

Taking Control and Managing End-of-Life Issues

Debra K. Thaler-DeMers, BSN, RN, OCN, PRN-c

TRACY PLEVA HILL: Hi, I'm Tracy Pleva Hill. I'm a Young Survival [Coalition] member, and I'm going to moderate this morning's session. I want to remind you that after the session and after everybody goes home from the conference, you can always get more resources from all of the websites at youngsurvival.org [<http://www.youngsurvival.org/>], lbbc.org [<http://lbbc.org/>] and [komen.org](http://cms.komen.org/komen/index.htm) [<http://cms.komen.org/komen/index.htm>] as well. This session is "Taking Control and Managing End-of-Life Issues," so make sure everybody is in the right room.

Let me introduce our speaker, Debra Thaler-DeMers. She is a clinical staff nurse, chemotherapy educator and end-of-life nursing education curriculum trainer at the Peterson Cancer Treatment Center at Stanford Hospital and Clinics in California. She is the founder of Cancer Access advocacy counseling, clinical education and survivorship skills. Ms. Thaler-DeMers has written and lectured on the impact of managed care in the oncology setting, long-term and late-term effects of treatment, the psychosocial impact of cancer on the family, fertility and sexuality after treatment, pain management and end-of-life care, assertiveness training and communication skills. She is one of the core team members of the Cancer Survival Toolbox, the National Coalition for Cancer Survivorship, the Oncology Nursing Society and the Association of Oncology Social Work. Ms. Thaler-DeMers is a 26-year survivor of three primary cancers. (Applause)

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Thank you. You should all have gotten one of these when you came in. This is the brand-

new edition of the Cancer Survival Toolbox [<http://www.canceradvocacy.org/toolbox/>]. You are the first people to ever have a copy of it. (Cheering) They told me there were 65 people registered for this workshop, so there are extras in the back. Please take some home for your support groups. It is a bunch of CDs that teach you how to deal with the cancer journey from beginning to end, and the two newest modules deal with the first five weeks after diagnosis and the end of life – preparation for the end of life and making sure that it's done the way you want it. There is also a resource book inside. This is the first joint venture that has ever been done, and I think the only one that has ever been done among survivors, oncology nurses and oncology social workers. We're very proud of it. It has won several awards.

You also should have picked up on the way in a piece of paper. Hopefully you all have a pen or something to write with, because you have an assignment during this class. (Laughs) This is a quote that I like: "Your life is measured not by the number of breaths you take but by the number of moments that take your breath away." This is my niece or nephew – I can't tell because it's only a headshot – who will be born in three weeks. While you're listening to me talk, I want you to think about, when you hear "end of life," what do you think about?

I want you to write a letter. Don't put your name on the paper. You know that talking about death is very difficult, and it's the typical elephant in the room that no one wants to talk about. So you start your letter with the words, "Dear Death." You write anything you want. It can be poetry. It can be just notes. It can be whatever. But I want it to be a letter from you to death. I am going to ask you to

hand them in at the end. It's part of a project that I'm doing. I ask all of my nurses to do this, too, when I teach the end-of-life nursing education curriculum. It's a way for you to vent and for nobody to ever find out about it, and it's a way for me to compare what nurses feel about death and what survivors feel about death and if there is a difference between the two – people who are walking the walk versus people who are walking alongside them.

I'm going to keep talking while you work on that. Your healthcare team is there to help you, but often your healthcare team does not bring up difficult issues. The other topic I talk about a lot is sexuality and intimacy, which is the workshop that was held in this room before me. They don't bring up sex, either. They don't bring up sex. And they don't bring up death until the very end.

Most people who are referred to hospice are referred in the last two weeks of their life. So the average stay on hospice is about eight days, whereas the average stay on hospice should be about six months. I just got a call this week from the local hospice telling me that they had kicked one of my patients out because they had lived too long on hospice and that we should re-refer this person when they got sicker.

Think about our relationship with our physicians, our nurses, our social workers, people who are on our healthcare team. How is that going to change? For a lot of people, they're afraid that they're going to be abandoned, that they're going to be turned over to somebody new and they're never going to hear from their primary care team again. This may be true. It may change so that the hospice physician is the one who is going to be

writing orders for you and not your prior primary care physician, but your hospice nurse will be the one who coordinates that care. That nurse, whether it be male or female – I’m going to use “she,” and I’m going to mean that to be all-inclusive – that nurse can coordinate between the primary care physician and the hospice physician so that your oncologist can remain actively involved if they choose to do so.

But you want to engage what’s called a palliative care team. This is an interdisciplinary team that specializes in symptom management. When you come to the end of life, where the focus is no longer on curing you, but on the quality of your life and the quality of your living day to day, you want a team that knows how to manage symptoms, how to take care of pain, how to take care of constipation. Because when you control pain, there is always going to be constipation when you use opioids. I’m a pain resource nurse, and when I took the training, one of the teachers got up there and said, “The hand that writes the scripts for opioids without writing a script for a bowel program, that’s the hand that’s going to disimpact the patient.” (Laughter)

WOMAN: I wish that were.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yeah, I wish that were, too. So this is a little about my story. I was diagnosed at the age of 25. I’m part of the largest family cluster of Hodgkin’s disease in the United States. I grew up along the Passaic River in New Jersey, and four members of my family had Hodgkin’s disease. Of the four, I’m the only one still living. My experiences going through the journey – mostly with my younger sister, who I took care of through three years of chemotherapy

and then a bone marrow transplant – before I was a nurse changed me forever. It made me politically active. It made me become an advocate. It made me get involved with the National Coalition for Cancer Survivorship. I’m kind of pushy when I get angry, so I’ve done everything, including testify before the President’s Cancer Panel on long-term survivorship and the needs of cancer survivors.

I also was invited to Texas when George Bush was governor and he was going to start having Medi-Cal managed care for people who were on what’s called Medicaid in Texas. These are poor people who don’t have insurance, who rely on the government to provide care for them, and he wanted me to talk about what the minimum standard of care should be for people diagnosed with cancer.

It was very nice. I flew into Austin, and I was picked up in a very nice limo and taken out to this very nice country club place where we were staying. It was a legislative retreat, so there were legislators from all around – not just Texas, but the southern part of the United States. I gave a talk, and I was on a panel, I remember, with a guy who had flown in from the Netherlands to be part of this panel. After I gave my talk, all of the legislators were very impressed, and they wanted copies of my talk. That evening, the people on the panel were supposed to have dinner with then-Governor Bush. I think he didn’t like my talk, because he canceled the dinner. So my joke is that the president still owes me a dinner from way back when he was governor. (Laughter)

When I was diagnosed the third time, I decided that I was to have fun with my diagnosis, and I was working at Stanford at that time. The top picture

shows some of the people I work with on the cancer unit. I decided to have a hair donation potluck party. There is everybody making 12-inch ponytails out of my hair. You had to cut off the ponytails and send them in so that they could be made into wigs for children who had alopecia for various reasons. Then I had one of the nursing assistants shave off the rest of my hair, so that was my debut as a bald woman. Then my oncologist decided to go on vacation the week before my chemo started, so I decided to get a tattoo. This is my chemo angel, and it’s on my shoulder.

I’m not the kind of person who anyone would normally think would get a tattoo, but my kids actually went with me. They couldn’t believe I was actually doing it. You’re not allowed to be drunk while you get your tattoo. You have to be sober, no drugs on board, and you have to sign that you’re doing that. (Laughter) They didn’t say anything about topical anesthetic, though, so I got a little tube of topical anesthetic and used that, but it really didn’t help. (Laughter) But I wanted the angel really badly, and when my oncologist came back, I decided it was easier to ask for forgiveness than permission. He looked at me, and he went and looked at my back again, and he looked at me and said, “Was that there before I went on vacation?” I said, “No, and it’s staying.”

The next thing that I got ready was bank accounts. I don’t know if you know this, but when someone dies, whether or not another person has a durable power of attorney for them, the funds in their individual bank accounts are frozen immediately by the bank. As soon as the bank finds out, you cannot access those funds. You can’t even access them to pay the bills of the person who has died.

In order to get around that, what you need to know is that if there's another person listed on the account as a joint owner with right of survivorship – and that's how you need to fill out the form – the funds will automatically go to that person. The funds do not go through probate. They automatically belong to that person because they have the right of survivorship, so that's another way to avoid estate tax on the money.

