

**The Power of Humanity By Mark Ganz
End Well Symposium, December 7, 2017**

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She was eight years old. And this little girl that I will -- for purposes of this, of today -- call Clara, was dying of cancer. Her curative treatment had come to an end and her parents had decided to discharge her from going back to her children's hospital, a part of which is here in Portland, Oregon. And to return to Southern Oregon so that Clara could live out her last days in her own room surrounded by her toys, her stuffed animals, and her family.

But there was a glitch to their plans! They got down, got in the home, everything looked great [00:01:00], but then Clara wouldn't go to sleep. And night after night, she would get close to falling asleep and she'd wake up. And the parents were really really puzzled... and they were worried that you know maybe it was something that's related to the cancer that was overtaking her body, or maybe it was a side effect of the pain medications that she was taking.

So they called Kathy Perko, a nurse practitioner at Doernbecher, a very dear friend of mine from back, all the way to high school, and they put the issue to her and said, "What do you think we should do?" And Kathy, initial inclination, the sort of autopilot [00:02:00] response was to think, "Hmm... there's a drug for that. Maybe we'll give her some kind of a sleeping medication to help her go to sleep or maybe we can just turn up the amount of narcotics that she's on and that surely, that will calm her down enough that she can go to sleep."

But in a moment of insight [chuckles], she stopped herself. And so when she was talking to the parents on the telephone, she said "Have you asked Clara why she won't fall asleep?"

And the parents were like, "No, we haven't..."

And she said, "Take the phone, go into her room, take me with you into her room by phone, and let's ask her."

Into the room they went, they ask her, "Clara, why aren't you falling asleep?" [00:03:00]

And without hesitation, Clara said, "Because I'm afraid that death will come for me when I'm asleep." Finished the conversation with her, parents go out of the room, continuing to talk with Kathy. And they fashioned the idea that they would get angel... little angel wings for her.

They did that. Parents went back into the room later with the angel's wings, and they told Clara, "Wear these, so that if you go to sleep and death comes for you, they will carry you to heaven."

So she wore them [00:04:00] for the remainder of her days. And she slept soundly. Every night.

Sometimes the healing thing, as we've been hearing from many today, is not a medical thing. And maybe the most profound thing I take away from that very true story, was that finding the right answer was started with asking. Asking even an eight year old girl what was really going on

with her. And because they did, they found out what was really going on and they were able to fashion a response that was truly tailored to her.

In my company [00:05:00], we spent the last 14 years focused finding a way to disrupt ourselves, for a hundred year old company, disrupt our own business model because we so believe in pursuit of the goal of fundamentally transforming the experience that individuals in their families have in the healthcare realm. And because we know we cannot boil the ocean, we've chosen specific experiences to try to transform and the experience of children and adults and families and caregivers, going through serious illness, facing the end of their lives, is worth spending time and creativity on. We've learned a lot in the process.

Let me share some of the learnings. Probably won't surprise you [00:06:00]: 97% of Americans want palliative care once they understand what it is. When have 97% of Americans ever agreed on something? [Crowd Chuckles]

The vast majority of physicians and nurses want palliative care for themselves when they're reaching, you know, when going through serious illness. Yet only 46% of physicians, even though I should say 46% of physicians are unsure and feel incompetent about how to have conversations and apply palliative care to their own patients. 70% of Americans want to die at home but only 30% actually do. Four in ten people [00:07:00] have or are caring for a parent. As we heard just a few moments ago how important caregivers are to this. Patients don't want to wait until they are declared to have only six months to live or be forced to forego curative care in order to receive Medicare reimbursement for palliative care. That law must change. [Crowd Clapping]

I'll tell you what I think. I think we need to light a fire of a social movement around changing end of life. I think that is what is our challenge that we should take away today. Several years ago, at the honor and the fun of having dinner with a [00:08:00] wonderful Ellen Goodman, a columnist for so many years and now the founder of *The Conversation Project* which I know many of you in this room are aware of, that works in this space. And we were talking about *The Conversation Project* before it had launched and were kind of coming up with ideas and brainstorming. And at one point in the conversation she said, "Mark, tell me what it was like when you were born." All right, so I don't actually have a memory of that, but she said, "What was it like for your mom? What was the experience?"

And I said, "Well, to my understanding, she was in a surgical suite, she was under general anesthesia. My dad who was a family doc was out in the waiting room smoking Camel cigarettes and she had no memory of the actual birth. And I was the youngest of six, so all six of her kids, she would [00:09:00] then undergo general anesthesia." That was the norm!"

She said, "So what was it like when you had your own kids?"

And I said, "Well, we were in this comfortable room, there was a stereo, it was a little lighting, you know there was a birthing chair. I was there, my sister was there, it was a great experience."

