BUILDING WEALTH IN CHANGING TIMES



The Solari Report

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Managing End-of-Life with Jo Kline Cebuhar



Managing End-of-Life September 25, 2014

C. AUSTIN FITTS: Ladies and Gentlemen, it's my privilege to welcome to The Solari Report an attorney and author, Jo Kline Cebuhar, who has joined us once before for a very engaging Solari Report. I hope you can go back and listen to it if you haven't.

Jo is very accomplished. In addition to writing some marvelous books that I recommend to you, we're going to talk about them with her. She, in addition to being an attorney, is also the former chair of Iowa's largest hospice. For those of you who know me, you know I'm a huge encourager of hospices for the end of life process.

Jo has a new novel which has inspired her joining us today, *Exit*. We're going to be talking about that as well.

Jo, you're coming to us from Iowa. Thank you so much for joining us on The Solari Report.

- **JO KLINE CEBUHAR:** Well, Catherine, thank you so much for inviting me. I couldn't have been more pleased when you extended this invitation. It's such a joy to talk to you.
- **C. AUSTIN FITTS:** I do my best to keep up with your work, and every time you produce another great thing I think, "Oh, how does she do it?"
- JO KLINE CEBUHAR: I ask myself that same question!
- **C. AUSTIN FITTS:** Let's go back. I want to cover some of your books so that our subscribers are aware of them. The first one we did a great Solari Report on. It's called *Last Things First, Just in Case... The Practical Guide to Living Wills and Durable Powers of Attorney for Health.* Could you just describe a little bit about that book and about The Solari Report we did



when you published it?

JO KLINE CEBUHAR: You bet, Catherine. What prompted me to write that book was my involvement with hospice. I am an attorney by education and practice, but actually when I was practicing I was a real estate and tax attorney but was blessed to be involved with that hospice. The more I got involved, the more questions I had.

What I usually find is that when I get enough questions, I'm like, "If I'm going to do all this research, maybe I should do it for the benefit of others as well."

Last Things First: Just in Case really came from my own need to understand what exactly your legal rights are at the end of life. What does it mean when you fill out those advanced directives and you're sitting with the attorney? We all do it – hopefully. Those who do it, do we really understand what we just did? More importantly, do our loved ones understand what we just did? They're the ones who are going to need to carry out our wishes in that event.

That's really what *Last Things First* is about – living wills and durable powers of attorney for healthcare so we understand the difference. Living wills give us the instructions. They really instruct everyone of what the patient wants done. The durable power of attorney for healthcare appoints that proxy substitute decision-maker, that substitute healthcare manager, if you can't speak for yourself.

I tried to write it in a very consumer-friendly manner so the people would really understand what their rights are and what their responsibilities are to know what they want at the end of life and communicate that and then document it.

C. AUSTIN FITTS: One of the reasons I really enjoyed that book is that you go into all the different things that can happen. It's very rich with examples of why good planning helps and what happens if you don't do good planning.

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I was inspired to read it and get you on The Solari Report when I went through the process. A very dear friend of mine had cancer for many years, and she had worked for the navy. She was a real planner. She had me and all of her friends unbelievably organized.

There were several times when I think that planning and organization saved her life along the way and extended the years that she lived. Then when she died, she just did it really well. It was because she had us all trained and whipped into shape and prepared. I saw the benefit of good family planning around end of life issues.

It was hard for me to understand before then, and the thing I loved about your book is – of course, I've lived through one fact pattern – but you had so many different examples of what can go right and how good planning makes an enormous difference.

- JO KLINE CEBUHAR: I think people not only enjoy stories, but learn best from stories.
- C. AUSTIN FITTS: Right.
- JO KLINE CEBUHAR: I've always tried to include them whenever I speak or in my writing because examples bring concepts to life.

"I've always tried to include [stories] whenever I speak or in my writing because examples bring concepts to life."

