

Death Expo 2016 on End-of-Life University (eoluniversity.com) Interview,  
“The Chrysalis Room” with [Karen Wyatt, MD](#) and Loretta Downs, Founder, [Chrysalis End-Of-Life Inspirations](#)

Karen: Hello this is Doctor Karen Wyatt and I am honored today to welcome my guest for today’s conversation about the Chrysalis Room, Creating Sacred Space for the Dying. My guest is Loretta Downs who is the creator of the Chrysalis Room and we’ll be learning a lot more about that in our interview, but first I’ll tell you a little bit more about Loretta. She is an internationally recognized inspirational speaker, writer, facilitator, and consultant on the subject of supporting the end of life experience with comfort and dignity.

Miss Downs is a storyteller with extraordinary experiences that suffuse her lively presentations with love, compassion, hope, and wisdom. Her inspiring perspective on the end of life is informed by over twenty-five years of being with the dying and the people who care for them. She has been a companion to AIDS patients, friends, family, hospice patients, and nursing home residents, supporting them through the end of their lives.

Six years of caring for her mother in a nursing home moved her to found Chrysalis End-of-Life Inspirations, to advocate for private rooms in nursing homes and hospitals, creating sacred space for keeping vigil with the dying.

Miss Downs retired from a successful business career in the Merchandise Mart to study dying and death. She holds a masters degree in gerontology, and is past president of the Chicago End-of-Life Care Coalition. She is a Metta Institute certified end-of-life care practitioner, a graduate of Roshi Joan Halifax’s Being with Dying Program, and a certified Respecting Choices advanced care planning facilitator. And you can learn more about the Chrysalis Room and about Loretta Downs also at her website which is [endoflifeinspirations.com](http://endoflifeinspirations.com) and I’ll repeat that later on in the interview so that uh everyone can go there and check it out. Loretta thank you so much for joining me today.

Loretta: Thank you Karen, I’m just delighted to be here.

Karen: Well I, ever since I first heard about the Chrysalis Room concept I’ve been wanting to talk to you to learn more about it so I’m very excited for our conversation today. Your bio told us

a little bit of your story but I was hoping you'd go a little bit more in depth about how you got interested in working with the end-of-life, how you go from working a business career in the Merchandise Mart to doing end-of-life work.

Loretta: I was surprised by all of this myself. I think somewhere within me, I've always been drawn to old people and part of that is watching people as they're aging, growing closer to death and eventually dying.

But beyond that, when I worked in the Mart, where I was in the home fashion industry, in the 1980s AIDS came through. Many of my friends and business associates were victims of the disease. I was able, because I was in sales, to be available for them. I could take them to doctor's appointments, take them to anything, and go to the parties--there were some great parties being thrown--and I became an observer of this process and it really fascinated me.

A few years later I became a volunteer on an AIDS ward at a hospital here in Chicago, and we had nineteen beds on that floor, where I watched amazing care being given to these, mostly young men. I spent time sharing with families and watching the different experiences. I noticed two things: that some of the patients were having terrible physical symptoms, they were having conflict with their families, and they were suffering in psycho-spiritual, emotional, and physical ways.

And then there were other patients who were having parties in their room. People were coming. They had a lot of visitors, and people would bring decorations. We'd even let them sneak in small dogs sometimes. I saw this tremendous amount of living going on for those people, and they were being supported in this journey.

That led me to become a hospice volunteer because most of those kinds of patients eventually went into hospice care, and I thought, "Well this is curious. I want to find out more about hospice."

I became a hospice volunteer just at the time my mother went into long-term care. That was the biggest turning point, in what became later, a career for me. I'd just retired, I was fifty years old, it was 2000, and my mother moved into a nursing home, which of course is a difficult change for any family to have to go through.

Because I had time, I was there five days a week. I tended to go in the evening, so I got free dinners, and I met all these other residents, and their loved ones. I watched what happens, and what can happen, in a nursing home. It was amazing. That's what started the Chrysalis Room.

Karen: Wow. I have goose bumps in a way because I've spoken with many other people through End of Life University and heard so many similar stories about people being inspired to work with the end-of-life because of the AIDS crisis, and so it really seems like in some ways this modern, movement toward end-of-life has been called forth in a way because of experiences in the past through the AIDS crisis. Many of us have been inspired and rallied to start working in this arena to try and make a difference and change things.

