Speaker 1 ([00:00](https://www.rev.com/transcript-editor/shared/QhsiE-Zzt_AHE8fr0Cjs45iim22iMGUeLFhMJNSy6a7dk0AJatJVIPeoKxxLWIQ7uhZEeBjFq0E28GimJScPe1cevII?loadFrom=DocumentDeeplink&ts=0.78)):

Hi everyone, and welcome to this episode of Ask a Death Doula. Remember that November is family caregiver month and we know that 80 to 90% of a positive end of life depends on two things. Knowing how to care for someone at the end of life that you love and planning ahead, and both of those Doula Givers Institute is offering to you for free. So please make sure to go to doula givers.com or you can go to the link in the show notes and download the free downloadable level one family caregiver end of life doula training. And you can get the Nine Choice, the Good Death Advanced Directive by doula givers. Do that now and 80 to 90% have a better positive end of life with those you love. Hi everyone, and welcome to this episode of Ask a Death Doula. My name's Susan O'Brien. Today we have Sylvia Cohen, and again, it's caregiver month and there is nothing that's more important than supporting patients and families with all of the care and education and kindness that they need to have a positive aging and end of life experience.

([01:07](https://www.rev.com/transcript-editor/shared/J6EPycfFhuuxMK89d5msWi67t39coZHyzjfaDQf14fTgLE2eZHGPhau3UoiAswkYoLO67aTPUyDcj2FMkvMrz-j0law?loadFrom=DocumentDeeplink&ts=67.98)):

We only have one opportunity to have that go well, and right now there are major, major gaps in our healthcare system. So in order to change that, we've developed so many resources and training and I have this beautiful woman on here today because she has touched my heart so many times with her passion, with her own personal story, sharing her own personal story with her, both of her parents, how we can have those as teachable moments, what do we need to know and do to not have that be the way that other people experience end of life. So Sylvia, I want to thank you so much for being here on this episode.

Speaker 2 ([01:46](https://www.rev.com/transcript-editor/shared/k1NjrPQ13reQGe6e4pmUnUWkaZ4N_eRtIsOQ0RGsO2VaF4wGOwc2s3rvOqeBJHCzinuq71aWDnxhytS3b1qL9cPBjnw?loadFrom=DocumentDeeplink&ts=106.95)):

Thank you. Thank you very much.

Speaker 1 ([01:49](https://www.rev.com/transcript-editor/shared/uD0BTRBarikoDo7v7-dVA1s6gr5V_R-Q8ZogaG2nXkkNmAjb1dR6UibqLV5UldahXyrp-tlobTRvHUce0yOKQ8pAXYQ?loadFrom=DocumentDeeplink&ts=109.5)):

You're welcome. So you're joining us, and I have to say that as we were talking about doing this episode, I was focusing on a story that you have shared about your mom, and I also then said to you, is there anything else that you feel is important to share in this episode? And you said, yeah, you said, I want to share about my dad's end of life in the hospital. So two very different scenarios and scenes, and they both, I'm so sorry and my love goes out to you and your family sounded extremely challenging and traumatic. So if I may, which do you want to start with? Do

Speaker 2 ([02:29](https://www.rev.com/transcript-editor/shared/GfP5jt2F6ziqrFY-1n_PpEttbZEUXmYhDdh5LySaC5a5jiPT46TKjCd-71Va1Daubuq42Ovdb907guAchbeE4Xxu8zM?loadFrom=DocumentDeeplink&ts=149.82)):

You want, I'll talk about my dad. He passed away about 10 years ago in a hospital. So my father's been on dialysis for quite some time and one day he was being picked up by his dialysis, this organization, I believe it's called La Vida.

([02:54](https://www.rev.com/transcript-editor/shared/1Bh2Vq4r-QJH1MGQxmv9JIoXYLXMaKyZhrWSDaoybwF9yOULE_8Ex1YS3rolmevf0FbZC8JsCUkaqvCQDx-0wyxAFuE?loadFrom=DocumentDeeplink&ts=174.3)):

Anyhow, they came to the house to pick him up and my father have passed out in front of our house and then my brother called 9 1 1 and also trying to apply CPR. And by the time that they brought him to the emergency room, the lack of oxygen that going into his system have put him into a coma. So when my father was hospitalized, they put him in ICU, but because we're Asian and we never really believe in the advanced directive, which is I find that the most important because then you know exactly what his wishes are. But because he didn't have one, we're kind of looking at each other. Well, my mother looking for my mom to kind of guide us, what do you think that we should do? My mother at that time was a basket case and she says she doesn't know, they never talk about it.

([04:06](https://www.rev.com/transcript-editor/shared/_vwsiEa25SWDZLNJNZTTxKiOQViVCkJxu5DU2FcqukIQOOwfvjUhGYTMxQ-DyjAsHUpyzCFfwpJupzm7hqgUnpP9TnU?loadFrom=DocumentDeeplink&ts=246.83)):

So it left my older brother to take care of the whole situation. And my brother, mind you, he's a physician, he's a doctor. And I came from a family where everybody is in the medical field. I have a sister, my oldest sister, she is a oncology nurse and a chemotherapy nurse for 35 years. And then me and then I have two younger sister. One is a social worker and then the other sister, she got a double degree in pharmacy and chemistry and she worked for the National Cancer Research. So she's a researcher, so very highly educated family. But when it comes to that death, we know nothing. We know nothing. And my father ended up having a major dispute with, well, my brother have a dispute with my uncle because of religious, my uncle's Catholic, he doesn't really believe in removing him off of life support.

([05:21](https://www.rev.com/transcript-editor/shared/14NP_mZX_MOKJNtXFsfqAcyJ7JFJJeAdeK7UW5lfWEGA14zajVLeZCgztgNdKzA4T1-nIzvfH3MF4LRGF2ls0lYAXBY?loadFrom=DocumentDeeplink&ts=321.61)):

So in the meantime, the family's having this massive dispute in the hospital when in turns we are supposed to pay attention to my father. So the family are arriving from everywhere, coming to visit and hoping that he'll come out of his coma. But after a couple of doctors confirm, pretty much it's time to make that decision to let, and my mom just couldn't really handle it. So my mother have left the hospital and left it for the five kids to handle it. So my brother told the doctor that we decided to remove him from life support, but because my uncle is disputing it, they have to have agreement from everybody. That's what we were told by the hospital. So my brother have to talk to my uncle to convince him that yes, that's what my father would want. So after four days of the whole family in ICU disputing and arguing, and they finally agreed that to let my father go. So that was the first hurdle that we have to go through. So then all the family member can really agree with each other on the same page. And now we thought by watching TV, once you take him off of life support and everything is done. Well, I tell you something, it is not done.

([07:19](https://www.rev.com/transcript-editor/shared/g5GJ0xalDqAyksyOa5EXDumAEAizvxIOko0nuplKJv1M6wxqpoXgqg_QaYgfrqd3g-XN_VzTapgErtntf46D0WRVquc?loadFrom=DocumentDeeplink&ts=439.73)):

All five kids were in the ICU room waiting for my father to pass. And 10 years ago, I can still remember now, sorry, my voice is a little shaky right now just talking about it, that his breathing and he was hemorrhaging from his nose all cavities, and it was what a horrific scene for us to witness. And in the meantime the nurse come in but didn't say anything. She find it. I looked at her asking her, is this normal? And she said, yeah, it is normal, but I think she's very uncomfortable. So she left and just the five of us just waiting for him to pass, it took three and a half hours for him to finally stop breathing and pronounce to call the time of death. But in the meantime, he was hemorrhaging everywhere. So my sister, she said, yeah, I'm an oncology nurse, but my patient, I don't think she was equipped to deal with her own father. And she was just a mess. She said, okay, you're going to have to help me. She gave me this suction apparatus thing that you suction out his mucus, but it was the most horrific three and a half hours that we went through in the ICU room.

Speaker 1 ([09:05](https://www.rev.com/transcript-editor/shared/dpP5whJpvSbM7KZuo_vKSn5TXeJYLfWovKoXST_kEmjJLSkbPx7ehjLnD17AZEkyoHAm6g5_Kr7X1uVUKpx7Py6UtaM?loadFrom=DocumentDeeplink&ts=545.07)):

Okay, let's hold the space here and really just bring a lot of love into this because this is honestly such an traumatic story and the shocker here. So there's a lot of pearls here that we need to talk about. One of the things that's completely shocking too is that you were in a hospital in the ICU, you got no guidance, no education, no support of what that would look like. You have a lot of medical professionals in your family that really didn't know this specific area. What this looks like, and I want to emphasize that even as an oncology nurse, you might not know what it looks like for somebody to be taken off life support and how everybody shuts down from that. And then again, it is your loved one, your father. So it's a very different level. So I want to start with saying that your father didn't feel any of that.

([09:57](https://www.rev.com/transcript-editor/shared/JTyfKGHiOJqKvMjXo7rpLYyXGbOfZo2iDrOMM2itNPAHLZVCte5DSPSzLoqtmc8H1fBUu9n_p8kt2zOEL6O9fwR56Z8?loadFrom=DocumentDeeplink&ts=597.69)):

So there's a lot of sounds and there's a lot of things that go on that look like somebody could be suffering, they're not. But that doesn't excuse how intense that time period is. But I wish you would have been educated and supported in that the fact that your nurse was uncomfortable, and this is not uncommon, is that people don't want to talk about that space so that medical practitioners, which are the ones that are supposed to be educating you, skirt it and disappear from the room. And this is leaving wounds and scars on people and families. So I have to say that we have to do a better job of all of this education across the board with supporting our medical teams and supporting families. Let's go back to the very beginning of this and talk about that your dad didn't have an advanced directive, that it's not something that's commonly done.

([10:51](https://www.rev.com/transcript-editor/shared/IMcf0JAgqehTbyvBboDJe4pblMipzxEXvZfxR4IIZQSOgyrJxYqf3hRxF63tPiHFEMpfJRA0dfSEdZKUxFyCRu1RIks?loadFrom=DocumentDeeplink&ts=651.66)):

Like you said, that they don't do that and that your mom didn't know what he would want or not want and that the family had to be around the ICU bed arguing and trying to figure this out. And I will tell you, Sylvia, if it's any consolation or comfort that I've worked with so many families and there's only been two that didn't have a plan and agreed unanimously, so you're always going to have that one family member that has a lot of fear and is just, but that's not the time. It's not around the bed and in ICU to argue and to try and figure this out. It's so important that we ourselves think about what we would want or not want to make sure our loved ones know that it's one of the greatest gifts you can give your loved ones. So again, this conversation at education is so important.

