



## Alzheimer's Talks Transcript

**Have you had 'The Conversation'? End-of-life Choices: Be Proactive.  
*How to prepare your family and make certain your wishes are honored  
with Ellen Goodman, Co-Founder and Director of The Conversation Project.***

**January 24, 2014**

**George Vradenburg:** Welcome to Alzheimer's talks. Thank you all for joining us this afternoon, this afternoon at least in Washington DC. My name is George Vradenburg and I'm the Co-Founder and Chairman of [USAgainstAlzheimer's](#). This is a suite of networks and coalitions all committed to the proposition that we will stop all Alzheimer's by 2020 and we convene these Alzheimer's talks to introduce interesting people talking about interesting topics around Alzheimer's. There are people from 28 states and the District of Columbia who've registered for this call, others will be dialing in directly.

Today I am delighted to introduce you to [Ellen Goodman](#). She is a Pulitzer Prize winning author, who founded [The Conversation Project](#), a public engagement campaign with a goal to have every person's wishes for end of life care expressed and respected. This conversation is so important to have sooner rather than later, particularly as there is ambiguity around the competency of individuals with mid-stage or late-stage Alzheimer's or other forms of cognitive impairment to effectively express their preferences. She's going to talk with us about how to talk with your family about your own wishes or how to start the conversation with family members about their desires for end of life care.

This call is made possible today by the generous support of Meryl Comer and the Geoffrey Beene Foundation Alzheimer's initiative, they are great friends, great partners and we're so grateful for their support and helping us to bring this conversation to you today.

Remember, particularly for those of you who've been on these calls before, if you have question during the call, please press star 3 on your phone. By pressing star 3 you'll be placed into a question queue, please have your question ready to share briefly with a member of our staff and then they will try to get you on the air as soon as possible when we open it up for questions. By pressing star 3 you will not be taken out of the phone call, so you're still be able to listen even though you press star 3 and even though you're in a question queue.

Ellen, thank you so very much for being with us today. You have raised and are raising a critical question for our society, particularly for those with dementia, and we deeply appreciate you being here today and deeply appreciate what you do continuously.

**Ellen Goodman:** Well thank you George. I feel like I'm here as a member of the family in a sense because I think we are all very much thinking about the same issues.

I started The Conversation Project some years ago, really because I had a story and that's one of the things that I've discovered in all my years as a journalist. I've never had a subject where I would say well I'm talking about people's end of life wishes and whether they can be expressed or respected and everybody will then stop you because everyone has a story. So the country is in a sense reaching a critical mass. I think that we are now facing a longevity revolution and the baby boom generation have been the social change agents all the way through our culture, they were the change agents for the civil rights movement, for the women's right movement, for the gay rights movement and now they're facing the longevity revolution and that is in itself, they are going to be the social change agents, we're going to change the way people die in this country. Very much the same way that we changed the way birth occurs.

And we started The Conversation Project because we knew that people were not dying in the way that they would choose. There are all kinds of statistics around this which most of the listeners already know. But some of them are pretty simple, we know for example that 70% of people would choose to die at home but 70% of people are dying in hospitals and institutions and in this case home is not necessarily a place, but it's an idea that people want to die surrounded by those they love and in comfort and that isn't really happening and so we believe that the linchpin to this, the change lever is that everybody has to have the conversation with the people that they love at the kitchen table, not in the ICU, and to have it early before there really is any kind of a crisis.

So what we did was we got together with a few citizens and then we started talking with experts and we went to the Institute for Health Care Improvement, who've been our partners all along, and they did pull together some wonderful experts for us and the message that we heard from people who've been in the end of life care work forever was that we needed to change the culture. We couldn't just work to change the medical system, we needed to change the cultural norm from not talking about what you want at the end of life to talking about it. So that's really what we set out to do in many ways, we've set out to be a cultural change program, campaign really, and we are a public engagement campaign as you said to have people's wishes for end of life care, expressed and respected. We believe that you've got to listen to what people want and put people at the center of this conversation.

