



The Reality of Caregiving: Anna Konkle on Love, Conflict, and Loss

Anna Konkle (00:00):

Nobody else is there to schedule the delivery. Nobody else is there to make sure the cockroaches go away. And yet I feel like I've been this massive imposition.

Annabelle Gurwitch (00:07):

Living with lung cancer, ask me anything. Real conversations with people living with lung cancer. Learn from personal journeys and expert insights. Subscribe and never miss an episode. This is Living with Lung Cancer, Ask Me Anything. I'm Anabel Gerwich, your host today. On this podcast, we're having the kinds of conversations that I wish I'd been able to have when I was diagnosed. We're sharing practical strategies as well as talking about the emotional impact, advances in science, community building, our challenges, and even how we're cultivating joy while living with lung cancer. If you're a patient caregiver, you belong here. Welcome. I'm sitting here with Anna Konkel, who you know from Pen15 and has a book coming out in May called *The Sane One*, which I can't wait to read. And, and you and I met through a bunch of ways. Mm-hmm. Um, I did a play with your partner.

(01:16):

Okay. 15 Maya. Mm-hmm. And so that was one way. And then the producer, one of the producers of Pen15 Debbie Liebling is a good friend of yours. And then I realized, oh my goodness, you have been a caregiver for your dad who died from lung cancer. Mm-hmm. And I thought, okay, we have just so many connections and I wanna talk about this experience- mm-hmm. ... of the caregiving experience because this is one of the least, I think, um, discussed and one of the, like, most important issues that affects how you get through treatment- mm-hmm. ... how you, how you live through these really big challenges. And, um, people don't really talk about it enough.

Anna Konkle (02:08):

Yeah. I felt like that when I was going through it and afterwards that it was like something sort of that you're supposed to disassociate from, especially after- Huh. ... you know, my dad passed that it was like ... And, and while I was going through it, um, yeah, it wasn't something that I felt like people wanted to hear about but so important. And I, I grew up with my mom as an RN nurse mostly for- Uh-huh. ... um, elderly homes or visiting, she was also a visiting nurse for that kind of population. And so it was something like palliative care and, you know, and very normal for us to be talking about at the dining table.

Annabelle Gurwitch (02:45):

Right. So

Anna Konkle (02:45):

I think also it's like I've all, I have this craving to, yeah, to talk about it and not just hide it away. So I'm happy to be here.

Annabelle Gurwitch (02:52):

Yeah. I think people, um, first of all, there's a lot of very taboo subjects- Yeah. ... about this, that surrounds this like, uh, it, it, it can feel like, uh, well, well, well to start with. Yeah. Let's talk about, let's set this situation up. Yeah, what are all the

Anna Konkle (03:09):

Taboo

Annabelle Gurwitch (03:10):

Parts? The taboo part- I love taboo. We love taboo. Like, like the idea that you could complain or the idea that you could have to, you could have conflict with the person that you are- Oh, that you're, that you're actually supposed to help. They're supposed to be helping. Yeah. And that, that you can have different disagreements- Oh my God. ... and, and that actually you don't, you're not always on the same page.

Anna Konkle (03:31):

Which is inevitable.

Annabelle Gurwitch (03:32):

Which is

Anna Konkle (03:33):

Inevitable. And I feel like I would go on these forums, you know, because there wasn't anybody to talk about it with. Right. 'Cause I, so my, my- So isolating. Yeah, so isolating. I'm my, you know, my dad's only child, didn't have a partner, didn't have, you know, other ch- yeah, another child. Right. So it was really ... And, but going online, there were so many people being like, "I don't know what to do. Like I'm the only one doing all of the, you know, physical work or whatever. And like, I feel like I'm an imposition." Right. I feel like they don't want me here, whatever. Right. And I, and I was, you know, the time I should say with, you know, with my dad at that time in his life of finding out about the diagnosis when he passes about two months.

Annabelle Gurwitch (04:14):

Oh my God. Okay. Well, let's, let's, let's- Yeah. I'm so

(04:18):

Here. Yeah. Because, uh, before we get to all that, and, and I just want to say this idea of isolation and also, um, you know, there's this image of like, oh, it's so great you're caring for like, oh my God, what about the really difficult things? Yeah. But let's talk about what happened- mm-hmm. ... just the actual circumstances. Sure. And to start with, you know, um, when I was diagnosed with lung cancer, it was so out of the blue- mm-hmm. ... because I've been a non-smoker and I just had no idea I was at risk for that. And I know I had like, is this like an old man hacking coffer disease-

Anna Konkle (04:57):

In my

Annabelle Gurwitch (04:57):

Dad's

Anna Konkle (04:58):

Situation, that's exactly what it was.

Annabelle Gurwitch (05:00):

Well, you know, there's- But not only.

Anna Konkle (05:02):

Yeah.

Annabelle Gurwitch (05:02):

But there's, there's, there's tons of range. There's a really big range and we know that, you know, like the majority of people who are being diagnosed right now in America are- Non-smokers, right? Non-non-smoking women- Yeah. ... which is just terrifying. Staggering. Yeah. And especially at a time when our government is now cutting, um, emission standards because the number two driver of lung cancer is particulate matter in the air. But hey, you know, uh-

Anna Konkle (05:27):

Tears.

Annabelle Gurwitch (05:27):

Yeah, really excited about that. Um, but so it was so shocking to me, but, uh, but was this shocking to you and how old was your dad? How old were you?

