

Interviewer: Hello, and welcome to Death Expo. This is your host Dr. Karen Wyatt. I'm so glad that you've chosen to sign up for Death Expo and that you've been able to join us for some of the interviews we're presenting here. This has been a great experience for me to meet our guests and have a chance to talk with them and have a conversation, and I'm hopeful you will find these conversations enlightening and inspiring as well. Today I have a very special guest for you, Dr. Monica Williams-Murphy. I've been wanting to talk to her for a year now so this is very exciting for me to have her here as a guest. Dr. Monica Williams-Murphy, is an award winning writer and board certified emergency physician who is on staff at one of the largest emergency departments in the nation, Huntsville Hospital.

She serves on the board of directors for both her local not-for-profit hospice, Hospice Family Care, as well as the Los Angeles Hospice at Anam Cara. Dr. Murphy also serves as a medical expert and writer for thirdage.com, the leading online baby boomer lifestyle site, and is guest faculty for the University of Alabama at Birmingham School of Medicine where she lectures on ethics and end of life decision making. Monica is a passionate author, blogger and public speaker whose focus is empowering patients and families in critical and end of life decision-making. She lectures widely about topics such as changing American beliefs about death and the crucial importance of advance directives.

Her book *It's Okay to Die* and companion website are tools devoted to transforming the end of life into a time of peace, closure and healing. Dr. Murphy's blog has also appeared in the New York Time's *Health Around the Web* column, and her lecture has been nationally broadcast by the Alabama Department of Public Health. In 2013, she was a winner of the Cost of Care National Essay Competition. Finally, she is hostess for the Trendy Death Café for Huntsville, Alabama. You can learn more about Dr. Murphy and her work at her website, okaytodie.com. So, Dr. Murphy - I hope I can call you Monica – it's so wonderful for you to be here, thank you so much.

Interviewee: It's so exciting to be here, and yes, please call me Monica. I have entirely too many names. It's fantastic to be with you and it's definitely my honor to talk with you. You're doing very important work and there are many people who need to hear what you have to say, and thank you so much for creating this forum. It's fantastic.

Interviewer: Thank you, and it's very exciting for me to talk to another physician who is not a hospice physician, because most of the doctors I find who are excited to talk about the end of life are doctors who already work in hospice or palliative care. I think it's extremely valuable for medicine right now that you as an emergency room physician are standing up and leading the charge here to help us change how we care for the end of life, because you have a different perspective from the work that you do and you have a new, fresh voice out there that everyone really needs to hear. So thank you for what you're doing.

Interviewee: Thank you and as a matter of fact I agree with you to some extent there's great power in standing outside of the field of hospice and palliative care, and saying go to these people because what they do is good, and your patients deserve this type of care at the end of life. So I joke with my hospice friends that I'm their greatest cheerleader. It also serves – I can look at the surgeon or I can look at an oncologist and I can say I'm not trained in this field, but it is my duty and it is your duty, it is our duty to ensure that our patients have a good life and a good death. So all of us need to do that; there's just not a set specialty that we call in to start this conversation and to make that happen. It's all of our jobs, it's part of our roles, it's part of what we do.

Interviewer: That's so true and I was reading some of the stories in your book, which are wonderful, and really recognizing that sometimes you are the only doctor a patient and their family encounters who actually presents to them the big picture that grandma is going to die. She's aging, she's on her way toward death, and that you sometimes are the only doctor who has ever had that conversation with a patient and their family.

Interviewee: Karen, this happens weekly. I just finished three or four shifts this past week and I had a 93 year old gentlemen who had stopped eating, he still lived with his oldest daughter. He was in pretty good shape, he could still walk around the house and enjoy some crossword puzzles and some visits from relatives, etc. But he had stopped eating and started putting his crosswords to the side, and he gave away one of his personal treasures, and he came in and he was in acute renal failure among other things. Of course, the body begins to not function normally, as what we consider normal at the end of life. So I very gently gathered the family around and said he's dehydrated today, these are the things have happened, but I want you to know and I want to talk to you as though you're my father and my sisters that this is an end of life pattern, and this is okay, this is normal.

Once a week I have this conversation, where someone is on the map of life, and to me maybe it's because I'm a stranger to my patients I'm seeing them for the first time, I haven't seen them over time; I can get to the point and it seems very obvious. So that's one way in which I think physicians in particular are failing in appropriate care and relationships with their patients and families. Because people have to know honestly where they are on the map of life to really make informed consent decisions about what kind of medical therapy someone would want or not want next.

In absence of that knowledge you're making decisions in a vacuum with some false notion that you have about your ability to continue living in this state. So I just wanted to – I was curious as to why other physicians who cared for these people have not given them an inkling about what this medical moment means, what this moment means in the larger scheme of the cycle of life, because it changes everything. That knowledge changes everything and it changed everything for that family, and it was so important.

Interviewer:

Absolutely. A couple of things I could say as a primary care physician: it's heartbreaking in a way for me to hear that, because it should be my specialty's task; we are the doctors who care for people for the entire map of their life. We are the ones who should be helping them see where they fall; I love your term the map of their lives. We're the ones who should be helping them understand and recognize when they get to that point, and for me in my mind I was thinking that we need to consider the end of life as the final stage of development. We need to make it a developmental stage just like infancy and toddlerhood and adolescence. End of life it's really a stage, it's a stage of life that's sometimes very short, sometimes longer; but we need address it that way so that we can say to people now you have entered this stage – this final stage.

