

The Time is Now By Aditi Malick
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We're here to talk about death. In my experience as a daughter, a doctor federal healthcare policy adviser, I've seen how death is hidden away. Care at the end of life is aggressive by default and values in nuances are often lost. But why is that? What shapes the experience of death and dying in America? From my perspective I see three major influences. One: culture. How we think and feel about death. We're terrified of it, afraid to talk about it, afraid to think about it, afraid to loose to it. Medicine, how we avert death. The medical establishment is designed to prolong life and really falters when confronted with the one thing that can never overcome, death [00:01:00]. In our systems, how we care for the dying often unintentionally disregarding values and oversimplifying complicated choices. Our culture plays an enormous role.

Almost exactly 20 years ago, my father was diagnosed with intestinal cancer. After multiple rounds of failed chemotherapy and a week-long stay in the ICU, it became clear that time was short. It was overwhelming. But we never once as a family sat down to talk about what was happening. We never once sat down to talk about what the end or would or might look like. My father passed away in a hospital... connected to lines and tubes and it's because I can't help but think that he would've wanted something different that I do what I do now [00:02:00].

We didn't talk about it coz it was never a good time... and because it was never a good time to talk about death it became hidden away. There's either no urgency at all. The conversation feels too soon, premature, or tremendous urgency, a sudden massive decline in health. In which case it's too late. In addition to not knowing when to talk about death, we don't know how. Not with adults; definitely not with children. It's difficult, stirs up difficult emotions. This photo's called *What Remains* sketched by a palliative care social worker in Australia named Margarete Ambridge. What I love about this photo is it so beautifully illustrates what's lost. We don't have those conversations. The data tells us that people think about their wishes for the end of life all the time. The challenge is in translating [00:03:00] one's wishes into action. In part, those challenges are cultural. This study from the Kaiser family foundation in the economist found that nearly 80% of people had thought about their wishes at the end of life. But somehow that only translates into fewer than 20% of people having had that kind of conversation with their healthcare provider. The time is now to talk about it. The time is now to change it. Our medical system also plays an enormous role. Oh yeah, I like this one too! Designed to always do something, fix something. The default pathway for most patients is the conveyor belt of medicine, and idea put forth by Dr. Jessica Zeiter, I know is here with us today. Additional treatments and interventions are the standard operating procedure and it takes a very conscientious decision to step off the conveyor belt and forego those things. Nowhere is that [00:04:00] conveyor belt of medicine more stark than at the end of life.

Researches looked at the records of 1.8 million Medicare beneficiaries who passed away in 2008. And they looked specifically at the surgical care that those folks had received in their last year of life. These are the results:

- One in three Medicare recipients had surgery in the last year of life.
- One in ten had surgery in the last week of life.

The data on chemotherapy is similarly stark. 6% of patients get chemotherapy in the last two weeks of life.

The language of medicine really feeds that conveyor-belt mentality. Right? We describe people as fighters and warriors. Always hoping for the best but often failing to prepare for the ultimate outcome. This overwhelming desire to preserve hope often overpowers the need to set realistic expectations [00:05:00]. The reality is most patients will be the rule and not the exception. But easier said than done, right? I mean, many of us went into medicine, myself included, with the desire to help people live longer healthier lives. We're fighters too, right? And even when we know the odds are against us and it's gonna be an uphill battle, we keep fighting on behalf of our patients and our selves, we just keep pushing. But in fact our medical system breaks down when confronted with unfixable problems. Let's face it. Death, unfixable problem. But what's not unfixable is changing the process and the experience of dying, which is why we're all here today.

Lastly our systems play a huge role. It's always striking to me in my experience as clinician and a health policy adviser that we reimburse more for doing [00:06:00] things to people than for them or with them. Fee for service medicine always incentivize doing more and not less. And don't get me wrong. This is absolutely starting to change but it's still much harder to have a series of conversations about end-of-life care than it is to continue on the conveyor belt of medicine. The consequence of that is complicated nuance decisions get oversimplified to the point where values are lost and more is always better — and it's not.

Take for example the Medicare hospice benefit. So since its inception in 1983, hospice-eligible patients have had to forego any kind of curative treatment once they enrol in hospice. Now that means that you can either choose physical, spiritual emotional comfort and alleviation of suffering [00:07:00] or curative treatment. The challenge is we don't always know what's curative. And we don't know whether a curative treatment is also going to alleviate suffering. So by framing these issues as black or white, we miss the nuance and ultimately end up doing a disservice to the people we're trying to help. It's clear that we have to do better. Death is as human as it gets. The things that scare us the most about death: vulnerability, decline, meaning, legacy, are at the core of what it means to live and to be human.

Every day in America, 2.4 million people die. At its core, this is a human-human-centred design issue. We can do better! Innovative people around [00:08:00] the world are taking on this issue and the solutions are gonna have to come from inside of medicine and outside of medicine. A diversity of skillsets in this area is more powerful and has more impact than any one group going at this alone. We saw that with the global response to the HIV/Aids epidemic, we're seeing it now with the mobilisation of people around childhood obesity. This can be that same sort of issue. More importantly, we're all affected by this. I'm interested in this as as a doctor and much more interested in it as a daughter. We're all gonna die one day... and most of us already lost someone we loved. Wouldn't it be nice if by framing this as a human issue, we can move to a world where death is discussed, wishes are known, care is individualized, person-centred. Values are articulated [00:09:00] and grey's okay. Getting to that place requires a deliberate and thoughtful transition in our culture, in our practice of medicine, in our systems of care. The time to change is now. The time to talk about it is now. I look forward to the rest of the day.

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