But going back to your dear friend, Catherine, and I recall how fresh that was to you. That was one of the things that prompted you to invite me to do that first interview about that book. When you look back now, I'm sure that you appreciate that your friend's planning not only was a very sweet reflection of how she lived her life – because our deaths will tend to be a continuation of the manner in which we lived – but also by being so organized and being so on top of her own passing, think of the time that she freed up for you all to spend quality times together. She eliminated, perhaps, a lot of the panic, a lot of the, "Oh, no. What do we do now?" and the indecision.

Instead your time could really be focused for you on care giving for her,

but most importantly that fellowship or that friendship.

- **C. AUSTIN FITTS:** Right. The other thing is we could act with power. We knew exactly what she wanted. We had clear direction. Frankly, navigating the health system that we navigated for part of it until we got her into a hospice we were in so many compromising and dangerous situations. We were completely clear and in power. I felt like we were protecting her from a system.
- **JO KLINE CEBUHAR:** Isn't it true that in that situation it is more true that knowledge is power.
- **C. AUSTIN FITTS:** Knowledge is power. Right. So we had clear legal, financial, and moral power together. You need that kind of power to navigate the way the hospital system is going.

Let me just also mention that one of the great things that came out of that Solari Report is you inspired me to get the Five Wishes Planning Form at www.AgingWithDignity.org.

- JO KLINE CEBUHAR: Yes, that's right.
- **C. AUSTIN FITTS:** I cannot tell you how many people have now gotten that form as a result of your suggestion.
- JO KLINE CEBUHAR: That's wonderful to hear. It's a great form; it's very easy to use.
- **C. AUSTIN FITTS:** Right. It's a form you can sit down with your family and start to discuss these things and bring them out of the world of 'let's be afraid of this and deny it'. Instead let's get organized and take this on as the learning experience and adventure that it can be.
- JO KLINE CEBUHAR: What I really like about that form, Five Wishes, Catherine, as you discovered is it's a great conversation guide. It leads to that conversation with your loved ones as well as being a very valid legal document. But it's not sterile and full of language that we're not too sure



what we just agreed to.

You never know about these specific scenarios until you talk through what your choices would be, so it's a very user-friendly form.

C. AUSTIN FITTS: Right, and I know you're an attorney. I love great attorneys, but the first conversation I have about this topic I don't want to have with an attorney. I want to think through all sorts of issues before I get down to the legal issues.

JO KLINE CEBUHAR: Absolutely.

- **C. AUSTIN FITTS:** Anyway, the second book that you published after that was *So Grows the Tree Creating an Ethical Will The Legacy of Your Beliefs and Values, Life Lessons and Hopes.* You also created a workbook for it. Could you just describe what an ethical will is and why you believe it's so important?
- JO KLINE CEBUHAR: Again, it's a great gift that came to me from my work with hospice. I was told that they were using ethical wills with their patients. I, of course, said, "What is that?"

What they were doing with it was allowing patients to talk about their life lessons and talk about their wisdom and share their values. That was in about 2005 or 2006 that I learned about them in my hospice work, and a light bulb went off. I thought, "Wait a minute. I have one of those."

Sure enough, about six years earlier I had discovered a letter that my Uncle Bill had written to his baby brother – who was my dad – back in 1963. He was about to retire and he wrote this letter to my dad that talked about his life values and lessons. He had good quotations. He had the serenity prayer. I'd always thought it was an incredible family treasure, but I had never realized that it was my uncle's ethical will.

What this is, Catherine, is 3,500 years old. The first ethical will appears in the book of Genesis when Jacob calls his sons around him. It is your



letter to your loved ones. It can be a PowerPoint. It could be a collection of quotations. It could be a scrapbook for that matter. What it is is defining. It's not a legal document – you're so right. It is defining your beliefs and values, your life lessons which you've learned from the school of hard knocks, and then your hopes for the future.

If it is done at life's end (which it does not need to be done then) you can certainly be talking about the hopes you have for the lives of your loved ones who you're leaving behind. It can be done at any point in life, and there are wonderful examples of young parents writing little ethical letters to their children as they go to kindergarten and then high school.

