

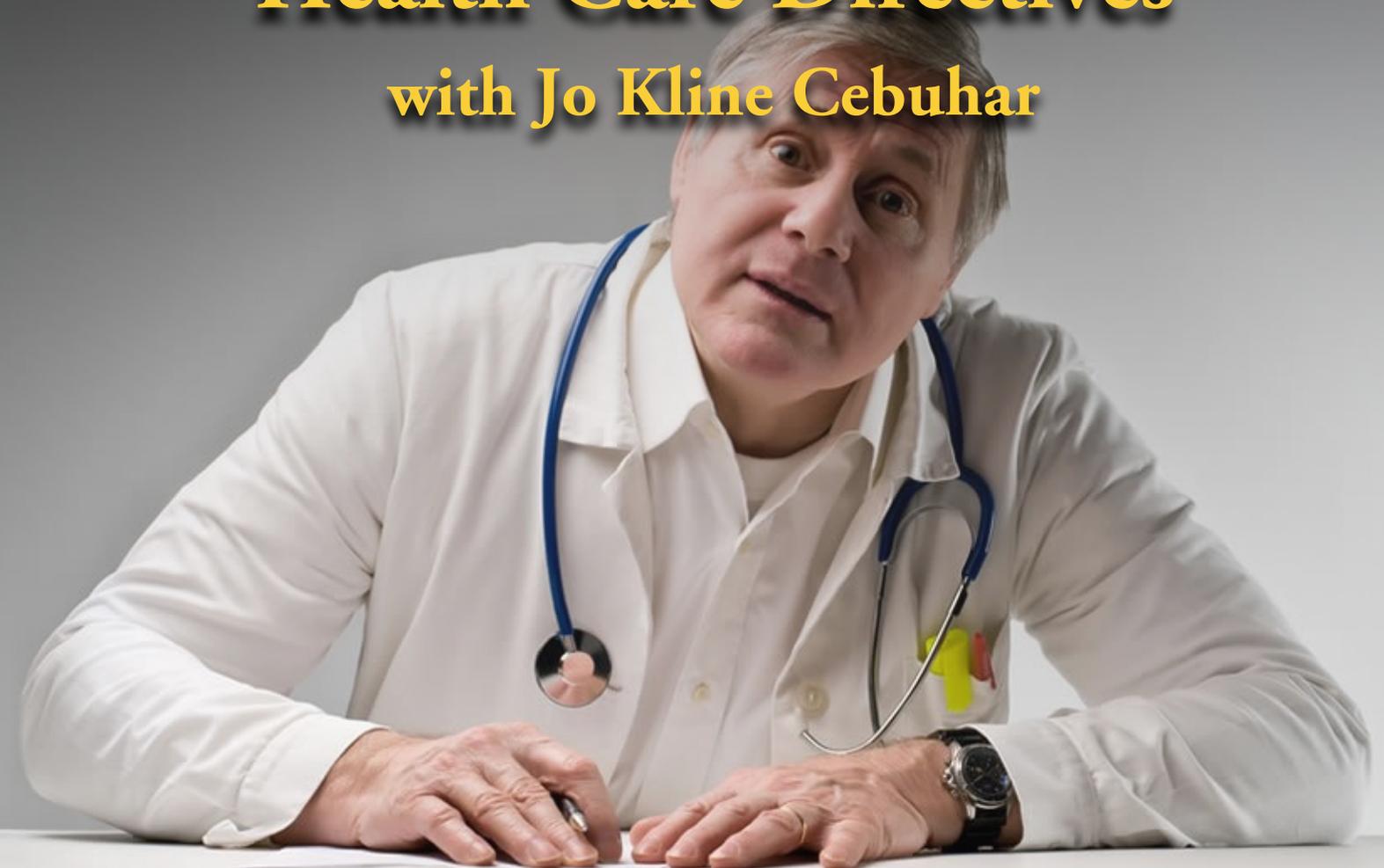
BUILDING WEALTH IN CHANGING TIMES



The Solari Report

NOVEMBER 5, 2015

Health Care Directives with Jo Kline Cebuhar





Health Care Directives

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C. AUSTIN FITTS: Ladies and Gentlemen, what a privilege it is to welcome back to The Solari Report someone who needs no introduction. Her name is Jo Kline Cebuhar, and she has joined us several times.

She is, as far as I'm concerned, the go-to person on both healthcare directives as well as ethical wills. She's an attorney, she's an author, and she has also chaired the largest Hospice in Iowa. If you know me, you know what a fan I am of hospice. I think her history and knowledge is very deep.

She has written a great novel that we've talked about on The Solari Report to help with end of life issues as well as hospice called *Exit*, but she has issued a new edition and I rarely say to people, "Thank God you brought out a new edition."

She has brought out a new edition titled *The Practical Guide to Healthcare Advance Directives*, and it's really super. I recommend it to absolutely everybody. Along with *The Joy of Cooking* this is something you must have.

So, Jo, it's so wonderful to have you back on The Solari Report. You're coming into us from Iowa, which is a wonderful place.

JO KLINE CEBUHAR: Catherine, it's always a pleasure to be with you, and I so appreciate the chance to talk to you and talk to your audience and your followers because there is some really interesting stuff going on.

C. AUSTIN FITTS: Oh, I know. This is a topic we all love to avoid, but from my personal experience this is intelligence that can save your life – literally.



So before we get into an update, there is a lot I want to talk about in what's happened since we last talked about this in 2012. Let's just go back and revisit for people who really haven't visited this topic. What is a health care directive? Break it down into the different pieces, and why are they so important?

JO KLINE CEBUHAR: A health care directive or a health care advanced directive, of course we've got 51 jurisdictions who rule this. All the different states have different laws, so there is some different terminology, but I think probably advanced directives or health directives everybody recognizes. That's the written part of an advance care plan. So this is both your verbal and your written directions for medical care and end of life care in case you are incapacitated in the future, in case you're not able to manage your own care and speak up and make informed consent decisions.

