

The Art of Dying Well with Katy Bulter

Katy Butler: [00:00:00] people who are willing. To contemplate their aging, vulnerability and mortality often live better lives in old age and illness and experience better deaths than those who don't. They keep shaping lives of comfort, joy, and meaning, even as their bodies decline, they make peace with the coming of death seize the time to forgive, to apologize and to thank those. They love, they rethink of hope and they often die with less physical suffering and just as much attention to the sacred as our ancestors did.

Yael Schonbrun: [00:00:38] That was Katy butler on psychologists off the clock

Diana Hill: [00:00:49] We are four clinical psychologists here to bring you cutting edge and science-based ideas from psychology to help you flourish in your relationships work and health.

Debbie Sorensen: [00:00:57] I'm Dr. Debbie Sorensen, practicing in Mile high Denver, Colorado.

Diana Hill: [00:01:01] I'm Dr. Diana Hill practicing in seaside, Santa Barbara, California.

Yael Schonbrun: [00:01:05] From coast to coast. I'm Dr. Yael Schonbrun, a Boston-based clinical psychologist and assistant professor at Brown University.

Jill Stoddard: [00:01:11] And from sunny San Diego, I'm Dr. Jill Stoddard author of Be Mighty and The Big Book Of Act Metaphors.

Debbie Sorensen: [00:01:16] We hope you take what you learn here to build a rich and meaningful life.

Diana Hill: [00:01:20] Thank you for listening to Psychologists Off the Clock.

Debbie Sorensen: [00:01:23] be sure to check out Praxis Continuing Education for their online trainings. Just go to the sponsors page offtheclockpsych.com to link to Praxis. And there you'll find a discount code you can use for registration on any live training events. So check it out.

Diana Hill: [00:01:40] We're also affiliates with Dr. Rick Hanson's online Neurodharma program and his Foundations of Wellbeing programs, you can find out more about them at our website offtheclockpsych.com where you'll get a \$40 discount

One of the drawbacks to COVID-19 and being on quarantine is that we don't get to see each other in person as much. But one of the wonderful benefits is that we do get to expand our relationships online and. I'm really excited that a workshop that I usually just offer here in Santa Barbara, I'm going to be offering online so that it's accessible to a larger community. And I'm going to be leading a workshop on Committed Action: Making Values Based Moves on Sunday, August 16th from three 30 to 5:30 PM. And that specific time through Yoga Soup, you can check it out at yogasoup.com and we're going to be exploring how to take your values and turn it into committed actions, whether it's through social justice, uh, maybe you want to make a change in your health behaviors, or maybe you want to show

up in your relationships in a more values based way. We'll be doing some real hands on experiential work together to put Acceptance and Commitment Therapy. Into committed action in your life. So join me. I hope to meet some of you there and really looking forward to it. Check it out at yogasoup.com

Yael Schonbrun: [00:03:04] As humans, we are programmed in with the fear of death, but opening ourselves up instead of avoiding thinking about death actually empowers us in ways that are really important and helpful. And particularly in this time of the pandemic were fears of mortality are really heightened. It can be quite useful to be thinking about death in more open ways. So I was really excited to have Katy Butler. Who's a journalist who wrote two books about end of life experiences, many, many articles. And she joins me to talk about the art of dying well and what we can do in the face of these fears of mortality

Jill Stoddard: [00:03:39] yeah. I found this episode to be incredibly useful in that I have to admit, I think that I want one of those people who's guilty of the like, Oh, I'll think about this later. You know, like, Oh, this doesn't apply to me. And of course we all know that we're going to die some day and the people we love are going to die.

But in each moment, it sort of feels like you can push it off until later. And I think that what Katy really, at least for me, like encouraged me to do is to think about like, if you yourself or someone you love, like, if you want this experience of dying to be a meaningful one and to avoid regrets, then it's something that you have to think about now and have these really difficult conversations about.

What do you want this to look like? And you know, one of the things that she talks about in the episode is not contributing to the suffering of the person who's dying and all, man, that like hit me like a gut punch because I was thinking back to when my own mom died. And, you know, based on a lot of the things she talks about in the episode, it really made me want to, you know, jump in the way back machine and do things a little bit differently.

But I think the gift of it was thinking, you know, I still have my dad and I can reach out to him and have this conversation and not end up having those same sorts of feelings of regret that I, that I do have around my mom's death.

Yael Schonbrun: [00:05:08] Yeah. It's interesting that you think about your dad. Cause I also think about myself with my own kids, my own mortal end and what kind of that I want to leave with them. And one thing that I'll say to you, because I do think that thinking about death feels like something that we just want to put away.

I mean, again, that's kind of what we're programmed to do is like survive and But there's this really powerful distinction between ourselves to die accepting. think emphasis on acceptance out to be quite empowering, we don't have to sort of give up on life, but recognizing that life is finite how to manage it more thoughtfully with more intention. Both through the living parts as well as to the dying part, because just as much as birth and life is a part of life. So his death not control how it goes, but we can influence some of the ways that it can happen. If we open ourselves up to thinking about it.

Jill Stoddard: [00:06:15] Right. It's almost like acceptance as the opposite of resignation. I also liked that she makes the point that even if you do these things

to create a more meaningful experience and to engage in dying well, as she puts it, it's still always going to be hard and always going to be painful.

And I think, you know, that's where an element of acceptance comes into.

Yael Schonbrun: [00:06:37] Absolutely. I think that part is important, especially now because people are dying in hospitals, surrounded by medical personnel and PPE, and from their loved ones. But there are certain things that we can't control, but there, again, we can sort of distinguish between acceptance and resignation. When we accept what is it empowers us to work with? What can be an, and I think her emphasis on that is, is realistic, right? It sort of acknowledges the struggle, the pain, the grief that goes along with that. And certainly that can be much more present in certain kinds of tasks. We just open the possibility of influencing it in ways that are important for you for each of us. For all of

Jill Stoddard: [00:07:24] Yeah.