Anna Konkle (05:38):

He was 71. Mm-hmm. Uh, so this was about five years ago. I'm 38. Wow. So yeah, 33. And, um, yeah, I mean, what's, what's unique I think about, just to set the stage a little bit- mm-hmm. ... about when I found out we had been estranged for about five years before that. He had been like my best friend as a kid. Uh-huh. And in my 20s, you know, late 20s had started to feel like, you know, things were changing with him and I was trying to figure out, yeah, a lot, sifting through a lot of childhood stuff. So yeah, there were five years where we were talking, but we weren't, we weren't seeing each other and around the time he got diagnosed, fortunately we had just been sort of talking more- Uh-huh. ... and I had seen him once. We had gotten dinner and it had been a really long time.

(06:32):

Uh-huh. So I feel really lucky looking back on that. And we had started writing letters back and forth. He was in Florida about, yeah, the estrangement and what was behind that and he responded thankfully in a way that like allowed us to kind of move forward and it wa- I guess he hadn't been diagnosed yet, but it was like a month or two later after we had reconciled where he called me, it was actually the day after the Emmys, I hadn't known he had waited till after. Oh wow. And I had FaceTimed him, which was significant because we hadn't FaceTimed in years at the Emmys. I had this feeling of like, "I'm just gonna

do it. " And, uh- Wow. ... you know, like cutting four to five years earlier or going like, "I need boundaries. You're in every, you know, you're too involved, whatever." So I'm FaceTiming him and he's crying when I FaceTimed him.

(07:24):

Oh

Annabelle Gurwitch (07:24):

My gosh.

Anna Konkle (07:25):

And I'm like, "Oh, he's just proud of me, whatever." And then the next morning I'm on the way to the writer's room- Uh-huh. ... and he's like, "I have to tell you something." And my dad had had cancer before, starting when I was 18, he had prostate cancer twice. And so it wasn't an unfamiliar, you know, role to be kind of told and to go like, "Okay, who's the doctor? What hospital are we going to? " Or like whatever. Um, but this hit in a, in a different way and he, there was very little he shared in retrospect, he really kind of minimized what was going on. Yeah. Uh-huh. But he was also really afraid. Uh-huh. And so I think he, he kind of just told me, you know, I, they found a mass and, and I remember going, you know, "Well, could it be the prostate cancer that, that landed on the lungs?" And he had done such a good job of transmitting over the years like prostate cancer growing slowly, like, don't worry, you know, whatever.

(08:25):

Mm-hmm. And-

Annabelle Gurwitch (08:26):

And did he tell you like a stage or anything or not that

Anna Konkle (08:29):

Moment? Yeah. So he just said, "Oh yeah, it could, it could be a prostate, it could be prostate cancer on my lung." I didn't do that. So that is kind of the, the, the patient, I guess, from my point of view that, that he was sort of consistently through was a little bit of like, like foot on the, the break of treatment.

Annabelle Gurwitch (08:52):

Okay. So, you know, the things you're talking about, and first of all, it just brings up these issues that are so present for me. Mm-hmm. So first of all, this issue supports systems that, you know, someone, someone gets diagnosed with something, they're not perfect. Like somehow or another, there's this, I think, um, the feeling you can have as a patient and, uh, that, oh my God, do I, am, am I, do I not have the support system that everyone else has because I, once I knew I was gonna be living in this long term situation, I was really concerned about the people in my life. Like I didn't want to wear people out. So I'm like, okay, how am I gonna spread this out over a long period of time? And there, so there, so to acknowledge that there's no perfect situation- Yeah. ... and if you're not in a situation where you have, let's say the most visible or- mm-hmm.

(09:56):

... or, or what you would say is a predicted support system- Yeah. ... there are ways of, um, building a support system. Definitely. And one of the things we do on this show is we always encourage people and their resources at Lung Cancer Foundation of America to be able to find support systems. Mm-hmm. Um,

we have a lot of community in this, uh, lung cancer support world. Mm-hmm. We have support for caregivers too. We have summits, we have, uh, groups that meet online, meet in person. Wow. So, so I-

Anna Konkle (10:28):

I wish I had all of that. I wa- it was, it was so quick. It was like this marathon- Right. ... of just trying to keep up.

Annabelle Gurwitch (10:33):

But also you probably didn't know this existed and- No,

Anna Konkle (10:36):

I, I,

Annabelle Gurwitch (10:37):

I wish I

Anna Konkle (10:37):

Did.

Annabelle Gurwitch (10:38):

I got the news, the first call was that there was some concerning mass on my lung in front of my son who was in the car together on the speakerphone. I thought a doctor was flirting with me, but no, he was calling to tell me that he had given me the wrong information, he'd rather be wrong- Unbelievable. In front of my kid. Unbelievable. Which is like the worst thing you wanna do to protect your child.

Anna Konkle (11:03):

How old was your son at the time?

Annabelle Gurwitch (11:04):

He just graduated college. He's 19. Okay, okay. He was j- just no, no, no, just turning 20. He was 20- 20 or 22. 21, 21.

Anna Konkle (11:11):

Okay.

Annabelle Gurwitch (11:12):

Okay. So, so 20 ... No, he must have been 22 now. So turning 22. Yeah. So then, you know, um, even, even now, I mean, this is what's so complicated about this is- Yeah. Oh, and then when I, when I started to find out it was lung cancer and started treatment and all, I really tried to keep as little, as much, as, as little information as I could, would get to him. Yeah. I was really trying to manage that because I was so concerned about him at that moment and I'm sure your dad- mm-hmm. ... was concerned about you. And, um, so, so then what do you do? How do you, how do you react to this information?