That person can then use the bills to maintain your household, pay your bills, pay your funeral expenses – whatever they need to do to keep your family going in the period between your death and when the probate is completed and the funds are available from your account, or from when the life insurance money is paid and funds come in from other sources. It's really important.

Yes? I don't mind taking questions as we go along, I guess – as long as you keep writing your letters.

WOMAN: Good morning. I just had a question. Is this the same kind of deal with a credit union?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yes.

WOMAN: Like, if you're involved in a credit union, the same rules apply?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Any financial institution is required by law to freeze the funds once they find out about the death.

WOMAN: Okay, thank you.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: I knew people were going to be interested in this fact.

WOMAN: Is that even if you're married but he may not be on that checking account?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: No, if you're married, it's a joint account, so the funds will go to the other person whose name is on the account.

WOMAN: But he's not on the account.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Oh, then they will be frozen.

WOMAN: So I have to add him. So I can't have my own money.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Right. They would have to be listed. (Laughter)

WOMAN: I need to do that for all of my accounts.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yes, if you have any individual accounts that are only in your name, the money in that account will be frozen at the time of death. The bank will not let anyone have access to that without a court order, and usually that order comes from the probate courts. Yes?

WOMAN: It can be anyone – your kids, anyone – on the account?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yes, you can name one of your children.

WOMAN: A minor?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Usually not a minor. But I'm not quite sure. I think that depends from state to state, on what the laws are for that state.

WOMAN: What do you mean by "right of survivorship"? As long as they're on the account, they're good.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yes, right of survivorship means that suppose the other person on the account dies first – then you would get the money.

WOMAN: So if both people are ...

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: If both people die at the same time, you're in the same situation as if there was only one name on the account.

WOMAN: Are all joint accounts with right of survivorship now?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Not necessarily. There is a box that you check when you start the account.

WOMAN: What if you have your children on an account with your name? At this point, if you're facing stage IV, would you recommend switching it so your husband's name replaces yours on the children's account? Or is it possible to have more than two names on an account?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: It's possible. You can have as many names as you want on the account. Yeah.

WOMAN: This is totally Tax 101 here. But you mentioned – now this is kind of a different subject. This is a way to also avoid estate taxes, is what you were saying?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: On this particular money, because it's with right of survivorship, that money doesn't exclusively belong to you. It passes to the other person on your death, so it doesn't pass through the estate tax, because it's not a part of the estate.

WOMAN: Awesome. Good to know.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: This is not the ultimate way to avoid estate tax, and I am not an attorney or an accountant. But, for instance, when I was diagnosed this last time with my third primary, my daughter was 18 and I took her aside. She's not the best with money. If she sees it and she wants it, she buys it. I wanted to put her on the account in case I got very sick. I wanted her to be able to pay the bills, but I also didn't want her to dip into the account and buy herself three iPods, that kind of thing. We had to have a long talk about, "This is Mommy's money and not your money," and, "Even though you're on the account, you're on the account so that if I go in the hospital, you're going to be paying the mortgage and the PG&E and all of the other bills that come month to month so that I don't get late notices and I don't ruin my credit rating." We had to have that lesson.

That went pretty well, and, in fact, I did need to use that, because I was in the hospital for a month and a little bit out of my mind. She was away at school, and I had fallen while I was in the hospital, which is why I wear my hair down this way, because I have a dent in my head from falling. I had passed out, and I don't know if I hit the floor or hit the side of the bed or what, but I had a concussion, and I was out of my mind for three days.

She called me on the phone, and I don't remember any of this, but she says I tried to convince her that we had the same parents. (Laughter) The first day, she thought I was kidding, and the second day that I tried to convince her that we had the same mother – and I would not believe that I was her mother – she got on a plane and came home from school. She took care of all the bills while I was loony tunes, and that's how we did it. She had been put as part of my bank account when I was diagnosed.

The other thing I did was to simplify matters for my family. I consolidated all of my accounts into one bank wherever possible, so they wouldn't have to go hunting for all of my accounts. Before that, I had them scattered in different banks, in a credit union, and I put them all in one bank. Then I made a list for them of where all of these things were. Now, this sounds pretty easy, but it's easier to open an account than it is to close an account.

When I went to Wells Fargo to close my safe deposit box, close my savings account and transfer the money to another bank, it took 30 minutes of being shifted from person to person with everybody asking me why I wanted to close the account. Then they would say, "Okay, well, we'll have to refer it to this person." Then they would ask me why I wanted to. ...

Well, I was already uptight about being diagnosed with my third primary and having to make all of these decisions. Usually I'm a very polite person and I don't get rude and I don't raise my voice. I don't yell. But after the fifth person and 40 minutes of this, I was standing at the counter, and all these people were in line at the bank, and I shouted, as loud as I could, "The reason I want to close my bank account is because I'm dying and I'm trying to make things easier for my kids." They went, "Okay, we'll be right back with your money." (Laughter) They were going to charge me 20 bucks for closing the safe deposit box early, but they waived that. (Laughter)

WOMAN: No mercy.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: They couldn't wait to get me out of there.

WOMAN: One tidbit on that, because I do work for our [accounting staff], and it is hard to close them. But if you

transfer, pay out all of the funds down to zero, it's a lot easier to get them to close your account when there's no money in it.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: When there's no money in it? Okay, good to know. Because then you're probably costing them money.

WOMAN: But you don't want to leave it that way, or they'll start trying to charge you dormancy fees.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: She said that it's easier to transfer all of the money out, because when the balance is zero, then the bank doesn't like to have that as the account. But she said do it quickly so they don't charge you a dormancy fee.

WOMAN: Thank you.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: It's a good idea to make a list of all your savings, checking, money market and other accounts. The easiest way to do this is to look at all of the statements that you get, and as they come in, just add it to the list. Keep that in a place where you know that your kids or your husband or whoever is going to take care of matters at the time of your death knows where all of these accounts are and who can access the funds in those accounts.

WOMAN: Passwords.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: And the passwords, yes. Now, if you forget about an account and your family doesn't know about it, you could lose that money. In most states, that money will escheat to the state. In other words, the state gets the money, and they hold it in a special fund for like seven years. If you don't claim it or no one claims it

after seven years, they keep the money and it just goes to pay off whatever the debts of the state are. It's really important to know where your money is. Then, any inactive accounts by law pass to the state government after a certain number of years. And in each state the number of years differs.

Safe deposit boxes: If you have more than one, you may want to move things to one large box so that it's all in one place and then put someone else's name with access to the box and let them know where the key is so that they can get in there and get whatever documents are needed at the time of your death. For example, I prepaid for a plot. It's actually a niche in a memorial garden right next to my church. The deed for that is in the safe deposit box, and the kids know that it's in there, so they won't have to spend money looking to pay for another niche.

WOMAN: One comment on that. You need to make sure their name is on your safe deposit box, because even though they have the key, the bank won't let them in to even view what's in the box. We're going through this with my husband's parents.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Right. Their name has to be on the card as being allowed to get into the box. Then, if your children are still minors, you might want to name someone else you trust as able to access the box and let them know where the key is. Then you want to tell that person what to do with the contents when you die. You may even have those instructions inside the box so that when they open the box, it's the thing that's on top. "If you're opening this box, then it must be time to distribute the contents, and this is what I want done with that."

It's a good place to keep heirloom jewelry, things that have been passed

down in your family. I'm first-generation American, so I have very few things that my parents brought from the old country, as they say. I'm half Transylvanian, and my mother came from Cuba, but she was originally born in the Ukraine. I have very few things that came from there, but they're very important, because they're my link to my past, and I want my children to know that. So you want to instruct people what to do with the contents and the things that you keep in there.

Now I'm going to switch topics a bit. Now I know that I've been diagnosed with my third primary, and I'm trying to figure out how to plan ahead and do what's best for my children. I had always thought that I survived this long; I'm going to survive forever, right? Just keep going one year at a time until I make each milestone. But now comes the time when I'm not sure that I'm going to be there for the kids' prom; I'm not sure that I'm going to be there for their 21st birthday; I'm not sure that I'm going to be there for college graduation or weddings or whatever.

One of the things you can do is write letters to them or make videos for the upcoming special occasions in their lives, to let them know that you wish you could be there and that you really are there in spirit, because they always carry you in their heart, in their memories, and you really are always with them, because love is the one thing that never dies. You can kill the body. You cannot kill the soul, and you can never kill love. That's something you want to emphasize to your children and to your loved ones. Just let them know that you want to be there for them, and write a letter with the things you would have liked to say if you had been there.

