

Elderly book end-of-life talks once labeled 'death panels'

May 22 2016, by Matt Sedensky



In this Wednesday, April 13, 2016 photo, Herbert Diamond, 88, left, of Fort Lee, N.J., speaks with Dr. Manisha Parulekar about his end of life preferences, at the Hackensack Medical Center in Hackensack, N.J. Such conversations, are slowly spreading across the U.S. as Medicare rolls out government payments for the consultations. (AP Photo/Julio Cortez)

The doctor got right down to business after Herbert Diamond bounded in. A single green form before her, she had some questions for the agile 88-year-old: about comas and ventilators, about feeding tubes and CPR, about intense and irreversible suffering.

"You want treatments as long as you are going to have good quality of life?" Dr. Manisha Parulekar asked. The retired accountant nodded.

"And at that point," she continued, "you would like to focus more on comfort, right?" There was no hesitation before his soft-spoken reply: "Right."

Scenes like this have been spreading across the U.S. in the months since Medicare started paying for conversations on end-of-life planning. Seven years after that very idea spurred fears of "death panels," supporters hope lingering doubts will fade.

"The more and more that that happens, the more patients, families and doctors will become comfortable with it," said Dr. Joe Rotella, chief medical officer of the American Academy of Hospice and Palliative Medicine. "Any distrust people have about, 'What is this?' really disappears when patients sit down and find out this is about empowering them."

The Centers for Medicare and Medicaid Services quietly tucked the change allowing for payment for end-of-life counseling into a massive package of regulations last summer, with billing permissible as of Jan. 1. To date, CMS has not released any data on how many people have taken part in the sessions, but a survey released last month suggests it may be off to a slow start.

Three non-profits—the California Health Care Foundation, Cambia Health Foundation and John A. Hartford Foundation—fielded a poll of

736 doctors who see patients 65 and older. Only 14 percent said they had already billed Medicare for the new counseling, though the survey was conducted February 18 through March 7, meaning the earliest participants only had about six weeks from the start of the benefit. Altogether, 95 percent of doctors in the poll expressed support for the Medicare benefit and a big majority considered such conversations important.



In this Wednesday, April 13, 2016 photo, Herbert Diamond, 88, of Fort Lee, N.J., meets with Dr. Manisha Parulekar about his end of life preferences at the Hackensack Medical Center in Hackensack, N.J. For years before the Affordable Care Act was written, there was bipartisan consensus on the value in helping people understand their desires at the end of their lives and make those wishes known. A 1991 law passed under President George H.W. Bush requires hospitals and nursing homes to help patients who want to prepare living wills and

advance directives. (AP Photo/Julio Cortez)

Some doctors had already incorporated end-of-life planning into regular visits, and certain private insurers began offering reimbursement for it before Medicare announced its change. But because Medicare is the single largest payer of [health care](#) in the U.S., this could stand to be one of the most significant developments in end-of-life care ever seen in the country.

It also gives Americans a glimpse into something many only knew through the lens of controversy.

Diamond arrived for his appointment at Hackensack University Medical Center on a mundane day in which he had reviewed investments, had a dentist appointment and ate a couple slices of pizza for lunch. In his last visit with Parulekar, she gave him a copy of "practitioner orders for life-sustaining treatment," or POLST, a doctor-signed document that makes end-of-life preferences known.

"Did you have a chance to look at the form?" she asked. He had, and they set out to review it as Parulekar filled it out.

"I wish to live a full and long life but not at all costs," she wrote as a goal of care, repeating language common in living wills, something Diamond long ago completed. This document will go further in its specificity and authoritativeness. It serves as a medical order to dictate the response to a health crisis should patients no longer be able to make their own decisions known.

The doctor calmly addressed questions as they moved through the document with Diamond: How long would he feel comfortable being on

a feeding tube? If hope seems lost, should CPR be performed anyway? Would you want to be put on a respirator?

"I wouldn't want to be on a machine for the rest of my life, that's for sure," Diamond told her.