C. AUSTIN FITTS: I want to point out in the beginning – and I apologize for interrupting – one of the reasons why I want everybody to read this book is this is not just for us elderly people; this is for everybody because this is something that comes up at all ages and all different times of life.

When I say that it can save your life, it can save the life of a young person if they've got this worked out and planned out. So just wanted to bang that drum.

JO KLINE CEBUHAR: Absolutely, and point well taken, Catherine, because one of the many changes that I made in the version between the 2015 version and the original version from 2006 – my *Last Things First Just in Case* – was that I really focused this time around and devoted a big part of the book to shared decision making and how to do that patient-physician communication.

At any point in your life, you could be having a surgery and have your loved one need to make a decision for you while you're under anesthetic, or you're too sick to speak for yourself, or because of painkillers you're incapacitated in your decision making.



So you are so right. This is not just an end of life issue, and it's certainly not just for the elderly.

C. AUSTIN FITTS: Right. Okay, so unpack directives. Or unpack what it is because one of the things you said in your cover letter – which always takes my breath away whenever you remind me – that 72% of Americans have not done this kind of planning: chosen people to help them, educated people to help them, and provided them with the kind of power and authorities they need to make sure that it's someone you love taking care of you and making these decisions as opposed to a machine that barely even knows you.

JO KLINE CEBUHAR: Right. Now the two most common forms of advance directives are a living will, which is your instructions, and then the durable power of attorney for healthcare, and that's the appointment of that substitute decision maker for you. And, yes, 72% of American adults have not produced or written advance directives. They may have talked about their wishes with their loved ones; they may have mentioned things from time to time, but they haven't formalized them.

“Yes, 72% of American adults have not produced or written advance directives.”

What's interesting when I look at these surveys and statistics is they are very consistent over the years. People say, “I didn't know where to get the information. I have a lack of information about this, and no one has ever talked to me about it.”

So it's not really that denial issue that we think or that we assume keeps people from doing this; it's a very intimidating subject because they don't know how to find the answers.

C. AUSTIN FITTS: Right. I have to tell you that the last time we spoke about this you pointed me to the Aging and Dignity website with their Five Wishes forum that makes it so easy, but I have to report back and tell you that the last time I said, “Just to get the form; you don't need to read the book.”



This time I'm going to tell them, "You need to read the book." What I've learned is that people will not force their family to go through the process until they understand how absolutely important it is and how urgent it is.

JO KLINE CEBUHAR: The form is that last step of four steps. Number one is education, speaking the same language as the ones who are drawing the forms. I will tell you that right now I'm in the process of creating a universal healthcare advance directive form.

C. AUSTIN FITTS: Good.

JO KLINE CEBUHAR: I recommend Five Wishes. You know I have for a decade. They have distributed 23 million copies, so that speaks for itself. But, I see some drawbacks in it, and the other thing – and we'll talk about this a little bit later on – is we'll really get into a whole new area now in this country, and that is the area of advanced dementia. I don't feel like that's being addressed in Five Wishes as strongly as it should be.

So I am in the process of developing my own form, but you're right. It is education. It is delegation, which is that appointment and that conversation with your proxy. It's communication. That's letting everybody know, including your physician, what your wishes are. Then, finally, the fourth step is documentation, and that's getting the right form – one that you understand and that really reflects your preferences, not the preferences of the guy who drew the statute up for your estate – because there's a lot of 'default option' statutes out there that assume we all think the same.

If that's the case, I guess we don't need directives at all, do we? Of course, that's not the case. You know where I stand on that.

C. AUSTIN FITTS: I've pushed clients very aggressively to do this, and what I've seen is the response they get from their family – who is, of course, very busy in their defense – is, "Oh, this is really depressing. We don't want to do this."



What they don't understand is they have a machinery called the health care system which is becoming more and more machine-like. If you look at both the liability laws and the protocols and procedures and all the different incentives in that machine, do you want that machine arbitrarily making decisions about you, or do you want someone you love to have the power to tell the machine no?

Unless they have the power and the clarity of planning and instructions, they can't stand down the machine. As you know, I bore you with my personal stories of when I've had to stand down the machine. You know my father was a surgeon. I'm trained to stand down the machine, but I have been in tussles where that machine is very smart and very aggressive and is moving counter to the individual's best interest, and it's a matter of life and death.

So this is really about the balance of power between you and the machine. I'm searching for a way to persuade families, "Look, we're trying to increase your power here. Let us do that."

I think the book does a very good job of doing that in a way which only a great attorney can pay attention to the detail the way you need it in a topic like this. So I think the book does that.

JO KLINE CEBUHAR: And empowerment is a big part of this. Advance care planning really isn't just about you. It's twice as likely that you're going to be able to manage your own healthcare at the end of your life because only about one-third of us are going to be completely incapacitated and lose our ability to make our own decisions. So, having learned all this and having learned about all your options and having learned the terminology, that makes you a much more competent patient, number one. That's about you.

Secondly, it is empowering your proxy. It is not leaving them out there hanging, wondering what you would want, being intimidated by the machine, as you most aptly put it, not understanding what your legal medical choices are, not understanding shared decision making. So you want to empower them. That's the second reason to have a good advance



care plan.

Then the third one is maybe you're going to be a proxy for somebody else someday, and this will make you a much better proxy by, again, understanding the terminology, understanding your role as a proxy, understanding what you can and cannot do. Patients' rights are abused on a daily basis in this country, but a lot of them they don't even need to abuse them; we just hand them over. I mean, people just give up their rights by not exercising them.

It's really all three: it's for yourself, it's for your proxy, and it's for when you become a proxy.

C. AUSTIN FITTS: Right, and we've all seen people who've gone through this. I was a caregiver who walked through into death with a very dear friend, and that can be one of the most gratifying, powerful, spiritual experiences. I mean, it was the most powerful and spiritual experience of my life.