Loretta: It's true. So many of the victims in that early period were young men in the early stages of their lives and careers just starting to bloom. I think that's why it was easy to rally. Whereas with old people there's this fear of aging and dying. There's a definite fear of nursing homes.

Do you know that sixty percent of the people in nursing homes have no visitors, and fifty percent of them have no close living relative? It can be a very abandoned population, and that's why the nursing home becomes *home* for these people.

Many of the residents make relationships with the staff. They are like having daughters and sons and sisters and brothers. I've seen some amazing things occur between a staff person and a resident in a nursing home. That caring also inspired me.

I'd become a hospice volunteer and I was doing home visits, I was able to see what you see all the time, how transformational dying can be for everyone who's involved. I wanted to bring that dignity to the nursing home.

Karen: Absolutely. That's really beautiful. I know in some of my previous experiences with the nursing homes I've seen some of them have been reluctant to have their own residents die within the nursing home, so they call an ambulance when someone seems close to death and send them off to a hospital. I don't know if you experience that as well.

Loretta: Oh yes. I don't have statistics but the percentage of people who are sent from nursing homes to hospitals is very high. The emergency rooms really do take a lot of the very old, and the very sick. It's a frightening experience. It's not the kind of quality of death that people want.

On surveys, seventy percent of us want to die at home with family. The nursing home becomes home for so many individuals. Having a Chrysalis Room is one more step they can take to allow the residents to die at home surrounded by loved ones, even if the only loved ones they have are the staff.

Many nursing homes have double rooms. That was another thing that moved me. I saw the need for privacy at this transitional period for the last week or days of life.

Karen: So tell us what a Chrysalis Room is exactly and maybe you could describe what a typical Chrysalis Room would look like, and how it would differ from the ordinary rooms in a nursing home.

Loretta: First of all it is private. And it's spacious. It really does not have to be huge but it has to be able to accommodate family members so they can be there in comfort. Many of them have a sofa that converts to a bed or they'll offer a rollout bed for a loved one who wants to spend the night.

Sometimes family comes in from very far away, and they don't want to leave once they get there. They want to be present through the whole process. Sometimes family live miles from the nursing home, and going back and forth is stressful on them so I think it's important to have accommodations where people can spend the night.

It's aesthetic. It's got nice furniture and soft lighting, and ideally a view of nature. They offer hospitality for the family. Many of my nursing homes will bring coffee thermoses and soft drinks, they have a refrigerator in the room so a family can bring food or they can order in.

It's about having support for not only the person who's dying, who is now getting heightened comfort care, and ideally is in hospice care. There are many rural communities that don't have hospices available to them.

It's about having a supported end-of-life experience. That includes supporting the family, and the staff, and the other residents. Having a large enough room, residents can visit in their wheelchairs.

When my mother was dying, at one point we had seven residents in the room. I think I was the only Catholic but they all said the rosary with me because my mother loved the rosary so much. It's amazing sacred space.

They can spend a little money, or a lot. Very often nursing homes will ask for donations from families to provide the furnishings. It's got artwork like nice pastoral pieces, or butterflies, on the walls. It's really about comfort, and quiet, and serenity, tranquility, and the sacred ground so loved ones can do the work they need to do.

I love this quote by Dr. Gwen London. She says, "Dying is a spiritual experience with medical implications."

Karen: That's perfect. I love that. Now you conceived of the Chrysalis Room while your mother was in the nursing home. Was she able to die in the Chrysalis Room that you imagined?

Loretta: She was. I have a three-and-a-half minute video on my website of photos I took during the last eight days of her life and the hours after her death. This is the kind of thing people don't see. Everyday we turn on the television, we open the newspaper, and we see violent death. It's very seldom that we're able to witness something that is supported, and peaceful, and participated in, and my mother's transition was meaningful to everyone who saw it. That was what she wanted.

Karen: When you came up with this idea, how did you convince the nursing home to creating a separate room, a separate space for dying?

Loretta: Before I thought of this, I had been participating in dying with some other residents as a hospice volunteer. My mom was there six years and some of her very close friends were dying. One of them had two daughters that had also become friends with all of us, which also goes to show that nursing homes become a community. People get involved with each other.

