

Dr. Shoshana Ungerleider:

By default, you will receive very aggressive invasive treatment, if you show up to a hospital and you're ill. This is no matter how old you are, how sick you are, and sometimes even if it won't help you in the end, our default protocols in medicine are to do everything. That makes sense if you're young and healthy and that's what you want, but it doesn't make sense for everybody.

LuAnn Heinen:

That was Dr. Shoshana Ungerleider who founded the nonprofit, End Well, after wondering what her patients would've wanted for their final days, if they were asked. A physician, speaker, producer, writer, convener, and host of the TED Health Podcast, Shoshana is passionate about transforming the end-of-life into a human-centered experience. A practicing internist, she's been involved with two academy award nominated Netflix documentary shorts, *Extremis* and *End Game*. Her most recent project is *Robin's Wish*, a documentary film about the life of Robin Williams.

I'm LuAnn Heinen, and this is the Business Group on Health podcast, conversations with experts on the most relevant health and well-being issues facing employers. Today, Dr. Shoshana Ungerleider and I discuss infusing humanity into clinical care, especially for those experiencing serious illness and nearing end-of-life, and the role employers can play.

Today's episode is sponsored by Virgin Pulse. Virgin Pulse empowers people to lead happier and healthier lives by engaging them in personal and rewarding ways throughout their health and well-being journeys.

Shoshana, I am so excited to have you on the podcast. I may be one of the few people you interview who's really interested in death, in dying, and end-of-life. I'd love to get started by having you tell us a little bit about End Well.

Dr. Shoshana Ungerleider:

Oh, well, my goodness. Thank you so much for having me. I've been really looking forward to this conversation for a long time. I'm a physician by training. I'm a general internist and really early on in my internal medicine residency, I was spending months and months, like all residents do, taking care of very, very sick patients in the intensive care unit. These were often very medically complex, physically frail older adults who were spending their final days, maybe even weeks or even months of life, in the ICU hooked up to tubes and machines, being poked and prodded. I realized that so many of them were really suffering and there was this gap of kind of awareness and expectations between what the medical team was doing and what the patients and family and even caregivers thought was going on or was going to be the trajectory of this person leaving the hospital or getting better or regaining their baseline function.

When I figured that out, I realized that there are so many points along the way of a medical journey, of an illness, that we can be forthright and honest about prognosis with our patients, with talking about things like goals of care. They don't happen and it turns out there's a million reasons for this. I'm sure we'll talk a little bit more about this later, but I realized that we were doing such a disservice and actually harming our patients in many ways because the care that they were getting in and around the end of their lives was care they didn't understand and oftentimes didn't want, but they didn't know to ask those questions and it certainly wasn't in line with their goals and their values. I got interested in thinking about how we can change medical education to make this better for everyone. Then I got thinking about how do we shift the cultural conversation around death and dying, inside of medicine and, of course, outside, because that's such a big part of the problem as well. So I started End Well really as a conference, as a national or now international convening, to bring people together from all walks of life, all different professional backgrounds, to talk about what living and ending well can look like and how do we come up with interdisciplinary solutions to make these experiences around serious illness, around caregiving, around death and dying, as well as grief and loss, less hard for people. What can that look like in a society when we do a better job of that. End Well started as a conference and it has grown into a content platform, and, of course, we're a non-profit and just trying to help push this movement

that's been going on for many, many years. We weren't the first ones to be talking about this, but we're certainly trying to push this movement forward so that ending well can be possible for more people.

LuAnn Heinen:

There have been efforts, as you mentioned, like the Conversation Project, and we talk about having the conversation. Why is it so much harder to have the conversation about end-of-life than it is to talk about other caregiving needs?

Dr. Shoshana Ungerleider:

Well, I think there's a few ways to kind of think about this. For me, and this is just my perspective, it starts with really a societal stigma or the taboo around talking about death and dying. I think it's inherently a really challenging subject. I think we're sort of wired evolutionarily to avoid death. That makes sense to me. I think also because illness and the end-of-life are really hidden away in modern culture. About a hundred years ago or so we didn't have modern medicine, so people would become sick. Granted, they were much younger than when people often died, and they would die in their homes, surrounded by family and community. That was sort of expected. We knew what to do when somebody died. We had ritual around it and it was sort of seen as a part of life. As medicine progressed, as science progressed, which is so wonderful, we have more hospitals and places for which people can be treated. Therefore, kind of the aging and ending parts of life are often relegated to institutions. So children don't grow up necessarily seeing older adults become sick or nearing the end of their lives. We just don't see it as a part of life. I also think, again, I could probably talk for hours and hours about this, but in medicine we see death as a failure. We do everything we can to avoid failure. I think that is tied in with sort of the cultural narrative around death and dying. I also think we have a lot of perverse incentives in medicine that I can talk a lot more about. All of that together puts us in a tough spot around talking about the end.