But I've also seen caregiving destroy people, and the risk can be very dangerous. So this is not something you playfully walk into. You need clarity and you need training. I think that the new edition plus the form – the Aging with Dignity Five Wishes form – and I can't wait for your form. That is the fastest, most professional way I know to do it. I've just got to beat the drum here. This time I'm getting everybody to read your book.

JO KLINE CEBUHAR: And you know, we really have to take responsibility for ourselves. I call it the perfect storm that's coming, which is the aging population in this country which is drastically, dramatically aging. I mean, we're going to have a 70% increase in the number of Medicare patients in the next 15 years. That will be doubled in 2050.

Now couple that with a real serious lack of health literacy in this country. We really don't know much about our own health, and we certainly don't know much about end of life choices.



The third part of that perfect storm is a scarcity of resources. We are projecting, again, by 2030, that magic date, when Medicare will lose solvency, we're going to be short 90,000 physicians in this country. We're going to be short over 900,000 nurses. Unfilled positions.

We are not preparing for that. In all the political rhetoric on both sides of the aisle no one is talking about it. When I contact my congressional delegation, I get the usual, "We're looking out for you," but nobody will give me specific steps we're taking.

"We are not preparing for that. In all the political rhetoric on both sides of the aisle no one is talking about it."

It becomes an even greater burden on the individual, Catherine, to say, "What can I do to protect myself and my loved ones in this system that is not preparing to protect me?"

C. AUSTIN FITTS: Right. The system that we dealt with 20 years ago is very different from the one we deal with today, and the one we're going to deal with in five or ten years I have a hard time fathoming.

Whenever I go through the numbers and the statistics – and you do a very good job of laying that out – I think, "Maybe I should move to Cuba now."

JO KLINE CEBUHAR: You know, it's the baby boomers. It's the baby boomers, stupid! Why do we have to keep telling them? We keep going knock, knock, knock, and they keep coming to the door and going, "Where did all these [fill in the blank] come from? Where did all these high schoolers come from? Where did all these college students come from? Where did all these people who want to buy first comes from?"

We're here. Forty-year-olds become 50-year-olds, and 50-year-olds become 60-year-olds. They shouldn't be surprised that we are now going to have this huge number of aging and dying in this country as we had kindergartners 60 years ago. But they always seem surprised, don't they?



C. AUSTIN FITTS: Somehow Woodstock was more charming than the notion that one-third of us are getting dementia.

JO KLINE CEBUHAR: Absolutely. Different milestones – some are more fun than others.

C. AUSTIN FITTS: The other thing is the one thing I've always been very good about doing is making sure I have plenty of insurance for traffic and car accidents because I drive so much. I want to go back. It's not just the boomers going through. When a young person has a car accident and heads into the emergency room, they're going to be trying to fit like a pig through the snake with a hospital facility that's dealing with this bulge.

So it's not just the age. Everybody is going to be competing for healthcare attention in a system which clearly is not set up yet to deal with it. How it's going to get set up we don't know.

JO KLINE CEBUHAR: Of course the older Americans – those 65 and older – are the ones with the most long-lasting diseases. They're the ones who really require a lot of hospitalization. We are going to drain the system financially, and the human resources.

As far as people will have to admit that they have had a loved one in the healthcare system, in the hospital or in hospice or a nursing facility in the last two to three years, they have already noticed that there is a great decrease in staff. We are medicating people to render them lower maintenance in our hospitals. It's really quite frightening if you have a loved one there.

To understand that, they bring that meal in. If they don't have a visitor feed them, an hour later someone will take the tray away. It's not that that hospital does not want to feed that patient; they do not have a person to fill that position. They have open positions all the time, and they're simply not filled.

C. AUSTIN FITTS: Right. Well, I want to talk about the legal and regulatory



developments since 2012 because healthcare has been reengineered in radical ways, including for new technology. There are many aspects of this, some of which are thrilling and some of which are gruesome, but no one I know has the time to read all the legislation and regulations that have been issued.

I know you had to go through a lot of that to produce this new edition. So start us into it. What has happened from a legal and regulatory and best practices standpoint since 2012 that we should know about?

JO KLINE CEBUHAR: Well, obviously the biggest change in the healthcare system is the Affordable Care Act, Obamacare. How does that impact our end of life? Well, there was a 10% cut in their hospice care and a 10% cut under the nursing home provision of Medicare under the Affordable Care Act. Again, this is something you see on a very face to face basis. Hospices have closed. When you take a pull a year out of a decade's worth of funding, they're not going to have as many people.

C. AUSTIN FITTS: Did they just cut the money just to cut the money, or did they have a plan on the people who were using that ten percent, what they are going to do now?

JO KLINE CEBUHAR: No. I think it was an easy target. I think it was easy to do because let's face it, the ones with the least amount of voice are people who are dying. So it was a fairly easy target. Again, we're high maintenance, so these are high maintenance numbers to pull benefits out of the aging and their last final years.

We're spending a quarter of the annual Medicare budget on the last year of patients' lives, but only two percent on the end of life.

So what are we doing? We're spending a lot of money and we're not really adding that much to people's quantity of life. We probably should be looking more at their quality of life. So that's really the first big regulatory thing. Nobody really notices until many months after Affordable Care Act was in effect, and then somebody said, "Oh my gosh! That had a 10% cut in hospice!"



The nursing home benefit is when you have been hospitalized for three days and then you're allowed by Medicare a nursing home, which many people need after hospitalization for rehab. Well, that 10% cut doesn't affect what you get as a patient. What it affects is what that institution gets for reimbursement rate. So obviously I can't pay as many workers if I just took a 10% cut. Maybe I won't even take Medicare patients in my facility; maybe I'll just say, "I'm not going to do that anymore. I'm only going to be a private pay care facility, and I have the right to do that."