Interviewee:

That's correct. I totally agree and we need to identify just like a pediatrician will tell you your preteenager is now going to experience these things so that you know what is coming. We need to have the same conversation with our patients. You've entered the end of life stage and phase, and these are changes that we begin to see, and these are the opportunities. Because as you and I both know as the body is dying there's an opportunity for growth emotionally, socially and spiritually that seems almost limited at other times of life. So I think when talking and educating our patients and families, because naturally in our culture we view the end of life and dying as so sad and limiting.

We need to be able to express what's actually opening at the same time the body is dying.

Interviewer: Exactly, that's exactly how I see it. I love that we've reached some common ground, because that's exactly what motivates me as well to want people to experience the awakening that comes at the end of life and take advantage of that opportunity to really transform and heal and experience spiritual growth in the last days of life. One thing I really liked from your book is that you not only tell stories about patients that you've cared for in the emergency room, and point out the fact that we as a society – lay people in our society - have really lost touch with what aging and the end of life and the dying process are like. We don't recognize it, we don't understand what it is, and in your book you have a list just for people to come to know what happens when someone dies. I think it's so important for people to understand the changes that take place normally as the body is dying.

Interviewee: What's so interesting, Karen is I had to learn about these stages after medical school and after specialty training, from hospice and palliative care literature. So first of all let me be in shock that I was not taught about these as a physician. Because if you are the average Jane or Joe walking along the street and you ask yourself who knows the most about life and death and the body and organs it's doctors. So if doctors aren't telling me about something it must be because A – it either doesn't apply to me or B – it's not important. So I'm not going to talk about something easily that I'm not trained to understand. So I'm shocked that nowhere along in my medical training did I get education about the patterns that occur naturally at the end of life.

As a matter of fact, and this is kind of funny and sad, of all seven years of medical training that I had the only thing I clearly remember about being taught how to have conversations about death and dying was this: to use the word "dead"; so if my patient dies and I couldn't save them that I should use the word dead with the family so that there's no question that a death occurred. Not to use euphemisms like passing or this or that; so out of seven years that's all I was taught about how to educate or have conversations with people. That's a problem don't you think?

Interviewer: Yeah. Absolutely. A couple of years ago my own mom died and I took care of her as she was dying, and I wrote about it in my newsletter. Two months later I got a phone call from a woman gynecologist, a physician in Boston, who called me up and said I read your newsletter, my mom is now dying in hospice and I don't

know anything about it. I don't know what to expect, I don't know what will happen, and she said I'm too embarrassed to ask the hospice nurses to explain to me what's going on. Would you talk to me? Would you just tell me? That's when I realized we're in trouble, we're in trouble when we...

Interviewee: We are.

Interviewer: We don't even know enough as doctors to take care of our own loved ones; we don't know enough about death and dying to be there for our own loved ones.

Interviewee: Yes, I know. I think it's crazy, but the bottom line is that historically we've become removed from the natural cycles of life and death. So 100 years ago the vast majority of Americans lived on farms, and so if you live on a farm and you have animals you see the cycle of life. So we live on a little farm and my children have seen chickens hatch and chickens die; so they know what it looks like. Now, today only two percent of Americans live on farms and even our animals die in medical institutions – people take their animals to the vet to die. So we've hidden our children and middle aged Americans from the process, and that's why people don't know what it looks like. But I have farming roots so when I am discussing with my lay population and giving lectures to nonmedical crowds I like to talk about pruning.

I'm from a family of farmers so after the blooms have fallen you prune your plants. At the end of life you can metaphorically say that the body – the physical self is beginning to prune, and you'll see it. The early patterns start with the person who's entering their end of life phase they begin to give away material items they own. My grandmother began to write people's names on pictures on the back of the wall, and she would give away photos or mementos and say you go ahead and take this. So there's awareness for the person themselves; they know that they're getting close to the end of their own lives. So Elizabeth Kubler-Ross, pioneering physician of the hospice movement, said that organically people are prepared in a deep inner way to know that their life is ending, and so they begin to have these natural processes like an animal that we must go through to prepare for this.

It's almost a nesting process for dying. So people began to shed material items and then we began to give away things, and change our daily habits. So we began to give away interest in our usual hobbies. I knew my grandmother was getting near the end of life, because suddenly she had no interest in her flowers and she wasn't

out collecting nuts and her drive to go out and grow things in the garden – she released those things. Then we begin to give up heavy social interaction; even extroverted people start to have a withdrawing from people. We begin to give up physical activity so a once vibrant grandma who's out working in her yard begins to sleep a lot and walk less. We give up our attachment to eating and drinking near the very end, people begin to eat and drink less, and this is normal.

People will stop eating solids and then ultimately prefer just liquids; before they don't want food at all they shed the eating process too. Then when the act of dying phase begins people are shedding the body; that's what it appears to be for me. It seems like it's the opposite of birth. So when I'm with patients who are actively dying in the ER it is almost like birth labor only it's death labor. Breathing is heavy and then it is irregular and then it's shallow, and then there's a change in consciousness and there's changes in skin color and tone and temperature and heart rate. So it's very interesting. We begin shedding from the outside in at the end of life; it's a pruning process. We're giving up the physical life, and so that's the metaphor I use most commonly to help people see that there's a pattern, and that ultimately we give away the body. So how do you describe it, Karen?

Interviewer:

I love that. Somewhat similarly in that I do see – I see aspects of the personality as falling away, and in a sense dissolving almost. Ego concerns fall to the way side as the physical body is declining. What I perceived in hospice so many times is that really the soul could shine forth even more beautifully as the physical body began to deteriorate and decline. Just recently I was with a patient, she just died last month, and when I would walk into her room in her home she was literally glowing with such beauty and radiance, and this was a week before she died. I really felt like I was seeing her pure soul.