And she said, "Exactly!" And she said, "That experience wasn't invented by some academic at Harvard University." And she said, "You know it wasn't invented by the National Institute of

Health either. And it wasn't created by some venture capital company in Silicon Valley." She said "The inventor of that, the thing that caused that to happen, were mothers. Mostly [00:10:00] mothers, some fathers who demanded a better experience. And the birthing movement of the sixties and the early seventies completely changed the landscape of how the birth experience happened in this country."

We can do this with intent and create as good of a experience at the end of life as we have now through a social movement not so long ago created for the beginning of our lives. And I would suggest that that is a task worth taking on. So every one of you in this room is a leader in some way, shape or form, wherever you are in your organization or in the community, you all are leaders. So what are the key ingredients [00:11:00] that each of us as leaders, when you boil down and take away all the leadership-speak, and just say what is the... when it boils down to it if you wanna drive fundamental transformational change and disrupt a current way of the things happen, that is sub optimal, what are the key ingredients? And for me, it boils down to three questions that I suggest to you that you ask yourself.

So I'm gonna speak out in the first person because that's how I would urge you to ask yourself this, in the first person. And the first question is: Do I have hope? Do I have hope, fundamental, deep hope that lights a fire in my belly that the experience to end of life [00:12:00] can be transformed, can be something that starts with human-centered design? That can be personalized to the needs of each and every person according to what they desire and need and what their families need? It's not an idle question. I think much of the reason that things don't change and haven't changed to the level we would like them to is because there aren't enough people in leadership who have hope, so they just keep doing what they're doing. And they call it good enough. Do I have hope? And so if you can answer that question yes, you get to the next question, which is Do I believe I have the power to drive this change all by myself? Not [00:13:00] not, do it alone but do I believe that I have something to give? Can I be the change I wanna see? And also not an idle question because a lot of people will say they have hope but then they'll say, "You know, administration needs to change in the hospital" or "Health insurers aren't doing their part" or "There ought to be a law that needs to pass." So they kinda pass the buck and say "I had hope that someone else needs to do it that does get the job done."

And if you can answer those first two questions, then you get to the really tough one. Thought those were tough? Third one is this: Am I willing to risk everything to achieve it? Am I willing to risk my livelihood, my comfortable existence, my job? [00:14:00] Because it is so important and I'm going to take that challenge and drive as hard as I can with as much urgency as I can muster.

I think the speakers today, the thing take away from today or the day, the speakers we have been treated to today are living in a state of yes to those three questions -- every one of them. Just incredible. Not just talking but doing. Things that I heard today, that maybe you heard too, I wrote down some. Probably won't capture all of it but it seemed like this [00:15:00] kept coming up. Number one: Death is a human experience, not a medical one. The only way we create something better then transform the experience is to start with the humans that are involved.

Secondly, the palliative care definition that we saw early this morning is what the definition of what healthcare in America should be. That's worth pursuing... and that is within our grasp!

Third: Healing is the goal, not just cure. Well I learned that one a long time ago from my own dad who as a family doctor truly understood that his job was to effect healing. And that healing, sometimes you can affect the healing even if you could not effect the cure, by how you **[00:16:00]** treated the patient, treated their family and created an experience for them that was meaningful even if it was about saying goodbye.

Number four: Ask me! Don't assume. So it's so simple but yet in healthcare we find that to be so darn difficult! And its close cousin is, and we've heard about this too which is design with me. Design for me based on what I tell you. Human-centered design. Embracing our fear of death and gaining a deeper understanding of it can actually teach us how to live well. That's what I'm gonna be thinking about for a while. **[00:17:00]**

Colored candies are a great teacher. [Crowd Laughing] I'll take that one away. I like that one a lot! I must admit I was hoping she was gonna throw some of the candy out to the audience. Urgency. Urgency. Every day, every hour that we don't act with that sense of urgency to address this, people are suffering. People are not having the experience at the end of life they should have. And if that alone, if you just ponder that, and to cause us racing out of here with fire in our hearts, and finally... Now I've said this before because I truly believe that in this realm **[00:18:00]**, it is so important that the focus on our investment, of our time, our creativity and our financial resources, is toward a return on humanity. It's not something about a return of investment. If we do the right thing by individuals and the families, the money thing will take care of itself. That is not the reason to pursue this.