This is something you can also keep in your safe deposit box. So nobody

has to know about it until the time they open the box, and then they would pass them on to your children. I really encourage my patients to do this, especially if they have small children at the time of diagnosis. Do it when they're feeling pretty good so the image your kids see is one they remember of you. In the video I made, I took video pictures of my kids at different ages with us, like Easter when they were 2 and 3 years old, and birthday parties. They had a mud party where it wasn't supposed to be a mud party, but they were playing in their little baby pool, and they made mud, and then they smeared it on each other – little fun pictures like that that they can go back and remember the good times by, instead of just remembering how much they're missing you at that time.

WOMAN: Another suggestion is if they're little children, you may want to make a scrapbook with them of Mommy's favorite food, Mommy's favorite flowers or trips you went on together. Scrapbooking is really big. I know we've done that with some of our patients.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yeah, scrapbooking is good, and there is a kit you can get where you can take your kids, if they're very little, and make their handprints, and then you put your handprints so they'll have something to remember always. The other thing is that you can arrange to leave them special gifts to be given on special occasions like birthdays, graduation, weddings, etc. Tell someone you trust, for example, "I want my pearls to be given to my daughter on her graduation from college. That would have been her graduation gift, and it's special, and I want her to be able to wear those to graduation."

Continuing family traditions: One thing

we have in the family is my kids' grandfather hand-carved them a cradle before they were born. They slept in it at the foot of my bed when they were very little, and I want my grandchildren to sleep in that cradle. They know they had better never get rid of that cradle, and that I would like to know they have used it at the time they have children of their own. You can let them know what family traditions you have. You might have a family quilt that Grandma made or something you worked on. I have some needlepoint things in my house, hanging on my wall, that I have made that I wanted passed on from generation to generation – different things like that, to be able to continue your family traditions. I know kids in the next generation are not so big on tradition as I am, but I don't know.

WOMAN: Give them a few things.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yeah. My kids were recently home from college on break, and they went through the house and said, "Why are you keep this? Throw it away. Why are you keeping this? Throw it away." They're throwing everything away. I was like, "Wait, stop," taking it out of the garbage. I was like, "I need to keep that; that reminds me of something." The other thing is, we have a family tradition that every time a child is baptized, we have one baptismal gown, and we cross-stitch the child's name and the date and their baptismal name on it. It has names of everyone in the family. I want them to use it when they have children and their children are baptized. They should be baptized in the same gown and the names added to that. Those are just a couple of family traditions.

Making a will and/or a trust: I highly advise seeing an attorney. Do not use the Internet make-a-will form. Do not use the box form, a family lawyer, to

make your will. Please see an attorney, and find an attorney who specializes in this and does nothing else but this. One way to look is if you see an ad for somebody who is an elder care attorney – those guys are great at hiding money from Medi-Cal, Medicaid, Medicare, everybody. Those are the people I would go to, because they know how to shelter your money from probate.

You want to ask that attorney to also review your durable power of attorney for health care as part of the package price. They'll usually do it for nothing, because they pretty much have it on their computer, and you just pick the paragraphs you want. Does everybody know what a durable power of attorney for health care is? It's where you designate somebody to make healthcare decisions for you if you're not able to make them for yourself. You can rescind it at any time. All you have to do is say, "I rescind my durable power of attorney." That's all you have to do, and that's it. The document is not valid anymore.

It also has provisions where you can check off the box as to what you want done, what your preferences are. Do you want artificial feeding? Do you want a feeding tube? Do you want to be put on a ventilator? If you want to be put on a ventilator, how long do you want to be kept on it? You can go on a ventilator for a trial period and say, "Okay, if I'm having difficulty breathing, you can try putting me on a respirator. Fix the underlying problem if it's an infection, maybe pneumonia, pulmonary edema, whatever the problem is. Then, if you can't get me off after a week and it looks like you're not going to be able to get me off, then I want you to turn it off. I don't want to stay on a ventilator for a long period of time." Tell very specific instructions.

Now, I want to tell you that you can't predict everything that's going to

happen. When my sister had her bone marrow transplant, she was a resident of New Jersey; I was a resident of California. She was having a bone marrow transplant at the Hutch [Fred Hutchinson Cancer Research Center] in Seattle. We went to an attorney. We had a 29-page durable power of attorney for health care. She was very specific about everything she wanted. She talked about it, and we thought we had figured out every possible thing that could go wrong, based on the information we had researched on bone marrow transplants and different ways people could die from the results of a bone marrow transplant. But we always figured she would be awake and able to talk to me as she got sicker and sicker. It turns out she went into a coma for 30 days.

I'm like, "Well, okay, she'll just wake up one of these days and tell me this decision about the ventilator and how long I should keep her on the ventilator." She never did wake up. She actually, I figured out, knew that she was dying. But I didn't figure it out. I was too dumb and too tired. I had been up for two days straight. She asked me in the ICU to get in bed with her. I said, "No, I can't do that." The nurses said, "Oh, yeah, you can. We'll just move all of this equipment out of the way." I got in bed with her, and she started thanking me for coming up to Seattle to take care of her during the bone marrow transplant.

What I realized long after she died was that she was saying goodbye. She knew that this was the end. Had I known that, I would have asked her about the ventilator. But I didn't know that at the time. I did agree to put her on a ventilator to see if that would help. We tried to predict everything, and my point is that we weren't able to predict everything. So think about it, ask your doctors if there are any provisions you should include in your durable power of attorney, any things

that might come up for you based on what your medical condition is and what they think might happen down the road.

I also want to talk to you a little about the high cost of death. The average cost of a funeral – and I think this is a low-ball figure – is \$6,500. This does not include the cost of flowers, obituary notices, limousines to get to the burial place. It doesn't include the cost of a cemetery plot, which can be very, very expensive, the headstone. They charge you for both opening and closing the grave. That is, making the hole in the ground and then closing it up. Some places charge you for the lining that has to go in that hole.

It's a very expensive deal to die in this country. I don't think it costs them that much, but I have noticed that most people who run funeral homes have nice cars and nice houses as well, so it must be very profitable for them. That really bothers me. I don't know if it bothers you. What you need to know is that there is a federal law, and you can comparison-shop for caskets for funeral homes and other services. They are required to tell you over the phone how much their services cost, and to give you an itemization of how much each part of the services costs.

They may give you a package price, and then you can ask them, "Well, if I bought that a la carte, how much would it be for each particular part of the cost?" That's part of the Federal Trade Commission requirements on funerals in this country. They are required to provide an itemized statement to you at the time that you purchase their services, and they cannot charge you extra if you buy your casket elsewhere. For those of you who don't know, Costco sells caskets online. (Audience Reaction/Laughter) And they are cheaper than at the funeral home.

You also need to know that when you go to a funeral home and look for caskets, they will not show you the cheapest ones. They are not on display. You have to ask to see them. They will start you out at the \$5,000 model, and it will be not so nice. It won't have the nice lining and everything. Then they'll show you, "Oh, but you really want this nicer one," which has the polished wood and the handles that are brass and the nice quilting and blankets and stuff inside, and the nice pillow.

I'm thinking, "Oh, my God, I'm going to be dead. What do I care?" I'm not planning to be in that body when they're going to be putting it in the ground. But your family kind of wants the best for you after you're gone, so they will spend that money if you tell them not to. The funeral directors kind of try to guilt them into it. It's like, "Oh, you want the best for your mother," or, "Oh, you want the best for your wife," and blah, blah, blah. They end up spending more than they ever thought they would, and some funerals can cost like \$15,000.

You can buy your casket elsewhere. You can buy them online. You can shop for them online. There are people who can even sell kits for you to make your own, if you're so inclined. Just know that you don't have to spend five- or six-thousand dollars for a casket.

Also, I told you they're required to provide their prices over the phone, but you also are required to be allowed to shop for services from an a la carte menu. They can't only offer package prices. They have to allow you to just pick and choose the things that you want for your funeral service.

WOMAN: Can they still charge you for a casket when you [inaudible] cremation?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: When you what?

WOMAN: Cremation.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Cremation? They charge you for a container. There has to be something that they put the body in that goes into the crematorium, because they can't just put the body in itself. It should be very simple. It can even be like a cardboard box that is incinerated. It should be very cheap. I thought I put it in here, but the average cost of cremation services is about \$2,500, and you can pre-pay for that.