Her body was fading away, her personality – the personality quirks and flaws were fading away, and I'm just seeing this pure being of beautiful light and love and joy. She said to me all I feel right now is love and gratitude and she said that is all that I am right now. That's what I'm becoming and that's all that I am, and it was incredible to see it just so beautiful. But as you've pointed out we've lost sight of those changes because so often when death happens, it is hidden from our eyes so we don't experience it in day to day life. We don't see someone when they're going through this process and care for them at home.

Interviewee: Right, it is two-fold. We don't know the patterns, we've lost cultural knowledge of the patterns that occur at the end of life, and then the other problem, which we've already spoken about, is our healthcare providers do not identify it for us. I've had so many people after I've had my map of life conversation grab my hand and say thank you, because how would we have known.

Interviewer: Exactly, and when oftentimes families might bring in an elderly loved one who is experiencing some of these changes that are normal on their end of life path think that there's something wrong, and the medical system is all too happy to do a huge workup. Let's do some blood tests, let's do x-rays; we'll try to find out what's wrong. We'll prescribe some drugs, we'll try to make this better instead of recognizing what's really happening and supporting the natural process.

Interviewee: Yes, it's really being unable to see the forest for the trees. I have some funny memories; once when I was a medical student I had a surgeon come into the room to see the patient and he said look the wound is healing nicely. But the nurse said yeah, but have you noticed the patient's dying; can you please tell the family. So in medicine we're not prepared, because physicians are trained in a very narrow and deep model of medicine; it's the biomedical model of medicine so we're really trained to see people as a group of organs and organ systems within an attractive bag of skin, the integumentary system. So that's how we're focused; we're focused on the lab values that the organs function, and we're really not taught to perceive and relate to people as a whole anymore.

Because we're so specialized – every doctor's got his or her own organ. There are very few of us that are generalists who have to see the whole picture. So if we're focused on the lab value we're going to talk about lab values, and that gives false hope to patients and families. Look your renal function is better today, yes doctor but he's no longer walking and he's stopped eating. That's the bigger picture. So it really goes back to education, but when doctors do have an awakening or they've been educated and they know the larger picture it is incumbent upon us to share that knowledge in a loving, gentle way, so we're a medical friend.

Because to not do so, and I have had strong words for my doctor friends, to not share this knowledge if you know it is medical malpractice. We rob people of the opportunity to create closure and meaning at life's end if we don't tell them where they are on that map of life.

Interviewer: Exactly, and I heard a story when I was attending a Death Café from a young woman whose father had recently died in the ICU. She told the group that no one explained to her and her mother that her father was probably going to die. They didn't realize that he would die, and she said she didn't take it seriously enough so she didn't visit him as often as she would have if someone had pointed out to her – yes he's in the ICU, we're doing these extraordinary measures to try to save him. But he is probably headed toward death. No one told her that and she felt so cheated, because when he died it was so unexpected and she said "I would have told him things I needed to say.

I would have sat with him longer. I would have been there. I would have shown him my love." And she was so crushed that she missed that opportunity because no one informed her. Now, I had a chance to tell that story to some ICU physicians who said "how could someone be that naïve; don't they know if your relative is in the ICU that their – it's a life and death situation?" But that's how removed we clinical people can be from lay people, and not even understand that you know that about a patient in the ICU, but their family members don't necessarily have that kind of knowledge or awareness.

Interviewee: That is such a powerful story, and because we're in the know, you're correct, we don't communicate that knowledge. The lay population gets their information from TV, and that's what I tell people. On TV what happens when you're in the intensive care unit – we save your life and you go home by the end of the show, right.

Interviewer: Sure, Dr. House figures it out.

Interviewee: Exactly. Actually there was an emergency physician who did a study in the late '90s and he analyzed TV dramas, illustrated medical events, and found that it's portrayed that 75 percent of the time if a person's in cardiac arrest they are resuscitated, and that 67 percent of those portrayed will wake up and walk back into their normal lives. That is an extreme lie for all comers as an emergency doctor and I focus on CPR. For all comers in hospital or out of hospital cardiac arrest 90 percent of people who are found dead stay dead, and so this is a huge disconnect between what Hollywood's showing us and what happens in real life. So based on Hollywood's standards most people could expect a miracle or that somehow in medicine we have the eternity pill and they're blinded by the sexy technology that we have.

We do have fantastic technology in the house of medicine, but we can't prevent death and dying, but we've – in the ICU in particular or even in the emergency department we can put people on so many machines that it's hard to recognize that everything is artificially supported. So how would one know that death is approaching unless the doctor says so? Because they have this vast hope for recovery and I see it all the time.

Interviewer: I know one thing that was so poignant for me reading the book – your book says that there were times when you tried to explain to the family your loved one is dying do you want us to take these extraordinary measures that are so likely to be futile, and then people would still make the choice, still choose to do everything possible.

Interviewee: That we've come to a time in history, and I think boiled it down to this, and I'm certainly open to other ideas; but I think that we equate technology with love so that if you felt that you really love your mother you're going to give her the best technology that money and insurance can buy. So no one has analyzed this relationship, because what I see is that I can apply enough technology to your body, and I can create a state of unnecessary suffering and I can artificially prolong your dying process, and I can rob you and your family of the opportunity to have a peaceful, graceful dying at home. But is that what any one wants and did that turn out to be love if I did all of that?