([11:37](https://www.rev.com/transcript-editor/shared/MLRcF8l5QaBDIOQp8swQi73qj0Pb_6E0pq-4XeglqtpT61v3lOT3X7r197ZN6iwr1TYh8AIaISiQ-uy-ZxXxbqMDs7o?loadFrom=DocumentDeeplink&ts=697.14)):

So here you are having all that energy in those couple of days deciding, okay, we've got everyone on board, we're going to take the breathing tube out, which by the way is so much harder than deciding to put it in. I just want everyone to know that. And then it's shocking to me, even though I am sure it's more common procedure, is that people aren't educated in what that's going to look like. But you need to know what that's going to look like. You're around the bedside and it can look really rough. My heart goes out to you and your family, and I hope that you have at this point realized and found that that was just the body kind of going through its final steps. But your father was so far removed from feeling any of that. Yes. That he wasn't suffering.

Speaker 2 ([12:23](https://www.rev.com/transcript-editor/shared/x1o6Myyr_bZB9q8VXZtgkCbzXVCLmiQZEwJWo1KvhhI4tkuDxJrQb_937vQJ24yhAP06_28FUbvJOQEB8-Gj4Ki-6QQ?loadFrom=DocumentDeeplink&ts=743.98)):

I mean,

Speaker 1 ([12:24](https://www.rev.com/transcript-editor/shared/e0kXGswaf0m5dBTCO3kmKDt_RQhBtAcJAQ6elDgTuTDX2x3JWHOVeARjlb77XE2jJufb4R6V2CK34XixX31nHsnaPKs?loadFrom=DocumentDeeplink&ts=744.91)):

Doesn't diminish what you went through at all.

Speaker 2 ([12:28](https://www.rev.com/transcript-editor/shared/JVsTAQY2twqJQ-jb5pS4nTJlWPchaFuPTysw1YuANwZ44gz-1YWrh7rnBu1wyUfEHowehZ4CpSJd8aQJuNx3cTHGO2s?loadFrom=DocumentDeeplink&ts=748.21)):

Thank you for that. Now I know

Speaker 1 ([12:30](https://www.rev.com/transcript-editor/shared/BhendeGL8MDDfUPz1KwDK8kZbjpEfcUf5a6SWI4nYUfPXB5n_Qw9r7C75GDPXMqubKuW5k2fdGfH9I74NHRzvEGbFps?loadFrom=DocumentDeeplink&ts=750.91)):

Of course,

Speaker 2 ([12:31](https://www.rev.com/transcript-editor/shared/as4jeKuQY5CeudkQXZ-8Hq1RoZFnHki0dHmqr0p3AQnndRSH-6P29DspLZ_NoMNTvLrCU8aBdTH2vY8J4qeCmSnjeIA?loadFrom=DocumentDeeplink&ts=751.18)):

But it was tough because I think that the hospital need to also be educated because we living in a country that is kind of like, it's like a melting pot. We have so many different ethnicity and cultures and religions. I don't think the nurse was really equipped to deal with our ethnicity, although we live in a very populated Asian community, which I'm very surprised that she's so uncomfortable and I can feel it because she's not sure what's going on and a different language being spoken. So she feel uncomfortable and I can see it written all over her face,

Speaker 1 ([13:26](https://www.rev.com/transcript-editor/shared/paQsy9YRjSZkXdQVGJ2mcbmlihb-kOTz3VZ9AQxCUG8zz36lemrZ_X3CWYCKXtsEgMrteSWJbOYKagE9i3eixQ9NkyQ?loadFrom=DocumentDeeplink&ts=806.17)):

But

Speaker 2 ([13:27](https://www.rev.com/transcript-editor/shared/4-FB4SxGar6fPwuSE_idkqnruHmSTwVBf30-Fay0AWHPlLTQH0_HyCQL8JrFnCjnrDGRLgz-uMC4V85M1gJjXCGMJyg?loadFrom=DocumentDeeplink&ts=807.07)):

I was expecting for her to come in and kind of take over the suction and kind of show us, but she didn't. She just came in and just look around and just asked to see we okay. I mean she asked, but she didn't offer any help, which is I find that kind of really strange. You come in, you ask, we're doing okay, and then you left.

Speaker 1 ([13:55](https://www.rev.com/transcript-editor/shared/MJjIwXpkQAcTuufNcIC-L4yq2M7E9634rXIvndR-e5ixEEw2Pd4sNBzIBaeRpiWymZc-Ojx61VtcXKDJRIECCDM4pY8?loadFrom=DocumentDeeplink&ts=835.27)):

It's very strange. It's

Speaker 2 ([13:57](https://www.rev.com/transcript-editor/shared/YfwU2ojeJGWwl9_p_4JCncpJn60fdGRQOPE3XpDI9h7Bt24W3ufTvzWRiZhCSuLdQQzAZBdERbcImIkSXxdY1XGPa1s?loadFrom=DocumentDeeplink&ts=837.85)):

Very

Speaker 1 ([13:58](https://www.rev.com/transcript-editor/shared/2TzqbG9pam3KWyE748QY9S67o7aU0OG2wm1Ao3i5wQdL2PlqfFPpxoVHO4Dwi7RI0hYRaZHXCob4qqWYQrWUVyiqsug?loadFrom=DocumentDeeplink&ts=838.21)):

Strange. Yeah. So at the end of the day, this is what I want to say, that we do have this beautiful melting pot of a world and we have different belief systems and it's for us as medical practitioners and those that are in this space to support you in your journey with upholding what your belief systems are and what's going on here. But at the end of the day, there's that practical humanity and human part of life that just sharing with you what to expect, letting us explore option. Telling you about again, the empowering things in this moment that somebody's intubated. And I'm sure your brother, it sounds like he did a beautiful job at this is the reality of that. Your dad is not able to ever get back to the quality of life that he was before. And that's a big indicator. And so I'm very sorry you had that experience at the ICU.

([14:51](https://www.rev.com/transcript-editor/shared/woxdAWhmrOz1DRT1eT8UXmkkfZgdnRPK1UHvz_1KLqjezy-P75DeeZ1txDL63-fqyZ2XundorUyFgt-ysgpEczQ35dE?loadFrom=DocumentDeeplink&ts=891.29)):

I really hope that that is not typical, but I have a feeling that because we have such a struggling medical system, but we need to educate everyone. So we need to again, educate our, just like you said in different cultural beliefs or even if I didn't know anything about Asian and belief system, what would be the thing that I could do? I could say, how can I support you? Can you share with me what your belief system is and how is all of your family members doing? And then you would say, my uncle is actually a little different and it's causing, and then I can bring in whatever I can bring in from my practical nursing standpoint to support your family in that especially, and I just want to highlight this, that when end of life and even home end of life, sometimes people, again, there's those labor breathings and the mouth hanging open and it doesn't always look so comfortable when they're actively dying.

([15:44](https://www.rev.com/transcript-editor/shared/zKlh_-sJmHMqRS2XPnoK3JukwHLmNgo3LFo2BWrEYyvsrIgRD8pgmX8keW1LY4RkQYnNu-Dc9NkTRllMbiQN452GXmY?loadFrom=DocumentDeeplink&ts=944.37)):

But just sharing with families what you're seeing is a natural part of the end of life process. Your loved one is not suffering, do not be afraid. This is what we can do to try and reposition that alone is what's missing in the world. And so there's so much fear and trauma attached to end of life. So my love to you and your family around this, and I hope that it was 10 years ago, but I know that things like this are branded in our memory banks and you shared that. And it's something that none of us should have to really ever go through. And it has to change. And it has to change now because every single family is going to go through an end of life with those that they love and it can go really well when we all get on the same page about how death is not a medical experience, it's human, and here's the things that we can do and here's the things that it teaches us.

([16:35](https://www.rev.com/transcript-editor/shared/lDswBjxXuI9_ZRonEQPoQDnhhfaAhehwlf5hdit1zFD4CPiAG-yxvwfcE7I3d7us_8j6fdDI0mxrvk8mYexae60syCU?loadFrom=DocumentDeeplink&ts=995.69)):

So I hope that you and your family are in a better place from that. And I know that I really feel that our personal experiences like this kind of catapult us into our purpose in life and really finding how we can, and we're going to talk about what you're doing now a bit, but I also really want to credit your dad and some of those life lessons that you really can't get anywhere else for propelling us forward into helping make the world a better place. So that was your dad and that was in the hospital. So a lot of people under the assumption, they're under the assumption that if somebody's in the hospital, it's going to go great. The hospital's got it. And that's not always the case. So yeah, because

Speaker 2 ([17:20](https://www.rev.com/transcript-editor/shared/Cc8MV7uAaj_bzapHhWWETmY9N7LeeTHPh29tYIZ7sCC980cHKxGVsCYKqzdlbUBFbNWlxXSF2ZQfL4HY6xyokpMcRT0?loadFrom=DocumentDeeplink&ts=1040.21)):

In the hospital, I'm on module 11 on my course, and you talk about spending time with your loved one and not rush it, but in the hospital it was such a rush because I think they're like, well, we need to clean up this room because we have the next patient coming in. And I remember we went to grab a little something to eat because we haven't eaten since midnight. I mean the whole family was pretty much hanging around the hospital. So we figured we'll go downstairs to get a little bite at a cafeteria. We came back, he was gone.

Speaker 1 ([18:09](https://www.rev.com/transcript-editor/shared/pxXT1Xfuw0rt0O6NEMB40WgwDCWJOzhABKwIiiSv2Hyuqig5Aq-ikKRsatEFu-w6rmjAaaxRN7Fqx9DzH1_IvHPiKdU?loadFrom=DocumentDeeplink&ts=1089.03)):

I

Speaker 2 ([18:09](https://www.rev.com/transcript-editor/shared/EwnEvXtoAF9LLJ0vMkNKjWCTY0EGzj3riPjSqxp-Jdetijesb01xvaKCWGdLdrqN_pa7R0VOPNgsgUgCOGvt0s3aqrU?loadFrom=DocumentDeeplink&ts=1089.21)):

Was just like, what did you do to my father? We came back and he was gone. They took him down to the morgue I suppose, but everything was so fast that we didn't have time.

Speaker 1 ([18:23](https://www.rev.com/transcript-editor/shared/QqDyffTsVtSwa4RaBThW-aSqC3ujaLnWgS-ryVQfggHoUnjMXvfv_lVFfxZ5ZwfhDrJvZKF03DNGk9fl2bVtn3SCCFc?loadFrom=DocumentDeeplink&ts=1103.28)):

End of life on all levels has got, we've got to change it. We've got to change it. We've got to slow down. We've got to bring back the awareness that it's a guaranteed sacred part of the life journey. And these are the things that we have that we want to think about. And one of the biggest things is slowing down that space, even if it's something that's unexpected in the hospital, it's such a very important time period for you and your family. So again, my heart goes out to you and your loved ones for that experience, and I thank you for sharing it with all of us. This is how we can make positive change.