There's one thing they told me that they can't guarantee the price of. You have to pay somebody to come to the hospital or the home and pick up the body and bring it to the funeral parlor or the crematorium. The transportation costs are not fixed because of the rising cost of salaries and gasoline. I think the inflation price on that is not very much, so it wouldn't go up very much. I've watched the prices over the years, and they haven't really increased that much for cremation.

The other thing is that when I bought my niche, I had to buy an urn to put the ashes in. There were three different kinds of urns. There was the plain one, then the little bit fancier and then the most fancy. I said to the guy, "Well, just give me the cheapest one." He said, "Don't you want to see them?" I said, "Well, considering the condition I'm going to be in when I'm using it, no." (Laughter) People ask you absurd questions.

WOMAN: Can I ask about if you were to donate your body to science? Do they want people whose bodies are riddled with cancer?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yes, particularly medical schools. There is a shortage

of bodies being donated to medical schools, and they could learn a lot from people like us.

WOMAN: I never thought I would say this, but both of my parents donated their bodies, and my grandmother donated her body. I thought it was the most morbid thing to even think about. Then I actually, at this point, am seriously considering it.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: From the other side, when I had my gross anatomy class, I will tell you that the bodies are treated with great respect. We all kind of have to psych ourselves up in order to do the autopsy that we're required to do. For me, it was an amazing thing when I figured out how my body had died, the gentleman that I was working on. The things that I learned from working on him – I mean, we started by dissecting a cat and then a pig, and then we worked up to the human body. There's no way a book can teach you what a human body can, and to learn how the body works and how intricately everything is connected and to figure out how this one thing that went wrong could absolutely stop a person completely is an amazing learning experience.

So, if you are so inclined to donate your body to medical school, really, the medical students will thank you a thousand times over. We always thought to ourselves how lucky we were that this person thought about donating to us. Yes?

WOMAN: What would be the cost associated with that? I was under the belief, and I don't know that it's true, that the family would need to pay for transportation of the body to the hospital school where the learning would take place.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: It depends on the

school. Each one is different in how it makes the arrangements. You'd have to contact them in advance and set it up and let your family know that that's what was arranged ahead of time and that's what you really want.

That brings me to a point about durable power of attorney for health care and predetermining all of your conditions. From the medical side, I've had patients who were supposed to be "do not resuscitate, do not intubate," because that's what's on the durable power of attorney for health care. If the family is not prepared ahead of time for what you want and what it's going to look like, if somebody in that family – it doesn't matter who it is – at the bedside turns around and says to the nurse or the doctor, "For God's sake, do something," that invalidates the do-not-resuscitate order right there. (Audience Reaction)

WOMAN: Oh, my God.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Because whoever is living trumps the person's wishes. The reason for that is that our country is very big on malpractice suits. The hospital is justifiably worried that the family is going to say, "You didn't do anything when we asked you to." So we take that as the family changing their minds, and the DNR is lifted, and we then come in and resuscitate the patient. So make sure that you educate your family members that you do not want to be resuscitated, and have somebody prepare them. That's why hospice is so nice, because the staff at hospice will prepare your family.

I'm going to talk about signs and symptoms of death so that you can help educate your family as well as to what it's going to look like when you die. When my sister had her bone marrow transplant, I researched every possible way somebody could die,

because I had never been with anybody who died before, and I was terrified – absolutely terrified. I wanted to be prepared. And I was.

I managed to get it down so that I knew that dying of kidney failure was the best way to go, because the person kind of goes into a euphoric state, and as the toxins build up, they're totally spaced out and feel really good and go into a coma and then just kind of die in their sleep. I thought, "Oh, kidneys fail – that's what I want. I want the kidneys to go before the lungs." But there are different ways that people can die, and it looks different for each person. You had a question?

WOMAN: Oh, a comment. Are some people who are thinking about donating their body to science or the DNR instructions worried that medical people won't try to care for them as well maybe, or maybe they'll let them die a little quicker than they would have if they had different choices? My husband is in the medical field, and several of our family members are as well, and it's really the opposite. Also, like with organ donation, a lot of people feel the fear, being an organ donor, that they will let them die sooner to get their organs. In fact, it's kind of the opposite with organ donation, because they really want to preserve the integrity of the organ in the body.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Absolutely. ... Whenever somebody is a "do not resuscitate, do not intubate," it doesn't mean "do not care." We always provide care, no matter whether that order is in place or not. Yeah?

WOMAN: A question following up on organ donation: Since we've had cancer, do they want our organs?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: No. They can use your corneas, your tissue and your skin – skin for victims of fires, people who need temporary skin grafts until their own skin can grow back. We'll cover that a little later.

WOMAN: Don't you have to get permission, too, if you donate your body to science, for them to remove any organs, even your corneas?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yeah, if you want to do both organ donation and donate your body, then, yes, you have to get permission.

WOMAN: We got permission for my mom's kidneys to be donated before the body ... and they were at least able to do that.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: She asked me if you had to get permission if you're donating your body and you want to also donate organs – get permission from the people who are receiving your body for the organs to be removed. Yes, the two need to be coordinated.

Communication with your family – communication is key in all of this. You need to communicate repeatedly. People under stress only hear about 5 percent of what's told to them. If you remember back to when you received your diagnosis, as soon as you heard the word "cancer," everything else shut off and you didn't hear most of the rest of what was told to you. The same thing happens when you say the words "death" and "dying." Anything to do with death and dying, boom, the brain shuts down. "I don't want to think about that. Please don't talk to me about that." You have to bring it up over and over again.

If you do purchase a pre-paid plan, you need to tell your family about it,

because the funeral director will try to rip them off and get as much money as possible from them and charge them for things that were already included in the plan. This happened when my grandfather died, and I actually went to the district attorney in New York and said, "My mom was charged an extra \$700 even though my grandfather had a pre-paid plan. Here is a copy of the plan. Here is a copy of the bill." They made the funeral director give my mom the money back. She was so impressed with me. (Laughter)

WOMAN: Will they let you pre-pay on credit, or do they expect money, especially if you're dealing with cancer? Is that something that ...

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: It depends on the funeral director. Some of them will take an assignment against your life insurance policy. Some of them want cash or credit card. And they will let you pay it off over time as long as it's paid for by the time you die. This is the way they have you over a barrel. Like, they won't start the funeral until it's paid.

I've gone to many patients' funerals, and when I go to the rosary on the night before the funeral, I'll see the funeral director come and talk to the family. Then I see the family getting really upset, and I go over and say, "What's wrong?" They'll say, "Oh, they want their money before we can start." They're very careful to get their money ahead of time. I hope no one here is married to a funeral director. (Laughter) They're nice people, but they're a business, and you have to realize that they're a business.

WOMAN: And they will [inaudible].

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yeah, and there is

a lot of fraud, particularly when people don't know the contents of the contract. There have been a lot of articles in the newspaper about this. People have actually written books about it – the fraud in the funeral industry. Make sure the price is guaranteed when you purchase a pre-paid plan, so they can't add on things afterward. Then look for somebody who is affiliated with the Funeral Consumers Alliance. That is a group of funeral directors who are pledged to be kind of ethical when dealing with consumers and to try to not rip them off and to give explanations of why it costs what it costs and what they're paying for. It's called the Funeral Consumers Alliance.

Oh, here is my cost for cremation. The cheapest cremation I could find was \$350. It can be in excess of \$2,000, depending on where you live, but that's a ballpark for you to know when you're negotiating about how much it should cost for cremation. Then the ashes can be scattered or placed in a niche or kept with a relative. They don't have to be buried. They can be buried, if you want, in a memorial park, or placed in a niche. Some of them can be very elaborate.

If you ever go to Hollywood, go to the cemetery where Marilyn Monroe is buried. Oh, my God. My cousin is actually buried there. It is the most elaborate thing they have. ... I think Rodney Dangerfield was one of the graves that stood out for me – just very elaborate things that have fountains and all kinds of things. If you have a million dollars, I guess you can have a fancy place like that. But if you don't want to do that, your ashes can be kept in a box at home.

Then, the Neptune Society [<http://www.neptunesociety.com/>] is one of the cheapest places across the country for low-cost cremation services. [The Neptune Society]

provides its services relatively cheaply.

Also, make sure your family is comfortable with your decision to be cremated. This is one that I really had to work on with my kids because they didn't want to think about it. They didn't want to talk about it. I made them talk to me about it, and I made them understand that I did not want to waste money on a big funeral. I considered it to be a waste of money. I wanted to put that money away for their college education, so I felt that cremation was an inexpensive way to go.