I think socially we've got to have a conversation where we disarticulate the notion of love from pushing medical technology. I certainly have seen in those people who out of love chose not to have an artificial nutrition tube placed in their mom or out of love chose not to have their mother with advanced Alzheimer's placed on the ventilator knowing that it would not make her better, there was no hope for full recovery. She wouldn't be who she used to be anyway because she already had advanced Alzheimer's or something of that nature. So I think we need to separate love from our technology, but unconsciously in American society the two are presently connected.

Interviewer: That really fits, because we're a materialistic society and so we view love in terms of physical objects. We view love materialistically in a way so it makes sense that technology is part of that and I'm willing to spend the money, I'm willing to go to any extent to have whatever it takes. That's such a good point that you made. Another thing that I became aware of; as I mentioned my own mom died last year and I was in the position of making the

decision to take her home without treatment so that she could die at home.

But I actually found how hard it was to do in spite of being a hospice physician and I knew – I knew really well the alternatives. But at the moment of making that decision and deciding to forego treatment it was more difficult than I thought it would be to live with myself, to live with all the questions and doubts in my mind like is it okay, is it really the right thing that we're not treating her and I'm taking her home. It was only the fact that she had filled out an advance directive and had the conversation with me and said I want to be at home; I do not want to be in a hospital when I die. I want to be home and I want you to take care of me; that is what I clung to having heard that from her – that's what I clung to give me the strength to make that choice.

Interviewee:

That is such an important part of the puzzle here, because two-thirds – almost two-thirds of people who've had to make a healthcare decision for someone that they love have experienced moderate or severe distress. Even to almost PTSD levels of distress; guilt and fear and love and handwringing for years and years about the rightness and wrongness of their decision. Less than 10 percent of people who make these decisions for someone they love actually felt at peace about it. Those people, the ones who have peace, say it's because I was doing what mom or dad had already expressed to me or already had written, and I was supporting their wishes. So that's why this is so vitally important that we have this conversation in America right now.

Because if there is nothing said and there are no plans made when you roll into the ER my training and all my colleagues training is to give you the full court press. We'll intubate you, put a central line in your neck, we'll do CPR and we'll crack your chest, we'll give you blood and antibiotics and all kinds of medicines, and put you in the ICU just naturally – that's what we do because that's the default pathway. But if you have wishes about how you want to spend your last days and weeks and even years you have to make this very clear, because the system does not automatically support a peaceful dying experience at home.

The system automatically supports you dying in the intensive care unit getting the full court press, and so if you have values and desires that are different from that they've got to be made explicit to everyone. Your children, your surrogate decision makers, all of your doctors, and even one lady said she left her advanced

directive in the mailbox – a copy for the postman. So that everyone would know and there'd be no question.

Interviewer: Cover every base.

Interviewee: Absolutely.

Interviewer: Yeah. One of the things I experienced after taking my mom home is that my older brother came to visit her, and this was in the last week of her life and he took me aside and said what are you doing, mom looks terrible. I said she's dying and he said yeah, shouldn't you take her to the hospital then. Because I realize that's just our mentality, just our why aren't you rushing her – why aren't you calling an ambulance and taking her to the emergency room right now. So I said remember mom said she wanted to die at home; that's why I'm here, that's why I'm staying with her. I'm taking care of her so she can die here at home. He said, okay I hope you know what you're doing, and I realized the pressure that the caregiver can receive from other people who may not necessarily agree with the choice or may not understand it that can be really intense too.

Interviewee: I think it can be very intense, especially if you think about how hard it would be for someone who was not you. What about a lay person? If brother had shown up we'd be going to the ER right; so it is incredible because especially I think that our personalities change when we're both at the end of life and in caring for people at the end of the life we enter more of a receptive state. Because this is unfamiliar unless you've done it before. You only have one set of parents so you're only going to do that one time, and each time is unique and unfamiliar territory for you. So I think because you don't have a lot of experience with it we can feel unsure, and so people's strong opinions can carry great force and sway us.

Just last week I had a gentleman and his wife come in and he had a neurological congenital disorder that was causing him to be weaker and weaker. This was his third visit to the hospital – the emergency department for aspiration in the past probably two months. He said you know I don't even really want to be here, and I said you know we don't have to do these types of invasive treatments. But if you go home and I already see where you are on the map of life and I assured them that we already know that. But I said if you go home this will probably be a life-ending event and I can call in hospice and everyone can be at peace, but we should do what you want to do. They said I think we want to do that, but they had just spoken with their primary care doc, and I called the

doc who expected him to be admitted, and said I think he doesn't want to do this anymore.

Because this is just going to happen over and over again; so the question is where do you draw the line and what does he want for quality of life. So I explained to the doctor the patient wanted hospice so I invited him to come in so we could all get on the same page. He came in and talked the family into being admitted, and so there's that power play, especially if you're a doctor who says I really think you ought to do this. But what we all need to remember is it's not about us, it's about the person having the experience. Our needs as a spouse or a daughter or a healthcare provider are all secondary to the desires and needs of the patient. But the story ended on a good note; two days into the hospital stay the patient was like I'm really done with this doc. I like you and all, but I'm going home.

Interviewer: So hospice took him home. That's fantastic the patient was able to speak for himself.

Interviewee: But I think he was only able to speak for himself, because I told him three times this is your life, this is your decision, it's no one else's and only you know what is best for you and your family. We're going to make recommendations, but you make the choice. I think we have to empower people, and all of the loud voices who show up will make this recommendation or that recommendation really what that's functionally doing is disempowering people. But we must empower people to make their own choices about their version of peace at the end life.