Speaker 2 ([19:00](https://www.rev.com/transcript-editor/shared/EeGfpSA47Usj9FAJOougBYOktd6Y8Vg3gqBD3TX-lgovPUd8Bl1_3O6FV5tLO5E1UliammDD-_SaWnK1KMZUPY1VHLs?loadFrom=DocumentDeeplink&ts=1140.9)):

So that was my father. Now, my mom just passed away this November 20th will be a year, exactly a year. My mother suffered from MDS and my sister because of everybody's medical experiences and very on top notch. My sister was able to find all the clinical trial

Speaker 1 ([19:27](https://www.rev.com/transcript-editor/shared/nzjiJ_bArnitU_yK4RRdJC9EytpCJrmw-o5U128ZOIyc0d9S7-tupImzSiOFusvow7nugB0Ob23VsPoEl5FmbLLs2yI?loadFrom=DocumentDeeplink&ts=1167.09)):

For

Speaker 2 ([19:27](https://www.rev.com/transcript-editor/shared/WFkfOFlBzcavylMrhACD9dSqDmNa4Njbo9dXJMEqfKZz00q1_iXGlNAtA3uRqD0bFgNhwnYdmBpfG7nkrHCjMLyD9vQ?loadFrom=DocumentDeeplink&ts=1167.24)):

My mom to go through, but her body was failing and nothing works. That's the bottom line. There's no cure for that. So eventually we decided actually her oncologist, he was excellent. He called for a family zoom meeting because I live in Texas, they all live in California. So we had a zoom meeting, a family meeting, and he just going around asking all the children, what do you think your mom would want? Because your mother didn't have again, the advanced directive. I know.

Speaker 1 ([20:04](https://www.rev.com/transcript-editor/shared/TsOHGUFr5QzSXogSEn6KmSt3eqj-ZyFM2sNHOI8oSyEIXL-EG4fLl90fpyam86rpdV3iOGU7W61tUIJ5S338kah8sZU?loadFrom=DocumentDeeplink&ts=1204.5)):

I want everyone to thought, I just want everyone to hear that. Okay, go ahead.

Speaker 2 ([20:09](https://www.rev.com/transcript-editor/shared/JrwIjjSAkvaeDFd4Ic332I1bDNYxTVmYgBX6FVDH51zEJtQmpeWYJHGGJBAWEFChrNR3rgnURLROBsf05D26X3paiAY?loadFrom=DocumentDeeplink&ts=1209.33)):

We thought we learned 10 years ago with my dad, and now comes my mom. As my mom was getting sicker and sicker, I keep asking her, mom, you need to get this done. And she said, well, in our culture and our belief, once you put it on paper, it's almost kind of like a curse. That mean I'm going to die soon. I go, mom, that's not true. You need to get this done. But she refused to get it done. So now we coming to that whole predicament again, having to make decision for her. So my brother is very close to my mom, very close, and he said, I don't believe she's ready. And then my oldest sister and I and my youngest agree that yes, it is time because her quality of life is diminishing and taking her to the hospital now she's needed her transfusion. It's not once every three weeks now it go down to once every few days and getting her out of bed, that's a huge thing for her. And I guess I'm the only one who kind of speak on her behalf. I said, no, you need to stop this. It's time. This is not what she wanted.

Speaker 1 ([21:39](https://www.rev.com/transcript-editor/shared/qUFi7_Kjj22vLFPPyKg13yAY-bR6ABSYLP3vnkecPYXzTu-nOAk8WyB0sO8MbW03OhYtall-VQcTZgrIjJpvwGx35_k?loadFrom=DocumentDeeplink&ts=1299.34)):

And I want people to hear what you just said about quality of life because I want us to know that that's your benchmark everyone, and it's going to be unique to each person. But when quality of life is not there for you or someone you love, and I want to speak as a medical practitioner, as a nurse, we take an oath to do no harm. There is a very fine line at a certain part where we become not helpful, but sometimes harmful when people are going through treatments and we're expecting them and dragging them to the hospital and it's not going to reverse their process and it exhausts them and sometimes it causes them pain. So again, if you can please think in terms of a benchmark for yourself of quality of life and when you would want to be fully supported with comfort care with eating ice cream all day, if that's what you want. It doesn't have to be always attached to a negative thing at all. More so an empowering thing. But you did say quality of life and I love that. And that your mom had not chosen herself and you could see that she didn't have quality of life. And you said,

Speaker 2 ([22:44](https://www.rev.com/transcript-editor/shared/VYTRCX63GD6xAfJXVn3eM7jwruL7hd8_USWziDDs0CgcdPmSO61x-lsyLtN6oymQMKmdBEyFDUiJfUpQ3iSMA5OFgk4?loadFrom=DocumentDeeplink&ts=1364.44)):

Exactly,

Speaker 1 ([22:45](https://www.rev.com/transcript-editor/shared/txyyhRPGWGZH3lWp9RgZymKAYtSDEUelpK_LOnHrRq5vocdlHc_QeVlUQKTvYVRgJ2b3_X1x951Um55Lw5T0JSF8e8k?loadFrom=DocumentDeeplink&ts=1365.34)):

This needs to stop.

Speaker 2 ([22:46](https://www.rev.com/transcript-editor/shared/RZrg0q2Gu307slO3TBGTMnj6b5iYY6ptV-PJ7yJ4Beg1iKMlHL70lkbpBDA2TbKo4xhSVycsqOIxG-mnSS9eeRM_mYQ?loadFrom=DocumentDeeplink&ts=1366.36)):

She can't really follow any conversation on top of it. My mother have dementia.

Speaker 1 ([22:53](https://www.rev.com/transcript-editor/shared/1HCbfQzAY5n8TYGYRTiHnh7pyJZNkjzndW069AAGICl4kVhsuqzjtB3REZ7xOC14IVgAgkQrSWG6iKvjjtuESV-Y9aI?loadFrom=DocumentDeeplink&ts=1373.41)):

Okay.

Speaker 2 ([22:54](https://www.rev.com/transcript-editor/shared/8kJzNUJotImQAhyfmMCf0lGEIelHU5wLbIa98MmbujA1Ce5G0fSsEHqLsT3NpZ-6wy8WuX0X3ljecBaCarbav00wClg?loadFrom=DocumentDeeplink&ts=1374.01)):

She has early stage of dementia, so she'll be talking and then she'll looked at me and Who are you again? So she doesn't remember things that we talk about sometimes. She mistaking me for my other sister, so it's very confusing for her. And I noticed she's complaining about pain, and I'm not sure where the pain's coming from, but once we decided to put on hospice, we all agree. And my brother said he's going to go find a hospice. And I said, okay.

([23:34](https://www.rev.com/transcript-editor/shared/xNRewLYfECYmEx_0YKxu_Ezp8GJhIeFowLxyi-Ze9xq9VbhaAQ8Cpn6eWY77zQZohePvILLJRggoCd-202-5DkA75qY?loadFrom=DocumentDeeplink&ts=1414.75)):

But we didn't realize the hospice that my brother put her on allowing her to continue getting transfusion as needed. So I didn't get that. So I kind of questioned my sister, who's the oncology nurse. I said, well, I thought hospice, once you go into hospice is that you're not going to continue your care. You're just going to let your body go naturally. And eventually you're going to go through that whole dying process. Correct. But she said, well, my brother's not quite ready to say goodbye to my mom. So he wanted to find a hospice that kind of worked with him to allow her to continue her transfusion. Well, ended up, she didn't get any transfusion. They couldn't even get her out of bed,

Speaker 1 ([24:33](https://www.rev.com/transcript-editor/shared/dWZgqTf6_M1I8nHt7-s__9reGZTBEA2KHD6gyUMeuLSpNQ-DwHJDY0VBwIhlrSX51n1idH0Ae6wllix0B_ZzKfSrrNg?loadFrom=DocumentDeeplink&ts=1473.62)):

I'm sure.

Speaker 2 ([24:34](https://www.rev.com/transcript-editor/shared/Wf4kCE7F-B7KQGO2m7VbM_gPKCxOTIQqo6yFTGkmRm8MRswu3Fcpseb3OYnhvvl2J_F0D7SQDWqKX-CCQ2xyZbsfGfU?loadFrom=DocumentDeeplink&ts=1474.49)):

So she saw that. But we already signed on with the hospice. This particular one, I didn't know that we can change hospice. I thought once we sign up with one, we are just going to have to stick with that organization. So my little voice tell me this is not the right hospice for her. But because I live out of states, my mother lived with my brother, I kind of held back. I didn't say anything. I'm just going to go along with it. And I rush home. I drive home. The minute they decided to put her on hospice, I went back to California. I was able to spend three weeks with her before she actually passed away.

Speaker 1 ([25:19](https://www.rev.com/transcript-editor/shared/8-zur3ZBkGnzaBQWbw-N2nkPpMdQ27RKfM1p6AXRUFIh9boFHdsKCsnE8Y5_9p3u6SedwNvqvJ08Bl5CAlrQH-6CF0U?loadFrom=DocumentDeeplink&ts=1519.19)):

Beautiful, beautiful.

Speaker 2 ([25:22](https://www.rev.com/transcript-editor/shared/cCFECBDvEfimcaoO4452OqFWtM5VVBZOFXFcFQXYnruPMx3vU7uCNVLoiD9Am7iDAd0fP5Tj3_DZchy8PpwATDC63ac?loadFrom=DocumentDeeplink&ts=1522.67)):

But because again, she doesn't have advanced directive. Everything is all dependent on my brother and my brother loves my mom. The emotion was just so he's a mess. So he couldn't really make proper decisions even towards the end, how much morphine to give her. And he said, if you give her the morphine, then she's not going to be able, she's going to slip away. And I said, well, yeah, that's what dying process is. And I think she needed the morphine because she has UTI on top of it, and she was so uncomfortable. She's moving all the time and her legs is always up and we keep putting it down.

Speaker 1 ([26:09](https://www.rev.com/transcript-editor/shared/7MDMIb16Sr_zt2csT2cV2rsjGLOmHFxViD-yTMylOveoraCu_7rpCWz4TEHl-imXcR1a_0wI2uixPFrMobIkcuNt1bg?loadFrom=DocumentDeeplink&ts=1569.77)):

Oh, Sylvia. Sylvia, let me ask you a couple of questions if I may. So your mom is now in California on hospice, living in your brother's home, right?

Speaker 2 ([26:18](https://www.rev.com/transcript-editor/shared/EpZYPvqZsav6cO28A-g9hT28usi2v56l2uUV3Roxn645J5gr5JtlZJVGBo9GZUqBOSRLZ3z93e7PMAvYA_I6qRF8gAE?loadFrom=DocumentDeeplink&ts=1578.08)):

Yes.