In this Wednesday, April 13, 2016 photo, Herbert Diamond, left, 88, of Fort Lee, N.J., meets with Dr. Manisha Parulekar about his end of life preferences at the Hackensack Medical Center in Hackensack, N.J. Some doctors had already incorporated end-of-life planning into regular visits, and certain private insurers began offering reimbursement for it before Medicare announced its change. But because Medicare is the single largest payer of health care in the U.S., this could stand to be one of the most significant developments in end-of-life care ever seen in the country. (AP Photo/Julio Cortez)

All told, it was only about 20 minutes before Diamond's white sneakers shuffled out of the room and the appointment was over. He was to review the paperwork with his two daughters before signing it, but he said he had looked forward to the session simply because it was a new experience. Diamond said he saw it as both necessary and comforting.

Medicare reimbursements for the appointments vary by region and the type of facility, but on average, an initial 30-minute session in a doctor's office costs \$86. As those experiences proliferate, the topic of discussing [end-of-life care](#) may return to the relatively uncontentious mantle it once enjoyed.

For years before the Affordable Care Act was written, there was bipartisan consensus on the value in helping people understand their desires at the end of their lives and make those wishes known. A 1991 law passed under President George H.W. Bush requires hospitals and nursing homes to help patients who want to prepare living wills and advance directives and similar efforts gained particular resonance after the 2005 death of Terri Schiavo, the brain-damaged Florida woman whose family fought for years over whether she'd want to be kept alive in a vegetative state.

In 2008, Congress overwhelmingly passed legislation requiring doctors to discuss issues like living wills with new Medicare enrollees. And just months before being tapped as Republican presidential candidate John McCain's running mate, then-Alaska Gov. Sarah Palin signed a proclamation recognizing Healthcare Decision Day to spread word of a statewide campaign about the importance of advance directives.

That history dissipated in an instant in 2009 as President Obama's health care proposal spurred angry protests. Early drafts of the bill included a provision to pay for voluntary end-of-life conversations. Palin claimed it amounted to creating "death panels" and said it would allow government

officials to decide whether sick people get to live.

"The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama's 'death panel' so his bureaucrats can decide, based on a subjective judgment of their 'level of productivity in society,' whether they are worthy of health care," she wrote in a Facebook post at the time.

Palin hammered the "death panel" idea. Her staff made clear she was specifically addressing advance-care planning. And the controversy led to the proposal being dropped from the bill.



In this Wednesday, April 13, 2016 photo, Herbert Diamond, 88, of Fort Lee, N.J., meets with Dr. Manisha Parulekar about his end of life preferences at the Hackensack Medical Center in Hackensack, N.J. Diamond said all the men on

both sides of his family died before they reached 65, and so he never expected to live as long as he has. But years ago, when his wife was hospitalized, dying with lymphoma, he recalled an old man in a bed next to her hooked up to all kinds of paraphernalia, in seeming misery. It was a lesson to him to make sure he never found himself in the same place. (AP Photo/Julio Cortez)

With the Medicare change in sight, at the close of 2015 Politico penned an obituary for "death panels." But fears stoked by the idea—which PolitiFact named the "Lie of the Year" in 2009—still remain. Obama even made light of the lingering impact in addressing the White House Correspondents' Association dinner last month, noting his own impending retirement and joking : "Eight years ago, I was a young man, full of idealism and vigor. And look at me now: I am gray, grizzled, just counting down the days till my death panel."

A March 2016 poll by Public Policy Polling, commissioned by Ari Rabin-Havt for his book "Lies, Incorporated," found 29 percent of respondents believed the health reform law established "death panels," with an additional 31 percent unsure. Among Republicans, 45 percent said they believed the law established "death panels."

Requests for comment from Palin via her political action committee went unanswered.

"Lies are very sticky," Rabin-Havt said, "and this is yet another example of how sticky lies are and the damage they can do."

Hackensack University Medical Center, where Diamond had his session, is taking part in an advance-care planning campaign to educate and encourage people to put their preferences in writing. Linda Farber Post, the hospital's director of bioethics, said the goal was to have all doctors,

not just those treating the elderly or dying, to have such discussions with their patients.

"This is not something where doctors should be saying, 'Let's just leave it to the geriatricians and the palliative care folks,'" she said.

Diamond said all the men on both sides of his family died before they reached 65, and so he never expected to live as long as he has. But years ago, when his wife was hospitalized, dying with lymphoma, he recalled an old man in a bed next to her hooked up to all kinds of paraphernalia, in seeming misery. It was a lesson to him to make sure he never found himself in the same place.

"It just seemed quite apparent to this layman that he was suffering and yet his family couldn't let go," he said. "I would never want that for me."

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