So it directly impacts the care you're getting in a hospice or the care you're getting in a nursing facility. So that's the first biggest change I think we've all seen in the last couple of years.

The one that I didn't think has gotten as much press as it would warrant – but there are a lot of shiny objects these days in the press – is the physician-assisted suicide legislation which passed in California.

C. AUSTIN FITTS: Tell us about that. There are four states now that have done it.

JO KLINE CEBUHAR: Right: Oregon, Washington, and Vermont already had laws. Montana is a little squishy. It's a little hard to pin them down. By court order they basically eliminated their laws against physician-assisted suicide, but the Montana legislature has never come up with a law.

So we really don't know what would happen if someone actually assisted there, so we're not going to count them as one of the four.

The fourth one is, of course, California. This is a big deal for the people in California, but it's a big deal for all of us because now one in every six Americans lives in a state with a physician-assisted suicide. And the real importance of that is: Do we understand what that is? Do the folks who have that as an option for end of life care really understand what it means?

I'm not sure they do, and I don't have a position on whether we should have it or not; it's the law. I mean, in those four states, it's the law.



I think what's important is that people understand what that law means in their state and what it means if they choose that and whether or not that's really the answer to the problem. What's always touted as the problem is: We don't want people to have to suffer and have pain at the end of life. But what is interesting is when they survey folks who actually take advantage of the physician-assisted laws in Oregon and Washington, which are the two states with the longest history of this, the pain and suffering is like number six. The top things are a loss of dignity and an inability to do the things that bring them joy. Those are the sort of things that we should be addressing other ways.

So it's not the pain and suffering. We have hospice and we have great pain relief. I think people don't know enough about that. So what are we really saying here, Catherine? I think we're really saying that the public is very afraid that the healthcare system is not prepared to treat them with dignity and help them find comfort at end of life, and I can't say they're wrong about that. I'm not sure if the system is.

“I think we're really saying that the public is very afraid that the healthcare system is not prepared to treat them with dignity and help them find comfort at end of life, and I can't say they're wrong about that.”

C. AUSTIN FITTS: I think a lot of the controversy comes not from the issue of people having the right if they so choose and the option to get a physician. I think they're afraid you create this power and give the machine access to turn it on and off, and it's going to go in ways that it's not intended. I think that's the big fear.

JO KLINE CEBUHAR: Yes. There is physician-assisted suicide, but now we have state-sanctioned physician-assisted suicide. We've really medicalized suicide. You will find in those states that the statute literally says that if a person partakes in this, this is not suicide. For purposes of insurance it is not suicide.

So now we have redefined suicide by bringing the state into the behavior.



C. AUSTIN FITTS: Under these laws, can the state serve as proxy and dictate a physician-sponsored suicide?

JO KLINE CEBUHAR: No. As these laws now stand – and they are virtually identical in these four states – the person must have 100% competency. You cannot provide physician-assisted suicide in a directive. That is not allowed. You have to have competency. You have to be able to administer the drug to yourself as the laws stand right now.

C. AUSTIN FITTS: Right. Tell us about what else has happened with the economics. As an investment advisor, I've been watching the healthcare sector literally lead the rise of the US stock market ever since the passage of Obamacare, and each time the Supreme Court rules, the healthcare stocks fly up even more.

So healthcare has really been the leader, and part of it is because you're talking about using technology to digitize everything and you radically reengineer it to squeeze labor out. So there is a tremendous effort. There are estimates that you're going to squeeze about a trillion dollars of labor out using technology, but how you address all of the needs of the baby boomer generation by cutting labor at the same time by that amount, to me it's a big question mark.

JO KLINE CEBUHAR: Before I answer that question, I'll just say we're talking about the boomers, and that's who we focus on, but those poor millennials. We've always talked about the pig in the python, that the boomers are this giant bulge. Well, in reality it's a python in a python because this doesn't end with the baby boomers. If the millennials think, "Boy, when we just get rid of [fill in the blank], and get rid of grandma and grandpa, and get these boomers out of the way it will be smooth sailing," that 70% increase in users of our generation turns into 100% increase when the millennials come around. So those poor kids not only have to pay for ours, but then they've got to suffer the same shortages themselves because this goes on into 2050 and 2060.

As we come out of the system by dying, they're coming into the system, and they're going to discover: guess what? There still aren't any nurses.



There still aren't any doctors. So that's one thing. This isn't a short-term problem; this is an extremely long-term problem.

I know you are so savvy about this financial stuff, so just picture this business model where there is just little new revenue coming in. And we've all paid for this. We've paid through our payroll deductions. As you know, we had nine workers for every retiree in 55. Now we've got 2.8, and by 2030 we'll have one or two workers for every social security retiree – every Medicare patient.

So we've got very little revenue coming in, the demand has doubled, the cost of reduction is skyrocketing, and your product is a matter of life or death. Now what are the chances of that business model succeeding? It's not a good business model – certainly not for the consumer of the end product.

C. AUSTIN FITTS: The model is going to come off the wheels. I keep using this statistic. I have a dear friend who is a fresh food expert, and he sent me the list of the grocery sales in the United States for the year period ending June 30, 2015. In that 12-month period, the American people spent \$2.2 billion on fresh fruit and vegetables. Guess how much they spent on carbonated drinks?

JO KLINE CEBUHAR: How much?

C. AUSTIN FITTS: \$10.5 billion. So they spent four to five times more on carbonated drinks than on fresh fruits and vegetables.

You just stare at those numbers, Jo, and you say, "This can never work."

JO KLINE CEBUHAR: Well, what are we doing in the way of health literacy or preventative? We're not. Everything is at the end. Everything is reactionary in the whole healthcare system.

You're right. It is a recipe for disaster. When I talk to people about this – policymakers – they just look at me like I'm literally not speaking the same language that they understand. I mean, they just never thought



about this or they never have heard this before. “How come I don’t know about this?”