It's something you can continue and add to through your entire life. I think the real value to me of the ethical will is it's a great first step to then create those advanced directives, your last will and testament, or to guide your charitable giving.

C. AUSTIN FITTS: I think it's important for people to understand that the greatest gifts you give somebody is not necessarily the estate that comes through. It's not financial. It's the human legacy – the traditions, the culture – and the ethical will is part of the process of passing that on.

My friend's name was Georgie. One of the things I discovered, and I learned so much in that process, was I got all of her photos and memorabilia. We put a tremendous amount up online and then put together a PowerPoint of pictures from all phases of her life. She was a great traveler. She traveled all over the world so we had pictures of Georgie in Copenhagen and Georgie in Paris and Georgie on the boat, and a lot of the different people she shared those trips or those phases of her life with.

We got it all up on PowerPoint. She was a member of a church and had many, many friends and many people in the church. What I had discovered was many of them didn't really know her. They didn't know the full context and story of her entire life.

Through that process I felt like I was introducing her complete story to



so many people and her family and her friends who had forgotten it. She died in her 80's and had a very rich life.

The other thing was by doing that we had a complete record to pass on. I find that one of the things that really detracts from the power of people in this environment is they don't know their family history; they don't know their traditions. They don't have their stories.

If you can capture all of these in the process of planning for your death and in the passage, then that becomes an accumulated history that contributes to the family history. To me that is so important.

JO KLINE CEBUHAR: Yeah. We both believe that people value those sort of things, but it really is statistically proven. Allianz Life Insurance did a study. They've done two studies now – their legacy studies. They asked baby boomers and their parents, "What is the most important legacy? What is the most important inheritance?"

Overwhelmingly these baby boomers and their parents said that values, life lessons, and family stories were the most important aspects of legacy – more important than real estate or financial assets or stuff. It was the values, life lessons, and family stories that people wanted to receive and that their parents wanted to give to them.

"Values, life lessons, and family stories were the most important aspects of legacy – more important than real estate or financial assets or stuff."

C. AUSTIN FITTS: Right. I think the idea of making that effort is really special.

I have a friend who started a company called Comfort Calls where you set up an arrangement and then everyone in the family can call in at the time of someone's death or passing before, during, or after. Everybody can record their stories and memories. Then you get a complete file and you can send that to everybody in the family. So everybody has a complete audio that captures the knowledge and history and traditions at that time.



I just think it's a great idea.

- JO KLINE CEBUHAR: I just wanted to tell you that in *So Grows the Tree*, if you didn't realize what you did for Georgie and what those folks are doing with this Comfort Call is an ethical tribute. An ethical will can be from the perspective of the person, but it can also be a way to make a tribute to them because you're doing more than just when they were born, when they died, where they went to school, and what their job was. We're really talking about the type of person they were, and when you think of them what you think of, and what were the values they passed onto you as a friend or as a loved one. That is an ethical tribute and it is invaluable.
- **C. AUSTIN FITTS:** Right. So my uncle just passed a big birthday. My aunt had everyone in the family write a letter about what they treasured about their relationship with them.

JO KLINE CEBUHAR: Wow!

C. AUSTIN FITTS: She aggregated this huge book of stories and letters of appreciation and photos. It was quite wonderful. It was kind of like the feedback on the ethical will.

Let's turn to your new novel *Exit* which is very exciting. I can remember once one of my favorite mystery writers, an attorney, said, "I gave up trying to communicate these things in non-fiction so I turned to fiction."

Exit is wonderful because I think you describe it in your copy as sort-of – and I love this – the 'Melford Series meets Tuesdays with Morrie'. What you found is a way of telling all the different issues that come up. I know you can't put every fact pattern in a novel, but maybe you could tell us a little about *Exit* and what inspired you and what it's about.

JO KLINE CEBUHAR: As I talked about *Last Things First* and as I talked about *So Grows the Tree* and gave presentations, that was all well and good. There is a certain percentage of people who are willing to sit and listen to the statistical and legal and hard facts that are part of death and dying,



but there was clearly a large part of the audience that I wasn't reaching.