Yael Schonbrun: [00:07:24] ones today,

Jill Stoddard: [00:07:25] Yep. Absolutely.

Yael Schonbrun: [00:07:27] we hope you get a lot out of this interview with Katy Butler on the art of dying. Well,

Katy Butler is injured analyst, public speaker and bestselling author of two books on death and dying, knocking on heaven's door and the art of dying. Well, she was a writer at the psychotherapy networker for a decade, and her other writing has appeared in places, including the New Yorker or Scientific American, the Atlantic and Best American Science writing her 2010 piece in New York Times magazine.

Titled what broke my father's heart went viral and form the basis of her two books. She writes about slow medicine, bioethics, family caregiving, compassionate care, and end of life decisions, and was kind enough to join me to discuss some of these topics.

Welcome Katy.

Katy Butler: [00:08:13] Thanks very much here. Yeah.

Yael Schonbrun: [00:08:14] actually discovered your books after witnessing a long and painful journey of my own father's passing and your writing was revelatory for me. I hadn't been able to put my finger on why so many elements of his last few years of life had pinned me, infuriated me and terrified me. And it was really in reading your books and articles that I realized both would I could have done better for him, but also how it like to handle it.

My own future in terms of people I love passing or my own mortal end. I really do think that your work has the opportunity to really change how people approach death and dying, which is going to be a part of life for all of us.

Katy Butler: [00:08:55] Thank you. I, the first book, which is knocking on heaven's store was very much the story. Of our journey through caregiving as a family, my dad had a major stroke when he was 79 and had up to then been really to talk quite healthy and active. And I watched my mother suffer greatly as a caregiver and I watched my father suffer and as he declined and developed dementia and a whole Panaflee. Cluster cascade of bad decline. And I also to see, I think this is what you were speaking to starting to name what is making this

so difficult. Now, we, we in a culture that likes to deny death in general. then we also live in a culture that in some ways over idealizes medicine and has sort of a taboo about saying anything negative about a medicine.

So the media, you will read story after story of. A cure is just around the corner or now a vaccine is just around the

Yael Schonbrun: [00:10:08] Yes.

Katy Butler: [00:10:09] this technological utopianism we're, we're going to be sort of saved from the struggles of ordinary life, which includes dying. And so I think that whole struggle of my parents, it was for us by the fact that. My dad was given a pacemaker fairly late into this process. And we all believe that it overtly prolonged the most suffering field period of his life. And so one of the things I was really trying to name is which I understand in a much more or sophisticated way now than I did at the beginning is that we have a medical system that's focused on curing. But at this stage of life, people actually need all kinds of practice, all kinds of caring. They need comfort care often. And instead we will deliver very expensive high-tech interventions to them and deprive them, neglect them of the kind of simple human caring and support that people are more likely to need.

Yael Schonbrun: [00:11:20] Yeah. And I think your book does such a great job of really putting those two issues side by side, where we tend to really focus on one. Or the other, right. This issue of longevity of life versus quality of life. And sometimes there really is a choice between the two of them. But I actually, and I actually want to come back to that because I first want to address one of those, the first points that you made, which is that we live in this culture that really.

Almost denies mortality in this very funny mental way. And, and that, that can be really problematic and I was recently reading to my older boys, the book, Natalie Babbitt's tuck everlasting, which really. addresses this issue of immortality and sort of how we get really idolatrous about this idea of mortality.

Um, and I just wanted to read a quote because it really just struck me as resonating with a lot of your work. And it's a conversation between Angus tech, the father who's gained immortality. And when he fostered the main character in the book who discovers the tech family secret of immortality, and it goes as follows

even she Winnie we'd go out of the world. Willy nilly some day, just go out like the flame of a candle and no use protesting. It was a certainty. She would try very hard not to think of it, but sometimes as now, it would be forced upon her. She raged against it, helpless and insulted and blurted out at last.

I don't want to die. No said calmly, not now, your time's not now, but dying the wheel right there. Next to being born. You can't pick out the pieces you like and leave the rest being part of the whole thing. That's the blessing you can't have living without dying. it's this idea that immortality doesn't exist and nor should we try to hang onto it existing, because part of the meaning of life is that it is finite.

We can make living better, even at the end of life. If we acknowledge that life is finite,

Katy Butler: [00:13:12] I totally agree. And I love you using that word idolatrous. And this is also something that the, the ancient religions were very clear on. You know, Buddhism says. I'm with the nature to grow old. There's nothing I can do to

prevent growing old. Um, the Yom Kippor service has these lines that I just love, which are like the grass that Withers the flower that fades like a fleeting cloud. I can't remember all of it, but it is so beautiful and all the images are natural images. So. You sort of see our place in the universe. We are one more natural thing with the cycle of birth and growth and development. And then finally death. I was thinking a lot about this before I came on, because I was thinking about how important acceptance is empowering us. Like right now, our culture is so terrified. Understandably. Of this new form, new to us, unexpected form of dying that is taking place widely people are, it strikes me. People are almost frozen. They can't really act because they're waiting for Santa Claus. They're waiting for it to go away or they're waiting for a cure or a better administration. It really doesn't matter how you want to define it. But my sense is the more people accept the nature of what's going on. The more we are going to be able to dream up solutions that allow us some sense of community. Um, could I read a short passage from my

Yael Schonbrun: [00:14:53] Yes, please.

Katy Butler: [00:14:54] to read a short passage from the second book.

Cause the first book was of falling in love with my family all over again, as a caregiver. Getting to really have a lot of redemption with my dad by being able to express my left hand very openly. But the second book is more the guide it's called the art of dying well, it's much more. Intended to be an empowering guide for me, you, not when we were at the very ends of our lives, but when we're still in the stage when we can plan. So I'm just going to read a short passage here in the S there's. I've spent listening to hundreds of people's stories of good and difficult declines and deaths.