“I don’t know why you don’t know about this, because it’s right there in your face.” This is not an imaginary problem. It will come to the time when you go to the hospital, and there might be a nurse with a bay of video cameras, and one nurse for every three floors. If you’re lucky, someone will notice that you fell out of bed, but you will not be seeing a nurse.

C. AUSTIN FITTS: One of the things that I do, I subscribe to a number of magazines that are all about international living. You see more and more Americans moving abroad either because of healthcare services or because they want to lower their cost of healthcare. Or, if they don’t do that, they engage in medical tourism.

We all know the movie *Marigold Hotel*. I don’t know if you’ve seen that?

JO KLINE CEBUHAR: Yes.

C. AUSTIN FITTS: It’s a group of Brits who go to India for their healthcare.

I’m just wondering: How much of that do you see? How much of that do you think is going to continue to grow?

JO KLINE CEBUHAR: You know, I can only speak anecdotally, but we do have wonderful healthcare in this country.

C. AUSTIN FITTS: We do.

JO KLINE CEBUHAR: What I’m seeing is very interesting anecdotally. Here in Iowa we have excellent care. If I call and say that I need to see a doctor, I can see a doctor within 24 hours.

I have friends around the country, more specifically the sun belt, where there are many more times aging, although Iowa is a pretty old state demographically. There are places that have much higher numbers than



we do in aging where they're looking at four to six weeks to see a specialist.

I'm sitting there thinking, "Wow! That's interesting."

Also, we are just barely starting to have concierge medical services here where you pay an upfront fee for the year. They've had them in many parts of the country for a long time, and if they didn't join a concierge practice when it was offered to them, they're pretty much out of luck. They're going to be at the bottom of that list.

"We are just barely starting to have concierge medical services here where you pay an upfront fee for the year."

So I don't know if that's going to push people. You'd have to be pretty bad for me, quite frankly, to move to another country. I just love America.

C. AUSTIN FITTS: Well you're in Iowa. You're not in New York City. If you were in New York City, you might want to move to Iowa.

JO KLINE CEBUHAR: Exactly. Well, you know what? Sometimes we hate to get our secret out, but life is pretty darn good here. I mean, we really don't want for that sort of thing, and we have the University of Iowa. We have incredible medical facilities and expertise here. We feel very comfortable with that.

But, having said that, I hear rumblings about concierge services and the really top-notch clinics saying, "You know, we're going to look at that." Then it becomes the have and the have-nots.

I just think we can do so much better in this country. We have the ability to serve everyone.

C. AUSTIN FITTS: Here's what I think, and it comes back to your number of 72% of Americans don't have health care directives. We're staring down a systemic change that says that each and every one of us has to be



responsible for our healthcare. That means educating ourselves now to build health. So we need to be in the business of building health every day. If we do need the services of the medical machinery, then we need to educate ourselves before we have to use it.

If you wait until you're really sick before you understand what your relationships are going to be and how you're going to use the system, that's the last time you need to go find a doctor. Do you know what I mean?

That's why the time has come. I went through a process where I had to drop my healthcare insurance, and one thing led to another, but I said, "Wait a minute. I've got to be my own doctor."

It's not that I won't use doctors, but I have to be my own doctor. Again, I've been educated by my family to think that way, and one of the things that I think everybody has to do is get your book, get the Aging in Dignity form – the Five Wishes form – and they need to think through, "How am I going to manage interacting with a machine if I'm not completely coherent and awake?"

That's all part of literally taking responsibility for your own health.

JO KLINE CEBUHAR: You know what? It's like you scripted this segue for me because I have to tell you, this is another thing that's happened, and I'm really excited about this. It has been a little bit in the news, and it's been literally since last Friday. Friday is when this came down.

The CMS, Centers for Medicare and Medicaid Services, which is, as you know, under HHS. These are the people who are kind of between us and Medicare. They're the ones who promulgate the rules. They came out with the final rule Friday night which will allow doctors to be reimbursed for meeting with a patient for the sole purpose of discussing their advance care plan.

In the past you got that as your, "Welcome to Medicare" visit, or you got it if, unfortunately, you got a diagnosis which meant that you needed to



start talking about an end of life plan. Those were the only times that your doctor could be paid for having that conversation with you.

Starting January 1st 2016 under Medicare you will be able to call your physician and say, “I want to come in and talk to you about my advance care plan.”

Now here’s the thing, Catherine. What are you going to talk about, and who’s going to lead that discussion? The doctors have to get up to speed, too. What I’m finding more and more and we’re seeing across the country is physicians, primary physicians, internists, family practitioners, are using hospitalists – which are people who never leave the hospital. They do nothing but see other people’s patients. They’re using intensivists, which are people who specialize in intensive care, and of course, we have hospice care which you and I are both fans of. They now service about 43% of American deaths – hospice care of some sort, whether it’s a residential facility or in a home setting. Who’s not present in that is the primary physician. He’s no longer accompanying the patient to the end of life.

When I call up and say, “I want to talk to you about my advance care plan,” what are the chances that my physician is going to be prepared to have that conversation with me? What are the chances that they’re going to be able to answer the questions of a patient?

C. AUSTIN FITTS: Do hospices help people with advance care planning?

JO KLINE CEBUHAR: At that point, it’s no longer advance. When you’re down to the hospice, you’ve made a decision. A person who’s admitted to hospice has made the decision because legally they have to under Medicare rules. They will no longer have curative measures.

C. AUSTIN FITTS: What I mean is: In the hospice community, are there people who will help people who don’t need hospice yet but understand they want to deal with people who really have a very good understanding of it?



JO KLINE CEBUHAR: You know, we have not seen a lot of that. That's why I say I think this couldn't be more exciting. I think this is a game changer in America in how we look at end of life because we really have now just 60 days for the medical community to get up to speed on this so that they can respond to these requests for these appointments, which is people finally saying, "Oh, good. There's that information that I've been looking for. I'm going to be able to go sit down with my doctor."

