

**Teaching Past the Taboo By Dawn Gross & Jessica Zitter
End Well Symposium, December 7, 2017**

Start of Transcript

Jessica: Last summer, I was on vacation and I got a phone call from my friend Dawn over here and she said, “Hey, you know what? There’s this design firm called IDEO and they have this online challenge called ‘Reimagining the End of Life,’ you wanna submit something with me?” The catch is it’s due in three hours. [Laughing] Okay, that gave me a little pause but I thought why not, I love Dawn, it’s raining outside, and reimagining the end of life is just about my favourite thing to do. So I told Dawn about an article that I had written that was in queue to be published called *Death Ed*. It was kind of like *Sex Ed* but about death. So [00:01:00] years earlier, to give a little background, I had taught my kids —two of my daughters — their classes in middle school and high school this *Sex Ed* Classes, I taught that but honestly I would’ve been very happy delegating, but it was a small school and there was really no one else to do it. So once I had done it, despite the giggles and the very serious discomfort, I realised that I just could never imagine having set my daughters out into the world without knowing about roofies, body shaving, date rape, STDs, and unwanted pregnancy. Okay! But *Death Ed*, well death, as well all know in this room is a lot like sex. It’s a taboo subject that makes us squeamish and so we avoid it. And like sex, if you aren’t prepared [00:02:00] for the end of life, it can go very badly. So Dawn was really excited about this idea because she had taught a class to high school students on Prenatal Education and she had also seen that knowledge is power when it comes to body health. And both of us have a lot of experience taking about death to teenagers namely our own kids. In fact, a few months ago, my daughter Sasha said to me, “Mom, can we have like one shabbat dinner without talking about death?” So it really was an idea that felt intuitively right to both of us. And we did the ultimate college move and we got this thing in within literally minutes to spare and we are proud to say that of the 299 submissions, *Death Education* was selected as one of the 10 top ideas.

[Crowd Applauding]

Jessica: So let’s talk about *Sex Ed* [00:03:00], it works. When it was first introduced as a composite in the late 1800s, people were like, “What?! Talk to teenagers about sex? You’re just gonna make them go and have more sex” or “You’re gonna make them socially deprived.” But that didn’t happen. As these kids learned about their bodies, they started to make better decisions and rates at sexually transmitted diseases and unwanted pregnancies plummeted. And soon many states said this should be required teaching at the high school level. Now unfortunately in 1990s, some states morphed their sex education programs into something called *Abstinence-Until-Marriage Sex Education*. And you can imagine how that went. In school systems where they don’t acknowledge that sex is a part of life, things get bad! And there just — again a resurgence of STDs and unwanted pregnancies. Okay [00:04:00] so what about death? Well, death is also a part of life that we don’t wanna acknowledge, but like sex, it’s happening around us all the time. And here’s something interesting, more than more three decades of palliative care research and probably even more, have shown us clearly that when people know more about the end-of-life, they live, and they die better. And yet, in these modern times, I think everyone in this room will agree that the majority of us know very little about death. Whatever we do know we learn in snippets from TV shows that are completely unrealistic. Now it wasn’t always this way. For much the majority of human history people knew how to manage their dying loved ones; when they were sick and dying, they were cared for in the home and after they died, they were laid out in the parlour [00:05:00]. Death was expected, it was accepted, it was prepared for. But things really change in the 1930s. At that time, two professors of industrial hygiene at Harvard School of Public Health, using the motor of a

vacuum cleaner, created a machine that went on to save thousands, many thousands of young people and older people from death from polio, given that there's the iron lung in those days. We now know it in its new iteration as the modern mechanical ventilator which we find in intensive care units around the world. At the same time, on the battlefields of World War II in Korea, doctors were learning how to measure pressure inside of vessels using fancy catheters and how to do resuscitation with fluids and volume and blood [00:06:00] and plasma, to save many thousands of soldiers from death; from haemorrhage and shock and infection, people who would certainly have died on the battlefields. And so we were being saved by technology and it felt like a miracle. And we began to believe in these machines if they could save young children, soldiers, maybe they could save us all. Maybe they could save the old, the ill, maybe they could save the dying. And the result is something that I call the end-of-life conveyor belt which I see every day in the intensive care unit. It's these situations, phenomenon where patients were truly approaching the end of life, get flood into a serious of machines and submitted to a series of technologies, treatments and protocols that compensate for all of their organs as they begin to fail [00:07:00]. And the final stop, is ventilator facilities where people are actually surgically connected to these machines and they frequently have their arms tied down... and they are frequently in pain, confused, and honestly probably if we measured it, most of them would never have realised what they were actually submitting themselves to or signing up for.

Jessica: This is a rising public health crisis of extraordinary proportions — and it's not what people want. It's certainly not what I want or what Dawn wants, right?

Dawn: No, it's not, Jess.

Jessica: Okay.

[Crowd Laughing]

Jessica: But teaching death to high school students? It was pretty terrifying. We looked to see what was going on out there, what had other people done, and honestly we found one program in Upstate New York 25 years ago. This isn't [00:08:00] being taught by my Google searches, maybe someone else knows about other programs. And what if we upset these kids? These are kids that go to school as our kids. These are parents who were co-parents in a school with us, what if people got angry? What if someone got traumatised and ran out of the room screaming? Would we incite depression in kids? But we were propelled forward by our commitment to educate much as we had done for the kids at *Sex Education*. We wanted to enable people to make decisions based on knowledge and not fear or fantasy. Denying reality never works whether it's about sex or a bad death. And the antidote to denial is education, death education. So we went for it.