I've learned one thing, people who are willing. To contemplate their aging, vulnerability and mortality often live better lives in old age and illness and experience better deaths than those who don't. They keep shaping lives of comfort, joy, and meaning, even as their bodies decline, they get clear. I learned about the trajectory of their illness they can plan. They regard their doctors as their consultants, not their bosses. They seek out medical allies who help them thrive even in the face of disappointment and adversity. And they prepare for a good death. They make peace with the coming of death seize the time to forgive, to apologize and to thank those.

They love, they rethink of hope and they often die with less physical suffering and just as much attention to the sacred as our ancestors did.

Yael Schonbrun: [00:16:40] I love that. And you and I had emailed a little bit as we were preparing for this interview, talking about how your work really applies to the field of mental health. And I think that what you just read and what we've been, what you were talking about in terms of acceptance, really fits into the kind of therapeutic approach that I am.

The other cohost of this podcast use, which is called acceptance and commitment therapy. Right? The acceptance part is really central

Katy Butler: [00:17:03] Yeah.

Yael Schonbrun: [00:17:04] and. I mean, it might kind of how I take what you're saying is while we can't change the reality of death, the inevitability of it. Well, we can do is learn to relate to it in ways that are optimal for each of us.

And according to acceptance and commitment therapy, ideals, we can ask ourselves. About values, what we want to stand for. We can reflect on how our values can be translated into committed action early on and, and closer to the end of our lives. And I really think what's so cool about much of your writing is that it really gets to the heart of how we can identify our values.

And also what kinds of optimal committed actions we can take to make end of life, something that's meaningful, you know, maximally meaningful for each of us. And for those that we love. Um, and so. You know, you talk a lot in your books about the differences in how you experienced and what you saw your parents experiencing that your father's death was really, um, disempowered, because he hadn't been able to ask those questions and communicate, and your mother's was very different in terms of her ability to accept the end of life and make really clear decisive decisions and involve you guys in them to some extent, but that it was really a lot of.

Her choice. So I wonder if you can talk a little bit about the difference in terms of acceptance and yeah.

Katy Butler: [00:18:22] Yeah. And I do think acceptance and action. They're always in a dynamic balance with each other. It's never just one way or just the other. My dad's decline and death made clear to me that the default option in modern medicine was not in attunement with the values of our family, because the is to treat, treat, treat until someone says stop or no. And the, even though. Regular human beings have a lot of values that they care about as they age and die. The assumption within medicine is very binary, which is people want to stay alive as long as possible. And that is their only goal. And so you actually to be quite proactive in these days to create a pathway to the end of life. That is in tuned with your values and you may fail then you have to be able to accept that to you. There's a limit to how much and influence you're going to have. But so my dad died over the course of seven years, really, um, destroyed my mother's health in the process as a full time caregiver.

Yael Schonbrun: [00:19:39] you talk a lot about your efforts to try to get the doctors to turn off his pacemaker and how you failed in those attempts and how painful that was for you and your mother.

Katy Butler: [00:19:50] it was extremely painful because it was so painful to even get to the point of asking. It was, I think about six or nine months before his death, when we actually asked to have it turned off because my mother just realized he was miserable. was miserable.

Yael Schonbrun: [00:20:05] Right. You have this quote in your book where he tells you I've I've lived too long.

Katy Butler: [00:20:10] Yeah. He said three poignant things.

In those years, he had a lot of stroke damage, but he, he said it would have been bad or for your mother, if I died of the stroke, I'm not going to get it better. And then he said, I'm living too long. And those were over the course of several years. Now my mother, as you might imagine, my parents were, my parents are South African. And I don't know, there's something about American culture around this. That seems different even from other Northern European type nations. Um, and they were very blunt about things like that. They had advanced directives. My mother, my mother had a mentor, right. South Africa when she was in college.

Who actually chose to end his life in his seventies cause he was developing dementia.

So she always had this sort of fierce Zen warrior to her. But I think when she, when she experienced what she said was the hardest thing in her life, which was caring for my dad for seven years. She, I don't know. I think she wanted to put us through one and I don't think she wanted to put herself through. And so she looked very, she developed heart problems. There was a big push to get her to have open heart surgery, but it actually turned out she had two different heart probe problems that kind of went in the opposite direction. So if they had treated one, it would have actually made the other thing worse. Um, and she had a heart attack about a month before her death went on hospice almost immediately after that. Wasn't easy for her. She said to me, at one point it's hard to give her a Pope and she was a very vital person. And then a month later, basically had a collapse and took off. This is the thing I loved. had these earrings, she wore all the time, the silver earrings. when she was in hospice, they took her to an inpatient hospice unit after the second crisis. And she said, I want to take off my earrings. And the nurse said, you don't have to take off your earrings. This is a hospice unit. You can wear whatever you want.

And she said, no, want to get rid of all the garbage. And I think that was her way of saying make it, I came into this world and make it, I will return. So she was, she was a warrior that didn't make her death easy, but it was definitely the death she chose for herself.

Yael Schonbrun: [00:22:47] Yeah. Well, and, and that's another part of what I love about your writing is that you talk about this question of what, what does it mean to die? Well, like what is a good death and you Don't make any bones that it's easy. It's not easier. Pain-free not for the person who's dying and not for the people who are around them witnessing it.

But, but I wonder if you can talk a little bit about how you understand, what does it mean to die? Well, what is it, what is, what does that look like?

Katy Butler: [00:23:14] You know, it's fascinating to me the first time I was asked that like, what's a good death. How, hard it was me for me to articulate anything, which again, speaks to the culture that we're so unconverted this landscape. I now see it as. Some people really argue with the term, a good death. They say, nobody should talk about a good death.