Interviewer: That's one of the beautiful things I see about your book, *It's Okay to Die*, is that it's not only full of stories to inform people this is what can happen if you don't prepare and what can happen if you do prepare, but it also includes action steps for people to take, and you really walk people through the process of how do you make these decisions, and what do you do when you've made the decision. How do you put them into effect and make them legally sound.

Interviewee: Yeah. At some point first of all I felt compelled to appeal to those right brain and left brain folks. Some people only want to hear stories and that's the way they learn, and then other people need a checklist. I'm a little of both and so I felt that you can't have one without the other for complete understanding here. Certainly, I've had people who've shown up who have family stories that gave them strong opinions about what they would want or not want for

themselves, but really in this day and age if you don't have it written in an actionable document, and if it's not well-known among your healthcare providers, and your family's not heard it from you it's not very likely you're going to get what you want for the end of life. So it is so important that we fill out these documents; advanced directives, living wills, five wishes.

If you've come to the point in your life where you are experiencing advanced frailty from age or you're living with a chronic or terminal illness, and you've made the decision that there are certain types of medical therapies that you do not want there are physician order sets that will be signed by a doctor that reflect your wishes so that the entire medical system is required to obey your wishes without question. In many states this is called a POST: physician order for life sustaining treatment. There are other acronyms used in different states, but essentially it takes your desires; whether you want a feeding tube or not or you would take a trial of a feeding tube. Whether you would want to be on a breathing machine or just a mask or whether you wouldn't want anything like that. Whatever your wants are and desires for yourself the doctors can then sign it, and wherever you are, at home, a skilled nursing facility, in the hospital, if you're picked up by paramedics this document can be obeyed.

So I think we've entered an era where you can get your wishes clearly documented and known in an unequivocal manner. Because certainly in the last 15 years I think there's been a lot of muddy waters about what is a living will, does this apply to this moment in time. Most living wills say things like if I am in a vegetative state or if I'm unconscious with a terminal illness; those are two very specific scenarios. But there are a whole lot of scenarios upstream from that where people may or may not want certain things. So these new generation directives such as the POST allow people to get very clear in the here and now about what they would want or not want. This is so vitally important just for reasons that you just discussed with your other so that we can focus on what the patient wants, and the family can be relieved of this tremendous decision burden that gets shifted over onto their shoulders if there is no idea of what the loved one wants.

Interviewer:

So you walk people through how to create their own advance directive and really how to think about the options and the alternatives that might be available. It's very logical in a step by step approach, but I noticed you also have resources for surrogate decision makers who might be in the position of having to make a

choice for a loved one when they themselves are not totally sure what the loved one would want. I think that's really valuable too.

Interviewee:

That is very important and I actually created a tool with one of my colleagues, Dr. Damon Fierro, because we saw that there's a huge gap in how to lead a surrogate decision maker along a pathway that would make the best decision for the person they love. Typically, in medicine we try to do something called substituted judgment; that's where the doctor or healthcare provider ask the surrogate to make a decision for the loved one that the loved one would have made for themselves. But here's the problem with that just very abstractly. The minute I say something like, Karen your mom has end-stage dementia and I know she hasn't discussed with you what she wants or doesn't want. But here she is, she has respiratory failure and so I need you to imagine what she would want or not want.

That's great, that's a fantastic ideal, but the minute you're placed in that decision making role all kinds of emotions get tangled up in front of you; guilt and fear and love, and they're so intense that they blind you. You can't see beyond yourself and your own emotions to be able to see over there to mom, to what mom would want or not want. So Dr. Fierro and I created a tool to help walk people through this, and so let's just walk through it now if you don't mind. This is how it works. So let's imagine you and I and all of our listeners are making a healthcare decision for their mom and their mom has never expressed what they would want or not want, and so it feels like a great burden to you. So we're going to imagine that your mom is going to make the decision, not you, and this is how. The four R's'; the first R is to reflect.

So reflecting things back about mom before she became ill, the woman she used to be, maybe even the woman who raised you; focus on who she was. The second R is reconstruct her preferences. So did mom like soup or chili, who was her favorite sports team, was she a democrat or a republican or an independent or didn't care at all; what were her favorite hobbies. So think about these particular things that your mom liked and didn't like. The third R is to reconstruct mom's values. Was she a spiritual person, did she have religious beliefs, had she ever seen anyone in this situation before and what did she think. What were her strong views on life and death? What were her strong opinions about big picture issues in the world? So please notice that you've actually forgotten about yourself and you're thinking about mom. So the fourth R is that in that moment you review the medical options and

decide, but you literally imagine that mom in her former state that you just thought about is standing here alongside you.

She sees herself here in the hospital bed, she hears what the doctor is offering so now the real question is what would mom want us to do or not do next. So I think this is a clarifying way to bring people to a place where they can make a more appropriate decision for someone that they love, which are the beliefs and values of that person, and they go a long way toward minimizing the decision regret that so many surrogates are plagued with in the months and days and weeks and even years to come. So to the extent that we can help surrogate decision makers and relieve them, and magnify or increase the opportunity to create a decision that's really aligned with the patient's values that's what we should be trying to do in medicine. So that's called Fierro's Four, and it's available as a free download on our website on the resource page to be used and reproduced freely.