We know that in America people have two conflicting fears: the fear that they won't get enough health care and the fear that they'll get unwanted health care. Only by putting people at the center of these conversations can we change that dynamic and rebuild trust in this system. So we got up our website and we did a lot of thinking and a lot of work to create a kit to help people start these conversations and we called it our [Conversation Starter Kit](#), not surprisingly. It's not a scary medical kit, it's not a kit that says you know if my left elbow and my right eyebrow are gone then pull the plug. We don't try to go through all the list of confusing things that can go wrong in the medical system. What we have done is asked people about their values, we've asked them what matters to them, not what's the matter with them but what matters to them, and who they would choose to make decisions if they were no longer

able to. We have a number of values questions that help you if you have to be a decision maker and help you if you're trying to share your point of view with someone who may be making decisions for you.

Just to give you a couple of hints and then I'll open to conversation and questions. A couple of things that we really think are important: we ask people as a patient do they want to know just the basics or do they want to know as much as they can, do they want their doctors to do what they think is best or do they want to have a say in every decision, do they want to live as long as possible no matter what condition or is quality of life more important than quantity? And we give people scales to sort of say where they are on these differences, would they mind being cared for in a nursing facility or not and do they want their loved ones to do exactly what they say or do they want their loved ones to do what brings them peace even if it contradicts their wishes. So we ask all kinds of rather intimate questions and one of the things that we have found, that's been a delight to us really, is that people who start up scared of having these conversations report back to us that they are among the most intimate and personal and important conversations they have had with the people that they love.

So all of that has been wonderful news, at the same time we know how much work there is to be done. We did a survey last September and the survey said remarkably that 90% of Americans know it's important to have these conversations, which is remarkable since 90% of Americans don't agree on anything and they do agree that it's important to have these conversations, but only 30% are having them. And so our job really is to get from the 30% to the 90%, and we've had some wonderful helpers. I can't let this call go on any longer without thanking Meryl Comer who has just been wonderful in helping us. We have some new posters up in airports, in Boston Airport and soon in the Charlotte Airport, saying 'we've had the conversation, have you?' So I'm the only one in America who is glad when there was a little trouble at the airport because all the people who were there got a real chance to look at our posters.

And we're doing a lot of storytelling and when people come on to our website which is [theconversationproject.org](http://theconversationproject.org), they have a chance to tell their story and to share it and that's the last and maybe most important part of our project which is shared storytelling. Because we know from all the experience of social change that it's only when people share their stories that things really start to change. When I covered the women's movement at its on-set decades ago, a lot of people felt, a lot of women felt they were the only one. They had these experiences, but they were the only one. And then they started sharing those stories and discovered that they weren't the only one, that these stories were just rampant throughout the culture and I think we're coming to that now because so many more of us have stories about good deaths and hard deaths about end of life problems or problems in late stage diseases and we're starting really finally to talk about how we can handle all this in a much more humane way.

And I'm happy to go on and I'm also very happy to take questions and talk if George, you and Meryl have any questions first or I'd be delighted to go forward. I just have to say of course, it sounds obvious but the reason why we're in such happy collaboration, such a productive collaboration I should say, with the issue of Alzheimer's is that there is no issue that makes it more obvious that we have to have these

conversations early than that of Alzheimer's. Both because of our own vulnerability to Alzheimer's and because of wanting to do right by the people we love who maybe suffering from it.

**George Vradenburg:** Let me ask a few questions and then we'll pick up others. One of the repeated themes that we hear is that even with people who've had the conversation, the conversation is not with every member of the family simultaneously, it occurs through time when opinions about what you might want change and as a consequence, it's very hard to get the family sort of unified at that time when in fact, the medical profession and legal profession is asking, what were your wishes? You made the point and it's quite right that you not only have to express your point of view, you have to get your point of view respected, and so when doctor confronts tension in the family that even with a living will. The doctor is in a sort of awkward place and if he doesn't have family consensus very often then he sort of holds back and says you've got to get your act together.

