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## Talking with Your Family about the End of Life

WebMD Live Events Transcript

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**Whether you are making decisions about your own care or need to know the wishes of a family member, straight talk is vital. Dale Larson is a professor in the department of counseling psychology at Santa Clara University and is the author of *The Helper's Journey: Working With People Facing Grief, Loss, and Life-Threatening Illness*. He joined us September 28, 2005, to offer advice about having an open dialogue with your family.**

If you have questions about your health, you should consult your personal physician. This event is meant for informational purposes only.

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### **MODERATOR:**

Welcome to WebMD University: "Planning Ahead." Your instructor today is Dale Larson, PhD.

Welcome, Dr. Larson. Why do we have such a hard time discussing the end of life -- our own or our loved ones?

### **LARSON:**

That's a great question and it gets right to the core of what we're going to talk about today.

We all remember what Woody Allen said: "I'm not afraid of death. I just don't want to be there when it happens."

Sigmund Freud said, "The ego cannot imagine its own dissolution." Once in a lighter moment he said to his wife, "If one of us two dies before the other, I think I'll move to Paris."

Ernest Becker, in his Pulitzer Prize-winning book, *The Denial of Death*, argued that death, anxiety and our attempts to deny it underpin much of human psychology. Finally, Kubler-Ross said that death was the greatest and last taboo.

So, approaching this topic is never easy, whether we're the person who's suffering from a life-limiting illness or we're a family member trying to find a way to talk about this very difficult subject. It really forces us to come to terms with some experiences that are very close to us and are tough to wrestle with.

### **MODERATOR:**

We have had very public examples of what can happen when we don't discuss our wishes for the end of life. It sparked much public debate, but do you think it motivated people to have the very personal discussions about our own wishes for end of life?

### **LARSON:**

I think that some of the recent issues, like those concerning Terry Schiavo, and the recent hurricane disasters, have really taught us that it is important for us to plan in advance because sometimes we don't have that opportunity.

**"We very often hear 'I wish we had known what my loved one really wanted.'"**

One of the things we hear from families, for example, is "Why didn't I hear about hospice earlier?" And we very often hear "I wish we had known what my loved one really wanted, we just didn't know when we had to make those very difficult decisions."

I do think we have a national conversation occurring about some of the issues involved and that is a good thing but it's also true that we have to, as individuals, begin to have these kinds of conversations more frequently with our loved ones before life-threatening illness or catastrophes occur. We have to talk about it when we're healthy.

One of the findings is that people appointed as proxies by individuals and their family have no more idea of what a person would want in a specific situation than someone chosen randomly. This might be a surprise for most people, but it suggests we really need to let our loved ones know what we would like to have done if we're unable to express our wishes.

In times of great grief, aren't logical conversations difficult?

**MEMBER QUESTION:**

But sir, in a time of great grief, logical conversations are very difficult.

**LARSON:**

That's a great point, and it certainly is true that these are very emotionally tough conversations.

The challenge is to begin talking about some of these issues earlier on so that we begin to get an idea how each of us is thinking about them and then when we get to a situation where there is serious illness, it will be much easier to talk about our wishes and to ask our loved ones what their wishes are.

There are several kinds of conversations that can occur:

- Conversations with your doctor
- Conversations with family members
- As a family member talking to your loved one

I'd like to talk about all three of those situations today in this program.

**MEMBER QUESTION:**

My parents are getting older and haven't talked to my siblings or me about their wishes. How should we initiate that conversation?

**LARSON:**

First it's really important to find ways to talk about some of these issues that are not too anxiety-arousing. You might talk about the experiences others have had in your social network. "Mom, look what happened with Mary," and then describe the experience Mary had which was not so good because they didn't do any kind of planning.

As you're discussing this situation with Mary see if your parents might say, "Well, I wouldn't want anything like that done to me." Then you have some opportunity to go into more detail. You can also share your own wishes. They'll say, don't talk that way. Don't let that stop you.

One thing we know: talking about death won't kill you, and we need to prepare. You have to kind of let that guide you and motivate you as you have these conversations.

So you can talk about your own wishes in some considerable detail and talk about advance directives, maybe some of your own fears about dying, your own spiritual beliefs, how you would make decisions about treatment options and possibilities, where would you want to be when you die; even your burial and funeral wishes.

Some of these are very tough conversations, of course, but you have a little more license to talk about it when talking about your own situation and that can lead the way.

You can take your parents to the movies if you find one that gives some good launch points to discussions, and then you can begin the conversation by talking about the movie with them. Once you get into the conversation, you can find out what they've told their doctor, find out if they have advance directives in place.