I guess if I kind of have sum it up, when I think about it, it was sort of what or you know, to borrow that phrase of some presidential campaign in the past, "It's about the culture, stupid." Because if you really think about the challenge that we all face in trying to design and implement, it's not unlike the situation **[00:19:00]** of... Imagine if someone had come to you twenty years ago. So I just say they come to me and they said "All right, show me your cellphone." And I pull out my cellphone it would be this sort of slightly heavy flip phone Motorola flip phone, with the little weird antenna that slid in and out and always broke, and they said "How can we make just the most awesome experience for you with a cellphone that would meet all your longings?" My perspective would be somewhat shaped by what I knew about or thought I knew about cellphones. And so I would provide lots of interesting feedback about... Hey, could you make the antenna more durable? Would you make the phone actually work, you know in longer distances? Could you make it waterproof? More shockproof? Can you make the battery life longer? I really doubt **[00:20:00]** but I would've said this... [Crowd Laughing] that's our challenge. We live in a culture that you know it's sort of we're kind of a, sometimes we're limited by assumptions that we make about something. Our challenge, now it's a great one! It's to figure out the iPhone for end of life. To get beyond, not just kind of trying to make a better Motorola flip phone, it's not easy.

Let me tell you about cultural signals and what they can do and how they can harm people. My mother had congestive heart failure. My dad had died in 2003 from multiple myeloma; he'd actually had a beautiful end of life experience at home with **[00:21:00]** incredible hospice workers helping us as a family... and him cruise to that crossing over point. The most spiritually

impactful and rich experience of my life! It was a thin place where I could just see the divine in the moment his spirit left his body.

Five years later, my mother having gone through a series of... as you know, those of you who know congestive heart failure it's sort of like, steady as you go, crisis, whoops... down the step, steady as she goes... then another crisis, and you never get better, you just kind of steady for a while until you have your last crisis. And so when she would go into the hospital, related to one of those crises, we had no idea and we almost got a point where it was like well, she's gonna make it through because she made it [00:22:00] the last time. But we sort of knew. So she went into the hospital in November 2009, November 15th. And things went kinda downhill.

I was not in Spokane where she lived, I called my brother who's a physician there who had seen her. I said, "Do you think I should, you know, get on my horse and get up there?"

And he said "No, I think it's gonna be all right. I think it's just another one of these episodes."

But it wasn't all right. And later that evening, my sisters -- my two older sisters -- had gotten there. They had spent some time with her. Again, I don't think they'd thought that she was imminent and passing. But my mom had a great sort of view about her life. She was very... she very much wanted [00:23:00] to live her life until she took her last breath. She was not preparing to die... but she was okay with it. It was her faith, she missed my dad, she was okay about when it might happen. And she wanted to make sure -- and this was so important to her -- that when her heart stopped, that there would be no attempt to revive it. Her heart stopped, she was ready to go. That's how she viewed it. Every time she went in the hospital, she insisted that they put not only a Do Not Resuscitate order that she had signed in her record, but put it in the door of her room! Because, she should've had it tattooed already, huh? Anyway sisters were with her, they were hungry, they said, "Hey mom, can we go now and get some food but we'll be back soon?"

"Oh yeah, certainly, go ahead [00:24:00] girl, it's fine." They left to go.

Minutes after they left to go down to get some food, her heart stopped. They did a full code. She did not come back. My mom was a willful person [chuckles]... [Crowd Laughing] And I just, we were all so blessed that she didn't but boy were we angry at the hospital and the workers there. So we... we talked about it. What were you thinking? They're good people. The hospital is a good hospital. It was about culture. The culture of the hospital [00:25:00], the culture of the people who worked there was that if someone died on your shift, that was a bad thing! That was kind of like a black mark. Extension of life was a good day. When dying, not a good day. And so it caused them to just go with the automatic pilot to not even think to look to, you know, to honor my mom's wishes. Culture is a powerful thing. And I think when you go back to where you work, where you're doing your work, I urge you to be a beacon around culture. And that takes a lot of courage and it takes a lot of perseverance. In our company, you know, a hundred year old company, we've been at this for 14 years [00:26:00] and from the very beginning, I knew this was not so much a strategic challenge. What we need to do seemed pretty straightforward, I knew it would be a cultural challenge and it has. Good news is we made enormous progress because we had been relentless about it. See if I can remove this.

So here's what I would ask, maybe you would just take with you as you go out for a drink and then back to your work and your families. I would like all of us to resolve here and now that these types of situations will not happen because of the work we do. That we will ensure that. And that we will go out with a sense of no longer tolerating **[00:27:00]** even one bad experience because I think every one of us has to have that kind of an attitude, that kind of resolve and commitment. If we're gonna be the kind of example in our organizations to drive change. Let's make end of life what it should be. What we want it to be. What we know the people who we serve wanted to be, which is a human, a healing, a sacred experience for individuals and those who love them. I urge you, I implore you, to go forth from this place with courage that is born from a deep hope and with a belief that you, you **[00:28:00]** alone have the power to drive the change you want to see. Good luck!

[Crowd Applauding]

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