So with whom do you have the conversation? How do you make sure that you're having it consistently with all members of your family and if you're point of view changes, how do you assure that that conversation is re-had with the same people. And there is really buy-in on the part of the family to respect your wishes when the time comes.

**Ellen Goodman:** Well first of all, I agree with you that there may be multiple conversations. In fact we thought about calling this, the conversations project, but it just didn't sound right. But it may be the first of many conversations that go on. Second of all, the question that you raise about family disagreements, Lord knows there are family disagreements. I had one doctor who told me that he, in his practice often saw what we referred to as the Seagull Syndrome and he described that as the adult child who lived furthest away flying in at the last moment and dumping all over the plan. Now, he had it somewhat more scatological than that, but there are without question disagreements and I think that's actually one of the primary reasons for people to have these conversations while they still can. Because the last thing that you as a parent of adult children want is to have the end of your life marked by the horrible conflicts and disagreements among your children.

So, it is your decision and it is yours to share with your adult children, or with whoever you choose. First of all, not everybody has a child and second of all you may find somebody else who you would want to be your healthcare decision maker. But once you have identified that person or persons, once you have expressed your wishes I think it's also incumbent on a doctor to work with the family too, or healthcare provider of any kind, to remind the family that it isn't your decision or your decision, it's mom's decision or dad's decision. And that it isn't about you know who loved you more. It's about what that person's wishes are and very often when that conversation can be turned around so that people understand that it is the person coming to the end of their life who is already made those decisions or given that perspective. Very often then the family feels less guilt, less unease, less depression. One of the primary reasons that we start The Conversation Project was not only so that your wishes would be expressed and respected, but that your survivors would be left in better shape because we know that when people have not had these conversations their survivors are often more depressed, more uncertain about whether what they've done is the right thing and more guilty. So another strong reason to do this is to leave a legacy that's the one you would choose.

**George Vradenburg:** And how other than the oral conversation, how might one record your choices and your preferences for end of life decision and get them respected. Just lay out the tools that are available...

**Ellen Goodman:** We have this Conversation Starter Kit to talk to your family. We have a second kit called [How to Talk to Your Doctor](#) which we wrote partially because we knew doctors were not initiating these conversations and so we have to initiate them with healthcare providers. We also refer people to a choice of some very good advance directives that they can use. Some of those advance directives as you know differ from one state to another, which is a whole other problem. But again you know, we do emphasize that the most important part of the procedure is choosing your healthcare decision maker because you can't write and have an advance directive to every conceivable eventuality. But you can find and share with that person what your values are and your general understanding of the conditions under which you would want to continue living or choose not to.

**George Vradenburg:** What is the strongest instrument that someone might use to assure that there is an obligation on the part of the medical profession or others to honor health wishes. So I'm thinking do not resuscitate orders or a durable healthcare power of attorney that enables another person to say that this person has the power to say, this person does not want further medical care. But what are the most powerful instruments?

**Ellen Goodman:** Well, I personally would choose to have the durable power of attorney. I think that is your security zone, that's your security blanket, that person. At the same time I think there's a lot of work to be done inside the system. I mean our project, we sort of think of this change as being almost like a double helix that we're bringing change from the outside in, and the system is changing from the inside out. So for example, The Conversation Project has a partner project at the Institute for Healthcare Improvement called the [Conversation Ready Initiative](#). Where they have some giant healthcare systems who are working together to figure out what it means for a healthcare system, a hospital etc. to be able to describe itself as conversation ready. What kinds of things do they have to think through? They have to obviously respect their wishes, they obviously have to have some way of documenting them and also we're now talking about what we refer to as a preventable harm. This is a phrase that hospitals and medical issuers often talk now. They used to talk about medical mistakes and now we talk about preventable harms. What's a preventable harm? Well, if you go into a hospital and you have an allergic reaction to something because somebody never asked what your allergies are and they never checked that off, that's a harm that hospitals are working to prevent. Well if you end up dying in a way you would not choose, that's a harm, and that harm is preventable. So we are working with people in the healthcare system to create a system by which that harm is mitigated. So we're bringing change from the outside in too.