Marcy was dying. My mom was a hospice patient three times before she died, and this was the second time that I'd moved into her room. I'd brought an air mattress to sleep on. At five in the morning I went to check on Marcy. She was hardly breathing. I called her daughters.

The three of us were sitting in Marcy's room, around her bed. One of them was squeezed up against a wall trying to hold her mother's hand, the other one was against a curtain with an oxygen machine on the other side, and we were trying not to disturb her roommate. I was sitting at the foot of the bed with my knees against the bed board, and we were whispering stories about Marcy and they were holding her hand and stroking her head. I sat there thinking, "This just is not the best it could be."

Even though everybody was there, we were all pretty uncomfortable. But her roommate wouldn't move. I later learned that Marcy was the third person that had died in that roommate's room.

That is not what any of us want.

Then another person died. She was a single woman with whom I'd become very friendly. Her sister had been a resident there for years and then she had a stroke and became a resident herself.

She had a whole slew of girlfriends. She was in a shared room and there was nowhere for anyone to sit when they came to visit her. So I pleaded with the nursing home. I didn't have to work too hard because Cheryl Morris, the vice president of operations said, "We've been thinking about doing something like this." So they allocated the money. I went shopping, and The Chrysalis Room became a reality.

Karen: Wow it's just such a beautiful concept. As you said, in my experience with nursing homes in the past, I found as well that there was a real community and a family feeling amongst the patients and the staff. I agree with you that the residents of the nursing home need to be able to die there because it *is* their home, it *is* the place where they're most comfortable and they will see familiar faces of people who know them, and **love them** and will, and want to be present during their last days of life. And so it seems vitally important that we help nursing helps

be able to accommodate the dying process in a way that *does* support the comfort and dignity of the patient.

Loretta: It is. When the other residents see this kind of care, they can be confident it's available to them. We can't stress the value on that enough. There's little recognition of that important process of transforming at the end of life. The Chrysalis Room allows the end-of-life experience to be a part of the community.

Karen: I could imagine. You mentioned before that it's better for the staff as well because I can imagine it's distressing for the staff when a patient disappears and they're taken off to the hospital, and the staff will never see that person again. When someone's been a resident there for six years, you feel close to that person, and so it allows the staff an opportunity to have a resolution, to say good bye, and offer the very last moments of care that that patient will receive.

Loretta: Absolutely. There's an element of anticipatory grief that helps us through the process of having someone die. If a resident's in the Chrysalis Room for let's say a week, which is ideal-- certainly five days is lovely--the staff is coming in and out and they're getting ready, they're grieving already, as is the family.

So having the sacred space makes a difference. It's interesting the way every family that moves into a Chrysalis Room sets up a little altar. They find a shelf or table or a windowsill, and they inevitably bring flowers, some religious objects, family pictures and they set up this little space. That helps create sacredness.

Karen: It's so beautiful and there's room to do that and then permission to do that, which they might not feel in a shared room with another patient.

Loretta: There's no space. Sometimes there isn't even one chair that doesn't have things on it in a double room. And then everyone's worrying about the roommate.

One family told me a story about being in a double room to keep vigil with their dad and the roommate on the other side had his family celebrating his birthday. Everyone was uncomfortable. How do we honor the birthday? How do we honor this family that's trying to keep vigil? It was unsettling.

Plus there's so much that goes on for the family. They make connections and heal old wounds in this setting. Oh, the kind of reconciliation I've seen, and the storytelling, and happiness and joy with the memories that goes on, and pulling out the old family pictures. You need space to do all that.

Karen: Absolutely. And so for the many patients who cannot be cared for at home for whatever reasons, because there's not a 24/7 caregiver or family members don't live close enough and can't be there. There are many patients who will need to die in a nursing home. That might be the only facility available to them, but it doesn't have to be, as many (people) in our society imagine it to be, a horrible death. It can be beautiful and sacred as you're describing, through the use of a special room.

Loretta: It's true. There's definitely a revolution going on in nursing homes, because they have a lot of competition now in senior care and senior housing. There is a movement to improve the culture of long-term care. One number I picked up was twenty five percent of us are now dying in nursing homes, and that number is expected to go to forty percent by 2020.

They need to be hospices. They need to provide extra comfort care at the end-of-life for the residents, and also provide the kind of space where families can be there, and the other residents can watch this process and participate in it.