Interviewer: That's just a fantastic model, and as you were talking before about our tendency to equate technology with love I think this process of going through the four steps is really a great way to get to the heart – to get to the heart and to really understand what a loving act or a loving gesture is, and remove people from the technology so that they can focus in on this is my mom, I love her and she's loved me my whole life, and this is the person that she has been who I really love. Forget about the shiny technology that's out there, focus only on her and what would she like to have next. I think that's a great solution for removing us a little bit from the influence of technology as the magical cure that's available.

Interviewee: Thank you and yes that is absolutely the goal is to give a little balance to this overwhelming cultural feel that technology will save us from all things. So we have to balance the technology with the heart, and any tools that will help us to do that and move that along in 2014 and all the years to come is very important.

Interviewer: Absolutely. Then it occurs to me I want to have this conversation too that at the same time as we're helping to educate and empower the public and lay people to make these choices and put them in writing in advance. The question comes to me how can we help our colleagues? How can we help the medical system and other physicians recognize as your books says that it's okay to die? How do we help move the medical system more in that direction? Do you have any thoughts about that?

Interviewee: I think you have to be brave first of all and be willing to openly talk about what you know. I know a physician in upstate New York, she has a fantastic quote. She says, “All it really takes is one physician champion and a receptive system administrator to change a system, to change the region. To change the mindset of a group of people.” So if you and I are able to ignite other physicians or to make them aware of this, and it resonates with them, and they’re willing to open their mouths and speak that’s where it all starts. So when I’m traveling the nation I tend to give grand rounds or speak to groups of healthcare providers, and my action call at the end of my lecture is essentially this; you already knew everything I said today.

I’m just here to remind you, and ultimately our thoughts and beliefs create the systems in which we live, and the system in which we will die, and the system in which our children will die. So it’s so important that you and I create a system that is good, that sets people up for a good death, because that’s the best that we can hope for at the end of life, and we have to be involved. Physicians hold a priestly role in society. There’s very little that happens or does not happen in medicine unless a physician says it or writes it. So it is our job to take this mantle back upon us, and to educate our colleagues and our patients, because everyone deserves a peaceful and honorable end of life experience. So what I’m trying to ask my doctor colleagues is to join with me in doing something they already really know in their hearts.

I’m trying to wake up that part of them, because it is our job, our duty, our role, it’s our honor to take care of people in this very important phase of living, and we can’t ignore it. To ignore it is to ultimately ignore it for ourselves, and if you can make it personal I feel like that’s when you’re able to change minds – minds and hearts. Winning minds and hearts should be our goal. There’s plenty of objective evidence and studies that say that hospice and palliative care provide the best end of life experience. That’s fine; no one believes they’re a statistic, however, and it’s personal stories like what you and I have – you with your mother, me with my grandmother where we say we’re doctors and this is hard for us, and we’ve got to do better.

Because that peer to peer conversation carries great power, and I do feel that if we are able to awaken a grassroots movement so that people start asking their doctors to help them create a peaceful end of life experience the doctor’s going to feel more open and comfortable in approaching that. Whether or not that physician has a lot of knowledge or education or background with it to begin

with. What I tell my lay populations is if you have a doctor who will not or cannot support you in your end of life goals to die at home in peace or what have you, then you need to fire that doctor and find another one who will.

Interviewer: Exactly.

Interviewee: So if we can create a reverse pressure that's going to help pull the physician population along with this movement. Because, ultimately, docs really want to make their patients happy and we went into this to serve other people. So we're just giving people what we think they want right now, because on TV you see that you want to go to the intensive care unit and get all these shiny tools used on you, and then you'll wake up and go back into your normal lives. But when people begin to know the reality of it and the truth becomes obvious or enough people – a critical mass of people have witnessed someone dying at home under hospice conditions and how sacred and peaceful and holy that was they'll be able to tell their doctor I want the same thing for my mom or I want the same thing for myself. So there's got to be a tipping point in society where there's enough interest in educating the population from the care providers perspective, and being willing to ask for it from the lay population. I think that's the beginning of changing the medical paradigm.

Interviewer: So part of what you and I are involved in really is empowering the masses, we're helping to feed the grassroots movements of people who are becoming educated and demanding a different process at the end of life, which will apply some pressure on physicians. Then I think also we will be there for our colleagues, because what I've become aware of as a baby boomer is that all of us ultimately will lose our own parents. I think that experience alone will wake a lot of doctors up to the end of life and to suddenly paying attention to wait a second what are we doing here. When their own parents are in – just as you said it becomes personal and their parents are in the same situation. Suddenly they're going to have to rethink how they've looked at the end of life.

Interviewee: Absolutely. I had the great privilege when I was first writing the book, and I'm going to say this is a privilege to have my grandmother die so that I could see what a good death was. Up until that moment I can't tell you that I ever really saw death as good or have not had the experience where I thought death was holy or sacred; even as a provider I had not had that experience. So I was working on Chapter 10 in the book, which is the Natural Stages that Occur at the End of Life, and finished the chapter that

day and a light bulb went off in my head and I thought you know what my very own grandmother's at the end of life. She fits this pattern. So almost miraculously I called her up and said, Granny, I'm coming to see you and we're going to do a living will. She said, that's a good idea; so I drove to her house and she had an event before I got there and when I got there she was very sick and she reached out her hand to me and she said Monica I don't want to go back to the hospital. If the Lord's ready for me I'm ready to go.

I was so shocked because I was coming to have this discussion, not to have these things, these events unfold before my eyes. I wasn't prepared, I had not prepared her, I had not prepared my family, I was failing my own family. So I said Granny I just realized today where you are in the map of life, and I haven't called in hospice and now you're acutely ill, and so if it was just about me and you I wish I could keep you here, but let us go to the hospital and I'll bring you back home and get things organized. She said okay, but over the next 16 hours she died, she died in the hospital and I was with her and other family members were with us, and it was one of the most beautiful and painful experiences of my life. It was sacred and it was holy, and at one point the nurse came into the room and he said thank you so much for letting her go like this. He said I have never seen anything like it. I felt so non-physician.