Speaker 1 ([26:19](https://www.rev.com/transcript-editor/shared/_T-zwFGSqqO2H1ui4_Ywwwdb2AsD-HPzPtg7vY8uba9bVvOFbTFCDBDlw4_251tvVqAz32tzoX8uLAZf_B2dqsiBEqo?loadFrom=DocumentDeeplink&ts=1579.46)):

Didn't the hospice team come in and educate all of you on pain management? No. No. Can you tell me about what your experience was with hospice to your best of your ability? Because they really should be educating your brother and making sure they're assessing your mom for pain. How did that get slipped?

Speaker 2 ([26:38](https://www.rev.com/transcript-editor/shared/TyhYbODsPE05Owl9G57Jfd1bgdv4pMSjf-ZPeBJl7E5lPvVnpV04bA4GHtOdzjwr1HOpN8y4nYxN-okTck3zOrwJiFY?loadFrom=DocumentDeeplink&ts=1598.99)):

So the nurse came out, I believe, because my younger sister, she worked from home, so she is my mom's main caregiver. So the nurse spoke to her only because she's the main caregiver and the rest of us, we don't know what's happening. And I think because she assumed that we are in a medical field, we know what to do. So she kind of go over it briefly with my sister. So when the time come, and I said to my sister, I go, she give you any medication to give it to mom? And she said, yes. And I go, well, why aren't we giving it to her? She doesn't look like she's comfortable. She's moving, she's restless. There got to be something that they

Speaker 1 ([27:27](https://www.rev.com/transcript-editor/shared/tle6CVPTBV7WLlUku6YBayAa_YgZxxJQc_MzzTA2Z8by4cPv7gD9Q0lBTyLbqpt6oPXVU6f199V45pMfz-s74MXw_3c?loadFrom=DocumentDeeplink&ts=1647.15)):

Of course

Speaker 2 ([27:28](https://www.rev.com/transcript-editor/shared/sl_lJA3YG0iIe4MncYjUwJPhVBi4lHMt0v0ze5SC3c43_CW43S2nn3F0txZk9dJKeF0sJ489SwiQsPfGM-nKH4eYEGo?loadFrom=DocumentDeeplink&ts=1648.5)):

Give us to give it to her. So my sister started to give her, I believe it was the Ativan giving her that. And she still very, it makes her even more anxious.

Speaker 1 ([27:41](https://www.rev.com/transcript-editor/shared/zkLmlKTP9oekL3bAgeCg00Njrw1qwvuzjlAs7urx4fuG-Yrp1cPbvs7hwS6j9lypsdf_bhDf6uSadbL0CUQZOGSKpPY?loadFrom=DocumentDeeplink&ts=1661.79)):

She's

Speaker 2 ([27:42](https://www.rev.com/transcript-editor/shared/0Ihv9GzAVsfGdeWmt4ERbA8P6cFbO26iopL5aYz50bAu6mdD5K4TYaic3q4BqXoI3-i-wA-YG-Fb0sauicsT8mLBWCg?loadFrom=DocumentDeeplink&ts=1662.03)):

Moving a lot. And I wanted her to put the railing on the side of because I was afraid that she might because her moving around so much. And my sister said she doesn't like it because she's so used to be able, my sister's bed is right next to my mom's bed. So my mom was able to see her, and my mom would have this panic look when she didn't see my sister. But anyhow, when the time comes to give her the liquid morphine, that's what I figure it out now in class, that's what my sister gave it to her on the cheek, on the side of her cheek. But I don't think we increase the dosage because we're not sure how much to give her. And she's so terrified of killing her by mistake. And then you have to write it down how much you've given her. And I keep asking her go, what is too much? And what is the level? I mean, how do we know?

Speaker 1 ([28:52](https://www.rev.com/transcript-editor/shared/A8INNmxx6AjH7uJcUQly5EOr-YbNbTJBaLC_Ee5XaAeJgPAouiUJa9pxSl8R_69bw9atvzUiSZYk_ttUp4GQZnnq1b4?loadFrom=DocumentDeeplink&ts=1732.5)):

We know that a hundred percent end of life is guaranteed not only for us, but for those we love. We also know that 80 to 90% of a positive end of life can be achieved no matter what the disease process is. With these two things, having the basic skills of understanding how to care for someone we love at the end of life, which 98% of the care falls on the family caregiver. And number two, planning ahead, choosing what we would want or not want for end of life care. And both of those are available to you right now for free. Go to the show notes right now and you can download the nine choices document and you can have on download the level one training. We want everyone to have the resources to be able to have a positive end of life experience for everyone in this world. Doula Givers Institute will give you everything you need to be able to do that. You can go to doula givers.com or go to the show notes and download those trainings now. Thanks everyone.

Speaker 2 ([29:52](https://www.rev.com/transcript-editor/shared/L9hqWTzcy3-YH19Aa3iW_sdYS_hW9bM_rG-qt87L98donX37wFrzAQDVj6yhRYspu_Wy7JXi0RKK79GT7FiJ-6bqaxc?loadFrom=DocumentDeeplink&ts=1792.27)):

How do we know how to adjust to her pain?

Speaker 1 ([29:55](https://www.rev.com/transcript-editor/shared/0-tarcesaXYhS0E_Lhzc9U7A9yJzmZBFoS03EGGMQ9IgueLrZOQLBxVtIhjc7lZIduo4RPYXPOM685TbmT6evO1rvWk?loadFrom=DocumentDeeplink&ts=1795.63)):

Well, and this is the pain management is the most feared and missed area by family caregivers. So that's something that is the number one thing that should be taught from the hospice nurse is the titration and the dosaging. You start with a little bit, you assess your mom. If your mom still looks like she's in pain, the doctor would allow another little bit. You get it to the point where you find that therapeutic level of that dosaging that your mom looks like she's comfortable. But this takes skill and it takes teaching and it takes a little bit of time and it's not being done. Most families don't know and they don't want to give it. They don't want to do it wrong. And people end up dying suffering many times. Correct. Yeah.

Speaker 2 ([30:37](https://www.rev.com/transcript-editor/shared/O6T4UUkhenrndz5WX-fP2hiJ7wGOf1M3VzFK7XUsS0-6fqcBbhsfBvidfGrmMmYf9YG-DlQCRPl1pLX8AxVVGlgnkuU?loadFrom=DocumentDeeplink&ts=1837.42)):

So that was a bit of a scaring part that we have to deal with. And then also her breathing was getting increasing. Oh, my mom was on, I guess a breathing tube that they're giving her, and she's still on the breathing machine that they kind of gave her. And sometimes she's having a hard time breathing. We just keep adjusting how much oxygen to increase or decrease. And I'm not sure. Is that part of hospice?

Speaker 1 ([31:16](https://www.rev.com/transcript-editor/shared/qk4UF-xyW3rrbKVcbs4fc9OF1vvr8VGNt4AaYC8TP0MuX0gpF34Z_g6Qy52iBXgikpEhPv81kem51E6nFEZzis4rfU4?loadFrom=DocumentDeeplink&ts=1876.96)):

Yes, it's part of hospice. Oxygen is a medication, so it needs a medical order. So this again, needs to be taught and titrated. And again, like families, it's so upsetting to me as the former hospice nurse because the education is key and the support is key. And we're asking families to take care of people that are dying that they love with basically zero education on how to do that. And yet we expect them to be able to do it. With me making an hour visit, this has got to change because that in and of itself, the education, the conversation is everything to that positive end of life, not just for your mom, but for all of you as well. And we can have it go really well, and we only have one opportunity. So you're fueling me even though I don't think I could possibly have any more fuel to work harder than I do for changing end of life. But it's okay because I do this so much so that people and your story can help others that we don't get in that space. So all of that should have been taught and retaught and titrated from a hospice nurse with your family. But okay, so your mom now, how does that go at the very end

Speaker 2 ([32:32](https://www.rev.com/transcript-editor/shared/GdVWmv6fcwVXwe9XUFoLjGbYXn1s_zthJU4bT_SegUIVRkU38KMAZmYYRM8__PXDTE40fd47_YG3Q8uClUIma3bsAjs?loadFrom=DocumentDeeplink&ts=1952.02)):

For your mom? Well, towards the end, there was a disconnect between my brother and us girls. My mother have four daughters. My brother's the oldest. So this really, there's disconnect between him and us, the girls. We understand that mom is time and we understand that our mom loves us and it's time to let her go, and he's having a hard time letting her go. So I remember we were so tired. My sister, my youngest and I taking turn being awake 24 7 because my other two sisters, she has to go to work. So we're the one who is pretty much doing all the bedside well, especially me because my younger sister still have to do zoom call meetings with her work. So I'm pretty much the only person left with my mom. I was terrified. I wasn't sure what to do. My sister have a baby monitor, so periodically she'll look through the monitor to make sure that I'm doing the right thing, the sponge for her mouth and moisturize her lips and keep doing that and massaging her, just talking to her. Beautiful

Speaker 1 ([33:55](https://www.rev.com/transcript-editor/shared/0OgVRoUuo3bOzNrhNtZkZ9pLHnRYX75coXeYmELm_cvsCjxpDkLHgV6sDy13iw_OL3SQgUq8eD0y8CjTOYVgox6SR_M?loadFrom=DocumentDeeplink&ts=2035.77)):

Sylvia. It's beautiful.

Speaker 2 ([33:58](https://www.rev.com/transcript-editor/shared/TkWYHs3SROViGCh240vNJCH0igDcsikgqaIn_sM5Qt0sgmX3XTubClXCooAsh08Zo_2uDOsOAeNG_1P18WQ8rHXN3EQ?loadFrom=DocumentDeeplink&ts=2038.31)):

And then I think the touching part is it's really, I find that very comforting for her because every time I kind of massage her foot, I notice she kind of calm and go into her little trance. But towards the end, one evening, I remember my mother was, so there's nothing, we keep increasing the Ativan, but it's not really doing the work. So I said to my sister, I go, you've been giving her the morphine and I didn't want to ask you how much you've given her, but I think we need to increase it. And she's like, do we need to go and ask a brother because he is in the other room. I said, okay, if you think because he's the oldest, he's the patriarch.

