

Working for Change By Torrie Fields
End Well Symposium, December 6, 2018

Start of Transcript

[Crowd Applauding]

I am so overwhelmed and inspired by the voices that we've heard. The stories that we've heard on stage today. And by how much change just a small number of dedicated individuals can have in the world. We heard about how people take their stories and apply them to their everyday lives. Apply them to your everyday life. Now I've heard from some of you today at the breaks and some of you are wondering... "I don't wanna start a movement. How do I contribute? It seems **[00:01:00]** a little big. These people are making huge change!" And with that, I wanna give you a little bit of parting advice from a person who has a story. From a person who had a dream. And a person who has found my calling in life. And I'm a young person who found her calling. Start where you are. Start with what you know.

Now, last year I was fortunate enough to tell my story for the first time. I had never [Crowd Applauding] told anybody about the first time I was diagnosed with cancer. Anybody. There were people in that room last year who I had known for years and had no idea **[00:02:00]** that I had cancer.

Step one: tell your story, whatever it is. We are all in this room and now we know something more than we did. We are responsible. Knowledge is power. And you are all required to share it where you are. So how do we start where we are? First, I'm gonna talk about identity. I'm gonna ask you to do a little checking, a little exercise before you go out to the world and share what knowledge you know. My friend Jethro Hiko who runs an organization called *Common Practice* taught me **[00:03:00]** really wonderful piece of advice. Now we're setting up on a public gameplay event to try and have advanced care planning conversations with the public! It succeeded, I tell you. The first thing that he said, the instruction that he gave when people walked in the door was to check your license at the door.

You are here, sitting here as human beings. We are all human. We all are the same on that level. We get overwhelmed with labels. I am a... right? Fill in the blank. I've got a lot of labels. Last year, I was a two-time cancer survivor. Most of the time, I am **[00:04:00]** I am the senior manager of Advanced Illness in Palliative Care at Blueshield of California and that is my narrow place that I know a lot about. I know a lot about the thing that I do. Now, I'm gonna ask you to think for a moment about what your labels are. Fill in the blank. "I am a..." What comes to mind? I am a physician? I am a mother? I am a child? I am a caregiver? For me, today, I'm a granddaughter and I wanna tell you why I'm starting there **[00:05:00]**.

20 years ago, I experienced five traumatic deaths of people my age. I experienced suicide and motor vehicle accidents. I experienced shootings. I came from a community that was rocked with tragic endings and I was grieving and I was lost. And I tried to figure out how to make my way in the world. Fast forward to 5 years later when I was able to experience something that I would say is the gold standard of death: my grandmother. Now my grandmother, Neeva **[00:06:00]** Pauline Fields, is 93 years old, independent, stubborn German woman. I look in the mirror and I still see her in me and that's a little scary but also my favourite thing about myself. My grandmother orchestrated her own death. She lived on her own until she was 93. And she fell in the shower one day and her life changed. She ended up going to the hospital, immediately wanted to get out of it, moved in with my aunt and she sat our family down and she said, "Look, I'm going to die...and here's how it's going to go." [Crowd Laughing] "I'm not

going to the hospital ever again. Okay? I'm going to move in with Helen, (who's my **[00:07:00]** aunt) and you're all going to take care of me."

"Okay, okay grandma, sounds fine."

So the reason I bring this up is my grandmother then over a period of eight months, with the help of a wonderful home hospice team, scheduled everybody in the family — her 11 children and 93 grandchildren — and she gave all of her belongings away one by one. And coz I'm the youngest grandchild I went last. And what I learned from this experience was that you can do it right. The day after my grandmother gave my special willed gifts to me, she died. She was done. And what I learned from that experience sitting in the room with my grandmother **[00:08:00]** and with all of my other family members as this woman took her last breath, her last word being my grandfather's name who had died in 1974, was something that Dr. Arabayak shared in my favourite book. My grandmother intrinsically shared four things that matter most. She asked for forgiveness. She gave forgiveness. She said thank you and she told all of us how much she loved us and she left — and that was a beautiful death. And for me, I knew what the difference was and I had a part to play in making better memories for people. I am in the business of making memories and so can you be **[00:09:00]**

You can start where you are. Start it at home. Start with talking to your parents. Start with talking to your caregiver, to your friends. I had played that game that I was talking about — Hello, wonderful game — on first dates! I asked every first date if they had advanced protective. [Crowd Laughing and Applauding] And if they don't we're gonna talk about it a little bit more. But you know, that translates into community. We, as humans, we start with our selves. Look at your biases, look at how you interact with the world and then remember, when you go to work, when you spend time with your family, when you go into your community or into your church **[00:10:00]**, remember what you know about yourself and others. Listen more. And then share. Tell your story. A collected number of stories starts a movement. And you know what movements do? They change policy. I get the opportunity to listen to stories all day long and then do something about it. I hear that somebody can't access services and I am in a unique position to help them access it. But you are all in a unique position. Think about what you will commit to. How will you contribute to this movement? How will you contribute to designing a better end-of-life experience? Now with that, go out and share your story **[00:11:00]**.

[Crowd Applauding]

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