Then as all baby boomers do, Catherine, you and I are not only experiencing these major events in our own lives, but we're watching as our friends do it. It's really quite poignant and eye-opening.

I was a little amazed. I still know people who are experiencing their first death – the first close death in their life – and it's typically a parent or a good friend. As they are going through those passages in their lives, they are kind of at a loss, and they are certainly at a loss as to how to deal with the labyrinth of the medical part of end of life and the hospice element. "I wish I'd called in sooner," and, "I didn't understand that my parents could do this or that I had a right to do that."

The more I watched them, the more I thought that there has to be a way to talk about this that will enlighten people – not terrify them. Let's face it. We don't get excited about talking about death and dying. So I decided – and I've always wanted to write a novel – I'm going to try weaving those end of life healthcare issues and legal issues into a story.

The best setting I could think of to do that, of course, is a hospice. That's where *Exit* takes place. It is a small town residential hospice facility. It takes place in Iowa, which is where I'm a native of and where I live now. We have great landscapes for stories. It was great to pick things right out of my own backyard.

The residential hospice is the setting, but – of course – the characters are the patients and my main character is a woman who is recently widowed. Her husband is in hospice care but not at a residential facility. He received care at home and she now agrees to be a volunteer, which she is very reticent about but decides to give it a shot because she simply needs to do something with her life. She finds herself single and in her 60's, which she hadn't expected.

We go down the road. There's a bit of a mystery in it. I think what I've been able to do is talk about those legal issues and healthcare issues and explain to people the difference, for instance, between a 'do not MANAGING END-OF-LIFE

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resuscitate' and having a living will or the ability to still have palliative care. Sometimes people even receive chemo in hospice care if it's relieving pain for them.

I'm trying to explain to people – which can be so intimidating – what the rights are and where they can seek answers as they approach their own end of life or are witnessing end of life with someone they love.

C. AUSTIN FITTS: I think my background is a little atypical for most Americans. I'm somebody who has dealt with a great deal of death in my life. You get to a point where you make friends with death, and you think, "Wait a minute."

Certainly my transition with Georgie was truly a great adventure and very gratifying – one of the most special experiences of my life. Death can be many different things. But, of course, it is something that can be very complex and require lots of planning.

If you don't get educated at it, like so many things in life, if we didn't learn to read and write, life would be very unpleasant. But if we take the time to get it, it's one of those things that really we all need an education in and we need to look at and deal with to understand it's a very natural part of life. In fact, death defines our life – the fact that we die.

I'm an investment advisor, and we always talk about, "Let's start with the end in mind. Before we go into this, what is the exit? How are we going to get a good exit? What is the exit strategy?" But in this one thing, I think the baby boomer generation lives in a shade of complete denial – certainly in North America.

Why is death such a forbidden topic?

JO KLINE CEBUHAR: It's an existential question. Is it really possible to envision life as you know it without you in it? I mean, number one, if you really try to stop and think about it – and I do on occasion just for amusement – because I can't begin to conquer that.



But just think about the day when you're not here anymore. Whether your faith tells you that you're going to be watching from somewhere else or you're nowhere, you're not going to be here.

As a culture, obviously, we are youth-centered. I'm not the first one to observe that. But what I find interesting, Catherine, is we now have gone from having funerals in the home where the body literally lies in the home and everyone came to the home and they stayed with the body 24 hours a day – and in many cases they may have helped prepare the body for burial and all that – to a funeral home where we turned it all over to strangers.

Now I see another tendency away from the personalization – which I'm not sure if I like it or not; I can't decide if it's good or bad – but we now

are using cremation to such an extent that we're not dealing with the body at all. Now we don't have funerals anymore. We have 'celebrations of life'.

C. AUSTIN FITTS: Right.

JO KLINE CEBUHAR: We've pretty much denied the fact that a death has occurred at all. We have managed to totally wipe that part of the equation out of our minds. "We now are using cremation to such an extent that we're not dealing with the body at all. Now we don't have funerals anymore. We have 'celebrations of life'."