But they wanted a place to kind of visit me, so I got the niche in the garden, and it's right in our church, where they belong to the youth group and everything. We have a vineyard that surrounds our church, so I am facing the vineyard, where I have helped to harvest the grapes and send them off to make our wine. So they have a place to visit me, and it isn't costing me a lot of money, so both of our wishes are kind of being met. I explained to my kids that the minute I die, I plan on vacating the body, so you don't have to worry about what's going to happen to the body, because I'm not going to be in there anymore. I'm leaving. I'm going somewhere else. It's something, particularly for children, that they need to understand. Yeah?

WOMAN: [inaudible] but in my case it's with my parents.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Your parents?

WOMAN: Is that something that can be trumped also? Or is that something that ...

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: No.

WOMAN: You talked about the do-not-resuscitate order being trumped. Is this something that if my mom says, "I don't want to cremate her ..."

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Well, who would be your next of kin when you die? Your sister? Then your sister is the designated heir, and if she can stand up to your parents, then they won't trump her. But if your sister melts under your parents' thing, then ...

WOMAN: [Inaudible]

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: She asked me if her parents can trump the decision to be cremated if they don't want it to happen. The answer is that whoever is next of kin makes that decision.

WOMAN: I would have a letter written and notarized from you stating that you do not want them to trump it. It takes some of the pressure off of your sister from standing up and [inaudible].

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Also, if you pre-pay for it and you've set it up that way, it becomes rather obvious that that's exactly what you want done because you've already set it up before you die.

WOMAN: Along those lines, how do you go about addressing with your family what you feel you want your decision to be, yet respecting their potential need for closure, especially when young children are involved?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: I think communication is absolutely the key to everything. If you are having trouble talking to your family about this issue because they don't want to talk about it, they don't want to listen, then I would ask a social worker or a family therapist or your pastor to get involved, but have a neutral third party

there to facilitate the discussion. Pastors are always really great, especially if they know your family members well. Then they know what's going on.

For example, my pastor is the third alternate on my durable power of attorney, because I've spoken to him and he has known my kids all their lives. If they freak out at the last minute about the DNR order, he can calm them down about it and assure them that this is the right way to go and that this is what I want. Having a third party facilitate that discussion is really important. If you're going to go with hospice at the end, which I highly recommend, you have access to that multidisciplinary team.

You have access to a psychologist, chaplain, social worker, nurse – they are very experienced at facilitating this discussion. They can talk to your family members – and talk to them repeatedly, because they know that they're not going to get it the first time – just to help them understand that this is your wish and that we're talking about your death the way you want it and not their death the way they want it or your death the way they want it. Everybody gets to speak up and say what they want for their dying experience. The hospice team's responsibility is to make that happen. They should ask you at the intake interview what you would like for your experience.

Sometimes when I have a patient in the hospital who had planned to die at home, but their pain is not under control so they come into the hospital to die, and I can see that the family is really upset at the way things are going, I'll say, "How did you guys envision this death would happen if you were at home?" A lot of times a husband or a wife will say to me, "We kind of envisioned that we would be cuddling in bed, and I would hold my

spouse in my arms until they stopped breathing." I say, "Okay, help me move the person over in the bed. It's a single bed; I know." But then I put them together in the bed cuddling.

I give them the call light, and I say, "I'm going to give you privacy. You call me if you need anything. I'll be here immediately with anything you need. But this is your private time together, and you share it the way you envisioned at home. Just kind of pretend that you're at home." I also encourage them to bring in pictures and put them up on the wall – they can decorate the room any way they want. And to bring music. Music is a great thing at the end of life. It's very soothing for people. It brings back a lot of memories. It's important to have those things around and to make the dying experience the way you envisioned it so it will be a peaceful experience.

Donation of organs or tissue – we kind of talked about this, but you are eligible to donate some organs, most notably the corneas. If you have a systemic disease or metastatic disease, they probably will not want any other organs. Tissue is good. They like to take tissue and skin; it's really good for burn victims. Make sure you've talked with your loved ones about this so that everybody is comfortable. Organ donation is another thing that can't take place if the next of kin doesn't agree, even if you have signed an organ donation card. They will ask the family's consent. If the family does not give consent, even if you've prearranged it, they can't take the organs, the tissue, the skin or the body.

There is a website called Five Wishes [<http://www.agingwithdignity.org/5wishes.html>], and these are the five wishes they ask you to think about and to write down for your family members so they know what you want.

Who is the person you want to make care decisions for you when you can't make them for yourself anymore? Always have an alternate in case that person doesn't want to do it, or they're afraid to do it. Let that person know that they've been designated. It shouldn't come as a surprise to them when the situation arises.

Also, the kind of medical treatment you want or don't want – do you want to be on a ventilator? Do you want to be resuscitated? I don't know if any of you know, but the resuscitation you see on TV is not the way resuscitation happens. On television, almost everybody they attempt to resuscitate comes back. In fact, less than 10 percent of people they attempt to resuscitate do come back. This is what they teach us in the advanced cardiac life support class. When we feel badly as nurses and doctors when we can't resuscitate somebody, they say to us, "This person was dead, and you tried to bring them back to life," and you need to look at it from that perspective. You're taking somebody who has died, and in that instant you try to bring them back from death.

Also, the resuscitation itself is brutal. I don't want to offend anybody here, but I'm going to tell you exactly what happens in order to resuscitate somebody. The first thing that happens is whatever you're wearing comes off. If you're wearing clothes, it gets cut off, because they need exposure to the chest area and all of the veins. They'll try to start an IV if you don't have one already so they can get medications into you, and they're going to shock you with increasing voltage three times. The new protocol is to shock three times and then give drugs. The shock is an electric current going through your body trying to restart your heart, which runs on electricity.

Then they need to get the heart

pumping, or they need to do CPR, because if they don't, the drugs they inject into your arm are just going to sit in your arm. They need to be circulated around the body to do any good. They're going to try medications, and then, if the medications don't work, they'll try shocking you again. It's not a pleasant procedure. They are very rough with the body. Usually, they are so focused on what they're doing to resuscitate you and remembering what the protocols are and thinking of what they can try next that there is really no attention paid to what's going on with the person as a person. They're just focused on their task at that time.

I tell you this because I want you to think if that is what you want for yourself at the end of life. Do you want to be kind of abruptly brought back like that? Or would you rather that, if you stop breathing, that's it – you just stop breathing.

How comfortable do you want to be? Let people know, as far as pain control, if there has to be a balance between being awake and being in pain, which do you prefer? Would you rather be sedated and be comfortable, or have a little bit of pain and be able to converse with your family members? Let them know that.

How do you want people to treat you? A lot of times, people are afraid of talking to you about different things. Death, we're not very comfortable with. You can help your family members to be more comfortable by saying, "Look, I don't want you to tiptoe around. If you have something to say to me, I want you to say it so that you're not haunted by it after I die, or you won't regret saying, 'I wish I had told this person this,' or, 'I wish I had said I'm sorry for this,' or, 'I wish I had told them that they hurt me at this time.'"

When my father-in-law was dying, he had hurt my feelings a lot of times in his life, but none so much as when I graduated from nursing school and he said to me, “So, you finally finished something.” Then, he didn’t come to the graduation ceremony. I was really, really hurt by that, and I was taking care of him in the hospital – it was my turn – while he was dying. He wasn’t even awake. He was comatose at the time, but people who are comatose hear things. Don’t ever forget that. Don’t say something in front of a comatose person that you don’t want them to hear, because they may wake up and tell you what you said.

I was taking care of him, and I was bathing him, and very gently I said to him, “I want you to know that you really hurt me on the day of my graduation from nursing school. I really wanted you to be there for the ceremony. When you said, ‘You finally finished something,’ that really hurt my feelings and kind of took the wind out of my sails for that day. But I want you to know that I’ve thought about it and that I love you and I forgive you for it.” The tears started coming down his face, so I knew he heard me. Then I said it again, “Remember, I forgive you, and I love you.” I wanted him to carry that as the memory. I didn’t want him to go to his grave thinking about [it]. ... At the end of life, you think about all the things you might have done differently. If he was thinking that way, I wanted him to know that I was okay with it now. I had gotten over it.

How you want people to treat you, what you want your loved ones to know – all of these things are elicited from this Five Wishes. ... The document should be completed ideally at a family meeting so that everybody gets to talk about it. When you’re talking about your wishes, it’s really important to use “I” statements. ... If I had said to my father-in-law, “You always made me feel like I wasn’t

good enough,” that would have put him on the defensive and made him feel worse than what I said to him: “I want you to know that I was really hurt.”