Deaths are not performances spiritual or otherwise. Right. So that's one thing to talk about the dying person and say they have no obligation to. Act in any particular way or say the right things or go gracefully. They don't, they could go angry. They could go frightened, but I think we do have an obligation to think about a well-supported death. Because dying takes a village. Dying is relational. The enemy is emotional. Dying is spiritual. Dying is practical and medical. It's all those things at once. So for me, there is some, it's almost like Maslow's hierarchy, cave needs, know, at the very bottom you want pain control. You want yeah. To be clean, you want to be in a safe environment. want to have privacy and then, then you go up from there. I think. Uh, well-supported death involves the people around you, not lying to you about what's going on, listening to you, letting you share. Um, there's some phrases in the hospice movement that I, I just love, which are thank you. I love you. Please forgive me. I forgive you and

goodbye. And obviously those are things better not to start it, you know, three days before you die. But within, you know, two or three months before you to clean things up as part of your emotional legacy to others, that you don't leave people behind with levels of regret or ambivalence or suffering. If you can, you know, you can't everything, but there's a lot of subtle, graceful, very brief conversations that are very, very meaningful and treasured by those you leave behind. So that's sort of my idea of a, of a good death.

Yael Schonbrun: [00:25:36] to me, that gets to this idea that you pose in your writing, which is, you know, to, to create some sanctity around death and whatever in whatever way that, that looks to you. I mean, I think. Often it doesn't look totally medicalized. And yeah, part of the problem is that we really dropped into this position of, um, medicalizing everything around the human body. And that really reaches out a lot of the sanctity that happens towards the end of life. And so anything that you can do even in, and you talk about this in, um, the art of dying well, but you, you can even inject some sanctity. When you're in a hospital room, but it has to be with intention. And that that's where the clarified values come in handy.

Because if you sort of say, it's important to me to have some rituals and some connection and you know, saying those kinds of words, like, thank you. I love you. I forgive you. Can you forgive me? Then? Then you can have it wherever you are. Even if you know your loved one is on a ventilator, you can, you can engage some of that.

Katy Butler: [00:26:37] Yes, you can. I don't want to pretend that it is easy or sometimes even sufficient, but do talk about. In the book, for example, I have a candle. don't think you can see it, but it's around the corner, but you could, you can't bring an open flame to a hospital, but you can bring Led candle. And they really, they really do have a very sacred feeling, even though it's not the same as, as the real thing, but it's close.

And to simply have some signal in the room that you care about the spiritual or sacred dimension of what's occurring, however you define it, I think is very helpful for people

Yael Schonbrun: [00:27:26] Yeah,

I was just going to share a personal story that, um, so my father. Similar to your father had a very severe stroke. The, his was caused by a metastasized tumor, and then he struggled with cancer for another two and a half years before he passed away. And he was in and out of the hospital a lot towards the end. And we did manage to get him home on hospice. I wanted to talk a little bit about hospice because I'd never experienced anything and with it, helped us as a family, get through it in a way that I wouldn't know and able to do without them. but what I was going to say is, he fell into a semi coma the day after he came home on hospice and we had a chaplain come and we're not a very we're Jewish, but not religious. And this chaplain performed this beautiful ceremony in the home with, um, My father, my mother and my two siblings.

And my father was in a semi coma at the time. And. It was so touching. Yeah. And at one point we laughed because my father we joked that he was going to sit up and say, screw this religious ceremony. But there was something so beautiful and connecting, and we were able to say all the kinds of things, you know,

express, gratitude, express, how he would live on through us. And it was one of the most meaningful things I've ever participated in. And I was so grateful for it.

Katy Butler: [00:28:48] Yeah, I did something similar with my father when he was on this hospice unit dying of pneumonia. We had decided not to treat the pneumonia let him go and a Anglican. Volunteer chaplain came by and I sort of with my mother. My mother would have, I don't know what she would have thought because they were both atheists agnostics.

Um, and we did the book of common prayer Anglican. , last right, and even though the language of the company of the saints didn't really speak to me and I didn't think he was going to like a conventional heaven. There was something about speaking words that said, essence, I turn you back over to the benign forces of the universe. You know, the great beyond that we all rise out of and return to. I was sort of almost surprised with myself that I ate that I did it and B that it was such a positive experience for me.

Yael Schonbrun: [00:29:52] Yeah.

Katy Butler: [00:29:52] are we going to talk a little bit about hospice? Do I, would I have a couple of thoughts about it?

Yael Schonbrun: [00:29:56] Yeah, please.

Katy Butler: [00:29:57] sure. First my father even went on hospice, a palliative care team came to the house, an outpatient palliative care team, was really very similar to what a hospice team would have done, but it was team approach and it was. advice, like up the throw rug. So he

Yael Schonbrun: [00:30:17] Okay.

Katy Butler: [00:30:17] and fall get a baby monitor for his room.

So you don't have to get up all the time to see if he's okay. It was like, It was like this global look at the situation where up until that moment, fragment male medical system, individual doctors had looked at individual malfunctioning aspects of his body. And that was about as far as anyone had gone, it was such a relief. So palliative care and hospice, I think are wonderful. I think there are drawbacks. I think people have extreme views about hospice on both ends. The most extreme negative view is they give people more phene and make them die. And people don't realize that people who are on morphine often develop high tolerances over time. And that. Morphine is very unlikely to hasten death. Um, although large enough quantities it can. So there's that feeling that, Oh, the hospice just wants to

Yael Schonbrun: [00:31:26] Okay.

Katy Butler: [00:31:26] There's I've heard that from very well educated people. The other extreme is hospice is the cure for everything. And again, have to return to our highly fragmented the medical system. They're only paid so much a day to come in. The result is that over the 20 years, that hospice has existed, it's reimbursed by Medicare. It's reimbursed by private insurance over the time of its existence. It's pretty much eliminated hands-on bedside care over time. Like you have to either have a strong social network or enough money to hire part time caregivers because they're hospice. The nurse will come in, like chaplain will come in. It will be very, very helpful. They are geniuses at pain control. They're probably the most informed of any medical professional, the most skilled. But if

you are expecting, someone's going to be there at the moment of death or that someone's going to help you diaper or change or any of those things. It doesn't happen. And I think that's a failing of it, the system, and we ought to be right organizing and benefit of the reimbursement they get should be tripled so that they can actually pay for more bedside care.