LuAnn Heinen:

In your documentary work and certainly in Atul Gawande's beautiful book, *Being Mortal*, and that was also a PBS show, you have been getting the word out and others have been getting the word out. I'm curious as to how you, in your content platform, how you've attracted kind of high-profile individuals, people like Andy Cohen, Maria Schriver, Meghan McCain, I think Roger Daltrey's on there, and maybe Tim McGraw, and all kinds of people who are present on your platform or have spoken at your events. Do you feel like that's a way of trying to destigmatize the subject and normalize the conversation?

Dr. Shoshana Ungerleider:

That's absolutely right. I actually couldn't say it better myself. I mean, that was really a strategic decision that we made early on when we realized that there was a there, there with End Well, with this conference, and with this content. After our first year of the conference, which we weren't even sure if anyone would show up because no one had done anything like this before, certainly not in the health care industry, meaning inviting really diverse groups of people together in a TED style, more narrative format. We sold out three months in advance and then had hundreds of people on the waiting list to attend. We realized that this type of content was really conducive to short-form videos that we put out on social and quickly got tens of millions of views of this content just organically. We were shocked by that. Then spending a little more time thinking about media and leveraging influencers, we said, well, everybody has a story, so what if we were to just ask some of these high profile people alongside the everyday heroes and the people who are academic researchers or others who are leaders in their field to come and speak and tell their story, could that maybe help, as you said, destigmatize and normalize these kinds of conversations. We've really done that and we've been able to kind of leverage their networks in order to push this content out. That's really allowed us to propel this forward even more. On stage when I got to interview Tim McGraw, who was, of course, a famous country singer, it was just an incredible experience to hear that he, in fact, dealt with palliative care and hospice with his own family and that his wife had been a caregiver for her ailing parent. It just really humanized the conversation in such a unique way for me, so we've continued to do that over the years.

LuAnn Heinen:

That's wonderful. Well, it is a really terrific website. I commend that to our audience. Any suggestions on how we can elicit and better honor people's end-of-life wishes?

Dr. Shoshana Ungerleider:

Yes, it's a great question and something I spend a lot of time thinking about. For me, depending on if you're a physician, you're an employer, you're a parent, or a caregiver, it first starts with a conversation. Well, even before the conversation actually, it starts with a personal reflection and thinking for yourself how do I like spending my time? If time were short for me, how would I want to spend it? What do I value most in my life and how do I optimize for that? Because I actually think it's more of a conversation about living, than about dying or the end-of-life. If we can revisit that conversation throughout our lives, knowing that at 25 it's going to be different answers than at maybe 45 or 75, or if you're facing a serious illness. The research shows that if somebody becomes sick and they're diagnosed with a terminal illness, a lot of priorities can shift. Knowing that none of this is ever set in stone, but that continued conversation, and again, reflection on those ideas and certainly talking with your doctor, depending on what's going on and your prognosis overall, I think can be really, really helpful and helps even within your own family culture. The more you talk about it, the less hard it gets. Certainly there are moments where these conversations can actually bring people much closer together and can bring more kind of joy and even laughter into your life in surprising ways. They don't always have to be dark, difficult conversations.

LuAnn Heinen:

The Lancet Commission, the journal, *The Lancet*, its editors pulled together these multidisciplinary, usually global experts who all come together on a subject. In January they released their report on the value of death and used that same phrase that I've heard you say, bringing death back into life. They focus on major world problems, climate change, things like that. They're now viewing this situation we have where some parts of the world there's undertreatment, people are dying of preventable conditions and without basic pain relief, and yet in high income countries, we tend to be overtreating at the end-of-life, fruitfully in many cases and sometimes inappropriately, right up into the last hours of life, as you described in your medical school training, and more and more dying in hospitals and care facilities. I think also, as you were saying, the role of families and communities is receding and our medical system has become the custodian of death. Instead of being surrounded by family members, especially in COVID, people were dying alone and not with family. Also, they're trying to resurrect this movement of understanding how the experience of death adds value to the living. I mean, it's actually a gift to be part of that. Do you think this will have an impact? Is this the kind of report that is going to reach more the professionals in the field?