Using “I” statements, it’s all back on me. It’s talking about my feelings and not accusatory toward him. It’s really important to use “I” statements when you’re talking about your wishes. Share your feelings openly with your family. Cross things off the document that you don’t want, and then have the document witnessed by a friend or a neighbor. It should be witnessed by two people who are not related to you.

Making memories, we talked about before, and people had some ideas about taking pictures, making videos, creating a scrapbook. You could sit down and do a cross-stitch, needlepoint or quilt. Tell stories. Stories are great. Tell stories about yourself and about your family, showing pictures of you when you were a kid. You’d be amazed that your children never think of you as ever having been a child. Just like they think you never had sex, they think you were never a child. You can show them pictures about that. Write about yourself. Write about your life experiences so those memories live on for your kids and they have things they can hold onto.

Now, you can’t plan for what you don’t know, and most people do not know about the actual process of dying. You need to know that dying is not the same for everybody. No two people die alike. I’ve been a nurse for 17 years, and I don’t think I’ve ever seen two people die in the same way, and I was a hospice nurse for a while, so I’ve been around a lot of people who were very sick and dying.

You can have some control over your dying process, but know that something may happen that is not in

the plan, and your hospice nurse or the nurses in the hospital will help you to get around the unexpected. They will be able to guide you through the things that come up that you’re not planning for. Dying is an individual, personalized experience. There is no typical death, but patients’ preferences are always respected, so if you have those in writing, you should bring them into the hospital when you’re admitted so they become part of your hospital record. Your nurse will advocate for your choices.

Members of the family and the patient may not be ready to let go at the same time. This is really important. Usually, the patient is ready long before the family is ready, and patients will hold on until they feel like their family is ready to let go. I’ll give you the worst case that ever happened to me as a nurse. This patient was dying, a gentleman, I believe, in his 70s. He had held on for a long time because his wife was in no way ready to let him go. She kept having us try everything. Finally he told the medical team, “I don’t want to be resuscitated. I don’t want to be intubated. I don’t want to go to the ICU. Whatever happens, leave me in this room and just take care of me here.” ... Oh, and he also said, “No matter what my wife says.” (Laughter) His kids were on board, and they were all in the room.

I got called to the room one night, and he had died. He had stopped breathing. I went in, and I closed his eyes. I said to his wife, “He’s gone. He has left his body, so I’m going to give you some private time.” She said, “Wait a minute. I want you to do something.” I said, “Well, what would you like me to do? He’s dead.” She said, “Well, Jesus raised Lazarus from the dead, so you do something.” I just didn’t know what to say. I said, “Let’s sit down and talk about this.” We sat and talked for a while. This woman really never got over it. She was in

pathological grief for a very long time in the grief support group. That was my worst-case scenario.

I've had some good cases, though, and I'll give you some examples. I had a patient whose daughter flew in kind of at the last minute. He was dying, and he was having a lot of trouble breathing. He was ready to let go, and his son was ready for him to let go. He held on, and we kept telling him, "Her plane is going to land at this time. It will take her this much time to get to the hospital," so he held on until she got to the hospital. She came in the room.

She was in the room maybe five minutes, and he stopped breathing. I happened to be in the room at the time. She went ballistic. She started screaming, "No, no, you can't leave me." She was just not ready. There was something she needed to tell him ... and she couldn't get it out in the first five minutes, and he didn't know that she was wanting to tell him something. I went right up to him, and I put my mouth right next to his ear and said, "Your daughter is not ready for you to go yet. If you can give me five minutes alone with her, I can get her ready," and he started breathing again. (Audience Reaction)

WOMAN: Wow.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: I've done this three times with patients, and one of the patients was my father. All three times, they started breathing again. I took her out in the hall, and I talked to her. I said, "Your dad has been struggling to breathe for a really long time. It's wearing him out. He wants to go. He waited for you to get here. We've been telling him all day what time your plane landed, what time you would get here. If you need to tell him something, you need to go in there, put your face right

next to his ear and tell him. Even though he's kind of comatose, he is going to hear you, because he just heard what I said."

She cried a lot. I watched the time to make sure that the five minutes – I didn't want him to leave before we got back in the room. My uniform was soaked by the time we got back in the room, but she pulled it together to go back in the room, and she did – she went right up, and whatever she said, she said it into his ear so only he could hear, and he got this kind of peaceful look on his face, and then he sighed, and that was it. He was gone, and she was okay with it at that time. Whatever it was that she needed to say that she had flown all the way across the country to say, she got it done.

The letting-go point can be controlled to some extent, but I wouldn't wait until the last minute. I would talk to family members and share things openly and let them know that it's okay to share things openly with you, no matter what it is, before that last minute.

There are two roads to death. The usual road is that people become sleepy. Then they get very lethargic. They start sleeping more than they're awake, and then they start sleeping quite a lot of the time, where it's very hard to rouse them. Then they become semi-comatose, where they can arouse if you ask them to, like when I asked that guy to start breathing again. Then they become very heavily comatose, because the toxins in their body are building up. They are not processing them. The liver is not working quite as well. The kidneys are not working quite as well. They may not be making urine at all anymore, so all of these toxic chemicals are building up.

They're kind of feeling euphoric, but they're not able to wake up anymore,

and they just kind of stop breathing. Usually their breathing changes; it becomes slower and slower, and there will be longer and longer pauses, where you think they've died and then all of the sudden they start breathing again. That's called Cheyne-Stokes breathing. That happens right before death. You may hear what's called a death rattle, and that is because they can't clear the secretions in their throat in the top of their lungs, and that's the air passing through those secretions. It's kind of a gurgling sound, or people call it a rattling sound.

The more difficult road happens when people sometimes have brain metastases or other metabolic processes where maybe there is not enough sodium in their body, and they become restless and confused. They may have spasms and tremors. They may see things in the room that you don't see. They may have hallucinations, but if they see in the room someone who has died in the family, that is not a hallucination. That is a real thing.

I have had patients tell me, "Don't sit in that chair, because Uncle Jack is sitting there," and the family will go, "Uncle Jack died 10 years ago." That's okay. It's a very common thing for people to see family members who have gone before them at the time of death. I like to think that those are the angels that have come to make it easier for the transition. I've had people tell me that there are angels at the foot of the bed, and they're not frightened by it. I've only had one person tell me that they didn't like what they saw, and that was a hospice patient. His wife said he was really agitated, and I went up there, and she said, "You've got to talk to him. I don't know what's wrong, but he's really upset about something."

I went up and I said, "Frank, what's

going on?" He said, "Jesus Christ was here last night." The guy was so Catholic. I mean, everywhere in the house there were crucifixes and pictures of Our Lady of Guadalupe. He was Mexican. I thought this would be very comforting for him, so I said, "Oh, was that a good thing for you? Did that make you feel better?" He said, "Scared the shit out of me. Tell him not to come again." (Laughter) I was stunned. I never expected him to say that. But a few weeks later, he saw the Virgin Mary, and by that time he was ready, so that was comforting to him. But I never expected that. (Laughter)

There are hallucinations. Sometimes the seizures precede the comatose state, and there are medications we can give that will relax the muscles and control the seizures. Sometimes people talk in their delirium. They're talking to people they see as part of the hallucination, and it's important for you – if you're a family member – if someone says something that is not correct that you correct them.

For example, there was a patient who kept going like this. His wife: "What are you doing?" He said, "There's all this garbage in the bed. I'm trying to get rid of it." She didn't know what to do, so I told her, "Tell him there's no garbage." She said, "I don't see any garbage in the bed." He said, "Well, it's going to be hard for you to pick it up then, isn't it?" She corrected him, and then he got it that there wasn't any garbage in the bed, so he stopped doing this. He realized he was having a hallucination. It's really important to correct people so they know. Yes?

WOMAN: Sorry, I missed the first part of your talk. I had questions specifically about the will and, more generally, about some good websites or resources that we can go to for things like getting the finances in order, the will. You mentioned an elder care attorney. Can you expand on

that? I just want some resources. It's a lot of great information, but some websites or some information ...

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: There are good resources in here [the Cancer Survival Toolbox]. The last module, the one that just came out, is on dying well. There is a resource book in here that talks about Five Wishes and some of the other websites. There are a lot of good websites in here, a lot of good resources, so utilize this. If you look on the web, there is always going to be like a <http://www.yellowpages.com/> or a <http://www.whitepages.com/>. Go to yellowpages.com and look for elder care attorneys in your area or call your local bar association and ask for people who specialize in elder care, because they are really good at durable power of attorney for health care, wills and trusts. ...