Anna Konkle (11:54):

Yeah. I f- I felt ... And, and I, I wanted to just say too that, like, I was very concerned about my dad not feeling alone because I knew that was something that he had grappled with because I had felt extremely guilty, feeling like I had abandoned him in this strange period. Wow. That, uh, you know, and thankfully we were reconnecting a way where I felt authentically like I could be there and I'm so grateful, but I also felt, had moments oddly, and this is probably gonna sound selfish when he was the one going through lung cancer, of feeling lonely as the, you know, lone caregiver. Even though as time went on, we started building more of a support system, and we could talk more about that because he wasn't super connected to a lot of his community. Slowly through those two months, he got more connected, ironically.

(12:46):

So he got to experience, and I did too, a lot of healing, um, during those two months, so I'm grateful for that too.

Annabelle Gurwitch (12:53):

You know, that's such a big issue, the idea of feeling lonely as a caregiver, like, and then you feel guilty- Yeah. ... that you, there's like this double

Anna Konkle (13:04):

Whammy- I'm not the patient, I'm not the one going through the physical pain and challenge and the psychological fear, all the things that I'm just like bowing, you know, to everyone about. And, but when the lights go off and you're laying in bed, you know, the moment before I click on Love Island <laugh> to disassociate, I'm, I'm thinking like, God, I wish that there was somebody, you know, I'd fantasize about my mom being there and being like, you know- Yes. ... why am I here alone dealing with this? Like da da da. Right. And then other moments I'd feel so grateful, especially coming from the estrangement period of going like, "Oh my God, thank God I'm here that I get to have this time with him."

Annabelle Gurwitch (13:44):

That's so many complex feelings- Yeah. ... and I think this sense that, um, do you deserve to have these feelings? Right. Like I, you're not the one with disease. Yeah. But like, like do you, but you know, like- Yeah. So, where do you put your feelings and, and what feelings am I allowed to have as a caregiver? And, you know, I think for my kid it was so hard because he was dealing with, um, trying to be a person who's just graduated from college into the pandemic and mom has cancer and- Yeah. It's too

Anna Konkle (14:25):

Much.

Annabelle Gurwitch (14:25):

It was just so much for him. I mean, I just had lost the capacity to do so many things and my sister steps in and really runs our life for my son and me and just sort of organizes my finances, but also just makes sure I have food and she's working too. I mean, it was- Wow.

Anna Konkle (14:47):

How were you physically feeling at that point?

Annabelle Gurwitch (14:49):

I was feeling so terrible because I, it was like a- Oh, that's when you

Anna Konkle (14:53):

Had first started

Annabelle Gurwitch (14:54):

The new,

Anna Konkle (14:54):

The medication.

Annabelle Gurwitch (14:55):

Right. I was asymptomatic for lung cancer, but the medication itself, and I had started at a higher dosage and this is something we talk about on the show. Um, sometimes it's your caregiver and your care team who has to help you to, um, be able to voice, you know, maybe I'm at the wrong dosage or not. Right. And, uh, we were able to change the dose, get it reduced and then I could function like a human, but I was really barely functioning. Yeah. And, you know, I had this fight with my sister at that moment- Uh-huh.... which was just like the most inappropriate thing. You know, she was cooking for us and she was, she was doing everything and one night she said, uh, "We're having turkey zucchini loaf." And I went,

Anna Konkle (15:43):

"Ugh." I relate to that so much and, you know, and when I was, you know, like caregiving and, but it feels inevitable. It's like there's no-

Annabelle Gurwitch (15:53):

Yes.

Anna Konkle (15:53):

Just because you're going into this sort of more, more boundaried roles, I guess in a way or more identifiable roles of like, okay, I'm agreeing, I'm not just your sister, I'm stepping in and I'm living with you and I'm, I'm in some ways stepping into caregiver shoes. Right. And so that is my role, but the rest of your history and identity and human beings does not- As if that's gonna fall away. ... this is gonna be invisible. Right. And it just gets, it can, I don't know, for my dad and I, in some ways it makes things simpler and then in other ways it makes things far more complex. I was supposed to go to script on an episode that I was writing and directing that weekend-

Annabelle Gurwitch (16:33):

Wow.

Anna Konkle (16:34):

... and I was like, "I'll do it in Florida." And at that point I'm thinking, uh, we're, you know, he's kind of going like, it could be stage one- Uh-huh.... it could be, we just don't know anything. I haven't done a biopsy yet, whatever. Oh gosh. So I'm like, okay, well, you know, and I'm going back to being 18 and going

like he, I, even then he, well there was a secrecy with health outside of him and I, he didn't want people to know things and there was also a hesitance to like super deal with it. So I don't know, there was something in me that was like, I'm going this weekend. So my partner and I flew in that weekend and it was just a very dramatic start where, you know, all I know is he's had this diagnosis and he's told me that he has pneumonia and so like he kind of warns me before I see him like, "Just so you know, like separately I have pneumonia and he's like, all my doctors know and blah, blah, blah." And I know nothing about lung cancer at this time.

(17:34):

Uh-huh. I'm not educated at all.