I think a lot of it is our inability, quite frankly,

for our human brains to grasp it. It is a cultural thing. You will find other cultures who embrace the passage. I have great faith in the baby boomers. We have reinvented many parts of the American culture. I'm really hoping this is going to be one of the things we accomplish before we leave, that we use death as a means to reflect on life.

As you say, it is a passage of life. Many would say it is the most important passage of life. Look at what you have gotten because of the deaths and passings you have been able to witness, and for me as well. I would never be in this line of writing had it not been for personal

experiences that I began to suffer at a pretty young life. That has made a difference in my life. I embrace that. That is where my life has gone.

C. AUSTIN FITTS: I'm a Christian. For me, death is just a passage. That has been my experience.

One of the things that has always happened to me when I'm very close to someone, including animals who die, is their spirit is around for a couple of days before they really take off. There are all sorts of varying interesting experiences you have as you go through the transition. Sometimes what you realize is the veil between the two worlds – or whatever is on the other side – is remarkably thin. Things can happen where they get remarkably thin.

To me, I look at it as much more of a passage. I've tried to read some of the near-death experiences. I don't know if you've ever read or listened to Anita Moorjani, *Dying to be Me*, which is quite a very interesting story.

- JO KLINE CEBUHAR: I'm not familiar with her. I would agree and share not only your faith, but also the concept that the veil is very thin. In *Exit*, in my novel, I talk about that. Many people have experiences of being touched from the other side. I think that is realistic – pennies from heaven and experiences like that. But I am not familiar with that specific book, no.
- **C. AUSTIN FITTS:** Georgie's sister was very instrumental in helping to raise me. She died in the 70's. Whenever something is very serious, Eleanor reappears. She shows up in people's dreams or with messages. As Georgie was dying, we knew she was going to die when I came into the nursing home in the morning before she went to hospice and she said, "Eleanor came to see me last night."

I said, "Uh-oh." That's when we know it's serious; Eleanor showed up.

JO KLINE CEBUHAR: Yeah. People who have not experienced any of this can scoff at it, but I will guarantee you that if you talk to anyone who is



involved in the hospice movement at all and has been around death, they will give you many, many examples of people who have been touched from the other side. People, as they are dying, are starting to see the visions of those who have passed on ahead and are welcoming them.

You know, what is interesting about this conversation, Catherine, is we're talking about our unique perspective and that is really what death and dying is. It's the unique experience of that person. It's not going to be the same for any two people as life is not the same for any two people.

C. AUSTIN FITTS: Right. It's really funny. I had several people around me who had experienced very important deaths – deaths of people very important to them or very close to them. I remember one of them calling and saying, "This has happened and I have to go deal with this."

You could see her thinking that this was going to be just horrible. I said, "Wait. This doesn't have to be horrible. Yes, this person you love is going to die and you don't want that to happen, but this can be an extraordinary experience for both of you. You're going to go on a journey together, and the first thing you need to do is you need to get help.

"You're thinking you're going to do all this stuff. No. You need to get other people to do that, and then you need to spend your time doing the journey because there is a whole spiritual and emotional and family process that needs to happen, and you need to be available to do that journey. You can't be busy running around doing the practical and the logistical thing so you need to get as much help as possible."

For people who have access to those resources, you do, but we all need to build in time for that. There is a personal relationship and sharing or an opportunity to do that, so you really want to also think about doing that.

JO KLINE CEBUHAR: I really look at the subject of end of life as being threepronged. You mentioned the word 'logistics,' and it's really legacy,



logistics, and legality. I mean, it may or may not be pleasant to talk about these things, but the more planning – as your friend Georgie did – the higher quality of the end of life and then there's no mystery about that.

If you have the energy and the time to focus on the person who is passing and your relationship with that person, you're going to have a better death and that person is going to have a better death than the one who is in the middle of the room with all the relatives arguing about what they would have wanted done at that moment.