You could put your house in a living trust so that it doesn't go through probate, but all of it is very specific to your own circumstance, and I'm not an attorney, so I don't want to give legal advice. I'm just telling you that you need to see an attorney who can help you shelter your assets from probate taxes. There is a way to do that by changing the title to the major things you own.

WOMAN: I have another question, though. This is all amazing information, but with all of us – most of us have a cancer diagnosis if we're in this room. We're already dealing with a myriad of decisions and doctors' appointments, and just being well is a full-time job, so in terms of planning the whole death piece, are there people who exist who can kind of do it for you?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: No. (Laughs)

WOMAN: If you give them specific guidelines? I'm wondering, for example, if it's an elder care attorney, can you set that person up to take care of all of ... I don't know, the majority of it?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: He can help you.

WOMAN: Just in general, because it's a lot of work, it seems.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: It is a lot of work, and that's why doing it as early in the disease process as possible – like, I did it right when I got my third primary diagnosis. I should have done it when I got my first one, but I was only 25 and still in school and I didn't own anything. Now I have a house, and I wanted to protect the house as an asset, so I went to an attorney to do that. You set down what you would like, and he takes that information. The first interview with an elder care attorney is going to be like an hour to an hour and a half of him asking you a lot of specific questions. What do you own? You need to know what you own. How do you want it disposed of? Who do you want to have possession of it?

Like my house: I don't know if you know about the California housing market, but if you ever sell your house in California, you'll never be able to buy a house in California again. I didn't want my kids to sell the house. That was an important part, and I put that in my will. You just have to be very specific with what you want. You have to do some of the work, and you have to look at these documents that he drafts, because it may not be perfect the first time. Make sure that you understand and go through with him, "Okay, suppose I die tomorrow. What's going to happen to my house? What's going to happen to my bank accounts?" He explains that document

to you, and you get that information.

WOMAN: My second question – because you were discussing fraud, in terms of funeral homes and things – is do you have any experience with life insurance fraud? Have you seen any situations where perhaps someone bought a life insurance policy where all of their end-of-life things were supposed to be covered in terms of the funeral and services, but then once all of that took place, the funeral director or funeral parlor went after the family of the victim or whatever because the insurance didn't pay, so on and so forth?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Yeah, I have one case.

WOMAN: Do you have advice for someone who might be going through that?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Well, the big thing is that you have to be totally honest when you apply for the policy. If you get your policy through your employer, it doesn't matter because it's guaranteed. They have a contract with the employer. But if you bought individual life insurance, you have to make very sure that you answer every question on the questionnaire honestly, because the way they'll get out of paying the policy is to go back and say that you didn't disclose something, some condition you had at the time you paid for the policy, and that makes the policy null and void. Then they will refund the premiums you've paid, but they won't pay the benefit.

WOMAN: Thank you so much.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: I have 12 minutes left. This is a slide about quality of life and what's involved in quality of life. It

has four components: spiritual, social, physical and psychological. I've found that people who have a spiritual life, whether or not they subscribe to any particular religious domination, have an easier time at the end of life, that they are more peaceful about it. People who have absolutely no spiritual life, have no beliefs at all, have been kind of antagonistic toward the mention of anything that has to do with religion or spirituality, they tend to be more afraid at the end of life. That's just my experience through 17 years of nursing, all of it in oncology or hospice.

Quality of life involves your ability to function, control of your symptoms, control of your anxiety. There is going to be a certain amount of anxiety. There is depression involved with a cancer diagnosis. It's a normal part of the diagnosis and dealing with it. Dealing with your pain, the fear of having pain at the end of life – there are great pain medications. There is no reason for people to be in pain at the end of life. If we cannot control your pain by using all of the methods available to us, which include nerve blocks and epidural catheters and all kinds of things like that, we can give you a drug called ketamine, which is a very strong sedative. It can be given IV or orally. It will sedate you so that you are not aware of the fact that there is some residual pain. Make sure, if you're not going to have hospice, that you have somebody who is really good at palliative care who can help you to know that you will not die in pain.

Then the social – I've dealt with the financial aspects of it and the caregiver aspects. Make sure if you are a caregiver – and I see some of them in the room – that you do not burn out, that you get some relief, that you have somebody who is supporting you as well. Dealing with appearance, dealing with being able to be in bed

with somebody when they're dying, having that closeness, that contact.

I think really the worst thing for anybody who doesn't want to die alone, because there are some people who do want to die alone – children are notorious for getting their parents out of the room when they die because they're afraid their parents can't handle it. But for people who don't want to die alone, that's the hardest thing, the thing that causes the most anxiety – that there will be nobody there with them. I can tell you that, as a nursing staff, we have seen people who have no family. If we know they're dying, we take turns going into the room to make sure the person doesn't die alone. That's just my particular unit and the nurses on my unit, but I think it's a pretty common experience among oncology nurses that we want to make sure they have human contact during the dying process.

I want to talk about the fear of the dying process, and I went over that dying process. There are medications to control all of the symptoms. Fear of abandonment by family members is another thing that comes up. Being aware that death is coming. Most people are aware that they're dying. They may not say anything, but they do know. When they know, they start to withdraw and go through what we call a life review, where they remember all of the things that happened in their life. They may talk about these things, but they're coming to peace with everything that's happened in their life. Then there are spiritual issues.

The physical symptoms: There can be confusion and disorientation, and it's important to make sure that the person is kept safe, that they don't try to get out of bed. They are not going to want to eat anymore, and that's hard on family members, because food is

equated with love. "If you love me, you'll eat this food, even though you can't." You've probably experienced that during your chemotherapy as well. As people get closer to death, they're not able to swallow the food, and they don't really need it. They don't really need the water. It's okay if they get a little bit dehydrated, because the body just doesn't need it anymore. The body is shutting down.

You'll find that their hands start to get cold; their feet start to get cold. The body is conserving the core up here, and it isn't using whatever energy it has left to deal with. We figure the feet are not going to be walking anymore, so we don't have to keep those heated, and the circulation is not there. The skin changes a little bit. It starts to get little red circles on it, what we call mottling. It also gets cold. They don't produce urine anymore. They don't have any bowel movements. They're sleepy most of the time.

Artificial nutrition and hydration: People think that if they don't provide artificial hydration through a feeding tube that their loved one is starving to death. That is not true. People don't need food as much when they are dying, and giving them a tube feeding doesn't reduce the risk of their aspirating – in other words, the food going into their lungs. It doesn't really change the fact that they are going to die. Giving them IV hydration is not going to change the fact that their mouth is going to be dry. That's just going to happen, and you need to moisten their lips and their mouth.

Then we have patients who refuse to eat because they want to die earlier than they would have normally. It takes about two weeks to fast and die, but those people have experienced peaceful death. It was their choice, and they chose to hurry up or move up the time of their death. I don't know how to make that grammatically

correct.

Some of the barriers are that people fail to acknowledge the limits of medicine, so they don't realize that we can't cure everything. There is, in this country, an inappropriate use of aggressive curative treatment, particularly up to the last minute. We have a lot of people who come to Stanford from all over the world because they've been told that there is nothing more that can be done for them and they want to enroll in a clinical trial, but they're so sick that they're really not eligible for the clinical trial, and they beg us to do something.

Sometimes the doctors will give them a drug off the record that might be used in the clinical trial, just a long-shot chance that it's going to work. Really, in the end, it just decreases their quality of life, because they experience the side effects from that drug, and it's really not going to cure them. It might buy them a couple of weeks' extra time. Doctors and nurses don't know when somebody is going to die. The person who knows that best toward the end of life is the person themselves, because they live inside the body and they can tell that it's not working correctly.

These are some of the services that hospice provides for you. I'm a big fan of hospice, because it's multidisciplinary care. You can have a homemaker and health aide services (a homemaker is somebody who comes in and cleans up for a half day); counseling for your family that goes on after the death; social work service, which includes helping you with disability paperwork and financial stuff; spiritual care (there is always a chaplain); volunteers who come in and give your family members a break; and then bereavement services afterward.

For the Medicare benefit, the eligibility

criteria are that the patient's doctor and the hospice medical director use their best clinical judgment and that they think you have six months or less to live if the disease runs its normal course. It's just a guess. It's not anything definite. The patient then chooses to receive hospice care rather than curative treatments for his or her illness.

