

Well, we all need a reason to wake up. For me, it just took 11,000 volts.

我们都需要一个醒来的理由。对我来说是11,000伏特。

I know you're too polite to ask, so I will tell you.

我知道你们太礼貌了不会过问，那就让我告诉你们。

One night, sophomore year of college, just back from Thanksgiving holiday, a few of my friends and I were horsing around, and we decided to climb atop a parked commuter train. It was just sitting there, with the wires that run overhead. Somehow, that seemed like a great idea at the time. We'd certainly done stupider things. I scurried up the ladder on the back, and when I stood up, the electrical current entered my arm, blew down and out my feet, and that was that. Would you believe that watch still works? Takes a licking!

在大学二年级，感恩节假期后的一天晚上，我和几个朋友闹着玩儿，决定爬到一列停在一旁的通勤列车顶上。它就停在那儿，缆线就在车顶上方。不知为什么，这似乎在那个时候是一个好主意。我们的确干过比这个还傻的事。我从后面的梯子窜了上去，当我站起来的时候，一股电流进入了我的手臂，一直到我的脚下然后就这样了。你能相信那块手表还没坏吗？真是金刚不坏！

(Laughter)

(笑声)

My father wears it now in solidarity.

我的父亲现在还一直戴着那块手表。

That night began my formal relationship with death -- my death -- and it also began my long run as a patient. It's a good word. It means one who suffers. So I guess we're all patients.

那天晚上开启了我与死亡——我的死亡——也开始了作为病人的漫长的旅程。

这是一个很合适的词。它的意思是一个受苦的人。我想我们应该都是病人吧。

Now, the American health care system has more than its fair share of dysfunction -- to match its brilliance, to be sure. I'm a physician now, a hospice and palliative medicine doc, so I've seen care from both sides. And believe me: almost everyone who goes into healthcare really means well -- I mean, truly. But we who work in it are also unwitting agents for a system that too often does not serve.

美国的医疗保健系统 有不少的功能障碍——当然，它也有杰出的方面。我现在是一名医生，安宁病房和临终关怀医生，所以我从两个角度看医疗系统。相信我：几乎每一个从事医疗的人 都是十分好心的——是真的。但是我们这些从事医疗的人也是 在一个有许多缺陷的系统中工作。

Why? Well, there's actually a pretty easy answer to that question, and it explains a lot: because healthcare was designed with diseases, not people, at its center. Which is to say, of course, it was badly designed. And nowhere are the effects of bad design more heartbreaking or the opportunity for good design more compelling than at the end of life, where things are so distilled and concentrated. There are no do-overs.

为什么呢？其实有一个很简单的答案，而且也能反映很多事情：因为医疗系统的设计是针对疾病的，而病人不是焦点，也就是说这个设计是有问题的。而在生命的尽头，不良的设计的影响更加让人心痛，完善的设计的机会也显得更有必要，因为在生命的尽头，所有的东西都是浓缩下来的精华。没有重新来过的机会。

My purpose today is to reach out across disciplines and invite

design thinking into this big conversation. That is, to bring intention and creativity to the experience of dying. We have a monumental opportunity in front of us, before one of the few universal issues as individuals as well as a civil society: to rethink and redesign how it is we die.

我今天的目的就是号召各个领域的人们，邀请大家把设计思维带入这个大话题中。也就是将好意和创意 带入濒死的经历。这是一个十分难得的机会，这是一个会影响到个人，以及整个社会的 普遍问题之一：重新思考并设计我们如何面对死亡。

So let's begin at the end. For most people, the scariest thing about death isn't being dead, it's dying, suffering. It's a key distinction. To get underneath this, it can be very helpful to tease out suffering which is necessary as it is, from suffering we can change. The former is a natural, essential part of life, part of the deal, and to this we are called to make space, adjust, grow. It can be really good to realize forces larger than ourselves. They bring proportionality, like a cosmic right-sizing. After my limbs were gone, that loss, for example, became fact, fixed -- necessarily part of my life, and I learned that I could no more reject this fact than reject myself. It took me a while, but I learned it eventually. Now, another great thing about necessary suffering is that it is the very thing that unites caregiver and care receiver -- human beings. This, we are finally realizing, is where healing happens. Yes, compassion -- literally, as we learned yesterday -- suffering together.