C. AUSTIN FITTS: One thing I will say, if you are the person closest to working with somebody who is dying, you do have this phenomena of people. I would say there is a certain portion of people every time I deal with a death who literally lose their mind and misbehave terribly.

If you're dealing in any one of those prongs with the legacy, the logistics, or with legal, you can get in a position where you're dealing with that portion of your family and friends who in these kinds of situations lose their mind and their manners.

JO KLINE CEBUHAR: Right.

- **C. AUSTIN FITTS:** Part of planning for end of life is learning how to manage the 'slugs' as I call them at the time of death. I hate to be so blunt.
- JO KLINE CEBUHAR: There are lots of them, Catherine.
- C. AUSTIN FITTS: You need to sit down and shut up!
- JO KLINE CEBUHAR: Some people call them 'the California kid' no disrespect to California. But around here it's usually some kid from California who comes in, kicks the beehive, and then leaves.
- **C. AUSTIN FITTS:** Right! The first time it happened to me I was absolutely appalled because people who I thought were perfectly sane, mature, and rational would literally lose their mind. You felt like you were dealing



with some different variation of their personality that you'd never seen before.

I think, to me, part of the planning is if you are going to be involved in a situation, being prepared for that to happen and being prepared to manage it and basically forgive them when it's over.

JO KLINE CEBUHAR: It does tend to bring out the very best and the very worst in people.

C. AUSTIN FITTS: Yeah, it really does.

JO KLINE CEBUHAR: I think so often the reaction to the situation is a function of that person's own perception of their own mortality and how they're dealing with the passage of their own years and how they're dealing with aging. Now they're seeing someone – a parent or someone – who is a jarring reminder that life does not go on forever. Then they react how they react based on that perception.

One does a lot of tongue-biting, but preparation really is very important at that point because I think it eliminates a lot of those unknowns. That bedside decision-making really does go a long way to easing a lot of that indecision and anxiety. "That bedside decisionmaking really does go a long way to easing a lot of that indecision and anxiety."

- **C. AUSTIN FITTS:** I'll say it another way. If you have given really clear directions or someone has given really clear directions, then the people who lose their minds simply are a form of entertainment as opposed to having real ability to cause plans and logistics to happen which are certifiably insane.
- **JO KLINE CEBUHAR:** Absolutely. Most importantly, it is contrary to the wishes of the dying patient.
- **C. AUSTIN FITTS:** Right. So good planning is a mode that protects you from the silly business that can happen at those times.

JO KLINE CEBUHAR: I believe so. I really believe so.

- **C. AUSTIN FITTS:** Anything else you want to say on the planning and preparing?
- JO KLINE CEBUHAR: I think people's knowledge of hospice and let's just focus on that for a moment because it's a subject near and dear to both of us – is that I'm always very saddened when I hear people saying, "We didn't understand that our loved one needed to go to hospice. Then when we took them, they were gone so quickly. We didn't even have the chance to say goodbye."

People really do wait too long, and our medical profession needs to step in as much as the lay person. I think we need to give our doctors permission to switch gears. We're constantly demanding the medical profession, "Cure us! Cure us! Cure us!" At some point that can't happen anymore. At some point the curing is over and we need to give our doctor permission to be honest with us about prognosis and then make the right decisions.

The median stay in hospice – half more and half less – is about two and a half weeks. That's not very long if that is the first opportunity that a family has had to take a breath and no longer be the full-time caregiver if their loved one is going to a residential facility, or even to have that emotional, physical support of a visiting hospice person. Two and a half weeks is not very long to get done what you need to get done.

I really encourage people to understand what hospice is ahead of time so that they'll know what it can offer to them, which is not a death sentence. There is so much confusion, Catherine, of people thinking that hospice is euthanasia or hospice will pain-medicate their loved one to death. That is never the goal of hospice. It is a philosophy – a multi-disciplinary philosophy – that focuses on one thing only and that is the comfort of the patient. Period.