Yael Schonbrun: [00:32:44] okay.

Katy Butler: [00:32:45] and you don't have a good social system, but you can't hire people to come in you live in a neighborhood that's so dangerous that you can't keep morphine in the house. The whole ideal of dying at home, which I understand people's they want to be full people as they die. And they also want to have autonomy in space that they're dying their family want to be free. You don't want to have to ask for everything. It's so understandable, but I think it's also out of reach for some people and that this is the acceptance part.

We also have to acknowledge that and not beat ourselves up. we can't it happen.

Yael Schonbrun: [00:33:24] Yeah, I think that you said in a podcast interview that I was listening to that, you know, death Oh, is involved some regret. I did too much. I did too little. I wish I had said this. I wish I hadn't said that. And that's inevitable and it do think self compassion is quite useful in that place.

That a good death is not, does not mean pain-free and does not mean without regret. It means, you know, whatever it means for you, but, but we can't aim for perfection cause there's no such thing.

Katy Butler: [00:33:52] Yeah, and I love the term, a meaningful death. I think it's possible to have a very meaningful death. a lot of that has to do with thinking about your emotional legacy. You know, none of us like 70% of people don't sign advanced directives, even though they're told constantly that they should. But the reality is that's an incredible gift to those who survive you, because at least you're going to take that type of regret off the table.

If you've been very explicit about what you want and don't want, and

Yael Schonbrun: [00:34:24] Yeah. Well, can you actually and define what an advanced directive is? Cause I would say that before my father passed away, I had no idea what it was. And when EMT came to our house, when I called them, after my father on a hospice, went, had a seizure and went into semi coma. They asked for the plus and I had no idea what they were talking about.

So here's, you know, the EMT is in my house. My father's just had this crazy wild seizure. We're all freaking out and we have to go find documents. It was chaos and traumatic. So I think it's a really nice opportunity to just inform people. Like what, what is an advanced directive? What, what is it useful for?

What is it not useful for? Because it's not like everything. Nothing is a cure. All.

Katy Butler: [00:35:08] Yes. Yeah. Don't call nine one one. In that situation, you really have to have an alternative plan to

Yael Schonbrun: [00:35:15] Yeah.

Katy Butler: [00:35:16] one. If you

Yael Schonbrun: [00:35:17] Yeah.

Katy Butler: [00:35:17] at home. Um, advanced directives came to be because there were some extremely troubling cases of people being kept. Alive, , for years and years with no brain function and, but maybe some level of suffering that we couldn't even gauge.

People being kept alive on feeding tubes on ventilators. Um, and these were very upsetting to the general public. The first thing that got invented was called the living will, which is now morphed into the advanced directive and its original purpose was to try to reclaim and restore autonomy to the average Joe and Jane, so that they would not find themselves in that position of having been resuscitated usually by an EMT massive brain damage had taken place. So these documents are to affirm our right. To choose and reject medical treatments. And we have a constitutional right to, to or regroup or reject anything and we can have our own reasons. So it doesn't have to be medically approved. So an advanced directive usually does two things. One, it picks somebody to make your medical decisions when you can no longer speak for yourself.

And that's very important because we have this advanced technology of medical care. You may very well spend some days or longer being unable to speak for yourself. So it picks somebody and then it also talks about treatments that you want and don't want. So you're women, know, some of them there's a lot of boiler plate.

And so I really advise people to talk openly, informally, go to a coffee shop owner. Can't go to a coffee shop now, but know, sit down around a table. can outdoors six feet away from each other couple of, a couple of cups of tea.

Yael Schonbrun: [00:37:20] With masks on.

Katy Butler: [00:37:21] Yes, exactly. Yeah. And really talk about like what makes my life worth living.

Yael Schonbrun: [00:37:27] Yeah.

Katy Butler: [00:37:28] I couldn't be restored to that level of functioning, what are the treatments that I would want? And what are the treatments I would refuse? So that's what an advanced directive is. It's unfortunate. They become so legalistic in their language, their check boxes. It's good for the medical people, It's not that great for the average person, because, because I think they're intimidating. They make your eyes. And they're very important though. So there is one called five wishes, which you can find online for \$5. You can get a copy, but what I love about five wishes, it includes things like. I would like to be massage with oil when I'm dying.

This is the music I'd like at my funeral. are, um, you know, I would like to be read the poetry of Mary Oliver. I would like to be read from the Bible, whatever, whatever makes you feel and connected to something larger than yourself. And I think if you could approach it in that spirit of giving to the next generation, And also the spirit of helping you die in a way that is meaningful for you and supportive, and comfortable or reassuring, whatever it is that you need. These documents can be very, very helpful. So do you want more detail or that's enough? Huh?

Yael Schonbrun: [00:38:53] Um, I would listen to you talk about this forever, but I just wanted to sort of add that for, for me. I mean, I think watching somebody that you love die is a really terrifying experience that you feel really out of control and I'll disclose, um, that after my father died, I, I just felt a lot of. Obsession around mortality and fear of deaths and what was happening to him.

And I think what was so helpful to me in your books was realizing that I don't have control over dying, but I have control over how I approach it. And I think

some of those things like, you know, being clear with myself and my loved ones about what I would want, which I think is actually pretty different than what my father would have wanted.

But part of what was so difficult about watching him die is that we hadn't had those conversations. And so I didn't really know, but what helps me to feel more. I don't want to say confident, but just more comfortable with thinking about my own mortality is knowing that I can even now, you know, 40 years old.

So I hopefully have more time, um, start having those conversations about what feels really important and it really reduces my terror and. I think right now we're living with so much terror around mortality because of this pandemic. And it can really give you something to hold on to.

Right. This question of what's important to me, how do I want to manage living and how would I want to manage dying if it did come to that. And I think that can be really soothing in the scary time.