I would just remind you of the parallels to how birth in America changed and it didn't change because the hospitals initially said, oh please come in and bring your video camera and let's have a baby in a bathtub you know. It changed because people in the outside said wait a minute this is not right, this is not humane. Birth was not meant to be exclusively medicalized, let's make this system work for people and the system responded. So too we're saying you know, death itself is not a medical mistake. Death is

a natural part of life and let's see if we can together find a more humane way in which people are dying in a way that they would want to.

**George Vradenburg:** I'm going to open up the line here to Ken Dychtwald who is the author of 17, 18 books on the aging society, the Baby Boomers and all of these issues. So Ken, line is yours.

**Question:** Also proud to be a board member of USAgainstAlzheimer's. Hi guys.

**Ellen Goodman:** Hi Ken.

**Question:** Hello this is quite a mother lode you've landed on here and so I wonder if I just might ask a couple of questions and you can take as you wish. I guess there's the conversation and then there's the actions and I'd love to hear your reflections on two things. One is in the action that are taken as a result of conversations, what have you noticed in terms of the medical folks, the ethical folks, the religious folks, families in terms of how people behave when it's time for the actions and then my second question is I agree with your opening comment about how the boomers who are so keen on choice this is going to be the next big turn of the wheel, I'm completely in agreement with you. What do you think is going to unleash that or what do you think is going to road-block it?

**Ellen Goodman:** Can I start with the last question first...

**Question:** Yeah.

**Ellen Goodman:** ... and if I've forgotten the first one you can ask it again.

**Question:** The legal, the religious, the ethical, the medical how are people when it comes time to take an action on a person's life that was like, the question how do these different constituents...

**Ellen Goodman:** Well can I just address that a little bit more. I mean I think we're moving for example from the concept of you know do not resuscitate, do not do things, to the concept of allow natural death under circumstances that warrant that. So I think we are shifting some of the language which helps. But I also think the real reason why some of this is changing is what I describe before as the longevity revolution, that we're living 30 years longer than we were a hundred years ago. And you have a whole generation of people who are now, you know sixty-five and they're children. They are, the 65 year-old child of a 90 year old or a 95 year old. They are the caregiver of somebody in their 80's and 90's, that is an incredible shift. We used to say that people, you know at 65 were old and now they are caregivers of the old. And people who are in the baby boom generation have watched and are right in the throes of dealing with declining parents and they are much more likely to want to make decisions for themselves and watching that experience is a real alarm bell. And the second question which I'm struggling to get back to, would you mind repeating that Ken?

**Question:** Yeah. What could get in a way of all of this? I mean, this is a thorny and lively and complicated theme that you've put your arms around and handled so well. But what could shut it down or where will the battles be around this issue?

**Ellen Goodman:** Well there are battles around this issue and everybody feels differently. But one of the values of The Conversation Project is we don't have an agenda. We're not saying what your decision should be, we're saying express it and have that be central, have that respected. So I don't think that there are a lot of people who read into that, oh, you just all want people to die younger or something. And no we're saying either way, whatever your choices, whether your choice is to extend life with every conceivable means or whether your choice is that you can reach a certain time when the quality is more important to you than the quantity of your days we're saying express that. There are certainly as we know as journalists, cases that come up that ring all kinds of alarm bells across the culture and make people very wary but I think those cases recede and the experience of everyday people who are caring for the people they love and who are encountering the medical system, sometimes for better and sometimes for worse. Those experiences will lead us to saying we really have to have people at the center of this debate, not even debate, the center of this experience.