C. AUSTIN FITTS: To me, when you go to hospice, in my experience hospice is a place where it's okay to die. In the hospital everybody is running



around acting like it's something to be terrified of and it's a risk issue. In hospice it's like, "Okay. Let's celebrate."

In fact, there are people who go to hospice thinking they're going to die and then they don't and they have to leave hospice.

- JO KLINE CEBUHAR: That is absolutely true.
- **C. AUSTIN FITTS:** It's happened. To me, if you look at somebody who is spending two and a half weeks in hospice, if they had spent the two and a half weeks before that they had spent in the hospital in hospice instead, it would be a much more wonderful death than just two and a half weeks.
- JO KLINE CEBUHAR: Yeah. When you see the statistics to be very pecuniary – of the dollars we are spending in attempting to prolong life, but more importantly, the time that people are spending in that CCU hooked up to machines and hooked up to tubes. I'm not even talking necessarily about life-prolonging measures but just curative measures where people are still getting chemo to the last days of their life with all the side effects and everyone is in complete denial of the fact that this life is ending. It's not a good death for those people in respect of everyone's individual right to define that. We can look at that and know that that is not a good death for those people.

That is typically just a lack of acceptance of the fact that death is coming. I mean, feeding tubes and all the things that are inherent with all the lifeprolonging measures that we can do and that sometimes we feel that we must do.

C. AUSTIN FITTS: I must say that one of the things I love about the great churches is you go into a great church and they talk about death all the time. They are doing funerals all the time. They are working with families on birth and marriage and death and all the different passages and transitions, and it just becomes a very natural thing. It's great if you can find institutions like that in your life where there is that kind of support and that kind of understanding.



It may be a church, it may be a temple, or it may be something else. There is a huge spiritual component of all this that we haven't dived into but it's there. To me, part of the key to being good at end of life is having that kind of institutional support. The legacy, I would say, includes spiritual. Then there is the logistics and the legal.

Hospice is one, but there are many other kinds of institutions. That is part of what we all need.

JO KLINE CEBUHAR: In my research on hospice, of course, one cannot research hospice without learning and talking about Cicely Saunders who is the British woman who really started the hospice movement. What is most fascinating about her work, which is incredible, was her definition of the term 'total pain'. Until then, they really were doing nothing but treating that physical pain, and there was a great focus on that.

You know, we've gotten pretty good at that. We just have between morphine and the opiates we have. Physical pain we pretty much have got a handle on.

Her concept was, "No, no, no. This is total pain." That is made up of the physical, emotional, spiritual, and social elements. If any one of those is not fully addressed, overall pain remains. It is not only making sure that the patient is comfortable and as pain-free as possible with alternative therapies and that sort of thing, but then that emotional element. What's going on in their life with relationships or perhaps unresolved relationships?

Then for social, they are leaving maybe a career besides leaving their neighborhood and their family. Maybe they have dependents.

Then there is the spiritual element, which is so important. Many times people have their spiritual awakening at the end of life.

C. AUSTIN FITTS: Right.



JO KLINE CEBUHAR: All that practice – all that religion – didn't mean anything to them practically speaking until they got to the very end of their life, and then, "I get it now. I now get why I'm a Christian. I now get why it's important for me to know that I'm going somewhere when I'm going to leave here, that this was just my body."

It's those four elements. It's interesting that you bring up that spiritual because I think total pain is the concept at life's end, but what if we practice total bliss during our life in those four areas and kept them in balance? It makes sense.

I think Cicely Saunders had a great model for life as well as for dying.

C. AUSTIN FITTS: We had a lot of the materials – photos and history – of Georgie with her and shared them with her caregivers so everyone in the hospice knew who she was and her whole life

story. It was great because they really made an effort to get to know her, and there was all sorts of extraordinary synchronicities between them.

"Hospice volunteers give over 21 million hours of care in this country every year."

JO KLINE CEBUHAR: Hospice volunteers give over 21 million hours of care in this country every year, and as a personal caregiver – and it

sounds like you were right there for your friend and with your friend – unpaid personal care giving in this country, if we had to pay people what they do unpaid it would be about the same as the Medicare budget.