I didn't feel like a doctor; I said I haven't seen anything like this before either and I think this is the way it's supposed to be. It was just so shocking for me that this was just so normal and incredibly important, and I had not ever experienced as such until that day. That was one of the big turning points in my career feeling like I had professional experience, which is one thing, but then I had personal experience and I suddenly knew how it should be and how it could be and how the system needed to change to support that. I'm so grateful if there's some choice involved in dying and I'm so grateful that my grandmother chose to die with me present, and to have us have that type of experience, because it taught me lessons that I could never repay her for.

Lessons that I hope will change other doctors in the system to help support this kind of thing. It was just phenomenal, and I totally agree with you, Karen. I think that's where the baby boomer doctor generation is heading; they're heading to these same kind of experiences for themselves. Then the critical mass will occur and we can begin to change the larger pattern so that the whole system is set up to help you find a good end of life and peaceful end of life and dying experience. So that's my hope.

Interviewer: Yes, absolutely. Thank you for sharing that beautiful story and I read about that in the book along with your eulogy that you wrote for your grandmother, which was beautiful as well. Thank you – I know that it makes you vulnerable to share such a personal story of loss and I really appreciate that, because that is what speaks to the heart of so many people to actually hear you tell your own story.

Interviewee: I think it's very important. – when I first started publicly speaking about all this the doctor's tendency is to just talk about population and statistics and studies. But, again, we also feel like that doesn't apply to us. No one feels like they're a statistic, and what really matters is personal experiences, it's when we see another person go through something that we thought we could never go through, and they go through it with grace that we go I could probably do that as well. So I just want other doctors to know that it is safe and fine to have these kind of conversations, and there are lots of personal experiences that physicians have that they're not willing to speak publicly about because we feel like we should keep our doctor hat on.

But there comes a time in practice where you've got to take that hat off and you've just got to be a friend, and you've got to tell people if this was me this is what I would do or not do. Or with my patients I say my grandmother died in my arms and let me tell you what it looked like. Or I have seen this, I have seen that, I have seen this good and that bad, and I think they long to hear our stories, and they long to hear our personal opinion. Because, again, we still hold this priestly role in society. We have great sway with our patients and we need to see them as individuals and not a statistic. So we need to share with them our personal stories because this makes a huge difference in the choices that they're going to make. Hopefully, ultimately, again with the same motivation that physicians have to give people a good life we need to give them a good death, and we need to be focused on that.

Interviewer: Absolutely. We need to help patients prepare for that good death by recognizing your – I love your term the map of life and having a view of the entire map of life and recognizing where they are on that map so that they can be more fully prepared and more ready for the changes that are coming.

Interviewee: Absolutely. It should be expected, and it's got to be so much better than the way things are set up presently. Because I never ceased to be amazed that, again, once or twice or three times a week I have a 90 year old great grandma in the emergency

department who's been put in rehab for the second time because she's not walking, and the family's trying to force her to eat, and talking about feeding tubes and artificial nutrition and hydration. Someone's got to be willing to say maybe this is not the best for her; we cannot – this doesn't fit where she is on map of life. These therapies don't work when we're here. So the real question what are we doing and what does she want. What would she have wanted, and how can we make this peaceful for everyone involved.

Interviewer:

That's just – it's just so beautiful, I'm so – I'm sitting here just so amazed to hear an emergency room physician saying these things, because I'm so grateful that you're doing this work. Because honestly, every hospice physician in the country could stand up and try to say these things, but it doesn't have the impact it does when you say it, because of the field in which you work, and because of these encounters that you have every single day in the emergency room. So I'm just so grateful for you Monica for being there and having the courage and passion to stand up and bring this message forward.

Interviewee:

It's an honor to be here and it just happened five years ago I had a moral crisis. This all really started with a couple of patients who really changed my mind and made me question what we're doing in emergency medicine. We're aggressive, acute care practitioners and that's what we're trained to do, and we act - resuscitation is the second main word in our vocabulary. One of the first patients who made me question what we were doing in emergency medicine, in all of medicine, and even culturally – I'd like to share this story with you. It was in the middle of the night and this 90 year old patient was being brought in by ambulance, and the paramedics called ahead and said this little lady's coming from a skilled nursing facility, and she's in shock and she's unresponsive.

So I said put her in my shock and trauma room and I'll meet you in there so I came in to meet the paramedics and this little great grandma was just a sad little thing. She weighed 70 pounds and was in contractures; she had not moved or spoken of her own accord in about two years. She had multi-infarct dementia and she had a feeding tube, and she was covered in bed sores. She was septic from that, meaning she had a bacterial infection in her bloodstream. Her pressure was in the 60s, she was unresponsive, and she had shallow respirations, and clearly it looked like she had been dying for many years. We have just artificially kept her alive. So I was digging through her papers to figure out what her advance directive was, and I found it finally on the bottom of all these 50 pages and it said full code.

Interviewer: Wow.

