**Undying Love By Lucy Kalanithi and Frank Ostaseski**
**End Well Symposium, December 7, 2017**

Start of Transcript

Lucy: This is so nice. I'm really glad to be here. This is such a special gathering and Frank and I did a planning call kind of thing like a conversation to get ready and it felt like — I felt like it was in therapy…

[Frank Laughing]

Lucy: …so I feel like we all get to do 25 minutes of therapy with Frank and it's not a 50-minute hour you have on earth so anyway, I'm go glad to be here with you and I think we were thinking we would start out just by talking a little bit about who we are and a little bit about what we've learned through what we do. You wanna go first?

Frank: Yeah, I could. First of all, lovely to be here with you and to — what a exciting dynamic conference, huh? You know in Japanese zen, there's a beautiful term. It's called *shussei* . Lucy and I **[00:01:00]** were just talking about it and it translates as birth-death. One word really, hyphenated word: life-death, you know? No separation between life and death. Just a thin line connecting the two of them. So in my work, at least, I think that we really can't be fully alive without including death. Death is not waiting for us at the end of the long road, you know? She's right here in the manner of every passing moment. She's the secret teacher hiding in plain sight showing us what matters most. And the really great thing is we don't have to wait until the end of our lives to find out what she has to offer. In fact, to imagine that at the end of our life, we will have the physical strength, the emotional stability, the mental clarity to do the work of a lifetime is a ridiculous gamble. So I'm glad that we're having this conversation now and one of the things that we talked about is that we just wanted to **[00:02:00]** visit with you and each other and just be real in the conversation. So I work with a couple thousand people that died. And death was sometimes beautiful, and messy, and painful, and awful, and also transformative. But most of all it was normal. It was ordinary. We all go through it. None of us get out of here alive. I mean maybe today you will but I don't even gamble…

[Everybody Laughing]

Frank: So that's just a way to get us started. How about you?

Lucy: So I was reflecting coz on the way over here, I'm thinking about what lessons I would bring or what I say and I think one of the things that I learned through our family's experience and for people who don't know about it my husband, Paul, was diagnosed with Stage 4 lung cancer as a senior resident **[00:03:00]** —he was a senior surgery resident at Stanford — and then initially went back to work as a physician and turned toward writing in the last year of his life, and wrote the manuscript for *When Breath Becomes Air* at that time. And when he died, the manuscript was like an — a word document on his computer and it was published about ten months after he died and I remember I asked his agent at the time and said, you know, "This book is coming out and Paul's not here to promote…" and "How do you think it's gonna do?" And "What do you think is gonna happen?" when I've started stealing myself for what might happen. And she said it's either gonna do terribly or fantastically and I was like, thanks, I understand the limits of how it might work.

[Crowd Laughing]

Lucy: How it could do and she said it really depends whether the people wanna read a book about dying via a person who recently died and it's been so interesting. It was on the *New York* **[00:04:00]** *Times* bestseller list for over a year! And I think that congregants in this room are hoping that we're entering sort of a different way of thinking about living and dying and that intermingling and how do we find purpose and how do we find meaning in both ways and death and I think the fact of Paul following in the wake of being mortal, and these bigger conversations we're having culturally sort of really speaks to a exciting, interesting moment. So that's one thing that I've noticed and learned. And then, I do think a lot about purpose and what it meant to Paul during the time that he was becoming more and more debilitated and isolated physically and socially somewhat. But to be pouring himself into these pages, and we had a small child at the time too who was born eight months before Paul died and I think **[00:05:00]** that sort of you know like the bodily distraction but then the ability — the fact that you can continue to find real richness in your existence and even think about your future as potentially outliving you when you think about legacy, was really striking. And then I also you know, getting to talk about Paul and talked about his book really teaches me something about grief and the ways in which we all come together over really difficult experiences and also the fact that my love and relationship with Paul has continued since he died and that's been — you know it feels good to be in love and I'm still in love with Paul and that's a really neat feeling and so anyway I think those foster who had been surprising things to me where I expected sort of this like wasteland at this time and instead all these really beautiful things have grown out **[00:06:00]** of it despite the desolation so you and I talked on the phone and I think one thing that we all have to learn from you is thinking about the ways in which pain and suffering enrich us and the ways in which turning toward those things, even though it's really counterintuitive to do that, we sort of wanna push it away, and in healthcare we have the battle metaphor of like, we'll fight it, we'll beat it, and that's it, we don't want it. I don't know if you wanna reflect on that with us.