我们从终点开始谈起。对大多数人来说，变成死人并不是死亡最可怕的部分，最可怕的是垂死，病痛。这是一个关键的区别。为了更好地领会这一切，那就非常有必要 区分一下死亡无法避免的痛苦 和我们可以改变的痛苦。前者是一个自然的，生命中必不可少的一部分，于是我们为自己预留空间，调整，成长。能够认识到有比自己更强大的力量是件好事。这能够带给我们均衡性，一个全新的自我认识。在我失去肢体之后，这个损失变成了一个事实，无法改变——这变成了我生活中的一部分，我认识到抵触这个事实就是在抵触自己。过了一段时间，我才最终认识到这一点。这种不可避免的痛苦的另一个好处 是它能够 团结照顾者和被看护者——增进人与人之间的关系。我们意识到这就是痊愈的开始。

是的，同情——就像我们昨天所学的——一起承担。

Now, on the systems side, on the other hand, so much of the suffering is unnecessary, invented. It serves no good purpose. But the good news is, since this brand of suffering is made up, well, we can change it. How we die is indeed something we can affect. Making the system sensitive to this fundamental distinction between necessary and unnecessary suffering gives us our first of three design cues for the day. After all, our role as caregivers, as people who care, is to relieve suffering -- not add to the pile.

从另一方面，从医疗系统的角度来看，有许多痛苦都是没有必要的，制造出来的。没有任何意义。但是好消息是：既然这种痛苦是人为造成的，那我们就可以改变它。如何死亡确实是我们可以改变的。让整个系统辨别不可避免的痛苦 和没有必要的痛苦之间的最基本的区别 给予了我们三个中第一个的设计暗示。毕竟我们作为照顾者的角色，照顾病人是去减轻他的痛苦，而不是雪上加霜。

True to the tenets of palliative care, I function as something of a reflective advocate, as much as prescribing physician. Quick aside: palliative care -- a very important field but poorly understood -- while it includes, it is not limited to end of life care. It is not limited to hospice. It's simply about comfort and living well at any

stage. So please know that you don't have to be dying anytime soon to benefit from palliative care.

这是缓和医疗的原则， 我的职责就是当一个支持者， 就像一个处方医生一样。 顺便提一下： 缓和医疗——是一个非常重要的 工作领域， 但是经常被误解—— 它涵盖， 但不仅限于病人临终前。 不仅限于安宁病房。 而是在任何一个阶段 都有舒适的生活品质。 所以不一定是 在病人临终前 才能得到安宁缓和医疗。

Now, let me introduce you to Frank. Sort of makes this point. I've been seeing Frank now for years. He's living with advancing prostate cancer on top of long-standing HIV. We work on his bone pain and his fatigue, but most of the time we spend thinking out loud together about his life -- really, about our lives. In this way, Frank grieves. In this way, he keeps up with his losses as they roll in, so that he's ready to take in the next moment. Loss is one thing, but regret, quite another. Frank has always been an adventurer -- he looks like something out of a Norman Rockwell painting -- and no fan of regret. So it wasn't surprising when he came into clinic one day, saying he wanted to raft down the Colorado River. Was this a good idea? With all the risks to his safety and his health, some would say no. Many did, but he went for it, while he still could. It was a glorious, marvelous trip: freezing water, blistering dry heat, scorpions, snakes, wildlife howling off the flaming walls of the Grand Canyon -- all the glorious side of the world beyond our control. Frank's decision, while maybe dramatic, is exactly the kind so many of us would make, if we only had the support to figure out what is best for ourselves over time.

现在，让我给你们介绍一下弗兰克。 他可以证明这一点。 我照顾弗兰克好多年了。 他患有前列腺癌， 外加艾滋病。 我们针对治疗他的骨痛和疲倦问题， 但是我们大多时间都在一起思考他的人生—— 其实，就是我们的人生。 弗兰克用这种方法表达他的悲痛。 他用这种方法面对他所失去的一切， 这样他才能去面对下一个难题。 失去是一回事儿，而后悔是另一回事儿。 弗兰克一直是一个探险家—— 他看上去像诺曼·洛克威尔的画里的人物—— 他从不后悔。 所以我一点都不惊讶有一天他来到诊所， 跟我说他想泛竹筏从科罗拉多河顺流而下。 这是一个好主意吗？ 考虑到他的人身安全和健康情况， 有些人会说这不行。 很多人都这么说，但是他依旧去了， 趁他还有能力去的时候。 那是一个美好， 奇妙的旅程： 冰凉的水， 干热的酷暑， 蝎子， 蛇， 大峡谷似火的岩壁上各种野生动物的嚎叫—— 都是我们无法控制的世界的壮丽的一面。 弗兰克的决定，或许有些戏剧性， 但是如果我们有所需要的支持， 去寻找做最有利于自己的选择， 那我们大多数人可能都会做出这样的选择。