The doctor is going to need a source of information, which brings us back to: Do we have a decent form that we can offer to people?

I feel sorry for doctors. The doctor is the one who ends up being the default interpreter of that advance directive form in the medical crisis, but the legal community hasn't been interested in having doctors' input when they draw these things up. So you know what? It's time for everybody to get on the same page now. We have a way to actually encourage people to come in and have that conversation, execute that form – and that's part of the doctor's job. Everybody is talking about it. Hopefully the proxy is sitting in the corner of the room.

We all know what's going on here, and we move on down the road. We could see a drastic change in the use of Medicare dollars as a result of this because we know that people who have advance directives are going to have much less futile medical care. They're not going to have procedures that aren't going to do anything. They're more likely to get the care that they want, and they're less likely to die in the hospital – all because they had an advance directive. I'm excited about this rule.

C. AUSTIN FITTS: It is good, but I think the doctors have a transition to go through which is going to be uncomfortable for them.

JO KLINE CEBUHAR: They do, but you know what? Medicare frowns on doctors saying, "I'm sorry. I don't want to provide that service."

So I don't think doctors will have the option of saying, "I'm not going to be taking those kinds of appointments." They are going to have to get up to speed.



I think it's a forced play. There's no question. But they're kind of getting the two-minute warning here. "We're giving you until January 1st, and you all need to get your acts together, and we all need to learn together, but something has to change here because people want this information."

C. AUSTIN FITTS: Right. To a certain extent I think it's great because it's going to get the 72% down. My only fear is: Are the plans that people come up with going to be digitized and go into the machine?

JO KLINE CEBUHAR: I don't care for that because I don't get excited about some admissions clerk looking at my advance directive.

C. AUSTIN FITTS: Exactly.

JO KLINE CEBUHAR: What they should plug into the computer doesn't work for me. But, again, if we had a form that that doctor or that emergency room nurse or that people could look at and say, "I need to go to the part where it tells me who their proxy is," or, "I need to go to the part where it tells me what they want to do if they stop breathing or their heart stops. Do they want to be revived?"

We've created this glut of forms that aren't legible to anybody. I mean, they're really intimidating in their lack of clarity, and I think the whole system has to be reworked.

C. AUSTIN FITTS: Well, I'm one of those people who when it says, "Who is your doctor," now because of Medicare I have to say that I go to Miracle Health Clinic, but basically I always write N/A because I want my proxy making decisions for me, but I don't want some strange doctor making arbitrary decisions.

JO KLINE CEBUHAR: Which is only a good idea if your proxy knows what they're advocating for, and I know you have, but you'd be shocked at how many people will tell me when I teach classes or do presentations,

"My only fear is: Are the plans that people come up with going to be digitized and go into the machine?"



“Well, I’ve named my son, but I’m not sure I’ve ever told him that I’ve named him.”

Well, if you haven’t told him that you named him as proxy, I’m pretty sure you haven’t told him what he’s supposed to be advocating for either. So maybe you need to have that conversation.

C. AUSTIN FITTS: We have to talk about hospices because not everyone knows what hospices are. There are two things I want to cover next. One is: What is a hospice? The other thing is: How can we revolutionize our entire culture on the topic of death? If we can make friends with death, a lot of these solutions fall naturally from that, and we can start handling death in a way which is wonderful for everybody, including the people who are exiting.

Why don’t we start off with just explaining what hospice is, and explain why it’s such a great idea.

JO KLINE CEBUHAR: Well, hospice is really a philosophy of care. So it is cross-disciplinary. It is not only the medical care. People say, “Well, wait a minute. If I’m in hospice, why would I get medical care?”

Because you know what? Treating your pain and treating your discomfort of any kind, whether that’s social or emotional or spiritual, that is treating you. So just because we’re no longer treating your underlying disease that is your terminal condition does not mean that we should stop treating you as a patient. It’s just like we know what a DNR is and expressions like that. The expression, “Do not treat,” does not exist.

If you ever hear a medical person use the expression, “Well, she’s a do not treat,” correct them. There is no such thing as not treating a patient. So hospice is focusing on the comfort and dignity of the patient and their final chapter of life as defined by the patient. How do they wish to spend that final time, as much control as they may have over it. We’re no longer treating the underlying condition.



So it's pain relief, of course, but it's also where you are able to be. Do you want to be home? Hospice can come into your home. Would you rather not be home? Some people don't want that to be a memory that lingers in their home, especially if they have survivors who are going to live there. Then we have, if you're very lucky and blessed, a residential hospice facility in your community.

Medicare pays for nine out of every ten hospice patient days in this country, so Medicare obviously is a huge force in hospice, which is not surprising because of the statistics of who dies. I mean, naturally it's just going to be older people.

Private insurance often has a hospice benefit in it, but as you know, Catherine, people are going into hospice much later than they should. More than a third of hospice patients die within seven days. Many people will die quickly in hospice because that's the point at which they know their loved ones have finally accepted that they are going to die, that we're not treating the disease anymore and it's time to let me go. It's a great sense of relief sometimes for people.

But it is mostly about compassion and respect, and it also focuses on the loved ones as well as the patient who is dying. So we want to look at the survivors. What are their needs? What are their upcoming needs? How are they dealing with this? It's a whole interdisciplinary philosophy of care that focuses on helping the person have the dignified dying of their choice.

C. AUSTIN FITTS: It's so funny because the few times I've participated in this you go from a hospital where death is considered a risk and it means they've failed to a place where, "Oh, you're welcome. Everything is wonderful and fine."

It's a natural flow of life, and I wouldn't say that death is celebrated, but death is just part of life.

JO KLINE CEBUHAR: It's accepted.



C. AUSTIN FITTS: Yes, it's accepted, and the difference in the energy is just – I don't have words to explain it.

JO KLINE CEBUHAR: I would agree.