- **C. AUSTIN FITTS:** Yeah. The difference that those hospice volunteers make is extraordinary.
- JO KLINE CEBUHAR: Oh, it is an institution that could not exist without its volunteers because there simply is no funding for that. I mean, it's impossible to put a figure on the value of volunteers because they couldn't provide those services if they didn't have the unpaid volunteers stepping in to help with it.
- C. AUSTIN FITTS: Tell us what's next for you. I watch you produce these



amazing gems one after another. What's next, and how do we stay in touch? How do we track your work?

JO KLINE CEBUHAR: I'm working on the marketing side of *Exit*, of course. It's starting to get out into people's hands so that's exciting to have people read it and give me reviews and to know that I'm accomplishing what I hoped to accomplish. But wouldn't you know it? I've got another book niggling in my head here because I wrote *Last Things First, Just in Case... The Practical Guide to Living Wills and Durable Powers of Attorney for Health* in 2006.

When I put it up as a Kindle book I updated it. But now I'm thinking, "You know what? We've got some new issues going on." There's a document called a POLST document which is a Physician's Order for Life-Sustaining Treatments which has gained a lot of popularity. It's a very simple little one-page form that you fill out and you literally stick it on the side of the refrigerator so that EMTs and hospital workers know what you want.

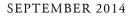
It's much more clear than an advanced directive. I need to talk about that. I need to talk about some of these issues that have changed. We've had a few more court cases. We need to talk about updating people on the issues of whether or not we have assisted suicide, which we have physician-assisted suicide in a couple more states than we did when I wrote that book originally.

- C. AUSTIN FITTS: Right. State laws can change.
- JO KLINE CEBUHAR: I'm thinking this winter is going to be the time for a 2015 edition of *Last Things First*. I think I'm going to update that and get that out.
- **C. AUSTIN FITTS:** And you'll let us know as soon as it's ready?

JO KLINE CEBUHAR: Of course I will. I'd be silly not to.

C. AUSTIN FITTS: Okay. Well, our quote for the blogpost, I saw it and it

MANAGING END-OF-LIFE





absolutely reminded me of you. It said, "To the well-organized mind death is but the next great adventure." It just inspired me because I think you have a very well-organized mind and you do a lot to help us get organized to understand and get educated about death. In fact, if we are organized about it, it can be a great adventure.

I think that there is no greater contribution to life than helping people manage that and deal with that. Bless you for getting us organized, Jo. I can't thank you enough.

- **JO KLINE CEBUHAR:** Thank you, Catherine. I really like that quote as well because if you're like me, when you're going to go on a really great trip a landmark trip or vacation the getting ready is as much fun as the trip.
- **C. AUSTIN FITTS:** Not all of us think of that. That's why we have you. Not all of us feel that way.

I'm like, "Oh, no. Can I just put this off until tomorrow?"

- JO KLINE CEBUHAR: But it is a great adventure, which none of us will know until we get there, but witnessing the passing of another and taking responsibility for what your end of life is going to be is a great way to put perspective on your living every day because your legacy is going to go on every single day until that last breath.
- **C. AUSTIN FITTS:** Right. Start with the end in mind. To me, dealing with death and getting good at death just makes life so much richer. That has been my experience.
- JO KLINE CEBUHAR: I would agree.
- **C. AUSTIN FITTS:** Okay, well Jo Kline Cebuhar, you are wonderful. You are the best. Let us know when the new book is out.
- JO KLINE CEBUHAR: I get so excited when I see your name on an email. I'm like, "Oh, it's going to be a good day." I love being able to have the time



to talk with you about a subject. You are so generous to have these long, long conversations because that really gives us a chance to really delve into this. I'm sure we've opened a lot of minds today and got a lot of people to think.

Thank you for your contribution.

C. AUSTIN FITTS: Good. Have a wonderful day.

JO KLINE CEBUHAR: You too. Take care.

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