So much of what we're talking about today is a shift in perspective. After my accident, when I went back to college, I changed my major to art history. Studying visual art, I figured I'd learn something about how to see -- a really potent lesson for a kid who couldn't change so much of what he was seeing. Perspective, that kind of alchemy we humans get to play with, turning anguish into a flower. 今天聊到的许多都是从不同角度看问题。 在我的事故发生之后， 我回到了大学， 我把我的主修改成了艺术史。 在学习视觉艺术的过程中， 我发现我学会了如何去观察—— 对于一个无法改变过去所见的孩子来说， 那是强有力有的一课。 观点是一种人们可以改变的炼金术， 可以把煎熬变成花朵。

Flash forward: now I work at an amazing place in San Francisco called the Zen Hospice Project, where we have a little ritual that helps with this shift in perspective. When one of our residents dies, the mortuary men come, and as we're wheeling the body out

through the garden, heading for the gate, we pause. Anyone who wants -- fellow residents, family, nurses, volunteers, the hearse drivers too, now -- shares a story or a song or silence, as we sprinkle the body with flower petals. It takes a few minutes; it's a sweet, simple parting image to usher in grief with warmth, rather than repugnance. Contrast that with the typical experience in the hospital setting, much like this -- floodlit room lined with tubes and beeping machines and blinking lights that don't stop even when the patient's life has. Cleaning crew swoops in, the body's whisked away, and it all feels as though that person had never really existed. Well-intended, of course, in the name of sterility, but hospitals tend to assault our senses, and the most we might hope for within those walls is numbness -- anesthetic, literally the opposite of aesthetic. I revere hospitals for what they can do; I am alive because of them. But we ask too much of our hospitals. They are places for acute trauma and treatable illness. They are no place to live and die; that's not what they were designed for.

往前快进：现在我在旧金山一个很棒的地方工作，叫做禅宗安宁病房项目。在那里我们会举行一个小仪式帮助我们换一个角度看问题。当我们的一个病人去世后，太平间的人会来，当我们推他的遗体车穿过花园时，在大门前，我们会停留片刻。任何人——其他的住客，家人，护士，志愿者，还有灵车司机——如果他们愿意，他们会分享一段故事，一首歌，或者简单的沉默，同时，我们在遗体上撒花瓣；只有几分钟的时间；这是个很美好，简单的告别场景，用温暖迎接悲痛，而不是厌恶。把这个和普通的医院中的环境对比，差不多跟这个一样——灯光照明的房间中排满各种管子和嘟嘟叫的机器，还有不停闪烁的灯光，尽管病人的生命已经停止了。清理人员立即进来，遗体被快速地接走，然后就好像那个人从来没有存在过似的。从卫生角度考虑，他们的做法当然有道理，但是医院很容易侵犯我们的感官，在那四面墙内，我们最多也只能期盼麻木——麻木不仁，字面意思上和美感完全相反。我敬仰医院所做的一切，因为有它们我现在还活着。但是我们对医院的要求太高了。它们是处理急性创伤和可治疗疾病的地方。它们不是应对生死的地方；它们不是为这个而设计的。

Now mind you -- I am not giving up on the notion that our institutions can become more humane. Beauty can be found anywhere. I spent a few months in a burn unit at St. Barnabas Hospital in Livingston, New Jersey, where I got really great care at every turn, including good palliative care for my pain. And one night, it began to snow outside. I remember my nurses complaining about driving through it. And there was no window in my room, but it was great to just imagine it coming down all sticky. Next day, one of my nurses smuggled in a snowball for me. She brought it in to the unit. I cannot tell you the rapture I felt holding that in my hand, and the coldness dripping onto my burning skin; the miracle of it all, the fascination as I watched it melt and turn into water. In that moment, just being any part of this planet in this universe mattered more to me than whether I lived or died. That little snowball packed all the inspiration I needed to both try to live and be OK if I did not. In a hospital, that's a stolen moment.