C. AUSTIN FITTS: You go from being part of something that is just terrible to something that's like, "Oh." It's like you're born, and you die. You go from fear in the dungeon to natural cycles, and everybody is comfortable. It's such a different mode.

JO KLINE CEBUHAR: Yes, and the other big difference, of course, is when you're in a hospital setting and the person is dying and nothing is going to cure them or treat their underlying disease, that is a total sense of failure on the part of many healthcare providers. That's how they view it. You will hear doctors admit that they are suggesting treatments and suggesting protocols and procedures for a client because, "I wanted to do something for them. I didn't want them to think I had abandoned them," and not understanding that you can still be on my team and you can still be supporting me by helping me find the best passing that I can have.

So it is a complete shift, and that's why I'm going to be a real Pollyanna about this new rule under Medicare because I'm thinking, you know what, if we can get doctors to be willing to look in the face – and it must be a face to face meeting – with their patient, and they're both admitting that someday that patient will no longer be there, we've taken a huge step. That may be the first time that doctor has ever had to face the mortality – face to face – of a patient.

It's very interesting because one of the areas that was commented on in these rule changes – you know they do a proposed rule and then they have a comment period with many, many, many organizations commenting to CMS, "We want other people to be able to do this besides doctors. We want chaplains and social workers and nursing home administrators and healthcare support staff to be able to have these paid for reimbursed counseling sessions."



I'm very pleased to say that CMS said, "No. This needs to be a physician or a physician's assistant or a nurse practitioner under the direct supervision of the billing physician." And you know what? They're right, Catherine, because this whole system is premised on us giving informed consent. It's the doctors' ethical obligation and legal obligation – but more importantly ethical obligation – to give us the information we need to make informed consent.

C. AUSTIN FITTS: So I'm going to be the bad guy now because I don't understand enough details. If Medicare paying for it means that Medicare and the doctor's digital records get a copy of it, I'm not going in to do that.

JO KLINE CEBUHAR: You know what? That raises a good question, and I don't know what kind of detail they would need. I guess I don't know. I'm just going to make a big note of that.

C. AUSTIN FITTS: It's great because you're teeing it up and you're having the conversation, and it's going to force everybody to get good at having the conversation. That's all good, but if everything sucks into the machine's digital statements and the Silicon Valley gets to use it in their databases to figure out how to reengineer the healthcare system, that makes me extremely nervous.

JO KLINE CEBUHAR: I'm going to ask that question. I'm going to ask about their detail of record keeping.

Of course as it now stands, the notes or whatever in there are fairly irrelevant to the actual decision making process. And I think you'll find that if a person is lucky enough to have as their advocate someone like you or me who knows what they're doing and knows their way around and will stand up to that doctor, and more importantly, knows the wishes of the patient, then you see medical professors backing down immediately.

“If Medicare paying for it means that Medicare and the doctor's digital records get a copy of it, I'm not going in to do that.”



It's whenever anybody has the deer in the headlights look, when they say, "Well, what do you think they'd want us to do?"

"I don't know. We never talked about it." That's when the doctor is going to step in and make the decision. That's when the machine decides.

C. AUSTIN FITTS: It's very frustrating for the doctor. The doctors would much rather have clear directives.

JO KLINE CEBUHAR: Of course!

C. AUSTIN FITTS: The doctors are stuck in the middle of this thing. But I have to tell you, I was surprised when I went through the process how aggressive and ferocious and smart we had to be. I never dreamed that the machine would be that dangerous.

JO KLINE CEBUHAR: It is. It's very scary. I went through a family situation earlier this year, and the children of the elderly person were healthcare professionals, and they were shocked at what they had to go through, and they were shocked at how they were treated and the lack of information and the 180's that her caregivers were doing on them. One minute it was, "I'm going to do a brain scan," and literally within hours, "We think she should go to hospice."

They said, "Whoa! Wait a minute. You were ordering an MRI."

"Well, we decided she's not really material for that." I mean, it was really very scary, but I watched them experience this, and these are really bright, educated healthcare people. Again, they had to be on their toes all the time.

It's truly one of those rights, Catherine, that if we don't hold onto it tight and practice it, it will be taken away.

I was just going to say there's one more regulatory thing that I do want to touch on, and I know we're kind of getting towards our end of time



here. I'll go as long as you want, but I wanted to make sure I got this in.

C. AUSTIN FITTS: Definitely. Bring it on.

JO KLINE CEBUHAR: In Canada, which we've had virtually no publicity about here, which is in February of this year the Canadian Supreme Court overturned their ban on physician-assisted suicide. So right now the country of Canada has no law banning physician-assisted suicide. This is being handled on, if you will allow this analogy, a federal level.

They gave their parliament one year. So February of 2016 the Canadian parliament needs to come up with some laws and regulations or, in the absence of those, it will be physician-assisted dying, and all forms will be legal in Canada. That is suicide and euthanasia.

C. AUSTIN FITTS: Ew.

JO KLINE CEBUHAR: Yes. That's a big "Ew" because legislature can't understand. They can't at this point say, "We're not going to allow it." That's not an option. All they did was give them the right in this year to come up with some rules. Do they need to be competent? Do they need to have a terminal disease, or can it be any disease?

The Supreme Court ruling was actually going to leave the door open that it could be anything which is causing you a great amount of suffering. It does not have to be a terminal disease.

In the US, our laws require it to be a terminal condition, but it's going to be very interesting to see what happens in Canada in February. Less than half of the people in Canada have ever discussed their end of life issues at all. They've never discussed them, not just not doing the paperwork, but have never talked about them.

That's huge, and it's right across our border. So are people now going to be going to Canada?

C. AUSTIN FITTS: I confess that privacy makes me nervous, but the thing that



makes me most nervous is you had a study come out. There was just a headline about all of this in the *New York Times* yesterday or the day before. A recent study showed that women my age, since 1990, who don't have a high school education in the United States, their life expectancy has dropped five years since 1990.