**Question:** Thank you so much.

**George Vradenburg:** I would say my comment Ken, is that right now the law generally in every state in the United States says that you may not terminate a life, right? Euthanasia, assisting suicide is illegal. So what we're talking about is natural death as Ellen has pointed out. Well natural death means, no mechanical or artificial or extraordinary means of maintaining life. But as our next question is going to point out when dementia kicks in that natural death can take a very long time and the circumstances under which you would like to have your life end if you contemplate dementia, could very well be long before the medical or legal professions, or religious professions, would say it was legal or ethical. Because it's not just withdrawal of medical treatment it is actual affirmative termination.

So I'm going to open this line to Michael Ellenbogen, who's a great friend of the Alzheimer's movement, is a person with Alzheimer's and very much has thought a lot about these issues. So Michael.

**Question:** How are you doing? I'd like to first of all thank you for wanting to talk about this subject. This is such an important subject that I think is not being addressed enough out there so I thank you for bringing this up. I recently had to go through this myself and I spent 6 months of doing investigative work and the things that I found out that I think is important to bring up here is: number one, it is extremely, and I mean extremely, important for people who are living with dementia to make this decision as quickly as possible once they have that diagnosis and the reason I say that is you have to be of sound mind when you are writing these wishes down. Whether it's a living will or will, whatever it may be, you have to be able to prove that you are of sound mind at that time. The second issue I'd like to bring up is the living wills that exist out there today, most of them do not justify being a good living will for somebody who is living with dementia. They may work if you have cancer or some other form of disease, but not dementia. The one that I have found, to be one of the best plans out there and it still needs as far as I'm concerned improvements but it's by far the best plan out there is made by Doctor Stanley Terman and it's actually called The Natural Dying Living Will. What makes this one exceptional in comparison to other living wills? There's actually 48 questions that you actually talk to your doctor and your relatives together to determine under what conditions you may want to stop being fed. So, while I

understand you can't, I guess have assisted dying or anything like that, but one can choose to stop eating.

**Ellen Goodman:** That's right. Yeah. Well, that's very helpful Michael. I'd love to see that question or that living will which I haven't or advanced directive and I haven't seen it. All the questions, the questions raised by dementia, you couldn't be more right in saying that, that is a prime reason to have these conversations early.

**Question:** George has my e-mail, I'll be more than happy to share you the whole works with you.

**Ellen Goodman:** Thank you.

**George Vradenburg:** A reminder to people that if you have a question, please press star 3 and you'll get into a phone queue. You won't be cut off in the conversation about the conversation with Ellen Goodman. So please press star 3 if you have a question.

We do have an inbound caller, I don't have the name but you are in area code 949. I'm sorry, they are still in discussions with our screeners. So, let me move on to another question. So the issues here in terms of the details of the circumstances under which you would wish not to be fed. Strikes me that it requires a lot more detail than what is typically in a living will, which in my experience sort of has three boxes, you know: use every mechanical or scientific way to keep me alive, stop feeding me when I cough two times or you know use your best judgment. It is, to Michael's point, the documents that we have to express our will are pretty inadequate. And sometimes it is difficult for people to sort of contemplate the range of circumstances that they might find themselves under in order to be able adequately to express their preferences for the circumstances under which they would not like to be fed. So I'm curious, Stanley Terman is an example, but we ought to understand that there may be other instruments out there. Actually we have a comment about the Stanley Terman's tool here from Patty Luten from Orange County, California. Patty?

**Question:** Hi, I really appreciate this exercise and having this group of people, having this discussion and here in Orange County we're in the midst of planning our national healthcare decisions day, information and education event.

I have a real concern when we bring into the conversation, the notion that we would ever encourage people to stop eating or try to hasten their death. Death sometimes doesn't come quickly and I think it takes away from the beauty of the initiating the conversation about people's wishes and choices if we bring in anything that smacks of either assisted suicide, euthanasia or somehow encouraging people to die more quickly for everyone including their own convenience. I think it's a really dangerous premise and I'd like to hear other people's opinions.