提醒一下——我并没有放弃把我们的医疗机构变得更加人性化的想法。任何地方都有美好的事物。我在在新泽西州利文斯顿的圣巴纳巴斯医院烧伤科呆了几个月。我在那里得到无微不至的照顾，包括针对我的病痛的缓和治疗。有一天晚上，外面开始下雪。我记得我的护士抱怨在雪天开车。我的房间没有窗户，但是能想象迷漫的雪花也很好。第二天，有一

个护士为我偷偷地带进来一个雪球。她把雪球带到烧伤中心里面。我无法描述我用手捧着雪球那种欣喜若狂的感觉，一股股寒意滴在我滚烫的皮肤上；这一切有多么神奇，我入迷地看着它融化成水。在那一刻，能够属于这个地球上，这个宇宙中任何一个部分对我来说比我的生与死还要重要。那个小小的雪球包含了一切我所需要的鼓舞，无论我试着活下去，还是接受死亡都可以接受。在医院里，那是我珍藏的一段回忆。

In my work over the years, I've known many people who were ready to go, ready to die. Not because they had found some final peace or transcendence, but because they were so repulsed by what their lives had become -- in a word, cut off, or ugly. There are already record numbers of us living with chronic and terminal illness, and into ever older age. And we are nowhere near ready or prepared for this silver tsunami. We need an infrastructure dynamic enough to handle these seismic shifts in our population. Now is the time to create something new, something vital. I know we can because we have to. The alternative is just unacceptable. And the key ingredients are known: policy, education and training, systems, bricks and mortar. We have tons of input for designers of all stripes to work with.

在我多年的工作中，我结交了许多愿意离开，准备好接受死亡的人。并不是因为他们找到了最终的安乐或者超越，而是因为他们被他们生命中的转折击退了——有一个词，也就是隔绝，丑陋。生活在长期病痛中和患有绝症的人已经是历史新高了，年龄也不断攀升。而我们丝毫没有准备好迎接这个银色海啸。我们需要一个有足够动力的基础设施去应对这些人口比例的重大变化。现在正是时候去创造一个全新的，重要的系统。我知道我们可以成功，因为我们必须要这么做。我们没有选择的余地。而且，我们已经把握住关键的因素了：政策，教育和训练，系统，砖块和砂浆。我们有无数的信息可以供设计师参考搭建。We know, for example, from research what's most important to people who are closer to death: comfort; feeling unburdened and unburdening to those they love; existential peace; and a sense of wonderment and spirituality.

比如说，从调查研究中，我们可以得知对于临终的人而言，什么更加重要：舒适；没有任何负担，也不牵累他们爱的人；心境平静；充满感叹和灵性的感觉。

Over Zen Hospice's nearly 30 years, we've learned much more from our residents in subtle detail. Little things aren't so little. Take Janette. She finds it harder to breathe one day to the next due to ALS. Well, guess what? She wants to start smoking again -- and French cigarettes, if you please. Not out of some self-destructive bent, but to feel her lungs filled while she has them. Priorities change. Or Kate -- she just wants to know her dog Austin is lying at the foot of her bed, his cold muzzle against her dry skin, instead of more chemotherapy coursing through her veins -- she's done that. Sensuous, aesthetic gratification, where in a moment, in an instant, we are rewarded for just being. So much of it comes down to loving our time by way of the senses, by way of the body -- the very thing doing the living and the dying.

在禅宗安宁病房将近30年的历史中，我们从我们的住客的微妙的细节中学到了很多。有些东西没有它看上去那么小。拿珍妮特举例。因为她患有渐冻人症，每一天她的呼吸都会变得更加困难。你们猜怎么样？她又开始想抽烟了——还是法国香烟，如果可以的话。并不是因为自我摧残的倾向，而是想在她还有肺的时候，去感受她的肺被充满的感觉。优先顺序不同了。还有凯特——她只想感受着她的狗狗奥斯丁躺在她的床脚，他冷冷的鼻子贴着她干燥的皮肤，而不是让更多的化疗流淌在她的血液中——她已经经历过了。在一刹那

间，能够感受到美感的满足 立刻成为我们活着的奖励。 这种感觉在我们珍爱的时间中 通过感官和我们的身体—— 也就是正在经历生命和死亡的东西。

Probably the most poignant room in the Zen Hospice guest house is our kitchen, which is a little strange when you realize that so many of our residents can eat very little, if anything at all. But we realize we are providing sustenance on several levels: smell, a symbolic plane. Seriously, with all the heavy-duty stuff happening under our roof, one of the most tried and true interventions we know of, is to bake cookies. As long as we have our senses -- even just one -- we have at least the possibility of accessing what makes us feel human, connected. Imagine the ripples of this notion for the millions of people living and dying with dementia. Primal sensorial delights that say the things we don't have words for, impulses that make us stay present -- no need for a past or a future.