Dr. Shoshana Ungerleider:

Yes, I'm a big fan of this report. It's 42 pages long and really dense, but it's an incredibly important narrative that I think, from my perspective, is right on in terms of how we should be thinking about this. The Lancet Commission and others have done this from time to time and put out large bodies of work, looking at death and dying around the world. I think it's really, really important and to do this also from an interdisciplinary perspective, I hope it makes a difference. I think that there are key points about relationships being so fundamental to the process gets lost a lot of the time when we're so focused on health care. I really love how they bring together this idea of networks across society need to be front and center when we talk about efforts to improve the experiences, because I truly think that that's a human-centered way to think about it. To make sure all the stakeholders are at the table when you're trying to come up with new solutions to problem solve. Certainly they go into the incredibly important and underrecognized inequities across care for people in societies for which access to care is a huge issue, access to pain medicine under treatment, and then on the flip side, as you said in these wealthy countries, certainly overtreatment in a lot of ways. We really have to continue to investigate this and we need to take steps to reduce this overall. The more that we can educate the public about the importance of palliative care and to ask for it. If you're somebody in a situation with a life-limiting illness or someone that you love hasn't been referred to palliative care services, it's so, so critical. Study after study shows that the earlier that people with terminal illness get referred to a palliative care team, which usually consists of a doctor, a nurse, a social worker, sometimes a chaplain or a pharmacist, the better

outcomes that they have. They have better quality of life. They actually, oddly enough, tend to live longer, which maybe is counterintuitive. But knowing that palliative care can and should be used alongside curative treatment, I think is really, really important. We need to continue to advocate for this. Then this whole idea about human-centered design. When we talk about creating new systems or policies or products and services, we need to consider how we care for each other through illness and death and make that a central piece of the conversation. I firmly believe that all of life is not going to be the best it can be unless we build how we die into the way that we measure ourselves as a society.

LuAnn Heinen:

I'm talking with Dr. Shoshana Ungerleider, founder of End Well. We'll be right back.

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LuAnn Heinen:

Can you explain the difference between palliative and hospice care?

Dr. Shoshana Ungerleider:

Absolutely. Hospice is a type of palliative care and hospice is typically designated as care for people that optimizes for quality of life, for people who are reasonably within the last six months of life. That's really an insurance designation. Typically, people are foregoing curative treatment at that point. Palliative care is a field of medicine. As I mentioned, a team-based approach to care. It tends to be an interdisciplinary, interprofessional team. They focus on how to reduce suffering for people facing a life-limiting illness. It can be from the physical to the emotional, to psychosocial, to existential distress that many, many people have in and around facing a serious illness, and can and should be used alongside curative treatment.

LuAnn Heinen:

We shouldn't be afraid of a referral to palliative care. You shouldn't confuse that with being in the last six-months of life. You shouldn't confuse that with giving up any treatment options.

Dr. Shoshana Ungerleider:

Exactly right.

LuAnn Heinen

That's great. Well, let's talk more about designing for positive end-of-life experiences. I've got to ask you about death doulas. Birth doulas have been on the rise for some time now, and we're hearing about kind of an analogous role at the end of life in a low-tech way, helping usher people through that passage, people and their families. What's your experience or knowledge about death doulas?

Dr. Shoshana Ungerleider:

Well, I love this field and I love that it's been really getting much, much bigger even throughout the pandemic. Everywhere I look, there's a news story about death doulas, or I hear of a new group of people around the country who are training people to be death doulas. I think the same ideas as a birth doula that we need support in and around this life transition. It's incredibly challenging, especially if you've never been around somebody, as a family member or a friend, who's nearing the end of their lives. The more support that you can have on hand, the better. Death doulas tend to be lay people, so you don't even have to have any kind of medical background. Although often nurses can become death doulas if they want, or of course they can become hospice nurses, which is a different thing that's more medically focused. But doulas really are non-

medical and serve as support during the dying process, during active dying, and then certainly around the death itself as well as after death and can be super helpful with everything from, gosh, what do I do with a body, to thinking about processing grief, looking for resources, being there just as another set of hands or support as in the process that I think is inherently challenging, no matter how many times that you've witnessed it or gone through it.

LuAnn Heinen:

I was also struck by some ideas in *The Lancet* report about we've lost kind of rituals around death. So that if you're a religious person, there are certain religious rituals, but for others who may be dying outside of a care facility or at home, you forget to think about music and aroma therapy, there's massage, there's all kinds of ways of bringing comfort, readings that you could provide and ways of engaging family members and friends to be part of the death experience.

Dr. Shoshana Ungerleider:

That's absolutely right. Again, the more that death is relegated to institutions, the more we've lost around ritual, knowing that for every family or every cultural tradition, these things vary, but absolutely bringing back the moments of connection for people who are sitting vigil with a dying person can be so, so powerful, and having someone there to help guide you through it like a doula can make all the difference from my perspective. I'd love to see the field continue to grow. Right now people have to pay out-of-pocket, of course, for death doulas and that makes it so that many, many people can't have access to this kind of support. I really hope that that'll change as time goes on and people continue to see the benefits of this.