**Ellen Goodman:** Well first of all, if I can say so, I think we've had a national debate about doctor assisted suicide that in many ways has produced a lot more heat than light. So that we have had knockdown, drag out fights about pro and con assisted suicide and then you look at states like Oregon which has legal assisted suicide, doctor assisted suicide and only one out of every 500 deaths used doctor assisted

suicide. So we've had this incredible fight over something that will only affect one out of every 500. And The Conversation Project is really saying, let's talk about the 499. Let's talk about how all of us will be dying and if we can't make it more humane and more in line with what they want.

So I'm going to suggest that the way in which this debate has been framed is not often as useful as it could be in terms of really making a difference in the culture. So I would also say the issue, we can go down the road of the issue of feeding or not feeding or choosing to or not choosing to. There are as many different stories along that highway as you can imagine and I can tell you just from my own experience, three or four completely different stories. But I think in general if we can say, let's start back, let's think about this, let's all talk about it, let's determine what we want and how we can engage our families to understand our wishes and engage the healthcare system to really listen to us and be sensitive, to put our beliefs at the center of this dialog. I think you are going to have a lot more change for the largest number. You know we have this kind of sort of food fight, political debate over death panels, which turned out to be a complete disinformation campaign. And I think we have to be very wary of getting stuck in these political cul de sacs.

**George Vradenburg:** Michael Ellenbogen has a comment. Michael, I don't want this to be, you know back and forth, back and forth but I do want to allow you to comment on another questioner.

**Question:** Yes, in reference to that woman who just posed that question there, I'd like to say, I don't think we're presenting that people should be taking their lives or deciding to take their lives. Sometimes this actually saves lives, and let me give you an example, I actually know people who are living with YOAD who right now in their house, they have helium tanks ready to take their lives because they don't want to go to those worst stages in their lives. By them knowing that they can take steps today that allow them to write some sort of rules in place that they can stop feeding at a later time when things do progress, that allows them to extend their lives and live a much longer life knowing that. So I think there's many ways to look at this, I mean there, there's so many people that some do want to take their lives and some don't. So I think you have to look at, in different ways and I think we just need to put it on the table, it's up to the people to make that decision, the people who are living with the disease.

**George Vradenburg:** Ellen, do you want to make comment?

**Ellen Goodman:** Well, I guess, I would concur in that there are so many different points of view about each aspect, and it's as specific as a specific story. And what we can do though is make a much larger change in having an entire culture begin to talk about this and I think it's great listening to these two people talking about what matters to them and I think it's also really notable how different their points of view are, so that may sound a little wishy washy but that's where I am on this.

**Meryl Comer:** I'd like to ask a question.

**George Vradenburg:** Sure, go ahead.

**Meryl Comer:** Ellen, for those of us on the line and so many of us who have lived the pain of trying to guess what a love one wanted or wants. The pain of not knowing or not having had that conversation or

not having been able to have the conversation compounds the cruelty of the disease. So I want to take you back to a very basic question. It's how do you start the conversation, what is that first line? Is it, do you do it around a holiday event, when do you do it, how do you do it, from your experience and from the stories you've heard, what are the most successful ways to take that first step, what's the first line of your story to start the conversation?