Speaker 1 ([34:45](https://www.rev.com/transcript-editor/shared/j79w1voh0AV2UhKrMSQ8NSPosb87Pxqu_cJslmaNN9k7eKWjSF1USlGQZFiP4yNq-HiW3M1APeSCwQFYNJEUyazgNe4?loadFrom=DocumentDeeplink&ts=2085.32)):

Yes, yes,

Speaker 2 ([34:45](https://www.rev.com/transcript-editor/shared/dWgiyLpE5wg6xE52rmz3ht8LLrhBUji5tnKIbqoDbOhpIhXWb6-by9VYo1L6lZ1LjtBLaqhKqo0zEapEgOujooAE-aE?loadFrom=DocumentDeeplink&ts=2085.83)):

Yes. So we call him, he came over and he said, do you understand if you give it to her another dose, that means she's not going to be able to really hear us. And I said, I don't really care at this time. She's in so much pain. You need to give it to her, give it

Speaker 1 ([35:06](https://www.rev.com/transcript-editor/shared/LDiCE5zWkF982np2xupwMcq0kvHDaQvh5a04TWJPSztUr0b3qj2Q7pXguLIAgCPRdQhj-zPqqwaNojE3F9-TeprKNlI?loadFrom=DocumentDeeplink&ts=2106.59)):

Good for you, Sylvia.

Speaker 2 ([35:08](https://www.rev.com/transcript-editor/shared/Y3YQj2AqZA7LhLWVNJttpb_6OTaEHni4QDemlgzI8mm-drq-Qeop0kfFp6WwxIqc4QQuBONEXxuuEV5thpSDQkkL4hU?loadFrom=DocumentDeeplink&ts=2108.03)):

I advocate for her and I fight him and I go give it to her, my sister go, he said, okay, do whatever you want. He left my sister and I gave her the morphin. And that's when it's starting to, we starting to see other sign, her eyes starting to get a little very glassy, and then there's almost kind of like ammonia kind of smell. I can smell it

Speaker 1 ([35:39](https://www.rev.com/transcript-editor/shared/C7FDJw0jCqzw0rfT5T__kvuQA5dI7cDkFzpwXOOecQ7dcBzwuPTQG8PEIGTDcXPQN0gyXW5X1Wc_AaJWpcAGBTaA6W4?loadFrom=DocumentDeeplink&ts=2139.69)):

As the body is yes, as the body is shutting down, things are not working and not, it's not working like you and I are body. So sometimes things can build up and there can be a little bit of an odor at times. It's all natural.

Speaker 2 ([35:53](https://www.rev.com/transcript-editor/shared/OaA9zfHu1J_lzsLnkgRJNE6R-YOkO_M8uYWkcGQbaT5eiEItnsMQAEJj4mDg-vhv76H8GokLEGi6xJHXOWBzsApOOhM?loadFrom=DocumentDeeplink&ts=2153.7)):

And then I can see on her skin, on her hands, almost kind of like spider vein. It's kind of all the vein that you can see. It's like bluish. And she's kind of cold to the touch. That's

Speaker 1 ([36:07](https://www.rev.com/transcript-editor/shared/Ac7I91wfkDXVUXDsf6RuKelfFgJB0Z4WEe5b1TXjbvelNAzo8iUbQmVjBp7QB8dYyYsW82ItEM5UeVi_SAJfCmBERFc?loadFrom=DocumentDeeplink&ts=2167.57)):

Right.

Speaker 2 ([36:09](https://www.rev.com/transcript-editor/shared/lyVdw4XGtFL18Qb1YLR0l8u-cLGxcSn232z7FVrcFG_thDWpcQZIJimagiFQJX-TGvZAh5wGF_GCPKa6IYu_XidCWEc?loadFrom=DocumentDeeplink&ts=2169.66)):

And around two o'clock, and my sister said, I think we need to crank down her oxygen. And everybody look around at each other. Nobody wants to do it because they're thinking if we turn it off, you're the one who kill mom. So nobody wants to do it. And my brother go, well, you are so advocating, so you go turn it off. And I said, okay, I will. I went to the bathroom. I keep cranking it down, cranking it down all the way down. But we have to do it slowly

([36:47](https://www.rev.com/transcript-editor/shared/wrRIS2evJBhFONIV763WVrDDD7dlVJrQvnu02XI24Olfkfofo8NCyW5jS9rQro73GikFwftlLsNOVRJwbV2QEX25F8M?loadFrom=DocumentDeeplink&ts=2207.61)):

And every 20 minutes we crank it down another notch until the final one. And that's when I said, I'm going to go and turn it down the last time. Do you guys want to say anything? Then say something. So I guess everyone is kind of quiet and ready. And I went, I turned it off. But it's amazing how amazing the human body works because she doesn't just stop breathing. Once I turn it off, she can go on for another hour and a half and then finally we don't hear anymore of her breathing. And then my sister take her pulse, zero, and then we call it, so now we're panicking. My brother go, I told you to go get her clothing. Did you not get her clothing? I go, yes, hanging up in her closet. And he go, well, hurry up. We got to hurry up and clean her up and wash her and change her into a new clothes before the funeral home come to pick her up. So we were in a frantic mode trying to clean her and bathe her sponge, bath her and wash her hair

Speaker 1 ([38:05](https://www.rev.com/transcript-editor/shared/zpNlqN8NwP0zq4iPOCOtXSOYrs1BsZ1BnCqhVuwyp_lDwVgC8st8amhjSsI3_MauUeVDjrOs2QVrDl1dY_5cl-a48m0?loadFrom=DocumentDeeplink&ts=2285.02)):

On

Speaker 2 ([38:05](https://www.rev.com/transcript-editor/shared/geRH06oKnOJENoBKQbYeC6NMff0JSTgYjSKdBykMBJCl_r_DFYDL0i3-1Re5Og6SPmIlpe-STQd9-BwIGC74Vq8pgeM?loadFrom=DocumentDeeplink&ts=2285.7)):

This bed. And then the five of us was doing all these things to her. And I'm telling you, we were laughing.

Speaker 1 ([38:14](https://www.rev.com/transcript-editor/shared/sw76F9UtGgh5bhh3AHXVC2DLqLGsSwwlmwdslF4VgySYV4VV37zNAanIsjk3Mpkp5-NCaV-wZN6K55FoLSf6ivEEE7I?loadFrom=DocumentDeeplink&ts=2294.49)):

The shoe

Speaker 2 ([38:14](https://www.rev.com/transcript-editor/shared/fHZ1JlFxfMTctThoy8LfAr3sTp8vU-tkq56L1Bnko-rw7LCP1vLVvTymUeLA_6HYtefASZR3QbAlRL_FaAvBwFYk-0c?loadFrom=DocumentDeeplink&ts=2294.94)):

Was falling off. Didn't God,

Speaker 1 ([38:16](https://www.rev.com/transcript-editor/shared/v1nHFk3TAha7oxNdii12EuGt50le8SHgEz1wrmW2jPjD9bTelq-88AES5V6GmwrIBCbKcOrFLDoWxafIZ9ci7dWToIM?loadFrom=DocumentDeeplink&ts=2296.41)):

Your mom. That is so beautiful though. But because, right, it's almost comical, right?

Speaker 2 ([38:22](https://www.rev.com/transcript-editor/shared/CseuLflZHYEFRjDLSxWc0wC0eFnrHFGkpPk0cvDgtnfE2i6teCu0uAkLNY81FipwSdqLBtKgZLLCZb2xZk8pHg_-_Dw?loadFrom=DocumentDeeplink&ts=2302.92)):

Yeah.

Speaker 1 ([38:23](https://www.rev.com/transcript-editor/shared/Civ9yWikzc7Z_5owgr6fdS4UrJFNnrums006CA4FCKXC-ytpBvNfujSIbPhVXwZ53qynfGRRl3nkMejGd5J1IZv5oCE?loadFrom=DocumentDeeplink&ts=2303.67)):

Because it's so frenetic, it's chaotic, right? It, it's so chaotic.

Speaker 2 ([38:29](https://www.rev.com/transcript-editor/shared/FbGGKanMMV5kk6-34x0QEbDOe_LbNI3uxGSVWiRqmbXv1DTMPhSnrcUVx_3_cbW2hA5f48o5qvXqkeJIyPhZgqOQPFQ?loadFrom=DocumentDeeplink&ts=2309.14)):

And we start laughing.

Speaker 1 ([38:31](https://www.rev.com/transcript-editor/shared/LIT3DpBTnXIaQbyvSZemDs8cIp-LRuflbYWsC64llsnkPfGRPd-pba_rP4nYRfRo8yIwId7Tcq5Ux3zDTZDGrHn156I?loadFrom=DocumentDeeplink&ts=2311.35)):

I feel the love of your family, so, so much in this moment.

Speaker 2 ([38:37](https://www.rev.com/transcript-editor/shared/JCeIqiG3Vtlza_YUVWnyFavzp14K_laRuhUUcDFkFXBrhZaOPpQNjymxyLJWupL-LCTeQHkGSJ_i7FinnDBnVlCyRaU?loadFrom=DocumentDeeplink&ts=2317.87)):

And then we trying to put her socks, her best clothes on, and then the shoe didn't fit. And I said to my sister, because shoe didn't fit. And I said, why don't we just take the socks off? Maybe it'll be better. And then we put the shoes on. And it's funny because we pick an outfit for her to wear. There's two outfit that we pick for her to wear. And I'm telling you, her spirit is talking to us because the first outfit that we pick for her, as we were dressing her, we realized, and I think my mom's playing a joke on us.

Speaker 1 ([39:16](https://www.rev.com/transcript-editor/shared/I7QEh9fGz4CUaB8vXnZ_iE-nBwGexqncbRa0LoM25Xr4XEfglhm_XeF6lCsmE9j6xIWumpqiyOqfhMSPDBRJi2D3gFk?loadFrom=DocumentDeeplink&ts=2356.9)):

Yes,

Speaker 2 ([39:18](https://www.rev.com/transcript-editor/shared/PukNotewUVwEaXbkKyBqDUf2bmIjobRQTR73xUWH12nlY5NMR7ROgRP8375p02OXVLj0lOoaGe7IjJoxnAblFelVEpQ?loadFrom=DocumentDeeplink&ts=2358.11)):

I checked the day before that it was good. So when we put it on her, the button was missing and my brother was yelling at me. He's like, I told you to check the day before. Didn't you check? And I go, I did, I did. And the button was missing. My brother,

Speaker 1 ([39:40](https://www.rev.com/transcript-editor/shared/LoWsyPj6jQKSx3FEIghY2aybNl0J4pWLcTKArf2lVLnoNPEJDGn2ai4U3jrijYAuVBKO2RINFetP96LmRjiUSM9nOWg?loadFrom=DocumentDeeplink&ts=2380.59)):

I love this story, put her

Speaker 2 ([39:41](https://www.rev.com/transcript-editor/shared/UrtberiJKQoJqeytDjkcoKS79tWAMyAvDobffFhsd6c-DaSuVqvlwjxB-3CY8o1QfFRL4Zk2_CZ8pJrk0dInrxrI50s?loadFrom=DocumentDeeplink&ts=2381.88)):

In the clothing where there's no button,

Speaker 1 ([39:44](https://www.rev.com/transcript-editor/shared/pxWb_Ap65tXhatccoSMewTnBIiH6kW_CsjRIDo45iwR_VQEqW6TeLgjD4Q16LKsO-o1m0X3w6ZTxvqLzMNliCaAcanM?loadFrom=DocumentDeeplink&ts=2384.35)):

Right?