Frank: Well you know, I mean both you and Paul were physicians and we've been talking already today about how death is much more than a medical event. And that we have to stop treating it as if that's all it was. That it's much more an issue of relationships. Relationships with ourself, with those we loved, with God or whatever image of ultimate kindness, we hold, you know? I think when we think of dying as making the best of a bad situation, we **[00:07:00]** rob it of its wholly significance, really. I think we steal from it, you know? I think the experience of dying is too big, too profound to be contained by any one model; model of medicine or for that matter most spiritual models. It breaks open all the doors and windows of all models, yeah? So I wonder what it would be like if we stopped compartmentalising death, and we turn toward it. Not simply as an event in our lives but as a keeper of wisdom. Then might we ask death, how should we live? How should we live this life?

Lucy: I heard you on a podcast where you talked about how that idea of thinking about death can help you with road rage. You remember that?

[Frank Affirms, Laughing]

[Crowd Laughing]

Lucy: Can you tell us about that?

Frank: Whatever. Like, I mean you know, right? And you know from your experience with **[00:08:00]** Paul that it gets really simple. In a way, all the complexities that surround the dying process gets really simple. We get down to the really basic things when we're nearing the end of life, you know? What matters most? Now in my case, most of the people I worked with, many of which lived on the streets in San Francisco here, you know they were folks who didn't

have families, they came with triple diagnoses, they were complex lives. Neil Nguyen was a Vietnamese man I remember he was really afraid of ghosts and his roommate was Isaiah who's an African-American man who was very comforted from visits from his dead mother every night, you know? There was a man I worked with who was hemophilliac and he contacted the HIV virus from a blood transfusion. And a year before he had disowned his gay son because he'd been diagnosed with AIDS.

Lucy: Ha.

Frank: And now the father and son were in twin beds in the same room being cared for by Agnes, the son's mother and the **[00:09:00]** father's wife. I think that what I've seen over and over and over again, all these people have been really my teachers, is that when it comes down to it, a couple of questions really matter. And the first of those is, am I loved? And did I love well? And if those are the issues that we face at the end of our life, why wait until then to address those questions? This I think is part of the wisdom that death has to offer us about our lives and that doesn't come about through the turning toward the experience of suffering. We're alway running in the other direction, it whacks us at the back of the head. I think that — is what happens if we turn toward suffering and say, "What do you have to show us about our life?" So that's a question I wanna ask you. How did that happen with you and Paul? What caused you to turn toward the **[00:10:00]** experience of suffering? This is something we spoke about on the phone, I know.

Lucy: Yeah… I guess a couple of things. One, I've always sort of thought about the practice of medicine that that's like a gift that we could have in medicine, being witnesses and I remember being in medical school and thinking. This is the first time I felt in my life that I'm using all parts of my brain and then I sort of have a front row seat to this human condition, right? And I think the human condition is like the way that we in English would say thing that you stud, right? It's like this concept of life-death. We don't have that, but we have this idea of the human condition. And then I think… well I'll just say a thing about incorporating suffering in our lives. I — when Paul was sick, we were trying to figure out whether we **[00:11:00]** should have a child during that time and we had thought at the end of residency when things are gonna get easier, and he's not working 110 hours a week, we'll try to get pregnant at that time and that moment was when he was diagnosed with terminal cancer and we thought, we looked at each other and said, "We're kind of still wanna try to have a child, then is that totally insane?" And the answer is yes and I was really worried about it and thought, you know what, adding anybody who has a child doesn't do it because it's easy. It adds all these levels of work and potential pain and definite uncertainty and then I thought, you know, I said to Paul, "Don't you think if we have a child that's gonna make dying more painful for you?" And thinking about this great loss, that you're then leaving this father person and he said, wouldn't it be great if it did?" Making it more painful and it really **[00:12:00]** crystallised for me that it was okay to have a child, that it was great to have a child and oftentimes I think the things we do in our lives that are the most difficult can also be the most enriching and I think deciding to do this work or traveling or having a child or entering fully into a loved one's illness and pain or suffering, is some of the richest's stuff that we do and I I think Paul had an intuitive sense of that. And Paul also had an intuitive sense that living well is sort of the way that you can come to terms with dying. I think those two things were connected as well. Yeah and then I think Paul in particular, was very willing **[00:13:00]** to talk about it and enter into it and when he was first diagnosed with it about half an hour in his hospital room, he said, he told me I want you to remarry after I die and I was like, it's so shocking to have your person say that to you, coz it's the last thing you want and but I also think encapsulated in that statement, is "I love you and I'm thinking about you and I'm willing to say out loud what's actually happening, and I'm willing to go there." And it sort of broke open this hallway of communicating during that time of you know, we're not gonna push

any of it away. There's only one way through which is through and we're gonna do it together and that was just really solidifying and really helpful.