也许在禅宗安宁病房中 最凄凉的地方是我们的厨房， 你肯定觉得这有点奇怪， 因为有许多住在病房中的人 就算能进食，也只能很少量。 但是我们意识到这样可以在 许多层面上给他们提供支持： 比如嗅觉，一个象征性的平面。 真的，在我们的病房中所有的重大责任中， 其中我们所知的尝试过多次， 也是最真切的治疗方法， 是烘焙饼干。 只要我们还有感官—— 哪怕只有一个—— 我们至少还有可以接触 人性的感觉，和世界连接。 对于全世界数百万的与痴呆症 生死搏斗的人来说， 我们可以想象一下这个观点的效应。 最原始的感官上的愉悦是我们无法用语言描述的， 是使我们珍惜当下的冲动—— 不需要回到过去或者展望未来。

So, if teasing unnecessary suffering out of the system was our first design cue, then tending to dignity by way of the senses, by way of the body -- the aesthetic realm -- is design cue number two. Now this gets us quickly to the third and final bit for today; namely, we need to lift our sights, to set our sights on well-being, so that life and health and healthcare can become about making life more wonderful, rather than just less horrible. Beneficence.

如果把不必要的痛苦从系统中剔除 是我们的第一个设计提示的话， 那么给予人们感官上的， 身体上的尊严—— 美感的境界—— 则是我们的第二个设计提示。 这也把我们带到今天第三个和最后一个部分； 也就是，我们需要提高眼界， 把重点放在人们的福祉上， 为的是生命，健康和医疗 可以使生活变得更加美好， 而不只是少几分可怕。 慈善。

Here, this gets right at the distinction between a disease-centered and a patient- or human-centered model of care, and here is where caring becomes a creative, generative, even playful act. "Play" may sound like a funny word here. But it is also one of our highest forms of adaptation. Consider every major compulsory effort it takes to be human. The need for food has birthed cuisine. The need for shelter has given rise to architecture. The need for cover, fashion. And for being subjected to the clock, well, we invented music. So, since dying is a necessary part of life, what might we create with this fact? By "play" I am in no way suggesting we take a light approach to dying or that we mandate any particular way of dying. There are mountains of sorrow that cannot move, and one way or another, we will all kneel there. Rather, I am asking that we make space -- physical, psychic room, to allow life to play itself all the way out -- so that rather than just getting out of the way, aging and dying can become a process of crescendo through to the end. We can't solve for death. I know some of you are working on this.

区别就在这儿， 在一个以疾病为核心 和一个以人为核心的医疗模式之间， 在这儿，医疗变

成了一种有创意、生产力，甚至好玩的举动。 "玩"在这里是一个很有趣的词。但它也是我们适应的最高境界之一。想一想人类每一个不可缺少的需求。我们对食物的需求带来了烹饪。我们对遮风避雨的需求构成了建筑。我们对遮蔽身体的需求促成了时尚。而因为我们要服从于时间，我们发明了音乐。那么，既然死亡也是生命中必不可少的一部分，我们又能创造出什么呢？说到"玩"，我决不是在提议我们轻视死亡或者指定某种特定的死亡方式。有许多悲伤是我们无法消除的，无论如何，我们都会屈服于它的。我只是希望大家可以创造一点空间——生理和心理上的空间，让生命自己走完它的路——而不是把它赶走，衰老和临终可以变成一个渐强的过程一直到结尾。我们无法避免死亡。我知道你们有些人在尝试。

(Laughter)

(笑声)

Meanwhile, we can --

在此同时，我们可以——

(Laughter)

(笑声)

We can design towards it. Parts of me died early on, and that's something we can all say one way or another. I got to redesign my life around this fact, and I tell you it has been a liberation to realize you can always find a shock of beauty or meaning in what life you have left, like that snowball lasting for a perfect moment, all the while melting away. If we love such moments ferociously, then maybe we can learn to live well -- not in spite of death, but because of it. Let death be what takes us, not lack of imagination. 我们可以针对死亡做设计。我的一部分很早以前就已经死了，不管怎么说，事实就是这样。但是我针对这个事实重新设计了我的人生，当你意识到你在生命中永远可以找到美好的事物和有意义的事情时，我可以告诉你们这是一种解放。就像那个停留在完美的一瞬间的雪球，同时一直在融化。如果我们能够拼尽全力去爱那些片刻，也许我们就能学会如何活得更加精彩——不是不顾死亡而活得精彩，而是因为死亡而活得精彩。可以让死亡夺走我们的生命，但别让它带走我们的想象力。

Thank you.

谢谢

(Applause)

(掌声)