Speaker 2 ([39:45](https://www.rev.com/transcript-editor/shared/L7EcOzaUqlkR3xhhQrdtBAuPqEy0LugP5dMhRZ8FU41FhuHVhQaYziLsNmdt2YdOKlnw8lDoaKV2D7j1QPD_-4luu2A?loadFrom=DocumentDeeplink&ts=2385.4)):

So we put her in the second outfit and that was the one that she always wears a wedding to every wedding

Speaker 1 ([39:52](https://www.rev.com/transcript-editor/shared/kPCQiAcypin5FhJO4Q6rn658nweyE8yIaYWHInP6U3uFTz9DeRTw2fGXbRLyOOXLFTCDRgKZ8wx2cTCkE1SCcR7olT4?loadFrom=DocumentDeeplink&ts=2392.82)):

She attended. This is so good. This is beautiful.

Speaker 2 ([39:56](https://www.rev.com/transcript-editor/shared/I4XmASoriKfOIMml5mvaUGCoQtwa-nfOqziXiy364OVKk-8AcQzwBOO0Yvgkr90yNli39PNPai54xUyiZ_ZJcBcPYsk?loadFrom=DocumentDeeplink&ts=2396.43)):

So she wore the second outfit, not the first one that we chose for her. She wore the second one.

Speaker 1 ([40:02](https://www.rev.com/transcript-editor/shared/mXI-BoeHCVNtWqbtinRZkSC15MmHeih9VEWQPrl3xIp7X2regE3XwOz6M4juYMogF2pKdXZokUxRUABG1u5qIVUPnTY?loadFrom=DocumentDeeplink&ts=2402.77)):

She chose it. She used to wear to weddings that she loved. Oh my gosh. That's

Speaker 2 ([40:06](https://www.rev.com/transcript-editor/shared/xtlGwpJYVYzxlMMR7jzPiPjPOmaQqnpFZZSv3RDo--2VxCw1xYlrHQDxVtlwgIFFbUeQX-kaw6FlTU0WifDCIY2OB7Q?loadFrom=DocumentDeeplink&ts=2406.19)):

Right.

Speaker 1 ([40:07](https://www.rev.com/transcript-editor/shared/Ks1h3POTpLOO2OaukV3KMrH7iBqqvUrzkPY_-ZtWJqzolNaZ8gxT1QZtmb7TTfHwtwTsc92HWxY-IdsPxw6-YIkYq9s?loadFrom=DocumentDeeplink&ts=2407.09)):

So beautiful. I love that. So very much

Speaker 2 ([40:10](https://www.rev.com/transcript-editor/shared/-f2OtEZAgORqA8xJ4D0NKb7cG3v_ZMlTEcfW4YBwhvdbP94iH4WZJZ4nw-zCoMJdR9EvcT2O89_B_Badiy3t_oGjhOA?loadFrom=DocumentDeeplink&ts=2410.18)):

So now we call the hospice, nobody answer. It was three 20 in the morning, my brother call, we call it went straight to a voicemail.

Speaker 1 ([40:23](https://www.rev.com/transcript-editor/shared/IP_2cBJHlkUoe0WTZKq_0kUsELE7SMFv64HH5Yu5vVXZLlc_Kwbok9GKQWfbCGXlrGX3X5l3LTl_C_BrHCKTXN9p9BA?loadFrom=DocumentDeeplink&ts=2423.95)):

No answering service, no nothing. No.

Speaker 2 ([40:27](https://www.rev.com/transcript-editor/shared/CrMRu37Wv6yEoz1JdAkMcz9DiorYZnyr7v7ebHR8Ebi_34RR3hnxPBuyNT8So8rNjY4aazaW7YlrqyRMOj23r-pKyVs?loadFrom=DocumentDeeplink&ts=2427.94)):

And we leave so many messages because we're not sure what to do now.

Speaker 1 ([40:32](https://www.rev.com/transcript-editor/shared/IAiSNQqKng0p5Dctw-SwM0vmxwxkG3oh9Dd4cUoFPyEzkQ-t9KosYjK2ubgg_vqpNOPVVa8p-4yi5jn9U0oUonc7nm4?loadFrom=DocumentDeeplink&ts=2432.77)):

Oh my goodness.

Speaker 2 ([40:33](https://www.rev.com/transcript-editor/shared/aCHhNROD4cu92ukwQaJy5BnwbbJQPEhkIMh2G_k4fl6lh_Jw6k5sWQXv1fXPbELh-ZtNrOz8AfyAvkrw4g6rwsd_lI0?loadFrom=DocumentDeeplink&ts=2433.59)):

So we're sitting there and we are like, we can't call 9 1 1 because it didn't fit. What are you going to say?

Speaker 1 ([40:42](https://www.rev.com/transcript-editor/shared/_cWVz6ZoKo3iprti_zjSiBd-8of6Xr6y288S5sX-LnK_FUFei7I67HU_39TZ3LT7n2kJCC5M9DNngtwVXOMyk4dIGV0?loadFrom=DocumentDeeplink&ts=2442.14)):

Right? So my

Speaker 2 ([40:43](https://www.rev.com/transcript-editor/shared/5prUh2fHaTBAHjSX8QKn1IomdLZxuXGNSR_NUcgn26QqOSKbu6q0Uj1GQHsHrxch9OEc7PNBMsJn2ylpWbTqYbEGF08?loadFrom=DocumentDeeplink&ts=2443.84)):

Brother have to go through his Rolodex and find a friend of his who is a physician and she's a hospice physician. So she came out around seven in the morning from Los Angeles, we live in Orange County. She came from Los Angeles to come to call the time of death because the hospice didn't call us. We waited until

Speaker 1 ([41:12](https://www.rev.com/transcript-editor/shared/EBqsyHxdnMAR7hxAXDXYnO8PHo1JUhjHqa0yu6d9kgMGOPxoS0Z0BmhmWBxDJ9S_-mT9f1dDPlWF3BZwgSGDpGaI0V8?loadFrom=DocumentDeeplink&ts=2472.19)):

Horrifying. The

Speaker 2 ([41:12](https://www.rev.com/transcript-editor/shared/J5HBRBYmVAi4PKzTSHBJN8xIucKZ9ekqyoT6B_NalUHtYx7mqOKu-e0j0H6cPnqIcBbblcJ8pYIKlOjz24F-r-xfW50?loadFrom=DocumentDeeplink&ts=2472.94)):

Funeral home came to pick up her body and then they call us. It was around 1130 in the morning, hospice finally call and asked, what can she do?

Speaker 1 ([41:28](https://www.rev.com/transcript-editor/shared/HRQ1mehlkZSoKga65KjxMUPjVR02RELV1Ne2iQI3CWf40QPrPd5wqfGJ4cvRIBuimP3RrsIniJLv_cb4F4erCM9_HuA?loadFrom=DocumentDeeplink&ts=2488.36)):

And my

Speaker 2 ([41:28](https://www.rev.com/transcript-editor/shared/wlggXBXSRlXu89dmsHa-0YpJZ-NHTjmCyitdMqjmsJZ46pDTXqEoHDYPEAOrGCAM2jG6J4WACWT1B4xh90AQRC7cL2I?loadFrom=DocumentDeeplink&ts=2488.61)):

Sister

Speaker 1 ([41:30](https://www.rev.com/transcript-editor/shared/J9XFpMRhcO5yDvjnhI01J087tHHu1ecztEKemorgPxQk-4knxT8xZ1zitsJOWkx5ij1uRl6jH0pm7f3P6-bRKp-ipWA?loadFrom=DocumentDeeplink&ts=2490.17)):

Was

Speaker 2 ([41:30](https://www.rev.com/transcript-editor/shared/5VI7Cfez4ZAW61Pqev_1s9iBLemaRUa6j2EeFHdRdKd7depi9UpodcIivS7qEyxiSYqv7BLKDZAOsKK3x4m09K7WPJs?loadFrom=DocumentDeeplink&ts=2490.73)):

Furious at this point.

Speaker 1 ([41:32](https://www.rev.com/transcript-editor/shared/b872__eO6gSOZYqtzrWyfrJr-ZZNnInZj-RBHJVj3tyyE54k0xsnvyeF0PrkQ42I-xfw9WOk4iiIyU1PWXYGxTgCLLY?loadFrom=DocumentDeeplink&ts=2492.25)):

Oh, I'm furious at them. So here's the thing I want everyone to hear this. Sylvia's talking about her mother being at home on hospice. This is in the state of California dying at three 20. At about three 20. They called hospice at three 20 and left messages. No one's answering. No one's answering. They don't know what to do. If you call 9 1 1, you never want to do that when there is an expected end of life because now it's an investigation. Now it goes into a whole ring, ring, correct. The police come out, everyone's a suspect. All of this craziness a doctor has got, or a nurse or a hospice nurse has to pronounce that time of death. And your brother, who's a doctor, has a Rolodex and is able to contact a hospice colleague that comes out from Los Angeles to Orange County to do the pronouncement of death seven o'clock in the morning. I mean, you're lucky you have that the hospice then that your mom is on calls at about 11:30 AM the next day. So from three 30 the call and says, how can we help you? Or what can we do?

Speaker 2 ([42:40](https://www.rev.com/transcript-editor/shared/q5KKKpRyrsbT_dNixLbk0MYKBa5bTS4NROT-9wmFWVD34afIb77ev8U-iA-8SEFL7B-SVPmDFcDiaKi1hZibwwyA7mA?loadFrom=DocumentDeeplink&ts=2560.55)):

Right?