Katy Butler: [00:40:26] Yeah, a friend of mine likes to say worrying doesn't do us any good, but planning relieves worry. I just, I love that. And to think about this time that we're in, um, this might say way really nicely into a question that you asked me an email ahead of time, which is that we're seeing this epidemic. Of what I consider the very types of deaths that I two books to help prevent, which are deaths in intensive care with somebody, with a tube down their throat, unable to communicate with family.

And now absolutely deprived of all family. A lot of hospitals, the minute you go into the hospital

Yael Schonbrun: [00:41:14] And even real and any social connection at all, because all of the medical personnel are wearing all this garb and it just feels so dehumanizing. I imagine

Katy Butler: [00:41:25] and I think it is creating an epidemic of moral distress and PTSD among healthcare workers. think it would be traumatic for them. In any case you might see eight or nine deaths in a single shift. If you're in a hotspot. But to combine that with this feeling that you were depressed, driving people of something.

So ancient, I mean, the idea of a death vigil goes back thousands and thousands and thousands of yeah. Of years. It is in our bones. It's in our DNA. And I think this whole concept of moral injury or moral distress when healthcare people feel that they are having to enforce rules that on some level seem really wrong is, is making it lot worse. And again, I, you know, this is the activist in me. I understand that hospitals surgeries may have to create. Draconian guidelines, but I do, I think six months in now, we know, I know enough about PPE. We know enough about how it's spread. This is inhuman to be running nursing homes and to be running hospitals and disallowing all visitors whatsoever.

I know some hospitals are changing, but I really. We, I think it's important to in a safe way. Change this, I wrote a piece that I couldn't sell to anybody and I have no idea. What about a pop up hospice that was created in new Orleans? This wonderful organization called the heart of hospice, which is a profit hospice chain in the South. Those women who were scattered across the South got together. And within two weeks they set up a inpatient hospice unit on a disused floor, one of the new Orleans hospitals, and they allow two visitors a day for as long as they

want to stay. They can even stay the night you know, it's family members, they're all gown.

They're massive Um, if hospice chain in the South can do it. Tell me why major, major medical centers with huge billion dollar budgets. Can't figure this out.

Yael Schonbrun: [00:43:54] Yeah, I would love to read that piece. I hope it, I hope it gets published so, so I can totally get behind some of the recommendations that you're advocating.

Katy Butler: [00:44:06] Yeah.

Yael Schonbrun: [00:44:06] Given where we are and given, you know, sort of our discussion of acceptance am kind of curious. What, what do you recommend? I mean, in terms of how can we seek to help loved ones or even ourselves die?

Well, You know, dying, meaningful death when death can mean at this point, not being with family, being intubated, being quarantined in a hospital, being surrounded by medical professionals and PPE. What, what can we do in the face of this tragic set of circumstances?

Katy Butler: [00:44:34] again, I think contemplating ahead of time. I mean, I'm in my seventies, I'm 71. That means I could die in a month if I got this thing, even though I'm very healthy, otherwise it's, it's a possibility in a way that it hasn't been a possibility really. at least not on my radar screen. I have several pieces of advice. The first is, do think about what links do you want to go to, to try to live. For someone in my age group, who's also a BESE or has heart problems, asthma lung problems, like 88% of people like that are dying in intensive care after they've been incubated. So you might decide those odds are not good enough for you. might sign an advanced directive that says, I don't mind going to the hospital, but, I don't mind supplementary oxygen and drugs or whatever. if it gets to the point where the only way to quote save my life is to intubate me.

That's the point where I would like to switch to comfort care and have lots of meds and hopefully a family member holding my hand.

And if not, to have to hold the hand of whoever reaches their handout and. Quite a few and doctors and chaplains and orderlies are doing that. They're sort of stepping into the spiritual vacuum and doing the best they can. So that's one thing is making that threshold decision of how medical care are you willing sign on for, despite the risks that you might end up having a death that is less ideal than the one you hope for. The other thing I suggested. I think a lot of this is about the survivors. Oh, if you are going to the hospital regard the moment, you say goodbye to your loved one at the hospital door, regard that as your final goodbye, sure you get said everything at that point going to regret.

Not saying whether it's thank you. I love you. That's the moment because there's no guarantee what you'll be able to communicate again. It could go South very rapidly. The other thing I would say is let's take care of the survivors. There's something in our guts that tells us we ought to be there to support the people we love.

It's very, very I have a couple suggestions and one, and they're all about using ritual ways. I was introduced to the yard side candle some years ago when I was mourning my mother's death and I just love it. So the yard site is a Jewish ritual on the anniversary, usually the anniversary of a death. So I would make a little

altar on a tabletop, basically. Candles flowers, photographs of my parents when they were beautiful, you know, in good health. And then you light this candle. It burns for almost exactly 24 hours and there's something so wonderful about really valuing and remembering them. Right.

And also having the light go out and having the sense of, okay. Life is evanescent evanescent. The LightSail. My thought is if you need to do a death vigil and you can't be there, physically use something like a yard side candle and hold a virtual in your own house. So put up photographs, put up flowers, light a candle. Remember that person and be with that person in imagination, the same way that you would like to be there with them physically. And can't be. There's also a really beautiful ceremony in my book, which she's a bathing and honoring practice. It sounds similar to what the chaplain I did with you, but it's, I I'd love to read it if you think you have

Yael Schonbrun: [00:48:41] Please, please. Yes,

Katy Butler: [00:48:43] there's other things.

Okay. Okay. So, and I've noticed that when I was giving bookstore readings, I would read this ceremony as the close of my talk. And a lot of people would close their eyes in the audience and then they would come up to me afterwards and they said, I did the ceremony in my imagination for someone that I loved who died and it didn't go the way I would have hoped. And so I feel psychologically the things we do in our imagination, they register on a deep level for us as real.

Yael Schonbrun: [00:49:21] Yes,

Katy Butler: [00:49:22] And that going to have to use things like this until, until we develop some other workaround, they're going to be. I don't know. And like you said, which is, also gotta be just grateful for what you do get, you know, grateful for that chaplain who takes extra time or conveys how you feel, or that nurse who holds the telephone up to the person's ear, whatever it is.