There are some things that hospice services won't do, and it differs from hospice to hospice. Some of them won't do blood transfusions anymore. Some of them will if they relieve symptoms like shortness of breath. Then the patient enrolls in a Medicare-approved hospice program. If you've been on disability for a year or more, whether you're 65 or 67 or whatever the age is these days, you're still eligible for Medicare. Keep that in mind as you go through your treatment.

Hospice reimbursement: Medicare will then pay a per diem rate that will cover all of the expenses related to the illness. It provides four levels of care: routine home care; continuous home care; inpatient respite care (if you have a symptom that's not being controlled at home, you can go into the hospital again and get that symptom under control; usually it's pain that people come in for, or constipation); and general inpatient care. The per diem is about \$120 per day. The cost of new drugs and treatments has risen faster than the hospice benefit reimbursement rate, so most hospices are not making any money. In fact, they have to raise money to stay in business.

Medicare-certified hospices must offer [to] all of the patients, even if the patient is not covered by Medicare and the patient does not have the ability to pay. If you go into a Medicare-certified hospice and you run out of money, they'll keep taking care of you. They're

required to do that. This is kind of the trajectory. You start with a curative focus when you're diagnosed, and then as you progress – this may take years and years and years, as you can see ... mine has been going on for 26 years and I'm still not at the end. Then there is a palliative focus where we work on symptom control, and at the end, after the death, there is bereavement support for the family.

Going through the dying process presents itself with a lot of opportunities for growth. Just because you're dying doesn't mean you stop everything. There are still new avenues that are open to you, and there are a lot of people who have had great insights just because they finally start thinking about death and dying and they start to review their whole life process.

It's good to have completion with worldly affairs. You've taken care of all of this financial stuff. You have your will in place. You have your durable power of attorney for health care. You can relax. It's not hanging over your head. You complete your community relationships, those people who are your friends. You get in touch with them and let them know what's going on. Then you derive meaning from your own life. Everyone's life has an individual meaning. We don't always know what it is. It's important to come to a place where you love yourself and to know that you love yourself. We're not always aware of that. Then love of others. Then you complete your family and friend relationships, and you accept the finality of life. Then you know that there's a new self beyond the personal loss. There's a meaning to life itself.

Then, finally, there is a surrender to the unknown, and that's the letting go. Nobody knows what happens after death, because nobody has actually come back and told us what happened

and stuck around. There are a lot of books about near-death experiences. There is kind of a common theme to them, but people have had different near-death experiences. There is a physician who writes about it. He's a cardiologist, and he studies people who have had myocardial infarction where they've had a heart attack and actually been dead and then resuscitated. They all describe a peaceful place.

I have a lot of unanswerable questions. I just wanted to show you what it's like in the ICU when somebody dies. This is very difficult for the staff as well as the family. It's not a way that I personally would like to die. There are a lot of machines here, usually IVs that maintain blood pressure. This person is intubated, so on the other side, there is a ventilator that's breathing for them. The tube has to be kept in place; they're not able to speak, so there is really no communication with the family, and they have to be kept heavily sedated so that they don't fight the machine.

If you're not on a ventilator, here is somebody who is simply on oxygen in the ICU but still has a lot of the equipment around, and there are always chaplaincy services available. This is just a chart of frequency of symptoms in the past 48 hours. The biggest one is agitation, pain and then the death rattle people hear. Not so much the shortness of breath, because that's controlled with drugs. We have decreased urine output, the cold and mottled extremities that I talked about, then the respiratory congestion, which is the death rattle. Then the death vigil is having people around.

For the family members – I talked about my being terrified about being with my sister when she died and researching it. It turned out to be not a bad experience at all. I got in bed with

her, I held her in my arms, and I talked to her until she stopped breathing. I just basically told her it was okay to let go. I had asked my parents to do the same thing, and my mom was great about it. She was actually the bone marrow donor, so I thought it would be hardest for her, but it was actually hardest for my dad. I listened at the door while he was doing his goodbyes, and he kept telling her it's okay to let go. Then at the very last minute, he couldn't do it. He said, "But if you want to keep fighting, I'll be right there with you." It's just really hard for people to let go.

We went through this: The signs and symptoms of death are just that there's no heartbeat. If you put your head on the person's chest, you won't hear a heartbeat. They're not breathing anymore. If you put your hand under their nose, you won't feel any breath coming out. Or if their mouth is open – often the jaw relaxes and the mouth is open – you won't feel any breath coming out of the mouth. Sometimes, if there is any stool remaining in the digestive tract, or any urine, the muscles all relax, so that lets go and they may be incontinent at that time. If you talk to them, there's no response. If you shake them, there's no response. Their pupils are the same size whether or not you shine a light in them.

The body color very quickly becomes white, and it looks kind of waxen because the blood is not circulating anymore. It's not coming to the surface on the capillaries. You'd be surprised how quickly someone becomes cold and pale. The body temperature drops quickly. The eyes may remain open. If they do, you just take your two fingers like this and close them, and they should stay closed. You have to keep your fingers on for 15 or 20 seconds in order to get them to stay closed. Then, as I said, the jaw relaxes.

The funeral home will come when you're ready and take the body away. About two to four hours after death, rigor mortis sets in. If the person is in a strange position, they're going to stay in that position. Then, after a certain amount of hours – probably they're at the funeral home by then – the body does relax and lets go. If their knees are bent or something like that, they will relax. If you move the person – like if you turn them from side to side to clean up the bed because they've been incontinent – you may hear air escaping from the lungs, and it sounds like the person is sighing. Do not freak out and think they're breathing again. It's just that the lungs are flattening out, and whatever air was in them is being released.

Embalming is best done within 12 hours of death, if that's what you want to do, so make sure the funeral home comes to pick up the body within 12 hours. I would remove any jewelry before the body goes to the funeral home, particularly if you want to keep it. Sometimes the fingers are swollen and you may not be able to get a wedding ring off. What you want to do is to get a lot of lotion like Jergens lotion or something like that, and put the finger between your hands with all of the goopy lotion on there. If you keep doing it and sliding the ring up like that, it will come up over the knuckle. You may have to work on it for a while, but it will come over the knuckle. ... Jewelry that you want to keep, you take that off before you go to the funeral home. If you can't get it off, sometimes the funeral director will cut it off for you, but usually you can get it off if you use enough lotion.

I want to end with my friend Elisabeth Kubler-Ross, who recently died. She was a great teacher for me when I was 25 and I was told I had six months to live. I had a 50 percent chance of living six months. I got very angry. I read a book by Elisabeth Kubler-Ross,

and in the back of the book it said she lived in Escondido. I called up directory assistance, and lo and behold, her number was listed. She invited me to come and stay with her for a week. This was one of her favorite sayings: Should you shield the canyons from the storms, you would not see the beauty of their carvings. Sometimes you have to go through a lot of difficulties to come out to a beautiful ending. Then this is the California coast near where I live. Do you have any other questions that haven't been asked so far?

WOMAN: This is a little strange question, but thank you for easing some fears.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: Thank you.

WOMAN: When someone dies – since you've been around so many people – do you feel the energy leave the room? Do you believe in all that?

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: I feel the energy in the room. A lot of times after someone dies, I'll clean up the body before the family comes in, and I always feel like the person is watching me from the ceiling. I'm weird – I talk to the person while I'm doing it and say, "Your family asked me to take off this ring; that's why I'm doing it," or, "Your family is going to come back in just a minute. I asked them to step out while I cleaned you up."

WOMAN: Thank you.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: I definitely feel energy in the room. Please give me your letters. Please give it to me before you leave, your letter to Death. If you haven't done one, feel free to stick around and do one. I'll be here for a few minutes afterward. If you want to ask me something that you

didn't want to ask publicly, I'm going to take off the microphone and you can come up and talk to me.

WOMAN: I just wanted to thank you for this presentation. I used to babysit for a hospice nurse, and believe me, everybody should have hospice with them through the end stages. It is a blessing for the family as well as the patient.

WOMAN: When do you recommend getting into hospice? A lot of patients and family members wait until two weeks before, and hospice can do so much before that.

DEBRA K. THALER-DeMERS, BSN, RN, OCN, PRN-c: I recommend talking to your physician. When you're at the point where you're ready to stop the chemo and stop all of the aggressive treatment, that's when you want to get in touch with hospice.

[END OF TRANSCRIPT]