Interviewee: Exactly. So that what you just expressed that feeling is the first time I ever consciously felt that before, and I felt nauseous and I felt heavy, and sick, and uncomfortable, and I let out a little uncomfortable sigh I remember that. As I turned to go over to start taking care of this little lady my nurse said Dr. Murphy she's lost a pulse, and so I ran over to the bed and I felt her femoral pulse and there was not one. She had stopped breathing, and I said she's full code let's start CPR. I was standing at her chest and I said call in the team and I'm going to start chest compressions. So I put my hand on this little frail lady's chest and I stood over and I did my first chest compression and every rib in her chest broke – the ribs just said snap, crackle, pop. Every chest compression I did they just crunched and munched and it was awful, and at some point we were hooking her up I just – I was in the middle of crisis and I looked over to my nurse and I said what are we doing.

This is wrong. Someone should be holding this little woman's hand saying thank you, I love you and good-bye. How do we even get to the point as a nation where we think this is the right thing to do for her? How did her family get here? How did she end up in the state of unnecessary suffering to begin with? I just felt shattered, I felt – I just couldn't even understand how I had gotten to that moment, and I continued CPR, and we did not veer from ACLS protocol, and I coded her and she died anyway. Only there was a big cavern in her chest and there was not even a single thing that resembled dignity about this dying, and that was the beginning of my change. This little lady just rocked my world, and I remember coming home telling my husband I did something terrible tonight. Because his normal question is how many lives did you save; that's what an ER doc does. But I came home and I said I did something terrible and awful and it was wrong. So those kind of stories and those patient experiences began to build up to the point that he said you're going to have to write a book, because I can't listen to this anymore. So it's – I'm here because of those people; those people are why I'm here. I want to give Americans a different chance. There's a better way and I think we can all do better and we need to be talking about this. It's a significant and vital conversation in America. Almost 90 percent of Americans say they want to take their last breaths in their very own homes held in the arms of those who love them the most. But the real stats are almost 74 percent of us die in medical institutions and way too many people end up like that little lady, and I don't think that's what people want.

Interviewer: I feel such gratitude for the patients like her who's suffering have really led to the awakening of some of us. We've been taught what we know through the patients that we've cared for, and I'm so grateful for those people whose lives really represented a major transformation for those of us who can now go out and make a difference for other people.

Interviewee: Absolutely. I have deep, deep, deep gratitude to these patients, and the families who've taught me so much. Really I know everything I know now because I am truly willing to listen to the patients and the family, and if someone is truly willing to listen they'll tell you what they want and it's our job to support that.

Interviewer: So true. That's just so touching. Again, I come back to being grateful for you Monica, because you were able to recognize, you were able to see what you needed to see through that story. You were willing to change, and willing to open – expand your mind on how you saw things and how you do things in practice. So I'm really grateful that you were called to do this work and to spread the message.

Interviewee: Thank you so much. I think that many physicians have probably had an event like that, but maybe they were afraid to allow it to change them. So what I'm telling my doctor friends is you've had experiences just like that and these are opportunities for us to think about doing things different; that there's a better way. So not to be afraid and not to suppress the memory of those types of things. Instead, deeply engage these patient encounters and ask yourself what about this can help me to change the system and what I do for the better. How could we make this better?

Interviewer: That's perfect, because I think you're right. Every doctor probably has had an experience like that and many times those painful memories just get locked away somewhere and repressed inside when we should be analyzing them, and should be utilizing them to grow and transform how we work and practice.

Interviewee: I actually think that would solve a lot of physician burnout, I think a component of physician burnout in this nation is that we ignore and repress and do not work through a whole lot of this emotional baggage that gets created by caring for people in extreme states of suffering. So instead of ignoring them if we can enter deeply into that and ask what gift is here for me I think it would heal us as well.

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- Interviewer:* Absolutely. That's just – it's just such a powerful conversation. I feel like we could go on talking for hours, but our time is running out and I guess this is a good place to end.
- Interviewee:* Probably relieve our listeners.
- Interviewer:* It's a good place to end though with – I guess with the hopefulness that you know ultimately life and death provide each of us with lessons we need to learn from – for us to learn what we need to grow in life, including physicians. So if we embrace all those lessons, the painful ones included and how they come to us, we will be able to see where we need to go next. We will know what changes we need to make.
- Interviewee:* I think so; I totally agree, Karen. Thank you so much for having me. This has just been fantastic and I want to support you in your ongoing work. I'm going to spread the word about you. This is just such a vital conversation and thank you so much for stepping forward to support it for Americans and even the world.
- Interviewer:* Thank you, Monica. I feel the same way about your work and I want to remind listeners everyone should get your book *It's Okay to Die*, because it's a fantastic resource. Not only – it's very inspirational, but just to have it as a resource for other people to share when someone's going through the decision making process about the end of life, and also visit your website because you have more resources there that can be downloaded and that's oktodie.com, is that correct?
- Interviewee:* That's correct; oktodie.com. It's a fairly easy – so I have a blog there. Feel free to sign up. I essentially a couple of times a month put stories that patients have taught me, of course, protecting their identity, but the patient experience is to teach us all what we should be doing and not doing and calls us to ask questions about our pathways. So if you're interested in reading please sign up.
- Interviewer:* Fantastic. So everyone listening buy the book, go to the website. Can they buy the book on the website?
- Interviewee:* They can buy the book on the website as well as it's available on Amazon.
- Interviewer:* Okay. So *It's OK to Die* by Monica Williams-Murphy, M.D. and your husband was a co-author with you, which is wonderful. So Monica I can't thank you enough for taking time out of your busy life and to just sit down and have this conversation with me. It's

been really wonderful. For all the listeners thank you for tuning in and I hope you have found this to be a valuable conversation. So take care and good-bye.

Interviewee: Thank you and the honor was all mine.

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