LuAnn Heinen:

We know also that, one of the things we might be afraid of is the kind of anxiety and dread and mental health issues that can come to people who are in their last weeks and days of life. To that point, I wanted to ask you about the potential role of psychedelics and end-of-life care, because we have a prior podcast episode talking about the role of medically-approved psychedelics for a number of different conditions. Are you familiar with that at all and do you have a sense of how common that may become?

Dr. Shoshana Ungerleider:

End Well hosted an entire international event last year on psychedelics and end-of-life. We really tapped into this amazing network of practitioners and patients and academic institutions, as well as entrepreneurs and funders really looking at this. The world of psychedelics is honestly exploding right now and it's really exciting to see. I'm somebody that grew up in the 80s. Very vividly remember the commercial of this is your brain, this is your brain on drugs, any questions, you know, with that fried egg. For me getting past that whole thing and thinking about psychedelic as an actual medical therapeutic for which there is no addiction potential, there's so many benefits and not a lot of harm that can be done if used in a controlled medical environment. I think I'm somebody that is still grappling with that a little bit.

I think for me as a physician and scientist, my interest is helping people and reducing suffering where possible and what we know based on scientific evidence and many, many studies now that psychedelics, and in particular, psilocybin which is the active component of magic mushrooms, has been used for people facing a life limiting illness to reduce anxiety and fear and the existential dread that very, very often comes alongside a serious illness diagnosis. I can tell you that in medicine, we have very few tools in our toolbox currently to be able to help people reduce these symptoms and the medicines that we do have tend to blunt the census and not allow people to live fully until they die. Again, getting back to the data on psychedelics of which there's quite a lot, one treatment, again used in a controlled therapeutic environment with a trained therapist, markedly reduces the fear and the distress for dying people, with no side effects, and the effects last for months and months.

There's no other medicine out there like this. It's really remarkable. I'd really love to see more study happen. I'd like to see the policy shift such that this can be made available to more people. Right now outside of a clinical trial, people cannot legally access psychedelics, except for ketamine, which is the only psychedelic.

There's a lot happening in the space. I think it's critically important as we continue to talk about the mental health applications for psychedelics and investment in them, that we keep the end-of-life distress conversation part of that, given that it's as common as mental health conditions.

LuAnn Heinen:

What is it that our audience, large employers and payers and their health industry partners, can do to support transforming end-of-life into a more human-centered experience?

Dr. Shoshana Ungerleider:

Yes, that's a great, great question. I think a lot of things and maybe starting with caregivers, given that we know that somewhere on the order of 45 million Americans, probably more now, are caregivers, but they don't often self-identify. Companies can certainly offer programs to ease this burden, programs that either provide support and training for caregivers of different types, leave programs for paid caregivers, and even bereavement leave. When you're caring for someone who then dies creating a pathway for them to be able to take leave and really the time to be able to process. I think things like allowing employees to donate their paid time off to other employees, and then of course, more robust employee assistance programs for people to help navigate the challenges of facing a personal illness, being a family caregiver, some of the legal considerations around advanced care planning and wills and trusts, which we know takes up hours and hours and hours of time for people who have never navigated it before. Then certainly around grief and creating a company culture that really is thoughtful about how to support grieving employees. Hopefully companies would do this because it's the right thing to do, but we also know that organizations that don't support their staff who are caregivers, or who are experiencing loss, there's decreased productivity and employee engagement and retention rates. We know that workplace culture now plays a really crucial role in where people are choosing to work. For this podcast I looked up some data, which is published by *MIT Sloan* in January of just this year, 2022, and that showed that a toxic workplace was far and away by nearly three times a leading contributor to the great resignation. Again, it's more cost effective to reengage employees and create a space that fosters kind of this safety and compassion around the caregiving and end-of-life and grief conversation.

LuAnn Heinen:

Yes, we've seen just a major uptick in employers offering caregiving to their employees. Now that's caregiving across the spectrum and in the work world most people's brains go to children, maybe older relatives, not necessarily to end-of-life, serious illness caregiving, although we certainly know that's a big part of it and needs to be more visible. And then bereavement leave - gosh, there are companies like Meta, General Mills, MasterCard, they all offer 20 days of bereavement, very generous bereavement leave. Then the median, 85% of our member companies who responded to a survey on this last year said they provide a median of five days for close relatives.