Speaker 1 ([42:42](https://www.rev.com/transcript-editor/shared/rYXAGBVCe7mJA0FzQbov9el6PDwwoBizJRKzyTLVgmWYWL80KyvqG12ui52BxiQ81YRtRBKgmZkLPLSz_xRRokeD54Y?loadFrom=DocumentDeeplink&ts=2562.26)):

Are you kidding me? I've never heard of that bad. I mean, that is terrible. How many people don't have hospice in the Rolodex, friends and family that can do this? So I don't blame your sister for being really upset. I'm really upset. I know that you were really upset and being upset is not going to solve the issue. But we've got to talk about the hospice gaps, the gaps that are out there that are making end of life go a thousand times harder for patients and families. It has got to stop. It has got to stop. Okay. So they call and they say, what can we do? And

Speaker 2 ([43:19](https://www.rev.com/transcript-editor/shared/f_F4aTRI2wCmedTcfMIIt6BZKonxAhUSTCcBJByz_gsLUI6R2YaW_ihvuHlJ9p1ofn-8x7sAWRtBLjBGnQGiUZkZfe0?loadFrom=DocumentDeeplink&ts=2599.37)):

My sister go, what can you do? We've been trying to get ahold of you. We've been trying, when we were upping my mom's medication, the morphine medication, we are trying to ask you how much can we increase? What is the protocol? No one call us back. We just kind of wing it. And now you calling us.

Speaker 1 ([43:45](https://www.rev.com/transcript-editor/shared/GOOA3EAdfMxT7CxboWRhhWOBp8UhOpTt4VIW0_mBE91Z5-Pfi5vu2vmUAZt4RhY-13lusS0k1ohW25iKICtYy_TwRbM?loadFrom=DocumentDeeplink&ts=2625.53)):

What did they say? Did they have anything to say at that

Speaker 2 ([43:48](https://www.rev.com/transcript-editor/shared/i9uWgG0JamQ-9vJ5wbNUAboJfqOt60X8yNC85jIO-AmHH-m5a19q6z_W5J-79OTSf3s6aJ5di-RaVT4S4VY7C8-J7xY?loadFrom=DocumentDeeplink&ts=2628.48)):

Moment? Well, she said, well, due to covid, the staffing here is very tight and we are not allowed to come out.

Speaker 1 ([43:59](https://www.rev.com/transcript-editor/shared/Hm1affJE_hOF_8afgEmSfwsLy1Hh5rUZTTsgMgCCNW_rQWlYy9PxFqYPg-5p_Rq99RB0Rik_oTZnuh89kGUHGAmls7Q?loadFrom=DocumentDeeplink&ts=2639.57)):

They can call to come

Speaker 2 ([44:00](https://www.rev.com/transcript-editor/shared/BrGfaun7Tzj63qNBnORh6tNBLUkD86fmzVTImG7B1SXb2yq-mi9BUZMEEGTqOu522_nDVj29xdyDCZDgfRcSdFxFQtI?loadFrom=DocumentDeeplink&ts=2640.2)):

To the house.

Speaker 1 ([44:00](https://www.rev.com/transcript-editor/shared/BI56z5y09un3MkcNO5F1X1fIqwlIDhovaUNQZzdyyXKOV775afBWLXJrGLPYyqcAOLTGvzoWw6EZCLnndOpFEAeB6fw?loadFrom=DocumentDeeplink&ts=2640.92)):

They can call shame on you and they can call you back and they can do many, many things. I'm not buying that. The staffing is an issue across the board. So I just want everyone to know that our medical practitioners, you all know this hospice, we all know that on a fragmented usually schedule. But here's the great news is that this is a human skill that used to be handed down generationally a hundred years ago that we know how to have end of life. We really do. We've been dialing for thousands of years, medicalized it, and we've removed all of the teachings of it. It's time to bring that back and to share that with families so that they have these skills before we ever need it. Then you get a medical to compliment to make sure that they're teaching the medications. But you also want to interview, like you said before, that you can choose your hospice. And if you're not happy with the hospice service that you have, you can change that service. You are the consumer. This is about you. So lots of education needs to be here. I can't even wrap my head around that story really.

Speaker 2 ([45:07](https://www.rev.com/transcript-editor/shared/oaSuT8zmAHQeBJFxXmpgOQIMOo0AvrjDBJRMi_PpnKhDuvaMXazXbImewlwfTjKNDLnxg2bF_4Unc-sW_1f2qtUe6Oo?loadFrom=DocumentDeeplink&ts=2707.89)):

It was like a circus. We don't know which end is up. And we thought, oh, we're in your hand and you're going to guide us. And when we call and they said, oh, don't worry. Oh, by the way, she only comes out once or twice on the three weeks period and the rest is like phone call. And also she said, well, if anything happened, she was saying, your mom is closed now. Anything happened, I'm on call. I'm the on-call nurse twenty four seven. And I said, yes, that's why we call you. But you didn't return our call. She called. I was with another patient and I know you with another patient. Surely you can find someone to just give us a call back. My sister even text her said urgent 9 1 1, texting her.

Speaker 1 ([46:05](https://www.rev.com/transcript-editor/shared/eJtLxJiZmzSWSsx8Hui740F2haMrYPb4iCTFPFT8kmTlgALD7UAR_UpVTFYSyAmiKnUg4Uk764Jy2zVo4LgS-76gMxs?loadFrom=DocumentDeeplink&ts=2765.82)):

And from a phone call at three 20 in the morning to 1130 in the morning, we have got to change. So let's talk about, Sylvia, thank you so much for sharing your personal story with both of your parents so that it can be a real teaching moment and a cautionary tale for all of us. Now again, the good news about propelling us forward into making positive change for everyone in this world, right? Because isn't this what connects us all? Is this thing called humanity and this thing called end of life and this thing called life. And where in this part of the journey of your personal journey did you start getting the calling that you really wanted to learn more and that you wanted to be a difference, a change maker in this space?

Speaker 2 ([46:50](https://www.rev.com/transcript-editor/shared/AcYLh1B6vo1fbRaxx0s4uddEpoI7CCU87BJXTZSVflQMGz_Jxo1Kt3N8MfLwCuQ_Hk8Ukr4r9ijYFmWUpWqxhEi8lF0?loadFrom=DocumentDeeplink&ts=2810.82)):

I was driving home after my mother's funeral and my husband and I stopped by Sedona, loved to spend some time in Sedona. It's very spiritual. And on the way home after I left Sedona, I feel that I need to somehow find a ways to help other people so they don't have to go through the same thing I'm going through, but I'm not sure where or how. And I was on YouTube looking at something totally different. And then I saw someone who was interviewing a doula and I wasn't sure what is a death doula? I never heard of it. I know there's a baby doula for birthing. I never heard of a death one. So I watched the video and I find it so fascinating is exactly what I'm looking for. So I started Googling different organization that teaches,

([47:57](https://www.rev.com/transcript-editor/shared/ExQbNqeP_cohVRxwceQvtUz9b-kzLCdd07VgkO3G4cJ3CnJ_8PPwGEITHjOfSPR7ejvFOeHrOCXAPalSLLgA6FZX5Kw?loadFrom=DocumentDeeplink&ts=2877.7)):

And then I stumbled onto your website, I believe I was on Barbara Ks and she mentioned you and I looked it up and I start looking at different organization that I wanted to study with. But I find yours the best match for me because number one, you're a hospice nurse, you oncology nurse, and you have all that expertise and all the clinical, and that's what I want. Although we don't do anything medically, but I believe as part of my learning, I should know, even though I don't use, I don't medicate or do anything a medication, but I should know all that detail. What's intel in the whole dying process?

Speaker 1 ([48:50](https://www.rev.com/transcript-editor/shared/XEHVHWEr7rguJlwekLqnwvApuuLvHzRmeKwGAFPvL-LVFJV2pw3C9l9Cg54DtsB_19By5weA_gZaHGUrs_lPwS6TsSM?loadFrom=DocumentDeeplink&ts=2930.5)):

Yes.

Speaker 2 ([48:51](https://www.rev.com/transcript-editor/shared/gWeJryEm6bJxYsjV5o8Ktc5YHJA57DgeB2yLCJY3Jps2ugNQ14l87f3zYetm6a1EvZ9C3Z7G1lx7655gViDgzBX7JR4?loadFrom=DocumentDeeplink&ts=2931.13)):

So that's how you win number one, going to see your client. So your client kind of have more trust in you that you know what you're doing.

Speaker 1 ([49:01](https://www.rev.com/transcript-editor/shared/Jt1lsv99fG-hrHSXWEUzi_Il_Xfz9mmYHCGAlo8Wb5s95cSd2BqbdzVnOn5aOixvwc4oey6POjOv669ms1Jww2Ktstw?loadFrom=DocumentDeeplink&ts=2941.33)):

And if they have the things in the home that they need, and when they need to call that hospice team and say, there's a change. We need things. It's different. If you don't know symptom management, if you don't know physiology, if you don't know disease processes, which most families don't, how do they know when their loved one is suffering or when they need something or when to call 'em? That's what you learn. And that makes all the difference in the world. It's so great that you're doing, yeah,

Speaker 2 ([49:29](https://www.rev.com/transcript-editor/shared/t7t08rgpVXIc0_xinM6wJgExXekZO3oL3IpW8SfulCMu1i10EJbT_IhnTPM4JvRrToZWvcRaMscz_hUJA4E3QWs1o6c?loadFrom=DocumentDeeplink&ts=2969.27)):

I have checked out other program and I decided, and I have an appointment with your webinar on Thursday. And then I was talking to another doula, doula institute and I told her I cannot make my final decision until I go to my webinar on Thursday with Doula Institute. And she said, yes, go ahead. You should do your homework to see which program fits you. And I told her, once I attended your class, then I can make that decision. So after I attended your webinar, I signed up and I called her up the next day and said, thank you so much. And she said, well, they'll be here. I think their one is called Doula la.

Speaker 1 ([50:23](https://www.rev.com/transcript-editor/shared/dVrwRQQeFVwvmMKsrKwuoQxnjmQo3tdcALQORuKyZKV8IBgI-NWoUDo9eZnuFy79fSVK7C6bX_AKf_ZzrPGL10Cz0YY?loadFrom=DocumentDeeplink&ts=3023.84)):

It's

Speaker 2 ([50:23](https://www.rev.com/transcript-editor/shared/Pj11e2nHSBiSWx35lgLa2Yug8K4zqHC_X3Wc_wzh4-AB5mC4We_XBJTAUdHcIjcM5xmBlvS0dhfLtBgtkd6V_e2vnXk?loadFrom=DocumentDeeplink&ts=3023.84)):

In Los Angeles. And she asked me why I didn't pick them. And I said, it's just your program has more clinical background that I'm looking for. I come from a heavily medical family and I myself do. Case management I think is really critical to know all that clinical background and it's the reason why and their one is also fantastic. I think all the classes from all these different organization that teachers doula, they all wonderful, but you just need to find one that works for you.