Annabelle Gurwitch (17:35):

Did you start to read about it? Were you-

Anna Konkle (17:38):

Honestly, I was working 16 hour days. Right. Like it was like, I was kind of already unfortunately in bad terms, but survival mode in my life- Yeah. ... that I was just trying to get there on Friday, you know, and he was kind of like, "My friend has been taking me to my appointments. Like everything's good, you don't have to worry. By the way, I have pneumonia." Oh my God. And so I'm like, "Okay, you know, fine." Thinking we're like in the beginning of things and when he opens the door, he's just clearly like having trouble breathing and- Oh

Annabelle Gurwitch (18:13):

My gosh.

Anna Konkle (18:14):

... is in pain. And so we try to have a really nice dinner because I haven't, and we haven't done that. I haven't been back to this place in five years while he's clearly very uncomfortable and I'm like, "Dad, are you okay?" He's like, "It's just pneumonia. I told my primary doctor da, da, da. He's good." And I'm like, "Well, can I call him because I don't..." He's like, "He's on a boat. It's Florida." I'm like, "Okay." My dad was a very funny, weird person. At a certain point, I'm like, "I think we need to go to the doctor. He won't go. I want him to call, you know, the ambulance. He won't. I call my mom." So this is a great actually care, the beginning of caregiving I learned very quickly. So I called my mom and they've been divorced for a gazillion years, but I'm like, "What do I do?"

(18:58):

Like I think he need, he should go to the hospital." My gut tells me that, you know, my partner's like, "Well, you said it's just pneumonia." And I'm like, "I really, my gut is telling me." And my mom is like, "Listen, and I worked in elderly homes for all this time. The thing that I learned is like, he's not an, he's not a child. He's an adult just because you are, you know, you can't just swoop in and tell him what to do. This is his life

Annabelle Gurwitch (19:20):

And

Anna Konkle (19:21):

You have to respect that. " And so I did and we said goodnight and I said, "Please just wake me up if it gets worse." Uh-huh. He promised and he woke me up at 30 AM and we called 911 and he was rushed to the ER.

Annabelle Gurwitch (19:38):

You know, I feel really guilty because I'm laughing.

Anna Konkle (19:41):

I know that's all, that's all that we did throughout it. I mean, the thing is like where we were in our relationship, and you can probably relate to this in terms of like you, you're writing a book about this, I chose to write a book about this because there were all these little moments that were so, felt so kismet or bizarre, but then I'm like, or do storytellers just remember those things and everybody else is going through the same experiences and just disassociate? It's a great question for you. Yeah.

Annabelle Gurwitch (20:10):

I

(20:10):

Do think that there are just moments that are, even when you're experiencing them, you just feel they are important in some way or let's say defining. And so this, you have this moment where you realize, and that's a really important thing for a caregiver because like to just sort of think about what we take from this conversation- mm-hmm. ... as we tell this story- Yeah, please. ... is to think, okay, there are these moments where you realize in some sense the limitation of your role, you know, you're, and that is, I think- That's massive, I think. Yeah. That is a massive thought to think, I can't solve every problem here. And I think this is a really big negotiation in the patient caregiver role of like understanding that ultimately you are not totally responsible, but that this is a, a, a shared experience. Mm-hmm. Every week on Living with Lung Cancer, Ask Me Anything Podcast, we explore questions that matter most to people living with lung cancer.

(21:18):

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(21:47):

I found, um, through the patient, uh, support community, Immerman Angels, I got matched with a, um, person who had the same, uh, diagnosis of me. I write about this in my book named Hardy, uh, who was also a member of EGFR resisters, uh, same diagnosis going every three months for her scan. So, uh, I, by bringing in Hardy, by bringing in someone who was going through the same experience as me and who could be there for me in a way that was helpful to me without burdening my friend who had every great intention, um, that was one of the adaptations I made. Interesting. So sometimes when I do one-on-one mentoring with other patients, I talk about, well, you know, who's, who's in your support group? Maybe we need to expand that support group because what you need for this particular kind of moment isn't- It's different.

(22:52):

... something that that person can give you. Like I don't call my son- Right. ... in those moments. Yes. Um, because this would be just really difficult for him and for me and I call Rose and other times. And so, you know, this is, this, we, we have to become sort of nimble and, and I think as a, as a caregiver, it's just really hard because you, uh, you know, you, you wanna be listening and awake to what someone needs and, um, at the same time, there's some limitations, just imitations. You can't be every,

Anna Konkle (23:32):

You can't be everything-

Annabelle Gurwitch (23:34):

Yes, to- ... When you

Anna Konkle (23:35):

Want to be.

Annabelle Gurwitch (23:35):

Right.

Anna Konkle (23:36):

And you wanna be able, uh, gotta get emotional to fix it.

Annabelle Gurwitch (23:39):

Yeah, you wanna fix it. And

Anna Konkle (23:40):

You wanna make everything easier.

Annabelle Gurwitch (23:41):

And also, you have-

Anna Konkle (23:43):

Selfishly too, for your own needs. You're like- Yes. No, no, to both of your friends that you're speaking about, it's like, it's gonna be, it, they're both trying to say partially to themselves, you know, it's actually fine. So,

Annabelle Gurwitch (23:55):

So, so, so then you're with your dad, you're, you're down there and-

Anna Konkle (23:59):

We're down there, we go to the hospital, it's the middle of the night.

Annabelle Gurwitch (24:04):

Oh my God.