Dawn: So we approached two bold, brave high schools in the Bay Area who happened to have two of our children enrolled [00:09:00] in them. And we asked if they would be willing to allow us to pilot *Death Ed* with their students. Fortunately they said yes. We then did what any science educator would do, we create an advisory panel to tell us how do we do this. That advisory panel was made up of our teenagers and their friends. And we said, "How do we make sure what we're going to teach actually is successful?" They said three things, straightforward. One: make sure you do everything as interactive as possible. Two: use candy wherever possible. And three: never hurts to use movies. So we did. We started day one with an exercise that involved candy and an activity. We told the students that each color candy that they're gonna be handed represents a possible relationship where they may have already experienced a death. Number one, red: a parent or a sibling. We asked them, if that [00:10:00] was true for them, to put it in a glass jar. Number two, orange: if they've lost a grandparent,

aunt, uncle or cousin... put it in the jar. Three, yellow: if they've lost, say a teacher or a counsellor or coach, put it in the jar. Four, green: a pet. Who here has lost a pet, put it in the jar. Just one, you can eat all the other green ones, you can keep them. And fifth, purple: someone in the stratosphere, someone who's an icon for us in the public eye. If someone dies that meant a lot to you, changed your world, put it in the jar. And then feel free eat the rest. Which they did. We then held up the jar after it had gone around the room and every student had added their appropriate color to candies and we said, "What do you notice?" In every single classroom, every time the students noticed two things. First, there were more candies in the jar, and second **[00:11:00]**, every single color was in the jar. Our job of creating context was done. They realised that death had already touched them and would likely to touch them again. They were present for us, now the question is, well, what do we know about it? We know what happens now, we care now, what do we know about it? Where do we learn anything? The media. So we decided to show a video. Something they were eagerly familiar with, one of their favourite programs *Grey's Anatomy*. In this case, in this particular episode, the heroine of the show actually died! She dies right before our eyes and that all the heroics of that medical conveyor belt come out in all their magical glory and resurrect her, she comes back to life! So that by the end of this episode, she's actually able to sit up by herself in a hospital room, looked at Dr. McDreamy in the corner who's smiling and then coyly say, "Hey." [Laughter] The students were captivated. They loved it **[00:12:00]**! And when we asked, "So tell us about what you just saw."

Dawn: They said, "Oh, no no no! We know that's not real. We know that's made up. "Okay good. So what is real?"

Dawn: They couldn't tell us. So we offered a different clip. This one taken from the documentary *Extremist* featuring our own Jessica Zitter, in her own hospital intensive care unit... where we follow patients, families and doctors who were facing very real life-threatening illnesses. Most of whom are either not in a position to answer for themselves what matters most or their families have never talked about it so don't know how to answer on their behalf. In this viewing, the students were equally as enraptured with watching the video but instead of laughter, what we watched them do is cry. When we approached some of them after to say, "Are you okay? Is that okay that we did that?" They reassured us that the tears were important and in fact the **[00:13:00]** fact that they're crying tells us we should be talking about it. In their intervening days between class 1 and class 2, while Jessica and I were recovering from pure exhaustion of teaching this course, we were also terrified because we realised we had let these students in the place of caring about talking about this but we had taught them how to. And we were worried about how they would come back if they would come back for day two. Fortunately the only phone calls that the schools received were ones of gratitude in the interim, saying "Thank you for being brave enough to teach this." Students told us — excuse me, teachers told us in fact that students had raised conversations with them that they were aware of but have never spoken of publicly or the depth that they were now doing, and they were grateful.

Dawn: So along came day two. Our work was cut out for us. It was time to teach them how to discover what matters most to them and then how to communicate it. And we did that by a game that's actually on every one of your tables called *Go Wish* and **[00:14:00]** this video is gonna demonstrate two students playing in real time during the class.

{{Video Presentation Playing at 00:14:05 to 00:14:34}}

Student 1: Is it what you want when you're like about to die?

Student 2: I guess so

Student 1: I'm not dying alone. I'm like connecting all of the ones that are related to family and friends together cause I put those down as the most important ones. Like not being a burden to them, like you said, and just everything. Just being with my family when I die.

Dawn: So what became very clear as the students has eagerly played this game, was that they could talk about this. And even though it was in the context of imagining they were dying, what they realised was that it was actually about what mattered most to them right here, right now, while they were very much alive. And as we did exact surveys to see how it was for them to experience **[00:15:00]** *Death Ed*, fortunately the vast majority said they were grateful that they took it, and when they gave us critical feedback of what was effective, our advisory panel was spot on! Number one, they loved the interactive things like the *Go Wish* game. Number two, candy, always good, and three they love the movies. So we're off to a big start! So Jess, I'm wondering in the last few moments, are you ready to play a little round of *Go Wish* with me?

Jessica: I sure am and I happened to have my favourite card with me.

Dawn: What perfect timing! Okay, great! Jess, it says that something that's important to you is to be kept clean. Can you tell me, how could I support you of being kept clean?

Jessica: I really want my family, my friends, to be able to lie down next to me in my bed and be next to me and not smell something bad. I want my sheets to be cleaned, I want myself to be clean, that's important to me.

Dawn: And what I'm hearing you say is that if you're smelling clean and if you're feeling clean, your family will want to be with you.

Jessica: Yes.

Dawn: And imagining you want family with you now. Not just waiting until you're on your death bed. Is that right? Yeah, we love to be **[00:16:00]** together. So *Go Wish* and talking about what matters most is about helping us uncover these things right now while we're very much alive so we can all support each other in living our life to the fullest. Jess, what's the bottom line?

Jessica: Bottom line. Over the last century, we have forgotten how to die. And for that, we're suffering greatly, and so *Death Ed* is our attempt to bring some age old wisdom back into the classroom.

Dawn: So the next generation can live their life fully all the way to the end. Thank you.

[Crowd Applauding]

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