Talk more directly about their conversations with their doctor. I think it has to be an incremental type of process, so don't think about it being one conversation; think about this as many conversations. Just getting advance directives in place is not enough. It has to be an ongoing conversation where we're continuing to learn from one another our wishes.

**"Hollywood hasn't provided good models for us in how we can die and die well."**

**MODERATOR:**

In order to talk about your own wishes in detail, should you talk with your doctor first? Many people don't have a realistic understanding of the choices available for end-of-life care; their knowledge comes from Hollywood.

**LARSON:**

I couldn't agree more with that. Hollywood certainly hasn't provided very good models for us in terms of how we can die and die well. I agree that we need to talk with our physician to understand what choices we have available to us.

How can we talk to our doctor and learn more about our situation and the choices we have? If you have a serious illness, what you don't really want to do is ask your doctor, "How long do I have left?" We've learned that that doesn't always lead to the most helpful kinds of responses.

Physicians, like everyone else, tend to kind of soften the blow, and their prognostications are also generally off, in that they overestimate the length of time remaining for seriously ill people.

We find that it's more helpful to ask your doctor, "What are the worst outcomes I might deal with?" Or the "surprise" questions: "Would you be surprised if I died in the next year," or "How is this going to affect my family?" or "I'm kind of planning to do things a certain way."

You can you spell out what you're planning to do, say a trip to Europe or something else in your life, then ask your physician, "Is that on track with what I can expect now?" So if your physician is not initiating the discussion, it's really important for you to initiate. Those are some of the ideas for getting some more candid and helpful guidance from your physician.

You do need to talk with your physician in great detail to get a better understanding of the options available to you, and I would encourage you to have some of these conversations with family present, so they can understand what your wishes are and that you, your physician and your family as a team understand what your wishes are and how you would like to negotiate this tremendous challenge.

How can I get my family to discuss my final wishes?

**MEMBER QUESTION:**

I have a serious illness and am fighting hard. However, I do want to be realistic and discuss how I want my ending to be. But family members feel any discussion of my death means I am giving up. I'm not; I just don't want to be left on machines or in pain. How can I get them to discuss my wishes?

**LARSON:**

This is a really common experience of seriously ill people in our culture. It is one of the toughest situations to be in. Families want to try everything and they experience anticipatory regret. They are terrified about losing you.

You are trying to deal with the reality of this illness, to have some control. To not talk about the situations, options and realistic concerns you have takes some of that control away.

The challenge is for you to really let your family know you're doing everything you can to achieve a cure and you are hoping for the best, but you have to prepare for the worst, and to not do that can lead to all kinds of problems.

What I would encourage you to do is to have that very difficult conversation with your family and to convey what your physician has told you. Sometimes it's helpful to have your physician involved in this conversation, as well, so that your family members can begin to negotiate the reality you're facing.

Most families go back and forth and are somewhere between hope and despair, talking freely and not talking at all. They're saying things to you like, "Mom, you'll be fine." It would be more helpful if they would say, "Mom, is any of this worrying you?" Instead it would be more helpful if they said, "Let's go through this together."

There's a wonderful book, *Handbook for Mortals*, by Joanne Lynn. You might find it helpful in having these conversations. You also might find another book very helpful: *Talking About Death Won't Kill You*, by Virginia Morris.

I also encourage you to take a look at the national newspaper series: *Finding our Way, Living With Dying in America*. This series was funded by the Robert Wood Johnson Foundation and includes 15 articles by national experts on many of the issues we're talking about today. You can access the series at [www.scu.edu/fow](http://www.scu.edu/fow).

My own article in that series is about some of these difficult conversations and how we can more effectively have them with family and our physicians.

**MODERATOR:**

How can completing an advance directive help this patient and their family have the conversations they need?

**LARSON:**

Advance directives can help because they should develop out of a conversation. It's very important to sit down with your family before life-limiting illness strikes, or after a serious diagnosis is made, and have conversations about what one would like to have happen. Go to the National Hospice and Palliative Care Organization web site ([www.nhpc.org](http://www.nhpc.org)), you can get copies of advance directives.

If you have those in place when you're unable to communicate your wishes -- perhaps because you're unconscious or in a coma -- then family have a tremendous sense of relief. The more they feel they understand what you wanted, even if they don't want that for themselves or even want that for you, there's a tremendous sense of integrity and doing the right thing when family have a clear and explicit understanding of what your wishes are.