Karen: So what are you seeing, is this concept growing in nursing homes across the country?

Loretta: It is. It's reducing hospitalization at the end of life. I think nursing homes want that to happen, and the *hospitals* want that to happen. They don't want to take people in the emergency room for them to die that day, or a few days later, because hospitals don't really have space for the dying.

Some hospitals are starting off with palliative care rooms, though not many. They have the dying on a medical floor, so it's not quite the same. Removing someone from their nursing home is just kind of unkind, I think.



The reason I call it the “Chrysalis Room” is because I started raising monarch butterflies when my mom was in the nursing home, which is a wonderful process. I would bring them in stages to show her and we would watch the caterpillars become chrysalis and then turn into butterflies. I’d have release parties for the residents.

Everyone has a chrysalis stage at the end of life. You go into that quiet space where you transform and this room is meant to be that holding space that I keep calling “sacred ground” for that final transformation.

Karen: I love that. I love being able to watch this, the life cycle of the monarch butterfly, and view that chrysalis stage it’s such a great teaching concept for people who have a fear of death to be able to witness it and let them see this new emergence after the chrysalis, there’s a new transformation.

Loretta: Yes. There’s a TEDx talk on my website that is very much directed at that process. I suggest people go and search it. In addition to the transformational aspect of the dying process and reduced hospitalizations. It’s about support, and having more support for people at the end of life. That’s the primary goal of the Chrysalis Room, not only for the person who’s dying but also for everybody in it.

I hear back from nursing homes and families how grateful they are to have this space, to do what they need to do with their loved ones. It’s consistent with the staff in the nursing homes, the nursing home administrators. There’s pride for them in having this space,

When it’s not used all the time and they find other uses for it, like at Central Baptist Village. They’ve done a beautiful project. They hired their architects to do the room. There’s a presentation that Dawn Zimmerman, then the Administrator and now the Director of the nursing home, and I have done at a couple national conferences. That presentation is also on my website.

Architects from Perkins Eastman got behind the concept and have spoken to a lot of nursing homes about including a Chrysalis Room in future plans. There’s a sense of gratitude. I think having the space creates a sense of naturalness in the dying process, that this is a human process that we need to know how to do, learn how to do, be present for.

Karen: Absolutely. It seems that this idea of creating a sacred space for the dying process could be done elaborately by hiring architects and creating a specially designed room. But are there some who've also made it very simple? I remember that you said that you found a storage space in the nursing home that your mother was that could be used, so I'm thinking is it possible for some nursing homes to do it with a low budget option if it's not possible for them to design a more elaborate space?

Loretta: Absolutely. Many of them already have enough furniture. They move a hospital bed out of one room, and chairs. I think the having a comfortable sofa that turns into a bed, or a daybed set up where people would have enough room to stay. Some of them use the geriatric chairs that recline. It really doesn't have to be Architectural Digest. People can donate artwork for the walls.

I've been told that some have resident groups that will make blankets, quilting or crocheting, for the resident who's in that room then they're given to the family after the death.

Karen: Oh wow! Isn't that beautiful? That's very beautiful.

Loretta: They create rituals and systems within the nursing home to make this better, and they personalize it. For instance, leaving the Chrysalis Room and creating a ritual for removing the body from the nursing home to the front door, instead of out the back door where it usually has been going. Creating a shroud that can go over it, and ringing a bell so that the residents who want, or don't want to be part of that can close their doors. The other ones often walk out in an honor guard with the body.

Karen: Wow. That's beautiful. I love the idea that it's giving purpose to the other residents as well to participate in this process with the friends that they now have, their new family members in the nursing home and to be able to be part of it, and participate, and then even to create something that becomes part of the ritual.

Loretta: I took care of two siblings who had Huntington's Disease. The both died before my mother did, and it was so important when Gabriel died that his sister saw a beautiful death, and

a ritual. When he died, at home, the family called their Church and many people came plus a number of family members. He was twenty-eight years old, and she was at the time twenty-six.

Something came into my head to do a flower petal ritual. There were always flowers in the house, so I tore all the petals off and put them in a tissue box. I gave the box to Janet and she stood in his room.

The idea was that the loved ones would take some flower petals and sprinkle them on his body, on his bed, as a final offering of friendship, so that when everyone had left, and before they removed his body, he would be covered in flower petals. That's what his sister was able to remember, and give her some comfort about the death that she was going to be experiencing, in the not-distant future.