Dr. Shoshana Ungerleider:

Yes, people I think certainly could do better. Unfortunately, from my experience, it often takes an executive like a Sheryl Sandberg, having lost somebody very important to her to recognize what it's actually like and that you really should offer more time off for people, more support for caregiving responsibilities and certainly for bereavements, because it's really how we'd all want to be treated. My hope is that COVID, the pandemic, has shown us that this is so incredibly important for many reasons.

LuAnn Heinen:

Shoshana, what do you think death and dying will look like 10 years from now, when you think about what may change?

Dr. Shoshana Ungerleider:

Gosh, that's a good question. I guess I'll say what I hope for. I think that one of the strange gifts, if you could even call it that of this pandemic, is that it's made the conversation about end-of-life care, and really all of our own mortality, really front and center. I think COVID allowed many of us to realize, especially before vaccines and therapeutics were available, that tomorrow was never a given, no matter how old you are. We're seeing

deeper, I think, and more thoughtful evaluation of advanced-care planning, making your wishes known to your loved ones and to your health care team. Again, early on in the pandemic before vaccines and medicines, so many frontline clinicians were providing palliative care for patients. We're really ill-equipped because we don't train all clinicians in how to do these things. I'd really like to see more training of our ICU physicians, our ER doctors, and even surgical colleagues, to know more about palliative medicine fundamentals, not to get rid of palliative care as a specialty, but even in normal times, we just don't have enough palliative care providers to go around. It should really be the job of all doctors to know when and how to talk to ill patients about their goals of care, how they want to be cared for if time is short. That makes a huge difference for patients and families. Then looking at it from a more consumer driven perspective, what I'd like to see happen in the next 10 years is much more of an openness to discuss these topics. Again, I think the pandemic sort of is driving this, stories about grief, about death and dying, about caregiving out there in the media. Part of the reason why I executive produced documentaries on this subject is because I think the more that we see these stories told the more likely it is to spark conversations in our own lives and I think that's where we have to start.

LuAnn Heinen:

When you talk about grief, we're almost so removed from death that we forget how to comfort people who are grieving, you know, if we haven't recently been through it or experienced it. I've been a hospice volunteer and I went through a pretty extensive hospice training for a lay person. Now I have people come say to me, someone's mother is dying, what can I write in the letter? I want to do something, what should I say? There are a lot of things that aren't helpful to say, that we've learned what not to say, but that's part of that disconnection. We go on living our lives and don't think about it. I used to have an old boss who said, the death rate is one per person. I actually think that was an odd statistic, you know, why would he say the death rate is one per person? I think it's because we really are able to kind of forget that.

Dr. Shoshana Ungerleider:

Well, I hope that now that so many people who have experienced grief on a personal level or this idea of collective grief, meaning society kind of grieving the sheer number of lives lost and the loss of kind of a normalcy of daily life. It is really hard to know what to do or to say to somebody after they've experienced an acute loss. Sometimes we feel compelled to give people space, or most of the time in my experience, that's not what really helps people who are grieving. I think showing up and being present, not giving people space, rather letting them know that you're there for them and checking in on them, inviting them out for a walk or a meal, and trying to listen more than you talk. I know for me as a physician, I'm always trying to fix people's problems and I've had to learn how to hold space for people who are grieving just to open up, if they want and let them speak without trying to fix it. I think accepting that discomfort is really part of the grieving process and sometimes that means for you as a friend or a family member comforting somebody as well.

LuAnn Heinen:

Would you like to say about a good death? What would a good death experience be?

Dr. Shoshana Ungerleider:

People ask me that a lot and I don't love the term good death because I feel like my answer is going to sound very prescriptive, but I do think that there isn't a one right way for somebody to have a good experience. I think it's about receiving care and support, again, that you really want, that's in line with your personal values and hopefully honors the life that you've lived. The only way to tap into that is to first think about it for yourself and to talk about it with the people that you love, with your health care team, if that makes sense. Sometimes it's thinking about not just what you want, but maybe what you don't want, as well. Our goal at End Well is to really foster these kinds of conversations so that when the time comes, people are better equipped to have an experience that they truly desire, because I think at the end, that's what really all of us want is to find comfort and peace.

LuAnn Heinen:

Shoshana, thank you so much for spending time with us today. I learned a lot and I think our audience will too.

I've been speaking with Dr. Shoshana Ungerleider, the founder of End Well. To join the movement, start by watching and sharing the compelling personal stories on <https://endwellproject.org/>. See videos from Meghan McCain, Tim McGraw, Maria Schriver, Roger Daltrey, Esther Perel, and others. You can also subscribe to the End Well newsletter and follow End Well on social media.

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