Anna Konkle (24:05):

Yeah. Very, it was so dramatic, but so he really at that point, you know, needed the support and- Yeah. ... and, and that was the beginning of treating acute symptoms that- Uh-huh that was an aggressive cancer- Yeah. ... that to get to a point where we could make a treatment plan and start treatment. Wow. So that was sort of the marathon- Uh-huh.... that we were under. So when we got to the hospital, he had, um, blood clots, he had had a mini stroke- Oh my gosh. ... that had no symptoms. Right. Um, he was on high oxygen and then, um, you know, that slowed everything down because we were at a point where we needed to do a biopsy and because- Uh-huh. ... needed to go on blood thinners, we, we couldn't do that, so that had to get slowed. So very quickly I was like, okay, you know, and then I'm going like, "Who's your oncologist?" And he's going like, "Well, we haven't quite," you know?

(25:01):

Right.

Annabelle Gurwitch (25:02):

And

Anna Konkle (25:02):

So I can say, you know, the thing that from a, from a caregiver and child of someone that, you know, had lung cancer, cancer in general, it's like, I have, I know he did his emotional best at that point that he could do to deal with it, but I, I, of course, selfishly, I wish that he had put his foot on the gas and gone like, "What are we doing every day to address this? " And I see friends and I see you going through, you know, their own walk with cancer and I have so much admiration because there's so much bravery in going to every doctor that you can and see, if, if you have access to it, at least is from my perspective of going like, ugh, like my, a friend that's going through this right now, she's, she's, she's doing all the things and I'm like, "Thank you.

(25:56):

" 'Cause I've been on the other side where I'm like, "Please go see that doctor."

Annabelle Gurwitch (25:59):

Yeah. I mean, I'm really glad you brought it up because it's a frustration between caregiver and patient. Yeah, this is so

Anna Konkle (26:05):

Important. Why

Annabelle Gurwitch (26:06):

Didn't you-

Anna Konkle (26:07):

Well, and it goes back to the earlier thing too of going like, "Well, just, you know, just go to the hospital now." And my mom being like, you know, you're infantilizing him. Right. Who are you? You're not his boss. Right. You're not, you don't know better, he's his own person. But it can

Annabelle Gurwitch (26:18):

Leave you with a feeling of, not anger, but like, I know, why didn't they just do that? It's

Anna Konkle (26:25):

So hard to not look back and you're, and our like human controlling thing wants to go like, "What's the equation so we avoid this in the future?" Right? Right. And, and to your point, like, that is a, that is very flawed.

Annabelle Gurwitch (26:38):

Well, no, but it's, but it's the real feeling and I think these feelings come up of like, why didn't you deal with it? Or you just don't, things, things can escalate quickly- mm-hmm. ... and we all have to be aware that, like, we're just doing the best we can. And your dad, I mean, I can't speak for your dad, but I'm sure he either was afraid or- Yeah. ... just didn't realize. And it's so human and- Yes. ... uh, just to, you know ... So, so-

Anna Konkle (27:09):

Yeah.

Annabelle Gurwitch (27:09):

Yeah. So once you, once you get over this triaging- Uh-huh. ... moment, did you stay involved with the- Yes. ... how did you do this between your job and-

Anna Konkle (27:19):

Yeah. It's a good question because I look back and think of, like, a few months of very little sleep, but when I was seeing what he was going through, it just felt like, you know, whatever. Mm-hmm. Um, I, yeah, so I was there then from that point I stayed for two weeks and that was, I mean, so much of it is a fog, but-

Annabelle Gurwitch (27:41):

Yeah.

Anna Konkle (27:42):

... that was like a lot of time in different ICUs essentially.

Annabelle Gurwitch (27:47):

Mm-hmm.

Anna Konkle (27:47):

And then, you know, trying to get him home and this reality that he was needing to deal with of like, now you're on oxygen. And so he's home going back to his apartment that he was always at. Uh-huh. But life looked very different and he was very frustrated by that, you know? Uh-huh. And so, and then there was the growing pains of me trying to organize everything he needed at home, like, okay, in his condo, he needs, you know, an, a backup oxygen tank in case of a hurricane. So that's being put in his bedroom next to his bed because there's not a lot of other areas that they said they could install and, and this is separate, but he had a cockroach infestation.

Annabelle Gurwitch (28:31):

Oh my God, but this is- Like

Anna Konkle (28:33):

All these things.

Annabelle Gurwitch (28:33):

But this is like- The air conditioning stop

Anna Konkle (28:35):

Working. Like

Annabelle Gurwitch (28:36):

All of the

Anna Konkle (28:36):

Things are happening at the

Annabelle Gurwitch (28:37):

Same time. Like things don't happen in a vacuum.

Anna Konkle (28:39):

It was funny because like I think part of the estrangement, ironically though, like looking back was me processing, feeling like his, like his caretaker previous to this- Uh-huh. ... for a long time or feeling like a wife or feeling like, you know, I learned the term like, you know, and feel free to cut this out, but emotional incest, like- Uh-huh. ... kind of processing these things in therapy and then all of a sudden I'm back, but it felt okay now because I had more boundaries and knowledge of it to go like, you know, I'm, I'm down to, to try to be there for you in a, a more holistic way in all the ways and yet I could feel this toggling that he would go through of being like, all he wanted was to feel loved and cared for by a community. So he'd go through times of feeling like that and then he'd go through times of feeling like, "Get the fuck out of my house.

(29:31):

Like what are all you people doing here?" Yes. I had gotten like, I knew he was coming out and I was like, went to Target and I got a bedside table and I saw in the hospital that he had to sleep upright, so I'm getting all the pills to sleep upright and like I have it all set up. Uh-huh. He has never been more angry at me in his life than coming home and seeing his bedroom changed into a hospital room. Yes. And in retrospect, I'm like, of course.