**"Fewer than one-fourth of Americans have an advance directive in place."**

The reality is that fewer than one-fourth of Americans have an advance directive in place. I would encourage

you to read the "Finding Your Way" articles. Read an article by Bud Hammes and Robert Bendiksen exploring the entire topic of advance care planning and advance directives.

**MODERATOR:**

State-specific advance directive documents -- along with complete instructions -- are available on the VistaCare web site. They are free to download for anybody who wishes to access them. Go to [vistacare.com](http://vistacare.com) and look for the link for advanced directives ([www.vistacare.com/hospice/tools/](http://www.vistacare.com/hospice/tools/)).

**MODERATOR:**

What kinds of conversations should we have as we approach the end of life?

**LARSON:**

This is a really important question. In hospice we talk about end-of-life closure and many conversations that seem to be instrumental in helping us achieve a sense of completion to our lives.

Some of these are conversations begin with "Forgive me." Some talk to the people in their life when they have had something they don't feel good about.

There is also "I forgive you," when there have been troubling things between them.

"Thank you." To give thanks to all the people you'd like to express gratitude toward.

"I love you." To say to all the people who have mattered.

And finally to say "Goodbye," because there will be a time when you last talk to someone in your life, and they're very difficult words to say, but they're remembered by the people who survive you.

My grandfather took the hands of my wife, though he could barely move, and said, "My darling daughter, I love you." Those were the last words he said.

Before you get to this point there are a lot of other conversations you can be having. You can tell your story to those who will live on. Be with the people you love. I think *Tuesdays with Morrie* taught us all that lesson.

And if you have the time, take that last trip and when you tell your story, you'll be leaving the legacy, your life, and those are all part of this self-determined life closure that we have found can make dying, dying well.

How can I face my own mortality?

**MEMBER QUESTION:**

I am having trouble with your first step -- making plans for myself. I find it very difficult emotionally facing my own mortality.

**LARSON:**

This is the ultimate struggle. Talking about death is the most intimate of conversations; it is profoundly spiritual in nature. It forces us to wrestle with probably the most difficult concepts we've ever really engaged with. It's almost easier to just do advance directives and not have this deeper conversation with ourselves and our loved ones.

If you stop and really begin to think about what the ending of your life means, it's a very powerful experience. Can we really say goodbye to the people we love? Could we possibly say no to a treatment that might delay death? These aren't mere intellectual questions, they really are questions that we're going to have to live through and find answer for.

There's really no way around death and dying, but I think there is a way through and we're all challenged to

negotiate this incredibly novel and challenging set of circumstances.

The idea that we can cope better or less well with death and dying is pretty new to our culture. In the past, advanced illness and dying have generally been viewed as crises that preclude any notions of manageability. There's a kind of collapse of self-efficacy, in the sense of "there's nothing I can really do so I can't think about this."

But I think a new stance is emerging, one that's not characterized by avoidance and powerlessness. It's a shift towards a stance in which this most significant life event is approached with planning, emotional preparedness, a sense of self-efficacy, and a kind of active involvement that we have in other domains in life -- and that as a culture, we need to move in this direction.

I think that conversations like ours can contribute to that enhanced set of personal self-efficacy and collective efficacy in approaching death and dying in our lives.

**MEMBER:**

Thank you!

**MEMBER QUESTION:**

Does hospice help facilitate conversations? As I get older, I look to avoid pain at the end and I think hospice can help with that. But can they help me talk with my family?

**"Hospice is the gold standard of end-of-life care."**

**LARSON:**

Yes, hospice can help. Hospice is really the gold standard of end-of-life care and it is superbly designed to address all of those issues. Hospice addresses the biological issues: pain, symptom control, and the other kinds of physical issues involved with dying.

It also addresses the psychological suffering and treats the family and patient as a unit together so you have support on all fronts and tremendous assistance in terms of having end-of-life conversations and achieving a safe and comfortable dying.

The goals of hospice even go beyond the death itself to include bereavement care, so that you know your family will have support after you are gone.

So hospice is really a tremendously multifaceted approach to caring, which includes an interdisciplinary team and support for all of the needs we have found important to people at the end of life.

**MEMBER QUESTION:**

The people I encountered with hospice are simply wonderful, caring people.

**MODERATOR:**

Unfortunately, we are out of time. Thanks for joining us, members, and thanks to Dale Larson, PhD, for sharing his expertise with us today. You can also learn more about advance directives by checking out our [Advance Directives](#) transcript with Tom Swanson, PhD.

The opinions expressed herein are the guests' alone and have not been reviewed by a WebMD physician.