There's so many of these acts of kindness. Taking place in hospitals under great duress. Okay. So now I will read the bathing and honoring practice, which was created by three oncology nurses in Santa Barbara. And there was a change in their hospital protocol so that instead of, of treating bodies with dignity, By a local funeral home, they were getting kind of zipped into body bags and trundled out the back elevator.

And they was very disturbing to these nurses because they knew these patients really well. Cause oncology people tend to come in and out, you know, for awhile. So this is what they did. Um, After washing and dressing the dead flows from home or a clean gown, the nurses encouraged relatives and friends to anoint the body with lavender oil. The physicality seems to be very helpful, said Beth coms is one of these nurses. I have a theory that after witnessing a death, we go into shock and our minds become numb and chaotic. When we start bathing and touching our loved ones, bodies understand what our minds cannot. And here is their ceremony. As the hair is anointed with oil, nurse, or a family member recites, we honor Jane's hair that the wind has played with. Next. A dab of oil is gently rubbed on the brow. As someone says, we honor Jane's brow birthplace of her thoughts. In each succeeding sentence, the name of the dead person is inserted at the appropriate place. We honor your eyes that have looked on us with love viewed the beauty of the earth. We honor your nostrils, the gateway of breath.

We honor your ears that listen, our voices. We honor your lips that have spoken truth. We honor your shoulders have borne burdens and strength. We honor your heart, heart that has loved us. We honor your arms that have embraced us. We honor your hair that have held our hands and done so many things in this life. We honor your legs carried you into new places of challenge. We honor your feet. That walked your own path through life. We give thanks to the gifts that you have given us in our lifetime. We give thanks for the memories that we created together. We have been honored to be part of your life.

Yael Schonbrun: [00:52:41] It's beautiful.

Katy Butler: [00:52:43] Yes. Yeah. I just love it. And um, and you can even. Recite it for yourself and touch the

Yael Schonbrun: [00:52:51] Yeah.

Katy Butler: [00:52:51] parts of your own body you go through it. as you know, a lot of us are very starved, whereas we're skin hungry. We're really starved for touch and even touching ourselves can feel healing and reassuring and comforting.

Yael Schonbrun: [00:53:10] Right. Yeah. Self touch. And so there's something physiologically powerful that happens when we engage that. Even when we can't do it with somebody we love. Well, I, I love, I love what you just read and I think that's, um, you know, just one powerful example of some of the suggestions are really practical suggestions that you offer in your writing in terms of how to handle the death process in ways that are meaningful. And again, I just want to sort of come back to this idea that, you know, there are things that we don't have control over.

We don't have control over death. We don't have control over this pandemic and the circumstances that it's bestowed upon our entire world, but there are some things that we do have control over and we can use the opportunity of being confronted with death and dying to help ourselves clarify our values and identify committed actions around dying, you know, asking ourselves the kinds of questions that you suggest in your book, making death more sacred, um, and. You know, asking ourselves that most general question of like, you know, what, what would make death and dying most meaningful for me and there. And then what can I do to sort of embody that? And Katy, you end knocking on heaven's door with some ideas of what you wish you'd known. you wrote that natural death is not the default pathway and that is what you. If what you want is a natural death that you need to be very deliberate in, carving it out. that the slow medicine path to death is one of acceptance, but it's not pain-free and sort of the difference between slow death versus the more, common medicalized death and that you can't control whether a loved one will die, but you can influence the manner of their dying

Katy Butler: [00:54:55] Yeah.

Yael Schonbrun: [00:54:55] and then acceptance.

Katy Butler: [00:54:57] and to address that question of, of meaning, like when you asked that question, I thought, well, I think the most important thing to me is that I don't leave my loved ones in worse shape than they have to be in. You know that don't contribute in some way to there. um, I think that's probably one of my goals and I did want to talk about, I have a Facebook group called slow

medicine, which everybody is welcome to join. It's about 6,000 people now, and it is a lot of family caregivers or people who have been family caregivers often with aging parents, but also very wide spectrum of people in medicine. Hospice nurses, social workers, So people get a lot of support as they are going through this bewildering process of trying to make decisions. About I say yes to what do I say no to, you know, is this a harbinger of the end or is this just a blip? All of this kind of question that we don't, we don't see it enough. We don't talk about it enough. We don't live in multigenerational families enough that we could have seen this with uncles and aunts and whoever. Anyway. So whole idea of slow medicine is that we now live with a very fragmented medical system. That honors and pays for big ticket interventions and not careful time consuming work of establishing a real human relationship, a healing human relationship with your cardiologist or your. Personal doctor. And this is really in contrast with fast medicine and fast medicine is fabulous. If you were just in a major car crash or you just had a heart attack and you rush the time to call nine one, one rushed to the ER, get, know, intubated, all of those things could really your problem, but slow medicine is very much for all the things we can manage, but we can not fix. And there's a movement. It's an international movement among doctors who are saying the same thing. We need more time with patients. We need time to think, especially when people have chronic illnesses doing more is not necessarily doing better.

Yael Schonbrun: [00:57:31] I wonder if you can actually give the specific example that you, um, given your book of the remuneration for a cardiologist who does an intervention. I think specifically the one who put in a pacemaker for your father's condition, this is a conversation with a family physician they're just compensated so differently and it really does.

Create a system that incentivizes fast medicine, instead of the careful thoughtful kind of approach that we might take when there's a lot of problems that can't be fixed, but rather need to be managed over time.

Katy Butler: [00:58:03] Yeah. Well, my dad's primary care doctor would have been paid something like, I can't remember if it was 46 or \$64 have a long involved. Discussion with my both parents. One of them was stroked damaged about whether or not a pacemaker was a good idea, but the surgeon who put it in got seven or 800, the people who made the goes something like 12,000 for what's actually like a.