She did die two years later. Her cousin, who at the time was seven or eight years old, asked me, "Can I hold the flower petals, Loretta?" And we did the same thing for Janet. Their mother is left with that scene, her children's bodies covered in flower petals.

Some of the nursing homes do that in the Chrysalis Rooms, so that the families and the residents create this ritual of a gift, something that they are doing, so the last view that the family has is of their loved one laying in a flower bed. You will see this on the video of In The Chrysalis Room With Anna on my website.

Karen: Wow that is beautiful, so creative of you to think of that idea in the moment.

Loretta: It's amazing what happens. I think this is a robust experience, being with someone who's dying. It's privilege. It's like watching a birth.

In fact that was another inspiration I had for the Chrysalis Room. A couple years earlier a close friend of mine gave birth to her first child. She had a lot of anxiety and she asked me to come over while she was in labor. Her husband was there, and she was in a birthing room. You know hospitals are building these beautiful Ritz Carlton kinds of birthing rooms, and I thought, "Well we should have birthing-out rooms." So that was also part of the inspiration for doing it.

Karen: Yes absolutely, I can see a big need for this sort of room in hospitals as well, because I think right now so many patients die in the ICU where there are monitors and noises and you know how rushed people are around them, or in a regular hospital room. I just think it's hard to even create the sacred space, to *dedicate* that space for the dying process. As you say to make it sacred, to honor the dying of everyone in the future as well who will be using the space. That alone, just to be taken to that beautiful space, transforms the process of dying.

Loretta: It does. It allows people to go deep within themselves, like the creativity with the flower petals. I didn't plan that. I think when we're in focused space, people are praying and meditating, they're hoping, they're uncomfortable, they're unfamiliar. Having that quiet space while being with someone who's taking their last breath is powerful. It's a human experience and we've been removed from it.

Karen: Absolutely. To our detriment as a society, I believe, because every person I know who has been a witness to the dying process and been part of hospice just has much less fear in life, and much more spiritual depth about how to live life and what's important in life.

Loretta: Oh yes, it's true. I think Socrates said, "If you want to know how to live, learn how to die." I've seen that with the families who come back to me and have said, "You know I'm not afraid to die anymore."

Karen: Which is really our goal for all of this, for all of this work. It's to help ease that fear of dying so that everyone can participate in this natural process and not avoid it or run away from it.

Loretta: That's true. I'm on a mission; this isn't a business for me. I'm very fortunate. I don't want to sell furniture. I want to inspire people who work in the long-term care setting and hospital setting to see what I'm doing and see that it's just the right thing to do.

Karen: Loretta do you have any idea right now how many nursing homes offer a Chrysalis Room? I suppose there could a lot of them that you don't know about or haven't heard of.

Loretta: I think there are. Just last month I picked up articles about two new Chrysalis Rooms in nursing homes. I haven't set up a tracking system. Like I said, this is not a business for me. I've

spoken at countless long-term care conferences, now to thousands of people, and I know many of them have gone back and said, “We need to do something.” It might not happen right away but I think it’s happening.

I found a Chrysalis Room that was built in the Powell Valley, Wyoming Care Center. Powell has a population of 6300 people and they don’t have a hospice provider. Two of their personnel had been at one of my presentations. They told me it took three years to get the room done. They posted an article in their local newspaper, which I was able to pick up on my alerts. They’re already using it.

The other day I got a notice from Harrisburg, Virginia, population 2700. They built a Compassion Room, at the community hospital. So it is happening in places that I don’t know about, and that keeps me going. Just when I think, “Oh, I’m not making any progress here, no one’s getting it.”

My website is very useful, people can go there and get information about how to start a Chrysalis Room, and some examples of Chrysalis Rooms.

Karen: I’ll mention the URL again, it’s [endoflifeinspirations.com](http://endoflifeinspirations.com). I was wondering, Loretta, do you have suggestions? What if someone out there is a family member who has a loved one in a nursing home, and they would love to see that nursing home create a Chrysalis Room, because that’s how you started this project. How would you recommend they to try to get through to the nursing home administrators and initiate a project like this?

Loretta: Look at the slideshow of my mother’s last week of life, and share it with the nursing home administrator. Because it shows what happened in the Chrysalis Room. It shows the staff being present, it shows other residents being there, it shows the different people who gave my mother care, and it shows how comfortable she was.

