that's been



a huge gift for me when I think about my own family grieving and my own grief over my illness.

Chitra Ragavan: Do the people you photograph, the families, do they know that you yourself have this incurable cancer?

Caroline Catlin: No. Not for the most part. I mean, I usually wear ... My hair is starting to come back now, but when I really didn't have any hair, I would wear a hat or a scarf around my head because those moments aren't about me. I think when I'm in the same hospital that I was treated in and the same ICU, I'll be in NICU or something, but it's similar to the ICU I was in, I definitely have moments where I'm like, "Oh my gosh, that's a similar scene or a similar hallway." And sometimes I'll share little pieces of that with the doctors, but generally with the families, they don't know and I don't tell them anything about it.

Chitra Ragavan: But your work is probably really inspiring to young people, others who are in the same situation and who happen to be-

Caroline Catlin: Yeah. Yeah. It's different when I'm working with an older, like a teenager, because when I work with a teenager or a kid that is maybe not at the very end of their life, I do use my own experience to connect with them. I think I worked with a teenager who was nearing the end of her cancer treatment and I offered to take off my hat if she would take off hers, and, "We can be bald together," and things like that are really helpful. I think I do use those tools of connection when I'm not in kind of the same dire situations, and that makes a big impact.

Chitra Ragavan: Now, you've got a long road ahead in terms of your chemo, right?

Caroline Catlin: I do. At least three more months, maybe nine more months.

Chitra Ragavan: How do you plan to navigate those three, to six, to nine months, in terms of life and work and family and your own coming to terms with all of this?

Caroline Catlin: You know, I think I reached a point in the last month really where I'd been putting my life on hold, and I'd been like, "I'm going to wait and see what happens, and wait and see what happens." And I realized my life is possibly too short to do that. I need to live as much as I can while I'm alive, and so I just signed up to go back to school part time, very part time in the fall. I'm going to keep writing and keep doing photos during the day and take a few evening

classes, and move forward with what I have wanted to do, because I think if I don't, I will really regret that, and I would love to experience as much of life as I can.

Chitra Ragavan: Is there any one thing you try to do every single day as a way of celebrating life?

Caroline Catlin: I think I practice gratitude a lot. I think I don't always ... The other day I was actually just eating blueberries, weirdly enough, and I was like, "I love blueberries. I'm going to ... I would miss ..."  
There's just simple things like summer, having to have fruit in the summer and be in the sun, and all these things that I get really stuck on, and then I say, "I'm really going to miss this." And I try to reframe it as, "Oh my gosh, I'm so grateful that I get to eat some fruit in the sun and be with the people I love." And every time I can switch it around, it feels less hard to bear.

Chitra Ragavan: Yeah. They say that gratitude is the most powerful emotion in the world.

Caroline Catlin: I think it's helped me beyond description. I think being able to look at the things that are really important to me and say, "I get to have this right now and I'm so grateful for that," is huge. And that doesn't mean I'm not angry sometimes and really sad other times, but when I'm able to be focused on where I am and happy, I try to take advantage of it.

Chitra Ragavan: And will you continue to photograph end of life moments?

Caroline Catlin: I hope to be able to do that as long as I am able to move. It's really important to me and it's been hugely healing in a lot of ways. So that's my goal.

Chitra Ragavan: Caroline, this has been a very inspiring conversation. Do you have any closing thoughts?

Caroline Catlin: You know, I think what I was saying earlier about advocating for yourself. I would just encourage anybody that's in any kind of similar situation to stand up for what they believe in and what they believe their body is doing and feeling. And then if you're met with kind of a huge tragedy of any kind, I don't believe everything happens for a reason. I don't think that's fair to say, but I think in every situation, something can make you more and something can make you a different person, and to look for the good in that.

Chitra Ragavan: Where can people read more about you and see your writing and your photography?

Caroline Catlin: I have a website. It's my first name and last name, [carolinecatlin.com](http://carolinecatlin.com), and I think that would probably be the best place, and hopefully there will be more of my writing out in the world sometime soon.

Chitra Ragavan: Caroline, thank you so much for joining us and for sharing your story.

Caroline Catlin: Thank you so much for having me.

Chitra Ragavan: Caroline Catlin is a writer and photographer. She's undergoing treatment for incurable brain cancer. Caroline documents those final precious end of life moments for families. Thank you for listening to When it Mattered. Don't forget to subscribe on Apple Podcasts or your preferred podcast platform, and if you like the show, please rate it five stars, leave a review, and do recommend it to your friends, family, and colleagues.

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