**Ellen Goodman:** That's a wonderful question Meryl and I think what we have found is that a great way to begin the conversation is with a story. And maybe it's telling or asking a story about a good death or a hard death. So for example, when I started a conversation with my elderly Aunt and Uncle, I started it by talking about a death in the family that we all knew about and shared. And then asked them what their memory was of that and how it affected what they wanted and I am their healthcare decision maker so it was not a loose question, it was a serious question. And by starting with the story, whether it's a family story or a story you read in the newspaper, it provides an entry into it. You can also start by saying, 'you know, mom, that sometime I might have to make decisions for you and I need your help'. So one of the successful strategies that we've learned is that when adult children in particular ask their elderly parents for help, it's the rare parent who refuses that. There are a lots of people who when you start the conversation would say, oh mom, we don't have to talk about that, you're fine. Or, oh, you know, I don't want to trouble the children by talking about that. But we can get beyond that by asking each other for help by telling each other stories and by beginning to share that. Some people do better in these family conversations literally across the kitchen table. Some people do better driving in a car together or taking a walk together. Some people do better writing a letter. You know your family best and you know how things work in your family best. So there are going to be all different entry points but again I would say that in our experience, the opening with a story seems to be a very successful strategy.

**George Vradenburg:** Next question is from Trish Vradenburg. Trish?

**Question:** Hi. Can you hear me?

**George Vradenburg:** Yes.

**Question:** Okay, well I know we've had this conversation. Both of us come out on different ends of the conversation and I remember when I would ask my mother, she would say, 'why? you want me to die? is that what you're talking about?' So it's not such an easy conversation to necessarily broach. But actually I just wanted to know what your story was, Ellen. How you came to this, I mean is there Alzheimer's in your family?

**Ellen Goodman:** Well, yeah. I have two stories. I usually do tell the stories that got me into this, I apologize because I didn't start with that but I started really towards the end of my mother's life and she did have dementia, she didn't have Alzheimer's, but my mother and I, we were able to talk about everything. I once wrote about her as a person who you know, my mother would listen to your problems until you were bored with them. So we have talked about everything except what she wanted at the end of life. And so I was very aware of making decisions for her and not knowing what it was that she would have wanted. And then my sister died of Alzheimer's a year ago, a year and a half ago now, so I'm very familiar with the downward trajectory and the painful loss, and loss before loss, of someone

you're very close to. So that issue to me as a motivation to have a conversation, is just absolutely huge. I knew my sister, I knew what her wishes were, but again by the time we really would have written them out, she was no longer really able to discuss them. She had lost her capacity for insight, which is one of the things that often happens, as you know. And her capacity to remember what she'd said the day before. So I'm very aware of that as a high motivation and in fact it's probably an extremely high motivation when I think about the work we're doing.

We have somebody in our group who always says, it's one of our team members likes to say, 'it's always too soon until it's too late'. And if there was ever a place where the work of the Alzheimer's people and the work of The Conversation Project completely over-lapped. It's in that belief that it's always too soon until it's too late and that is one of the chief reasons to have these conversations early.

**Question:** Thank you.

**George Vradenburg:** Next question is from Carmen Pastor from, it's 305, is that Florida, Carmen?

**Question:** Yes. Hi. How are you? From Fuerza Contra Alzheimer's or Force Against Alzheimer's. For Fuerza Contra Alzheimer's main vision is to help the Hispanic community in the fight against Alzheimer's and I'm sorry, I have a very bad cold. But I have two questions. The first one is, you mentioned that 90% of Americans saying it is very important to have this conversation and you also mentioned that about 30% only have this conversation. Do you have any idea of how many Hispanics are having this conversation? You know that Hispanics are one and a half times more likely to develop Alzheimer's. Do you have any idea of how many Hispanics are having this conversation? If it's not in your [conversationproject.org](http://conversationproject.org). Are you doing or do you have any information in Spanish so that we can help, Spanish out there to have this conversation?

**Ellen Goodman:** Yes. We have our conversations starter kit is on the website in Spanish...

**Question:** Oh you do, wonderful..

**Ellen Goodman:** ... Yes. As is our How to Talk to Your Doctor kit. Also in Spanish...

**Question:** Oh great.

**Ellen Goodman:** ... it's in Spanish and then English obviously. And we'll going up in several other languages but of course we thought Spanish was the most important one.

