

## Ways & Means Transcript—S1E2—A Beautiful Death

Emily Hanford (EH): From Duke University's Sanford School of Public Policy, this is Ways and Means. We share bright ideas for how to improve human society. I'm Emily Hanford.

Heidi Hannapel (HH): I remember many conversations with my mom [in] the last ten years where she'd say, "Well, I don't know what I want to do, but I really don't want to be a burden." And it's been such a joke, because it has been the greatest burden on us imaginable.

EH: This is Heidi Hannapel. Earlier this year Heidi found out her mom, Linda Jay, was dying from a brain tumor. Heidi took a leave from her job and moved her mom into her busy home on a tree-lined street in Durham, North Carolina. Heidi committed to care for her mom until she passed away, whether that happened in days, or weeks, or months. It wasn't an easy decision. Heidi and her mom have always had a complicated relationship.

HH: I walked into this thinking, "Oh, gosh, here's this event, and maybe we can do some really good healing from this- all of us and, you know, we'll hold mom's hand and we'll walk towards the inevitable." But that was not what she wanted.

EH: Heidi and her mom- they handle things differently. For example, one day, Heidi heard her mom talking to one of her caregivers.

HH: And I remember her saying to this one nurse, "Heidi's doing so much more than anyone would really want someone to do." And I realized, "Oh! This isn't what she wants. I'm doing the things that I would do for me, but that wasn't what she wanted."

EH: Coming up on this episode of Ways and Means- how listening carefully to what seniors want when they're dying could lead surprisingly to cost savings for big government systems, like Medicare. It could also give the dying and their loved ones more control over the quality of their final days.

HH: Everything was just so overwhelming. Suddenly, this is how her life was gonna end. Suddenly, all of her financial burden became mine. Suddenly, everything, her entire life just became my responsibility. And my husband and I were at a point where we were looking at the light at the end of the tunnel, raising four kids and thinking of all the wonderful road trips and crazy fun that we were gonna have and that door just slammed shut.

EH: One of the initial problems was financial. Heidi knew her mom was running out of money; and, while she had decent medical insurance and Medicare, and even long-term care insurance, Heidi was worried it wasn't enough. For example, Heidi says her mom's long-term care insurance provided \$110 dollars a day for a nursing home, but the average daily cost in the area was nearly double that. And, since Heidi wasn't sure how long her mom would live, she didn't want her to get in over her head financially. And so, pretty soon, Heidi's mom, Linda, was living in Heidi's spare bedroom and Heidi was determined to make her mom's last days as good as they could be. Figuring out what her mom wanted, though- that was hard. Her mom would not admit she was dying.

HH: She didn't want to process this. She didn't want to think about it. I mean, she's a fighter... She just- she wants to live, and she has always lived very, very hard. But she didn't want to talk about the

tumor. She didn't want- she just kept saying, "I'm gonna get better. I'm gonna beat this. I'm not ready to die. I have so much work to do. I have so many grandkids to live for." So, we never really had a conversation about it. And, initially she said that. She said, "I don't want any of my friends to know and no one is allowed to come and visit me." And I just looked at her and I said, "That's impossible!", but I was very careful at first, because I was struggling so much with this. What's the balance of giving her what she needs and honoring her as a patient with this horrible diagnosis?

EH: But it's been hard. Heidi feels many people in the system- nurses, physician's assistants, occupational and physical therapists- were almost colluding with her mom. They'd say things like-

HH: "When you get stronger," and "When you get better, this is what you're gonna do to get stronger and better and you've got to do all these exercises, so you're getting stronger and better." And everybody was always talking about "stronger and better" and no one ever said that it's not gonna be an uphill climb, it's a downhill climb with an ending. No one would say that. And, she would always throw her hands up when someone new would come into the room and say, "Don't give me any bad news! Just keep it positive. We're here to keep things positive!" And I, you know, of course I love hope and positivity, and I think I'm a positive person, but there's also the reality and no one wanted to touch the reality.

EH: And the reality was this: Linda was not going to get better, and there were a lot of choices to be made, and because her mom wouldn't or couldn't face her diagnosis, Heidi ended up making the choices for her mom using her best judgment. But, Heidi really wanted the two of them to make those decisions together.

HH: I think what I would have liked her to say is "I'm scared as shit. I'm scared." Because I was scared. "I'm scared. I don't know what to do. I don't know where we're going." To just be honest about that, I think is what I wanted. Instead of, what I felt like was- we were constantly tiptoeing around this huge beast that sat in the middle of the room.

EH: Don Taylor studies the economics of the end of life at Duke University. He says Heidi and her mom are not alone. 65 million people in the US are caregivers to someone sick, disabled, or elderly. And, no matter what your relationship is with your parent, it's really hard to talk about end-of-life issues. Just like Heidi, caretakers often feel they're on their own, without guidance or financial help, figuring everything out from scratch, including what to do and how to pay for it. "Medicare," he says, "is the system that should help." In the United States, 8 of 10 are on Medicare when they die.

Don Taylor (DT): People are stunned, "Oh my gosh, eight out of ten people that die are Medicare beneficiaries!" So, what that means is that Medicare is inherently in the end-of-life business period. And so, that means that that should be the epicenter of deciding how to communicate information to patients.

EH: Beginning in January, for the first time ever, Medicare will pay doctors and nurses to talk with you about end-of-life decisions, not only when you enroll in Medicare at age 65, but when you most need it- any time, including when you're really sick. And for many of us, what we want at the end of our life actually changes the closer we get to it. Don Taylor points to a study he did with terminally-ill people, where researchers showed them a list of benefits Medicare offers then researchers asked the

patient's a hypothetical question.