Frank: Yeah, beautiful. I mean we have this idea that we should direct people away from their suffering, that that's the whole role of **[00:14:00]** compassion, to remove people's suffering, it's not my experience that that so. My experience is that when I'm actually residing in a compassionate heart, truly is there, what happens is that people are willing to go towards something that feels absolutely dangerous for them. Not because it's all safe and tidy but because they're not alone in it, they're companioned in it, yeah. I mean in my own life, and two of them call, you know I've — my growth, my transformation doesn't happen in my comfort zone. It happens in the places, the edges of my life. And this is a time of edges, the time of dying is the time of edges. One of those edges is to figure out how do we deal with the grief of loss. I mean when someone is dying, they lose everything. They lose everybody and everything. Those of us who are left behind who are survivors, we also have to reckon with this grief. What surprised you most **[00:15:00]** in that grief?

Lucy: I made one sort of reflection on what you just said and something I believe is you're talking about suffering and how maybe we shouldn't alleviate our suffering. I kind of think we should alleviate everything we can, like physical pain and we've talked about that but I think there's so much we cannot alleviate and I think you know, dying and loss are the biggest ones. And I sort of don't feel like there's a purpose to those that I can see that's greater than the fact that we are connected to all other human beings through that pain, right?

Frank: It's kind of like a common ground.

Lucy: Yeah, it's like real common ground that we have and I think the things that we're kind of most surprising to me, one was that thing I eluded to about how to me my relationship with Paul and Paul is a person and even learning about Paul **[00:16:00]** has continued since he died, which is and some of that's through connections with our community, and then we talked about this, too, what the physical symptoms of grief were so shocking to me, I had a really severe tingling in my hands, just like I would look at my hands and they're like burning, on fire, and I would wake up in the middle of the night, my hands were on fire and I meanwhile had totally catastrophic thoughts about it, too. You know in this period of — I knew I feel sad, I dint realised how anxious I would feel and how my own identity would feel shattered at that time and I had all these catastrophic thoughts that like, I'm gonna be disabled and not be able to use my hands and then I can't take care of Cady, and then our whole lives are gonna be ruined and I think all of that in retrospect makes sense but at the time, I didn't understand why it was happening and I thought I had a disabling neurologic disease **[00:17:00]** coincidentally, right? After Paul died, and…

[Crowd Laughing]

Lucy: … and I think it was conversion disorder which is so interesting I think really was conversion disorder the way your psychological stress can play out in your body in these profound ways. So I think, and later actually I read this some beautiful poem about grief, I can't remember the reference but it's sort of a Elizabethan era poem or something and it says something like, "And my wrist were broken." It's a metaphor and I was like, that's me, my wrists were broken. You know?

Frank: Yeah. Yeah I mean it's curious to me that we had so many models about managing our grief. There's so much emphasis on getting over a grief. How come we don't talk about managing our joy or getting over our joy?

[Everybody Laughing]

Frank: I mean this is, as you said earlier, this is the human condition sort of flowing through our life.

Lucy: Yeah.

Frank: I think it's beautiful what you say about your wrists. I mean, I think one thing's we underestimate is **[00:18:00]** what a physical experience grief is. In all our models working with grief are all often cognitive. They're all about talking about the experience. You know when I was in the middle of the AIDS epidemic, we lost and take care — I had 20 or 30 friends die in a week. In a week! And it was devastating. And so I do a few things. I would go back to my meditation cushion to stabilise and then I go to my body worker and I walked into his office and he says, "Where should we touch today, Frank?" And I say, "Oh just here, just on my shoulder." And he put his hand on my shoulder and I would just weep for about an hour. And then I get up and I say, "I'll see you next week." And there was something about the physical contact and also the relational quality that allow that grief to come forward in a way and to be metabolized, to be included. The other thing I did was I used to go to one of the hospitals here to the maternity ward where there was some — my friends were taking care of babies who were born to addicted mothers and I would sit with these babies and I would just wrap **[00:19:00]** them for about an hour and there was something about being able to sooth their bodies that gave me a kind of resilience to go back into the belly of the beast, so to speak, the epidemic and take care of so many people. So those things were ways of looking after myself but also ways of metabolising this experience of constant loss. When we think of loss, it's this big thing that happens at the end of life, but we very rarely just talked about the everyday grief of our lives. You know? The not getting what we want or getting what we want and fear of losing it or not or getting something we don't want. This everyday grief of our life that often characterises the way in which we move to the world. So I think that dying has that possibility of showing us that this is here, right here, right now, you know? It's not just something that happens at the end of a long road. And so you know the beautiful thing about being in a room like this, to me, is that there's so many beautiful caregivers in the room and clinicians which there are **[00:20:00]** of course. It's that people have come here today for some reason. The whole world is running in the other direction but for some reason, we all came together today. Why? I don't know exactly but I think it's because we understand there's something here that the world needs. There's a wisdom of the dying process that the world needs and I really applaud you for coming and being willing to explore that. I think that's brilliant. Yeah, yeah. I wonder if we might in the last few minutes that we have, just talk a little bit about. One, how can we — how can us as healthcare clinicians, can we change the way in which we've been relating to this experience with dying. And how is your experience with Paul change the way in which you deal patients?