**Question:** Okay. Are you approaching any organizations so that we can start helping the Spanish community? Are you been doing any partnerships? ..... Okay, we can get in touch with you?

**Ellen Goodman:** Please, please do get in touch. Yeah, we have been working with a variety of communities, most of our communities, we've been working with are sort of geographic-based. I'll tell you what has happened, which was really quite wonderful for us, we didn't know that we would also become a grass-roots organization because we are a public engagement campaign. But various communities started reaching out to us to bring The Conversation Project to people and so we have a

conversation-ready communities initiative, which we have about 20 communities on it already. And we brought The Conversation Project to people where they work, where they live and where they pray in these communities and now they have monthly calls back and forth to share best practices and what the best way is to get the whole community involved. So we are glad to have you contact us.

**Question:** Oh, wonderful. Okay, I already gave Jennifer my number so definitely I would love to get involved.

**Ellen Goodman:** Okay, and please, please download the starter kit in Spanish too.

**Question:** Great. Thank you so much

**Ellen Goodman:** I should say that we have had just about a hundred and sixty or seventy thousand people now, who have come to our website and half of the people who have come to our website have downloaded our Conversations Starter Kit which is amazing. So that has been really incredible.

**George Vradenburg:** A question here from Sue Canale from College Park, Georgia. Sue? Miss Canale? Hello? I guess she dropped off.

I have a question here about something that is modestly technical but very important and that is, a lot of individuals with Alzheimer's are cared for in their own home. And I am curious whether you can explain the difference between a do not resuscitate order from the physician and an out of hospital do not resuscitate order?

**Ellen Goodman:** I'm going to ask Meryl to answer that. I thought I have a feeling she can answer that. And I'm not exactly up on that.

**George Vradenburg:** Meryl?

**Meryl Comer:** Yes, and I have the information from Compassion & Choices in looking at their literature, one of the problems is many of us care for a loved one at home. To have a do not resuscitate order informs the healthcare providers but doesn't apparently protect us in our homes. So it is not enough just to have a do not resuscitate order, if you're taking care of a loved one at home, you're supposed to talk about having an out of hospital do not resuscitate order. And it is again signed by your physician but it provides assurances that if 911 is called, that the responders don't provide a cardio vascular resuscitation and it also helps you manage... responders can give a comfort care but they will honor your request and they don't do anything to artificially prolong your life. So it's sort of a space that most people don't even think about but because of the trend and the goal to keep people at home as long as possible, this is an issue coming up and it's a legal issue so it's important because the first responders will do what they are told to do and unless you have the document, you have no recourse.

**Ellen Goodman:** Thank you.

**Meryl Comer:** One more wrinkle and technicality.

**Ellen Goodman:** I know, I know. I do think all these technical details are really important and it's also really important that we start big. That we start with the recognition the most important thing that we can do is start this public dialog where we're willing to acknowledge and share talking about dying. That is probably the biggest cultural shift that we can embark on. And that's the one that I think is really underway.

**George Vradenburg:** I think we're about out of time. We may have one more question but I'd like to begin to close here. I want to thank you Ellen for joining us today..

**Ellen Goodman:** Thank you. I appreciate it and I hope you will all come to our, our web page and share your stories with us because we would love to have them.

**George Vradenburg:** And thank you to Meryl Comer, Board member of USAgainstAlzheimer's Network and President of the Geoffrey Beene Foundation, Alzheimer's Initiative for introducing us to Ellen and for sponsoring this call.

Thank you all for participating in this Alzheimer's Talks. In about a week, we'll have a copy of the recording and a transcript on our website for you to share with your friends. And as always, please stay on the line if you would like to leave us a message with a question or a comment. Sorry to the questioners if we couldn't get to you but Ms. Goodman and we are always prompt in trying to end these calls at precisely, in this case, 3:00.

Good afternoon and goodbye and thank you for being with us today. Thank you.

**Ellen Goodman:** Thank you.