DT: And these are patients who are very sick. They're very ill with cancer. So, we said, "If you couldn't have everything that the Medicare program now pays for, what would you pick? What would be most important?"

EH: What the researchers found was a lot of people between 40 and 50 percent didn't choose last-ditch chemo treatments or experimental therapies. They chose care that would make their final days more comfortable.

DT: So here you could think of care, like, helping an elderly person get in and out of bed. Perhaps, going and cooking lunch for them and making sure they were okay in the middle of the day.

EH: So, just think about that. A huge percentage of people who are staring death in the face- about half of them say, if given the choice, they'd really rather have Medicare pay for the little things. They'd like help with their daily needs as their lives are winding down, rather than more expensive treatments intended to prolong life. This is really different from how Medicare operates now.

DT: Basically, now in the Medicare program, if something's not experimental, it will be covered, and if a doc and a patient decide they both want this treatment to happen- roughly speaking, it will happen.

EH: What he's saying is the big stuff- medical treatments like x-rays and cat scans, those are covered. That probably explains why Linda's doctors were more focused on treatment than palliative care, but the kind of care many people say they want is something Don calls "high-touch, low-tech". That kind of care is relatively inexpensive, yet it's usually not covered by Medicare unless the patient is in hospice, and hospice, in general, is for those with six months or less to live. But, for patients like Heidi's mom, Linda, who are not in hospice yet but are very sick, they need long-term care.

DT: And the Medicare program, the biggest hole, so to speak, in the benefit package is long-term care services, and that's just care that helps people deal with the fact that they can no longer do things that most people take for granted- you know, getting in and out of bed, take a bath, put on a shirt, go to the toilet, and make a meal. Those types of things.

EH: So, this idea- asking people who are dying what they want and designing Medicare options around that- this idea could have tremendous financial implications. Traditionally, policy makers have said, "Well, there's just not the money for that, because such changes would be seen as adding services to an already-giant system, but Don's work shows what dying people want could not only make the person more comfortable, it could actually save the system money because these "high-touch, low-tech" options actually cost less than what patients often get: expensive treatments in a hospital. "The key," says Don Taylor, "Is both doctors and policy-makers need to consider what people want when they are dying."

DT: These people were fully in touch with their mortality and we're more in touch with the reality of trying to live another day, another day, another day as best they could. And so, you know, 40-50 percent of them had gotten to the point where, you know, "high-touch, low-tech" services would be likely to help them live a better life tomorrow, or today. And so, they were the ones ready to have the hard conversation.

EH: With these new Medicare rules, more and more doctors will talk with patients about their wishes at the end of their lives, but doctors need to be trained for these sensitive conversations, the very kinds of conversations Heidi wanted so much. And that training is not always happening. Don remembers, years ago, he was advising a relative who was really sick. On the first couple of doctor's visits, the doctors asked him, "Do you have any questions?"

DT: And so, I asked questions like, "What's the likelihood this is gonna work?" and also started asking some questions about cost. I was saying, "Well, how much will this cost first, that and the probability that it might work." And basically, the doctors were irritated by the questions- and then I was kind of irritated back. I was like, "Well, you're the one that said, 'Do you have any questions?' So, if, you know- don't patronize us. If you don't care if we have questions, don't pretend like you do."

EH: Don says he thinks there's a simple reason why the doctors were annoyed. They didn't know the answers. The questions he was asking- likelihood, probability, cost- doctors just aren't trained in that.

DT: We should be consumed with that. We should be consumed with the idea that we sometimes are offering patients therapies that we really- when I say we, I'm talking about the health system, the providers- they don't really know what the cost implications are for the family. They don't really know what the likelihood that something might work might be. They don't know how to communicate uncertainty- and again, part of the reason they don't know how to do it is because it's hard. So, it could sound like I'm saying, "All bad doctors, well they should just learn how to do this simple-" this is really difficult stuff.

HH: So, I kind of like to hold mom's hand. "I don't know if you're awake mom, but, um, I have a friend here, and she's from Duke..."

EH: Heidi Hannapel is sitting at her mother's bedside in a small bedroom, off the entryway to her home in Durham, North Carolina. Linda came to live with her daughter in March. Now, it's five months later, and we're here hoping to do an interview with Heidi and her mom, but Linda is lying in a hospital bed that her daughter had brought in to make things easier. The shades are drawn, Linda's eyes are shut, her breath is coming lightly.

HH: Your story is our story. I guess I hope that you feel that know that we were here for you, and um, Henry was here. Claire was here. Nora and Brenda were all here. We just wanted to give you a place that was peaceful, and safe, and filled with the love of your friends and your kids. I think you feel that. I'll let you rest, mom.

EH: Linda Jay died a week later, August 17, 2015, peacefully, in her daughter Heidi's home.

Thanks to Heidi Hannapel for sharing the final week of her mom's life with us. We've gathered links to resources to help you have an end-of-life conversation with a loved one, something Heidi definitely recommends you do sooner, rather than later. That's at our website, [waysandmeansshow.org](http://waysandmeansshow.org). You can also find a link to Don Taylor's blog at the website. Don's been detailing the many big changes coming to Medicare in 2017.

Ways and Means is produced by Carol Jackson, Alison Jones, and Karen Kemp. We're a production of the Sanford School of Public Policy at Duke University, and we thank you so much for listening. If you

like what you're hearing, please write a review on iTunes. It will really help a lot, thanks. Until next time, I'm Emily Hanford.

DT: I have three teenagers, and they'll say, "Daddy's going to another conference where everybody's talking about dying people." And they think that's really weird, but the way I think about it from a health policy perspective is that the only thing that each of us are guaranteed to do is die. So, the health system better pay attention to that.