Pretty simple electronic metronome. And hasn't really changed that much in 20 or 30 years, you know? Um, shouldn't be more expensive than an iPhone, really less complicated than an iPhone. So there's this tremendous disparity and I'll give you another one that is in the second book, which is unfortunately, oncologists make their money from essentially a commission or markup the price of chemotherapy that they deliver.

So. It's just terrible. They get almost no pay for having a discussion with you about whether the third or fourth round of chemo is even a good idea, which the fourth round is not. And the third is, you know, maybe, maybe not.

Yael Schonbrun: [00:59:13] I just,

Katy Butler: [00:59:14] all their money.

Yael Schonbrun: [00:59:15] And so my father's oncologist was , it's just, the

system is so messy, but after he passed away, it fell to me to call the oncology office, to let them know that he wouldn't be coming in. And the response was, Oh, that's too bad. He had really wanted to try another round.

Of chemo and it was, I just, you know, it was one painful experience in a very painful time in my life, but I just remember being like floored that that was the response because he had been so sick for so long. And I actually think he did want to keep trying to fight, which, you know, I, I'm not sure that I would have made the same choice, but it did.

It just, it pained me to hear that kind of a response and I think that the system is just set up in this way that, you know, more treatment begets more treatment until it's past the point of possible to even offer anything.

Katy Butler: [01:00:14] And more treatment equals hope or Mo more treatment equals caring, know, doing everything is somehow the same as caring for somebody, I think. Yeah. I think it's, it's really and it's like, it's expecting people. You know, I'm, I'm not saying that I think oncologists are like just money driven and that's why they do what they do.

Yeah. But it's like, you're asking people to go against their own self interest in order to do the right thing. And if you look at that on a systems level that just like never works.

Yael Schonbrun: [01:00:48] Yeah.

Katy Butler: [01:00:49] I think one of the hopes of both books that is to restore people's confidence in their own best judgment and the best way of knowing that your dad. Was being helped or not by chemo on how he was actually functioning, how he felt. I have a yeah. And people lose touch with that. And the oncologist will say, well, let's wait for the next scan. Let's

Yael Schonbrun: [01:01:16] Right.

Katy Butler: [01:01:17] until we see the scan, the scan might show shrinking tumors. the bizarre thing is the shrinking tumors have absolutely no relationship weather.

That treatment is quote, working on the ground in the city. the person feel better? a person going to get better more or weeks or days of life? It actually has no relationship. And yet the FDA approves these drugs

Yael Schonbrun: [01:01:42] yeah.

Katy Butler: [01:01:42] considers them effective. If they shrink tumors. see what I'm saying?

Yael Schonbrun: [01:01:46] Yeah.

Katy Butler: [01:01:47] I mean, a friend of mine right now, now, you know, a woman who married me the first time. I'm sorry. That's very confusing. She was the officiant at my wedding. Um, she had dementia. She also had stage four cancer. She was being given immunotherapy. She was getting every side effect in the book and her tumors were still hurting her. And yet the oncologist wanted to keep going until the next scan.

Yael Schonbrun: [01:02:18] Yeah,

Katy Butler: [01:02:19] I had a big email exchange with her daughter, um, where I was blunt, but hopefully not too directive. Um, and I really just had to give her and her brother some support about so that they could actually act on their own

gut feeling about it. So one of the things I just want to leave people with is. You know, trust your gut, check in with your gut, you know, more than you think, you know, and it may be intuitive and you may not be able to use medical language to describe it all. But I, I started with my gut and then I did I didn't what seven years worth of medical research. And it sort of came back to wow. A lot of those gut instincts they were right on. So my big thing. Believe in yourself and in your love.

Yael Schonbrun: [01:03:10] Yeah.

Katy Butler: [01:03:11] you know, the people you love better than anybody else's. And you're the only one who is the expert on your values and what makes sense for you and how, how much suffering you are willing to undergo return for the gamble of more time on earth. But at the same time, I mean, the book talks about this it's really. Has a whole section on coaching, you speak to a doctor because do need to draw out an honest answer and there are forms of hope that are different from you're going to live forever, or you're going to beat this. That is not the only kind of hope. You know, there's a hope of leading you, leaving your daughter in good shape. There's the hope of maybe doing a watercolor or dying under the stars. There are other hopes besides. one hope. And I think it just is, it's only fair to us to know when that hope is unrealistic hope, dishonest, hope.

Yael Schonbrun: [01:04:09] Yeah. Well, I love the message to trust in ourselves and not to overly, um, idolize medical experts because they have expertise, but their expertise is you're saying is not in us. And our values are in what is going to necessarily make the most sense for our loved one. And I'll just also read a quote that I love from your book.

I like to read people their own writing, which is that the time may come when the most loving thing is to actively advocate for doing less. And I think in our culture, that that is really hard thing to do because we equate love with doing and doing more. But. Like in so many spheres of life. And I talk about this a lot on the podcast in return in terms of parenting, but I think in terms of mortality, that, that is true too, that it, and it is important to check in with yourself about when that time is to sort of let go and find peace.

Katy Butler: [01:05:06] Yes. Yes. And very much so, um, in the art of dying well in a hospital death, maybe you want to bring in candles. Maybe you want to smuggle in the dog. Maybe you want to get the person moved to a room with natural light, but there also comes the moment when you need to just surrender. Because the point is not any perfection or external stance, it's a peaceful death. And that might require I'm not arguing with anybody just accepting everything as it is, and being as able as you can to really just be there with an open heart and be there.

Yael Schonbrun: [01:05:53] Thank you. Thank you, Katy. We'll link to your books and other writing, because this is certainly a topic that many of us really need to sit with before we can find sufficient clarity. And thank you so much for your help. Um, and to me personally, in taking this important part of life's journey,

Katy Butler: [01:06:09] Right. Thank you. Yeah, you enjoyed it.

Diana Hill: [01:06:13] thank you for listening to Psychologist Off the Clock. If you enjoy our podcast, you can help us out by leaving a review or contributing on Patreon.

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