The pictures that happen after she died happened because her hospice nurse was scheduled to come that day. She didn’t even know mother had died, and she showed up about half about an hour after mom died. She started to bathe her, and there are pictures of this. Like my mother was a queen being bathed. Margaret was doing what she does.

Margaret Tunney worked as a hospice aid at that point in time, seventeen years. She was like a priest offering mass, it was so beautiful, and residents came and went, and we did the flower petal ceremony on my mom. It was ten years ago and it still moves me to think about how her friends and the staff came, and how much being there meant to them. In fact, we had to make the funeral director wait to take her away until bingo was over so Muriel could come and say goodbye. That's the last picture. The story told in these pictures is moving, and it makes people think differently about dying.

Karen: So that might be something someone can use if they wanted to make a presentation to their local nursing home about the value of having a Chrysalis Room. They could actually get resources on your website, find these photos and slides and show that to help them understand what it is, and to encourage them to move in that direction.

Loretta: Oh yes. They can contact me. I'm more than happy to help people with this. I don't make money doing this. I just want to inspire and motivate people to create this sacred space in long term care and in hospitals so that people can die supported by staff and loved ones, in peace and tranquility.

Karen: And I wanted to emphasize too, as we talk about sacred space, we're not talking about any one religion or another. It's a space that anyone can use regardless of their religious affiliation. It's a space that's held there for everyone to bring their own beliefs into the space and utilize it during the dying process. No one would be excluded or limited from that space.

Loretta: Exactly. You know it's a universal experience. No matter what faith a person has, the process of watching someone die or dying is very much shared.

Karen: So if there were someone from a nursing home staff listening to this interview that said, "We have to do this at our nursing home right now," you are available for questions if people want some guidance on how to create this?

Loretta: Absolutely, the contact information is on the website. They can email me. They can call me. I'm more than happy to help. As I said, I'm on a mission, Karen. I know that the outcome of this benefits more than the person who's dying. It'll ripple out like a pebble in the water. I get the feedback, I hear from the people who've experienced the Chrysalis Room.

It is actually a hospice unit in one room. A hospice unit has multiple rooms, and they'll have a sitting area for people, maybe a little kitchen, you know for hospitality or someone has put out a tray of cookies, and thermos of coffee, that's all in this one room.

Karen: It seems like for most nursing homes that's really all that's necessary, one room that's utilized over and over again for any patient who needs it. It doesn't require much more than that, just one room.

Loretta: That's true. There have been occasions where the room is occupied and somebody else needs the room. The nursing home then will move a roommate out or move the person who's dying into another room where they have privacy. That doesn't happen very often.

One nursing home I visited has a library, a room set up as a library. It was a pretty good-sized room, and when they had someone dying, they would move their bed in there because it had multiple chairs and a table where the family could sit, and it was in a quiet corner of the nursing home. So there's another way to have a flex room. It was very attractive.

Karen: Yeah, a very interesting idea. I would think, as you mentioned before, it's because long-term care facilities are having to compete with one another more and more for patients that this is something every facility would be so proud to have, and would be so honored to mention to potential resident families that they offered this.

Loretta: When I first got the Chrysalis Room opened in 2005 at the Fairmount where my mother lived, it was right before she died. That was part of my motivation, too. I wanted her to be able to experience it.

The admissions director wouldn't take families of potential residents there and show them the room. She said, "I can't tell them we have a hospice room. They're upset already, and that'll upset them more." Now that's part of the tour. So things are changing. It's very good.

Karen: I'm so glad to hear that. Well I would love to see a Chrysalis Room or something similar in every nursing home, but also every hospital. I think it's really important, I think it's not realistic to think we're going to suddenly have every person dying in their own home, I don't think that's

possible, we don't have enough caregivers to go around. We need to be able to convert the spaces where people die right now, into sacred spaces that can honor the process of dying.

Loretta: I think it's important that we all start looking at our own desires for the end of our life, and advanced care planning is a really big part of that. In long-term care, it's not only for the residents who come in, but also for the staff. We have to build a familiarity with dying that is lost.

Historically, everybody took care of the elders, and the dying, at home. Now, everybody's working, and we have distance. Most of my friends don't have children living in Chicago anymore; they're all over the country. This is an obstacle to having family being able to keep vigil and give care.