Annabelle Gurwitch (29:57):

So, uh, did your dad leave all this s- stuff in the room or did he move it all around or you would, you'd done something great, right?

Anna Konkle (30:05):

I know here, I mean, it was like, it was like, you know, every day was like a race to try to get everything ready and to get what he needed and is how it felt on my end at least. And in retrospect, the thing that had also added to the moment is that he had been given an oxygen tank at the hospital that was not working. Okay. So we had waited for a while for this portable oxygen tank. We get like, you know, we're sent out with it. We need to get some medications at CVS, we need to get a nebulizer, we need whatever. And he, it's like blinking red and I'm like, dad, I think it's not working, whatever. He's like, it's fine. He's getting more and more upset in retrospect probably because he needed oxygen. His brain was like, "I'm not happy." But he also was sort of OCD in general and you add to like, what a shock for him to come home to.

(30:59):

Yes. He'd been living as a bachelor. Yes. He already liked things how he liked them. And then any human being, I think in retrospect would feel like you have invaded my home, I did not give permission, you know? And here I was thinking that- Right. ... these, these, this was inevitable. So I just facilitated- Right. ... what needed to happen. Right. And nobody else is there to take the phone calls. Nobody else is there to schedule the delivery. Nobody else is there to make sure the cockroaches go away and yet I feel like I've been this massive imposition. So I feel like the caregiver, you know, if you're, if you're invested and you're there, it's both sides of the coin where you have ... I, I, it took me a second, but like I did understand. After he screamed at me <laugh> and I cried and then I said, "I'm gonna fucking leave, you know, in my room or whatever."

Annabelle Gurwitch (31:48):

Yes, things really happen and I think you can feel like you're really- So isolated. And then also like you failed. Yes. You're the only one that

Anna Konkle (31:55):

Has

Annabelle Gurwitch (31:56):

These kinds of just-

Anna Konkle (31:57):

I'm not doing it right. Right. Or he's too hard on me or whatever. And then I would go on these messaging boards and feel like, oh, everybody is going through a version of this and everyone's trying to figure out- Yes. ... their place to be additive, but to not control to empathize with the, with the person you're caregiving to understand that it's their body, it's their life and you're doing this dance of facilitating all that you can while understanding that you're not in charge. And that's a hard pill.

Annabelle Gurwitch (32:29):

It's really hard. And, and were you, uh, involved in the, the, the, uh, treatment, developing the treatment plan for your dad?

Anna Konkle (32:39):

Yeah, I think there was like, it was pretty quick where I realized that he wanted to tune out- Uh-huh. ... with what the doctors were saying. Interesting. And what, the simple part of that is I, I didn't know where my role was in the beginning and then quickly I realized he wants me to manage the care. You

know, he wants me to take all the notes. He wants me to call the oncologist and tell him what I think the next plan should be. Wow. And then he would sort of say like, "I don't think so. " Or, "Yeah, that sounds good." Or whatever.

Annabelle Gurwitch (33:12):

Wow. So you, that's really, that's stepping into a role with a lot of responsibility.

Anna Konkle (33:17):

Yeah, it was, but because he was inpatient for a lot of it, there was a real infrastructure of support. Uh-huh. And as long as I got there at 5:00 AM or 5:30 every day, I could be like a real part of the team and help make- Right. ... you know, the decisions every day. And once he got home, you know, the, unfortunately the being at home part was just not long. Uh-huh. Like he, he ended up needing more oxygen. And so he would end up back at the hospital and then we'd be making a plan, you know, to put out that fire and to get him back home and, you know, over time it went from a one to five year, um, kind of estimation of, of what life would look like. And it was, yeah, it ended up being two months. So it-
Wow.

(34:05):

... it turned into palliative care pretty quickly, but the positive part of that is we had so much time to just focus on each other- mm-hmm. ... and there was so much FaceTiming with his community, there was so much music, there, it was like a very happy time and we had come from five years of it being really tough and so - So grateful that we had that time together.

Annabelle Gurwitch (34:33):

Yeah. Yeah. It's a really charged moment, you know, um, that makes me think about as difficult as it was, I mean, these, these, the way that we metabolize these situations, every situation is so different. So different. There's just no cookie cutter situation- Yeah. ... you know? And I, I think about when I was a caregiver for my parents, I did step into that role where, very often where I was the person helping design the plan. Yeah. And, you know, um, my son is younger and so I did not want him to take on that role. Yeah. And I was really lucky that, um, because, uh, I, I have a sister who's so organized that she has done that, but also because, uh, I was able to get this, um, the disease progression under control, I've had the mental acuity to be able to be the person who makes the plan, but that isn't always the case.

(35:41):

I was gonna

Anna Konkle (35:41):

Say, do you get fatigued with that? Are you ever like, "Can I just hand this over to my sister?" Are

Annabelle Gurwitch (35:46):

You

Anna Konkle (35:46):

Kinda like the driver's seat is a nice place?

Annabelle Gurwitch (35:49):

Every situation is so different. Yeah. And people's needs are different. And I think that this kind of negotiation- mm-hmm. ... between, um, the person who has this disease, the person who's the caregiver like you did with your dad, I mean, it's a profoundly amazing, it's a great responsibility, but it was also an amazing experience for you. And I mean, it, it's, I don't wanna put words into, I don't wanna give you the words, but- No, please do. ... sounds like a really defining, like a really- Yeah. ... like, uh, I mean, you must have really felt like you stepped into, I don't know, some kind of real power in terms of your own, not power over your dad, but of like, wow, I'm a, if you ever questioned your competency as a person, I think that would just convince you immediately.