Lucy: **[00:21:00]** So I don't know if you saw last year about a year ago a study came out of Penn, that looked up Yelp reviews of hospitals, like what people say and when they're writing extemporary and usually on Yelp, and then they compared it to age gaps, the hospital quality measures, and they're super interesting that people generated — when they did a qualitative study in groups, I think, people generated 7 out of the 11 age gap measures… and then 12 other things that are not included at all in age gaps. And it was things like compassion, and thinking about family caregivers, and I think about that a lot, how in healthcare, there's like the medical piece of it and we all expect the medical care we receive to be high quality for whatever it is, but there's this whole other layer of the human piece of it which includes **[00:22:00]** a whole bunch of things we do for each other as human beings that are not at all measured. I remembered when I was 38 weeks pregnant, and Paul was a patient in the intensive care unit at Stanford, and he was getting really excellent technical care and it was

great and they were paying attention to all his organ systems and talking about them. And then meanwhile there's this whole side thing going on with the nurses about if she goes into labor while he's still a patient — the L&D nurses were talking to the ICU nurses — can the baby come in here? Can we wheel him over there? What can we do? And I was like, no one's getting paid to do this. No one's measuring if anybody's doing this but it's like by far the most important thing to our family right now. And so we think a lot about that. Like, what are the extra ways in which we're taking care of each other or acknowledging the tears that are in somebody's eyes or whatever and then how do we help people shape their care so it fits who they are, coz that's this whole **[00:23:00]** other question. And then I think a ton about the battle metaphor and how it's so simplistic and it doesn't contain what we do in healthcare and certainly toward the end-of-life idea that we'll fight it, we'll do this, we'll beat it. It doesn't tend to do us any favour and it robs us of this huge rich way to talk about what's actually happening, and to prevent trauma on the other side for the people who've survived and I think people in this room are really aware of that, as a sort of a one of the big moral questions of our time is "How do we do this kind of care better?" In a really human ways so, yeah, I think about those things.

Frank: You know, a few years ago, Lucy, I had a heart attack. And it resolve to a triple bypass surgery, it was an urgent situation and when I was in the recovery unit's room, I realised that everybody who came in the room, whether they were clinicians or my Buddhist friends, were all future oriented **[00:24:00]**. They'd asked me, "How are you today?" well, actually they didn't ask me how I was today, they asked me whether I had a bowel movement…

[Lucy Laughing]

[Crowd Laughing]

Frank: …and where my pain was in a scale of 1 to 10. And if I've been doing my breathing exercises. And when they asked me, you know, "How you doing today?" I'd say, "Miserable." And they'd say, "Well, you'll be better tomorrow." And tomorrow wasn't today. And so sometimes in situations like this, we have a kind of fix-it mentality. We have a protocol procedure for everything. And but it's very difficult to stay present in such environment. You know I liken it to you know when you were a nurse, as we have nurses in the audience, you help someone move from the bed to the commode. And to do that you lend them your back and you lend them the strength of your arms and legs. I think we can also lend people the stability of our minds. And I think we can open our hearts in such a way that it might inspire them to open theirs, too. Yeah **[00:25:00]**? So I think instead of just being problem solvers, we can be portals. We can be portals to another opportunity. And I think that's equally our work in healthcare, is to be portals to another possibility, particularly around the time of dying.

Lucy: I love it. It's like that phrase, "Don't just sit there, do something." And it's the opposite, right?

Frank: Yeah.

Lucy: Don't just do something, sit there.

[Frank Giggling]

[Crowd Laughing]

Frank: Yeah, and ask people simply what's important now. You know, what's important now? What do you need now? I think those are the really simple questions that can really help us as

caregivers; to meet in the middle with people and to really regard the person in the bed as much not just as person-centered care or relationship-centered care but to really view the person in the bed as a teacher. I think this is a respectful way, you have to go through this process with someone.

Lucy: Yeah, and I think also **[00:26:00]** if the person in the bed is dying, they're not only dying, they're also living, right?

Frank: Yeah.

Lucy: Like…

Frank: Dying is just what's happening to me, it isn't who I am. Hey our time is up.

Lucy: Yeah, too bad. [Laughing]

Frank: We could go on for another couple of hours if you like.

[Crowd Applauding]

Lucy: Yeah, thanks.

Frank: Thank you very much.

End of Transcript