As you point out, we're not going to have enough caregivers, so the nursing homes are going to be the places that need to provide this kind of comfort. Doing advanced care planning gets us familiar, makes us think about, "What kind of treatment do I want at the end of my life? Where do I want to be? Who do I want to be there? Who do I trust to speak for me if I can't speak for myself and I'm in a hospital?" The more we do this, the more familiar we become with the end of life and the less we want to avoid dealing with it. I think there's a natural desire to go into it.

Karen: Absolutely. Just as you're saying, even in the nursing home where your mother died, now the end-of-life room, the hospice room is something that they're proud to show to everyone who wants to come there because our attitudes are changing and we're opening our minds a little more to the naturalness of the dying process.

Loretta: It's true. It's great public relations. I remember when my mother first went in. I was so crabby about everything. Nothing was right. Then she was crabby, and my sister was crabby. It took us months before we settled down and realized how hard all these people were working to enhance the quality of my mother's life.

That's their mission to keep the highest quality of life for their residents that they can. It's time for them to consider the highest quality of *death* for their residents.

Karen: Absolutely. Well Loretta, what can the rest of us do to help you with this mission of yours, like me for example. I live in an area that we don't even have a nursing home or long-



term care facility where I live. Are there ways that we can be supportive of this movement? Interviewing you is one way I could support you but, for others out there who say, "I want to help move this forward," do you have any thoughts about what we could do to support you?

Loretta: I think sharing my website helps. I have a Chrysalis End-of-Life Inspirations Facebook page where I post all kinds of articles. There's a lot more being written about end-of-life and advanced care planning than ever before. So I think that's one way to do it.

Again, doing your own advanced care planning so you can get more familiar with dying and what it's about. Read your book, Karen. Really, there are ways to stop being afraid of dying. Look at it as a transition, like the monarch butterfly makes. It's a natural thing. If we all have to die, it cannot be a bad thing. What's happened is (that) we're not making it the sacred transition, and supporting it the way humans used to. It's time to take it out of the medical institutions and make it something that's an act of love.

Karen: Yes, absolutely. I really believe this change has to start from the ground up. It's going to come from the grassroots, and from consumers, and from just ordinary people making changes. I think that will happen before the medical system will begin to change its attitudes about death and dying.

Loretta: That's so true. Social change, social movements, take place because people rise up together. Think about car seats, cigarettes, and condoms even. There was a time I remember my mother saying that was a dirty word. Yeah, we've come a long way. I was walking on the lakefront during a Lollapalooza concert and there was one of those flying planes with ads on it. It was a Trojan ad. I'm thinking if that can be happening, there can be Chrysalis Rooms everywhere.

Karen: That is true, that's so true.

Loretta: We just have to start demanding it.

Karen: Yes. So each one of us who hears about this concept can also just talk to people that we know because everyone of us knows someone who has a loved one who's entering a nursing home or already in a nursing home, and we can tell everyone we know about this concept. We

can encourage people, go to the nursing home administration and ask them if they would consider creating a special room, and keep agitating and asking for it, because that is how change will happen.

Loretta: That's what I did. I just asked and I was fortunate that I only had to ask once. Some of the nursing homes also use this room for quiet time for staff, or family members. I can remember going to the nursing home one day and put my hand on the door and I said, "I just can't go back in there again." It was too hard and there was no place I could go and sit and be quiet. Central Baptist Village takes their dementia residents and staff volunteers to do hand massages in this room because it's such a peaceful, pretty space.

Karen: So... Very nice. So there are all kinds of ways to be creative with this idea and the space and I'm sure it's something different in every nursing home and they find a way to create it but we need the catalyst for it. We need a lot more people out there with this idea in mind and speaking up about it and asking, "Why doesn't your nursing home have a space or a room for the sacred process of dying?"

Loretta: Karen, from your lips to God's ears.

Karen: Absolutely. Loretta I just want to thank you so much for the work that you're doing, for being so passionate and being on this mission for so many years, making a difference in the world, making an impact on how people die.

Loretta: Thank you. I consider it to be a great gift that I was brought to this work, and I thank all of my friends and teachers. Many are dead, so they live through me.