Anna Konkle (36:43):

Well, that's nice for you to say. I mean, I think that the thing that is h- if I'm being totally honest- Yeah. ... and this is a space for- Yeah. ... for that is, it's hard though to not, you know, that, of course I would've loved to have more time with him. Yeah. And so it's hard to, when you're the one that was responsible for the care plan- Yeah. ... that's a really hard thing to not turn on yourself sometimes or going like- Yeah. ... did I miss that? And, you know, uh, it's, and to like, and to feel ... It was so dual because sometimes I felt that isolated feeling of when the lights turned off and, you know, I'm thinking about myself for a second- Yeah.

Annabelle Gurwitch (37:31):

... of going like,

Anna Konkle (37:31):

"Oh, this is a lonely place to be. " And then sometimes it would be so simple when I would hear about other people's journeys of caregiving or going like, "I don't have to ... The only person that I'm negotiating with about what the care should look like is my dad." Yeah. And that's the person that I'm just trying to facilitate the best - Right. ... experience that he wants. Right. And, and, and I'm not fighting with my brother or my whatever about what it should look like. Like, we're doing this together and, but yeah, there's also that there

Annabelle Gurwitch (38:10):

I'm just crying. I know, I'm sorry.

(38:12):

No, no, it's, it's really, it's, it's very moving- I could just cry. ... to hear you say this. And I just can't help it because I, you know, I think one of the challenges that everyone faces on either side of the equation is the moment where you say, "What if I had dealt with this?" " 'Cause I, the thought is that I probably had lung, this beginning of lung cancer for years, but I remember thinking I had acid reflux at a certain point, coughing here and there, what if I had had this, you know, an, an x-ray, a scan so much earlier? And in some ways, I mean, I think it's first of all, it's very human- I know. ... to think these things. And in another, in other ways, I think this, it's important to acknowledge those feelings. I, I, I think those are just really human feelings- Yeah.

(39:09):

... and I, and I wanna say I can't afford to review the past. I mean, this is like- Yeah. ... a bigger philosophical issue- No, but

Anna Konkle (39:20):

I,

Annabelle Gurwitch (39:20):

But- ... So important. It's so important and I think these kinds of situations really bring this up. And so some people have spiritual practices, you know, I- Yeah. ... try to keep, "Oh, our producer, Laura Swisher, is coming in. Come on with some tissues." Oh,

Anna Konkle (39:42):

I know I wanna give you a big hug too. Thank you. Oh,

Annabelle Gurwitch (39:45):

Thank you.

Anna Konkle (39:45):

I was full, I was full sobbed like two minutes ago, so ... Okay. I just stuffed it back in where it belongs. I'm just kidding

Annabelle Gurwitch (39:53):

No, I, I think that, you know, in these kind ... When people are going through these really profound things and there are listeners who are gonna be going through profound things like this, you know, we have to acknowledge that, you know, it's, it's, it can be important to find some kind of framework for- Yeah. ... uh, dealing with these things, whether it's a spiritual practice, maybe a meditation practice, some kind of way, it's, it's important to find a way to live with this that doesn't destroy you. And I think, you know, it, it ... Well said. Yeah. You know, it, it, it ... I wanna say it can be done. Look at me, here I am crying and, uh, you know, I'm a great example.

Anna Konkle (40:37):

Crying isn't a

Annabelle Gurwitch (40:38):

Sign though.

Anna Konkle (40:38):

I know you're joking, but like,

Annabelle Gurwitch (40:40):

That's- But you know, that's exactly right. ... important with, with ... I mean, any kind of long-term existential challenges, so you have to make decisions, and you make decisions with the best information you have at that moment, and then we have to live with those decisions. Yeah. And I think that's challenging, and that's one of the reasons why I encourage community, and running things by ... We have this, we have websites, we have support groups where like, like, like a chat board, like- mm-hmm. ... I'm gonna do this and this, what's your experience? Mm-hmm. It, you know, because there's no perfect and we have to find a way to make these choices. And I think as a caregiver that's, if you're also a survivor,

um, you have to make ... We have to learn how to, uh, strategies. We have to work on strategies for-mm-hmm.

Anna Konkle (41:34):

'Cause it's not gonna be perfect

Annabelle Gurwitch (41:34):

Mitigating any kind of survivor guilt that we are left with

Anna Konkle (41:38):

Yeah. Yeah. I mean, therapy for me has been very, very important. Um, and writing this book

Annabelle Gurwitch (41:48):

Yes,

Anna Konkle (41:48):

Yes. ... has been really important just because it's been processing. You wrote the

Annabelle Gurwitch (41:51):

Same one. Um- mm-hmm. ... do you write about this?

Anna Konkle (41:54):

Yeah. Yeah. This is, it's hugely about my ... I mean, it's funny in my own, own stuntedness and trying to grow up in sort of like a dysfunctional family that very eccentric parents bought. I know, weird.

Annabelle Gurwitch (42:09):

Never heard of such a thing.

Anna Konkle (42:11):

Look at me, I'm weird. Um, yeah, and then, but like throughout it is this kind of best friendship with my dad as a kid and then growing up and the thing that happens to all of us or most of us is like seeing your parents not as the God like figure anymore as the real person. Right. And that's sort of like being a, um, extreme version of that in our case, I think. And this far fall off the pedestal that probably went farther ... He probably fell farther than he ended up at, definitely. Um, and I think that that was, you know, like a really beautiful part of the fact that I got to be his caregiver is like, I got to see, ugh, the sides of him that I saw as a kid that I admired. And so that's really awesome. But, um, thank you.