If you look at all the things going on within the lives of people who are now depending on this machinery, they're under a whole variety of pressures which is particularly financial pressures, which is increasing stress, damaging their health, and then if you add on top of that more flexibility for the machine to pressure an earlier death, that, of course, makes me very nervous.

JO KLINE CEBUHAR: There's your perfect storm. And I think that the lack of health literacy is a big factor in there. I mean, we're talking about 90% of Americans who don't really understand how often they need to have a colonoscopy, a mammogram, a physical. I mean, we're not teaching that. We're not teaching it in our public schools. We're not teaching it in our institutions of higher learning. We're not doing public education on this. I guess we're just supposed to know this, and clearly we don't.

C. AUSTIN FITTS: I confess, Jo, that I avoid mammograms and colonoscopies.

JO KLINE CEBUHAR: Well nobody likes it, Catherine.

C. AUSTIN FITTS: Oh, no. That's why I do colon cleansing and all sorts of stuff.

JO KLINE CEBUHAR: But you're doing something. You've educated yourself, and you're making a conscious decision about which health procedure you choose to have or not. You have given informed consent, and that's based on solid information. I'm talking about people who don't even know what they don't know.

C. AUSTIN FITTS: Right.

JO KLINE CEBUHAR: If that affects our life expectancy, I'd be surprised.



C. AUSTIN FITTS: Right. Well, anyway, remind us again. We can get the book online, but we can get it also through your website.

JO KLINE CEBUHAR: My website contains lots of other information, and it will shoot you to Amazon.com. You are so kind; you have a link on your website, and my name is a little squirrely so it's hard to remember. It's www.JoKlineCebuhar.com. But if you go on Amazon and you just click in 'Kline' the book will pop up.

C. AUSTIN FITTS: I know you were trying to save them time by saying, "Just use the form," the last time we talked, but I really think from now on I'm going to encourage them to read the 2015 edition because I think you really have to understand. I'm one of those people who always tries to oversimplify things, and the advantage of reading the book and reading lots of different examples of what can happen is this is a complex topic, and directives involve very complex issues. Every person and every family and every situation is different.

This is one where we need to slow down and get into the complexity of it, and then think it through. At the time when you need it, there won't be a lot of time, or you may not be available to be there.

"This is one where we need to slow down and get into the complexity of it, and then think it through."

This is something that it's worth getting into the complexity, and I think if anybody has made the complexity of this simple and clear, you really have worked for decades to do that, and I think it really shows in this new edition. I'm just going to beat the drum. I don't know if I should give them the book for Christmas, but maybe that's what I'll do.

JO KLINE CEBUHAR: It's kind of a downer, and obviously I thank you for your support. It was an interesting process because you were gracious enough to have me on a little over a year ago to talk about the subject 'Death as a passage' which is really what this is all about. At some point you have to come to terms with the spiritual side of the end of your life in order to make any of the rest of this make sense.



At that time, I remember I had just started working on this. I was so naïve. I thought it was going to be a refreshing of this 2006 book, and I really did. I thought, “I’ll update the statute coverage, I’ll update the case law and see what’s happening with the terminology,” and I got into it, and I looked at this perfect storm of what’s coming, and looked at the statistics and looked at what’s going on. Then I thought, “No. This has to be much more than a refreshing. I need to emphasize different things this time. I need to talk about the shared decision making and how to make decisions with your doctor, whether it’s a decision to have a surgery or an end of life decision.”

We’re not practicing shared decision making, and our doctors are not asking us what our personal goals are when they present options to us. I’m really proud of this book. It came out quite different than I thought it would when I started, which wonderful things often do, and I couldn’t be more proud of it. This is a very exciting time to be thinking about end of life decision making.

C. AUSTIN FITTS: Right. I have to say that my experience with doctors and all healthcare practitioners is, with rare exception, uniformly excellent. The horrors we ran into with Georgie when I was a caregiver was the exception to the rule, but I find that most doctors are pretty wonderful.

My concern is that if you look at the strictures that now the law and regulation and insurance practices are putting on them, that’s my concern.

JO KLINE CEBUHAR: I think that’s a valid concern, but I also think that our healthcare providers, like many things in life, will meet our expectations. I think, as you mentioned earlier, coming into a doctor knowing what you want and asking them – as I put it – “I want you to be on my team, doctor, but understand that I’m going to be the captain. You are part of the team, but this is my life. I am willing to take responsibility, and I’m ready to take responsibility to make the decisions that affect my healthcare.”

C. AUSTIN FITTS: Exactly.



JO KLINE CEBUHAR: But you have to be ready.

C. AUSTIN FITTS: It's back to that responsibility thing.

JO KLINE CEBUHAR: It is. If we delegate it to someone else, someone or something will absolutely step in. There's no question. Someone will step into the gap, but it may not have the ending you want it to have.

C. AUSTIN FITTS: Exactly. Well, Jo, you're a national treasure.

JO KLINE CEBUHAR: You're so sweet. I just love talking to you. It is so stimulating and so much fun to have one of these conversations. We just don't know where it's going to go, but, boy, I always learn a lot. I hope everybody else does, too.

C. AUSTIN FITTS: I have to tell you that I would love to see our society have a revolution in its understanding and approach to death. If we're going to go through this period and this process and come out a better society and a better culture for it, we really need to revolutionize our way of thinking and understanding of death and our participation with death.

JO KLINE CEBUHAR: Wouldn't it be great if this was the thing that the baby boomers were remembered for?

C. AUSTIN FITTS: Yes. We've got the culture to make friends with death. That would be fantastic. Yes, let's have that as our prayer for our generation, that our going out is even better than Woodstock.

JO KLINE CEBUHAR: Oh, I like that! That's a bumper sticker.

C. AUSTIN FITTS: Okay, well you have a wonderful day. Thank you so much.

JO KLINE CEBUHAR: You, too, Catherine. Thank you. Take care.



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