Karen: You definitely are honoring them with your work. It's been my privilege to just talk about it with you and share it with everyone out there who's listening and I'm hopeful and excited that this will spark some ideas in people's minds and they'll go out and start creating changes in their own communities.

Loretta: Thank you, Karen, thank you.

Karen: Thank you Loretta. I've been talking with Loretta Downs who is the creator of the Chrysalis Room and the website again, to learn more about Loretta's work, the Chrysalis Room, and get access to her contact information is [endoflifeinspirations.com](http://endoflifeinspirations.com). Please go there and check it out. It's a beautiful website and you'll find lots and lots of resources there. Loretta, thank you again for taking time out to talk with me today and I hope we have a chance to meet again some day in the future.

Loretta: Thanks Karen. I would enjoy that very much.

Karen: That concludes the interview with Loretta Downs, and Loretta is here with us on the phone. Loretta I'm going to unmute your microphone so that we can say hello. Hi, Loretta.

Loretta: Hi Karen. There are 16,000 nursing homes and 5600 hospitals in America. It seems like every single one of them needs to have a special room for the dying. These are the places in which most of us are dying and I don't know that that's going to change because the family structures has been so changed with the caregivers working and the geographical distances we're now living in.

I think it's important. For those of us who experience the death of a loved one, we remember that for the rest of our lives. You know the space, the environment they were in, the people that were around. We deserve, as survivors, to make that a peaceful experience for us--and certainly those of us who are making our final transitions deserve to have it honored and supported.

Karen: Absolutely. This is such a worthwhile project, I think, for any of us to pursue in our own communities, knowing that if we can help create rooms for the dying at our hospitals and nursing homes now, they will be there for us some day when we have a need of them.

Loretta: That's part of my plan. I admit to that. I think you know moral distress is something that healthcare professionals deal with all the time. I think the increasing need to be charting everything and not being able to have a lot of face time with people is exacerbated when you're dealing with somebody that you know is dying. To be able to be present for them and their families, in the sacred way where what you're doing is giving comfort rather than discomfort benefits everybody.

Karen: Yes. I can see it also would allow the healthcare staff to resolve their own grief issues in real time. In a sense I mean by being part of the dying and by being present, instead of what I think happens now is that many healthcare providers just have cumulative grief from losses of patients that there's never time to process. They never have time to reflect on it, or honor the person who has died or even be present for that moment. This would allow so much healing in the moment, in real time as it's actually happening, and prevent some of that cumulative grief that happens.

Loretta: You are so right. We're beginning to see some examples in movies now and occasionally on a television show, although I think we see a lot more that isn't realistic than we do that's realistic. There are stories being told about experiences when families are with someone who's having the kind of death they want to have, which is peaceful and surrounded by loved ones. We just have to change the way we're dying.

Karen: Yeah, for sure. Loretta, thank you, first of all for your work, and thank you for doing the interview with me and then agreeing to come back on again to talk a little bit more at the very end here. I hope that this interview inspires people to look into this idea. If someone out there knows they'd like to do some work in the end-of-life arena, that they're not sure what to do, consider this idea in your own community, it might be something you could become a champion for a Chrysalis Room in your hospital, and in your long-term care facilities.

Loretta, you said you are available through your website if people need advice or guidance from you, and I really appreciate that.

Loretta: I'm happy to help. The results can't be questioned. The families who are able to spend time keeping vigil with loved ones at the end of their lives feel so much more peaceful, and isn't that what we all want?

Karen: Oh exactly. It's time for us to face that we cannot realistically imagine that every baby boomer that wants to die at home will be able to have that experience, so we have to prepare and plan for these alternatives and I think that this is a perfect step to take.

Loretta: Thank you Karen. I appreciate this opportunity to share my thoughts on the subject and I will help anyone who wants to contact me.

Karen: So the website again is [endoflifeinspirations.com](http://endoflifeinspirations.com). Please give it some thought, everyone out there listening to us. Loretta, thanks again for joining me twice. It's been really fun, to connect with you again.

Loretta: You're welcome. I've been enjoying the conference myself and look forward to tomorrow's speakers. I'm in very good company. It's been quite an honor. Thanks Karen.

Karen: Thank you. Thanks for being part of it, and thanks to everyone who's tuning in. None of this would really happen if it weren't for you. I we didn't have an audience out there eager for this information, so I appreciate your time and attention.