(43:09):

But like, yeah, when he, when he got sick, it was, yeah, at the, at the tail end, as I said, of, of our, like, winter, let's say. And, um, it was a new relationship that emerged after I got to take care of him. So yeah, it's, it was the mix of, like, really the day-to-day, um, in and out is definitely in there of, like, what that looked like between us and trying to, um, navigate, like, these new boundaries that I had found with him-

Annabelle Gurwitch (43:45):

Yeah.

Anna Konkle (43:46):

... w- well, figuring out what that meant when, then, like, I'm with, I'm with you all the time, sleeping in the lounging chair next to your bed, you know what I mean? Yes. Like, what does that, what does that look like coming from a time in my life where I was, like, trying to learn what boundaries mean, you know? Yeah. Something so simple. So it was, it was complex.

Annabelle Gurwitch (44:08):

Yeah. It's ... Well, the way that it unfolds, this caregiver, patient relationship, it doesn't look, it's not gonna look anything like you thought it would. Mm-hmm. I think that's what's unknown. Yeah. It's gonna look completely different and there is no perfect ... Everyone is going to have boundaries that are crossed- mm-hmm. ... and, you know, the idea that, that there's any known right or wrong, we have to throw that out- Yeah. ... and we have to say we each, we, we negotiate- Yeah. ... that's a negotiation of, of how we do this. Mm-hmm. And the more communication we can have around that, the more compassion and empathy we have for each other, for how hard it is for the other person, I mean- Absolutely. ... you know, is, is, I think, I think really important- Yeah. ... because there's no perfect and we, we have to know that this schlep is very- Schleppling.

Anna Konkle (45:10):

... complicated.

Annabelle Gurwitch (45:11):

Very schlepmy.

Anna Konkle (45:12):

The schlep is schleppling, as the young kids would say. Yeah.

Annabelle Gurwitch (45:14):

Yeah,

Anna Konkle (45:15):

And I also think that, like, you know, beyond that, that dynamic, the caregiving dynamic in all dynamics, but it's like, it is a living organism. And like, my father that I'm, that I'm caring for in that case is, like, his own history, his own- Right. ... who knows why he kind of shut down and was like, "You take, you make all the decisions." Yes. You know, who knows, like, and why certain things bother me or, like, we both, we come from a history that's both together and separate and, like, we're both reacting at a very important moment in, in his life and my life to, you know, different things in that, you know, I don't know, that those things best, best you can need to be spoke, that they're all di- I don't know. Yeah. Something about it being like a living organism and, like, the dynamic is different between ... I'm not, I'm, it's,

Annabelle Gurwitch (46:08):

I'm butchering it, but- No, no. I, I think that's really important because it's not static and it's, it's something that's- It's not

Anna Konkle (46:14):

Repeatable.

Annabelle Gurwitch (46:15):

It's not repeatable, it's not static and, and that while we, we can say that there are, there are hallmarks of these things- Yeah. ... how it's gonna play out, uh, for some reason and- Yes.

Anna Konkle (46:25):

...

Annabelle Gurwitch (46:26):

Well, that's-That's it.

Anna Konkle (46:26):

That's what I meant.

Annabelle Gurwitch (46:27):

Yes. How is You said that- What she said. Yeah, what she said. And I think in the caregiving role, we can't know what is going through, like, you can't know why your dad reacted in certain ways. It's a living organism, as you said, and we just have to suspend our judgment and try to, if possible, have a sense of humor about some of these ridiculous situations. It's, it's, it's not funny like you're laughing at it, you're, it's the absurdity of the situations you find yourself in.

Anna Konkle (47:03):

Yeah. I always, I've, I've come to realize that for me, brutality and humor are like one- Yeah. ... for whatever reason.

Annabelle Gurwitch (47:12):

Yes.

Anna Konkle (47:13):

Yeah. And-

Annabelle Gurwitch (47:13):

I feel the same way. Really?

Anna Konkle (47:15):

Yeah. And, and with Pen15, for example, it got called like cringe comedy and I never got that, but I, I get it more with time, but like the mirror of holding up the mirror to the brutal things in life. I'm like, it can be sad and devastating, but it, if it's not all so funny, then like, I don't know, life tends to be pretty brutal-

Annabelle Gurwitch (47:38):

Yeah.

Anna Konkle (47:38):

... again and again. So I'd like to be able to laugh at it as much as I can or with it or whatever, but my dad had a similar sense of humor.

Annabelle Gurwitch (47:47):

So first of all, Anna, thank you. I'm so glad to spend time with you and laugh and to cry. Same. And to hear about your book, *The Sane One*. Take your book. I can't, uh, the end of my life is killing me. Killing me. Uh, I can't wait to celebrate that book and, and, and read your book. Um, but also just to share on this really honest level about these things, I think it's really important, really profound. And if you're listening, thank you so much for listening to *Living with Lung Cancer: Ask Me Anything*. Thanks for listening to *Living with Lung Cancer Ask Me Anything*. I'm Anabelle Gurwitch, if today's conversation helped you, follow, subscribe, share this episode with someone who might need it. Together, we can change the way we talk about lung cancer, and if there's a lung cancer related topic you want us to explore, let us know in the comments, find out more at lcfamerica.org, you can find me on the socials or at my website, Anabellegurwitch.com.

Anna Konkle (48:44):

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