Speaker 1 ([51:07](https://www.rev.com/transcript-editor/shared/PyjfYqC5JVV_kiKKtfHlG3Zg6kzf178v-uby5iVK3w2RwYkEcITFgYHNHa3Pic_R7m-h0WKjwpwZc0d1HphQTi9y-mg?loadFrom=DocumentDeeplink&ts=3067.04)):

Yeah, and I think that, again, you said it beautifully. My background is a hospice nurse and non-oncology nurse. I'm going to bring that all to this training. Why? Because this is, in my opinion, critically important for the highest quality of every single day for that patient and thus that family. And that's really kind of why doula giver specialists, the practitioner is with a death doula within it, but it's a much broader, it's a full spectrum non-medical holistic practitioner because of all the medical. And it's wonderful because if that's what resonates with somebody, then there's that availability. So I love that. Sylvia, I want to ask you this. You've been so gracious with what you've shared today. What would you advise somebody that is going to be responsible for caring with their parents? What would you say to them that they should probably be doing now or what's available to them, that it's not just mainstream medical that they need to be dependent on or just hospice? What would you share with them about how they could take a step or two to make sure that they have everything they need? We have only that one chance to have that end of life go. Well,

Speaker 2 ([52:15](https://www.rev.com/transcript-editor/shared/stcveWBMCG21gEio5HL77tRzoYPfk7i4NYgqti96foKXQnDGSCUWOD4ZzfzfEiaENBpe4z5SEyDS0YrqDR2KlM-P4b4?loadFrom=DocumentDeeplink&ts=3135.56)):

I just recently got my advanced directive done and then I also got the five wishes, which is very detailed and that's what I would advise. Sit your parent down, explain to them. It is not a finality. You can always change it, but it's good to have something on paper so then people know your loved one around exactly what you want and how you want it. Because now I think my mom, if we take the time to actually sit down, talk to her about it, I might be able to change her mind. But because of her illness going to hospital all the time, she's not available to even talk about that. I think we left it a little too late. So I would advise people that would be the greatest gift that you can give yourself a peace of mind and also your parent so they know exactly what they want and you know what they want so you don't feel guilty afterward. Now we have to second guessing ourself. Is this what she want? I'm not sure. I hope I'm doing it right.

Speaker 1 ([53:34](https://www.rev.com/transcript-editor/shared/ztTTodzuxSvtKVMDbHmz1bjyAFcd7sdKd1B82N8YedPzrOVIlcSvOxFuR28tDq2Fix1vMH94v_upGXYsRR4jrf48Dco?loadFrom=DocumentDeeplink&ts=3214.2)):

Yes, that is exactly correct. It's the greatest gift. Doing your advanced directive and letting your loved ones know what you would want or not want in that end of life space is the greatest gift you can give yourself for peace of mind because you'll get what you want. You're asking, right? I want to be at home. I would like my dog there. I want to be kept with pain at a minimal. And it's the greatest gift you can give your loved ones, they don't know if they're trying to guess. And most families will never unanimously agree on care because there's too much emotion here. So do your advanced directive and choose and choose now. Have that conversation and thank you. I want to thank you from the bottom of my heart for everything that you share and for your family story, because I think that those are the things that we can all relate to. And the fact that you had both of your parents in different settings have challenges in this end of life, and that's putting it mildly. What we can learn from what you just shared is absolutely priceless. So I want to thank you so much for being here.

Speaker 2 ([54:42](https://www.rev.com/transcript-editor/shared/FV2Es2NGXY73BJm1DU3gXUvmIcOpMytr1U97KqKmHCoPheZe9tPipcvrIIFklOIJxO9W6uiBfJNAwMrLeGUA_ef4Z5s?loadFrom=DocumentDeeplink&ts=3282.3)):

And one thing I'd like to add, I have two sons, 27 and 28. So when I was looking for the medical proxy, my husband would be the first one and the second one, you have to kind of know your children, you

Speaker 1 ([54:57](https://www.rev.com/transcript-editor/shared/rUDHl2WknBQktu8FXcLZSoD_kyFQS8DIdRdYTDFG_4TgsvCMJsKHFezLd75HEyK8XQ_xtZWGJxV0zPo2ShYSFuEXaJo?loadFrom=DocumentDeeplink&ts=3297.15)):

Do,

Speaker 2 ([54:58](https://www.rev.com/transcript-editor/shared/MiJe8070Y6vm7W7kRkZ7Z00py_xioiDrcxdLbx63S2Qy4YweKWsg7HY1MTBnJL8XusD-6BJ8WYAwniMw3DtNFX8SI4E?loadFrom=DocumentDeeplink&ts=3298.14)):

Who can make certain decisions.

Speaker 1 ([55:00](https://www.rev.com/transcript-editor/shared/ERB8IPBllx_dMThi3PzkuVTgIlcGMS-tOmE_kmbec7BIv8N7KW6wU44sWZSAJF_rauz6RXscAaLF_rGgm3FRaJXaFHk?loadFrom=DocumentDeeplink&ts=3300.72)):

Yes.

Speaker 2 ([55:01](https://www.rev.com/transcript-editor/shared/SbLs8HYuOzDLFtZqUbHU9azqJMNy-w5NZQBwK_HB5_uMQGXMB2WAZElQPdPstcDQ9W8MYWWWTJ2O4qJmWwizD1rskdk?loadFrom=DocumentDeeplink&ts=3301.14)):

So I chose my oldest son because he's a nurse, he's a trauma nurse, so he knows and I ask him, and I also talk to my younger son. So then he understand there's no feelings, hurt, not I don't trust you that you can make that decision for me, but there are certain things with your different personality would fit you more. And they love it. They're like, thank you so much mom for doing that. So now we don't have to worry about when your time come, what do we do? And I told him that's the best gift I can give them. So I'm planning and putting everything together in a binder, my advanced directive, the five wishes and my will and everything else in this binder.

Speaker 1 ([55:53](https://www.rev.com/transcript-editor/shared/ykx6N_QQL8SoE8Tuqj784Jy3fUpvH-QkSSXRJ-9j5ASZq2FK1Ym9BboVYTwluP5Fim7BoRfcwHrx25r-XxTq8tmshPE?loadFrom=DocumentDeeplink&ts=3353.52)):

I love it. I love it.

Speaker 2 ([55:55](https://www.rev.com/transcript-editor/shared/qib45AJ4xeJ9sLmrfK-_36kTJc7LH1xC6xtYmvgomXA8rdWbIPwUGRrKm5Oq5_CEmmc5k4oBmWIxVi914kuY9CPSoGI?loadFrom=DocumentDeeplink&ts=3355.9)):

Yeah. So now my next step is to work on my legacy box, putting things together.

Speaker 1 ([56:03](https://www.rev.com/transcript-editor/shared/Ro4RDjf_hFK4Tk-5NPr-s158yyxK7DXQxfjf-5iH17nSGHW2mmrq_oDym-urt-_tT4EJpfM2iSpUi54EnCMeg1v526A?loadFrom=DocumentDeeplink&ts=3363.3)):

So beautiful. So

Speaker 2 ([56:05](https://www.rev.com/transcript-editor/shared/pR-9laeKO0Gw3eKi3Daf2dtmszO6EpI7yHi2TtjGMzIKtrc3hzOmBL-LAvQJhHHKxZjy4uY84DbU50ZYNYIzYVF1ypk?loadFrom=DocumentDeeplink&ts=3365.05)):

I figure since I'm studying and preaching people, I might as well do it for myself. Course

Speaker 1 ([56:11](https://www.rev.com/transcript-editor/shared/EM9t8fSpShjcDlXPYNWwB3yAuG88McBYUSCxx9_lsyJFcb61Sz1tHIbzxOVWjttaHIdQlHz_ur6w5WgGZFs0HLbUFng?loadFrom=DocumentDeeplink&ts=3371.16)):

We got to do it ourselves, we got to get to it, do a legacy box. I have something called love letters that you write and I put in that beautiful box that's going to be opened at some point. It's just an abundance of love and education is the key to everything. And I will honestly say that end of life can be one of the most beautiful, sacred experiences when you have the right education and support and kindness. And Sylvia, you have just given us so much that we can use in order to go. So I want to thank you so much for being in this world and also being a doula giver and sharing your story. I know that all of us benefit from that. So thank you my dear.

Speaker 2 ([56:49](https://www.rev.com/transcript-editor/shared/sPdGCOAMnEo6sZWzWut32a52ExGmTvCtNgQ-ztSsbz73FtJbY49UsOWiIDUV26jj1moCwI3uEhG2CE6Gxql6glRflRc?loadFrom=DocumentDeeplink&ts=3409.36)):

Thank you very much for

Speaker 1 ([56:50](https://www.rev.com/transcript-editor/shared/o2nE2PdxwwvVDKkJksF_CMhdOXaKKoHm_8OYdCxtxszFoIKsQo45rraPdiyph-HWAhqxiCVfPQbFfDwiuvh5v607GLU?loadFrom=DocumentDeeplink&ts=3410.77)):

Having me. Alright, you're welcome. And don't forget everyone, you can get free family caregiver training to learn how to care for your loved one for free at doula givers. That webinar is on demand now. And there's also the nine choices document that we have for advanced care planning. Both of those are free. Both of those are free. So access them, do it today. And if you have any questions, let us know. And thank you so much. Is

Speaker 2 ([57:10](https://www.rev.com/transcript-editor/shared/mm5qLGrTzqzae8lZ4H7UU0nR8c5A36wZucD2YaMOp-omW7YLJpj_y3mbUJJgrY18c229yg6VpjCC9RuUa48TfSylPvk?loadFrom=DocumentDeeplink&ts=3430.45)):

That in our course?

Speaker 1 ([57:12](https://www.rev.com/transcript-editor/shared/pRUILTRFm3Jyh-kzU0gTpGm4wW5PRUdSetyniJRMQGtofzENGxyYIPKKp8N0Ud58YPfBRQxZ1syFh1GxtcVpjTW68-c?loadFrom=DocumentDeeplink&ts=3432.37)):

Yeah. So this is something new that we just rolled out. You'll be getting it as well, the nine choices document and it Wonderful. So stay tuned. Yes, you'll have that very soon. And again, you can access that for free@doulagivers.com. And I want to thank everyone for being on this podcast today and we'll see you in the next one. Thanks everybody. Thank you so much.

([57:32](https://www.rev.com/transcript-editor/shared/pzSzbkkf2t80dMdjvUYccXzo5NOHQNx23GBhJgoCo4I0CNphh48dYeiIvjTgvn97uxp8PDM5B5bPFKrhYiDrg2-SEoc?loadFrom=DocumentDeeplink&ts=3452.66)):

Thank you so much everyone, for being part of, again, ask a Death Doula podcast. Remember that 80 to 90% of a positive end of life depends on two things. Planning ahead and having the basic skills on how to care for someone you love at the end of life. And both of those are available for free with Doula Givers Institute. You can go to the show notes right now and click the link to download either the training or the nine choices document or go to doula givers.com. Thank you so much everyone, and we'll send you in the next episode. I.