The Toughest Conversation | Loss and End of Life

Part III: Questions & Answers

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Presented by:

***Dr. Daniela Wittmann (PhD, LMSW)** is a Clinical Assistant Professor in the Department of Urology in the University of Michigan Health System. She has 30 years of experience in individual, couple and family psychotherapy with patients with chronic illnesses including cancer and severe mental illness.*

Question #1: If you are being cared for through a smaller doctor's office in your community, how do you access or find or know where to go to get a social worker so that you have someone to help that with some of these decisions?

Dr. Wittmann: If there is not a social worker attached to the treatment center, then I would suggest contacting the American Cancer Society that is closest and ask them to help you find a social worker who can help facilitate. There are also mental health centers in most localities that have social workers who can be helpful. Just because it's a mental health center, it doesn't mean that these social workers cannot be helpful in locating resources.

I mean social workers are trained to understand that people have lots of emotional reactions to chronic illness and that they also need resources. Contacting your local mental health center would be another way.

Question #2: Is your spouse responsible for any medical bills after death of a patient normally?

Dr. Wittmann: I do not know the answer to that. Somehow, I can imagine that that will be the case but that's a good question to try to get the answer to and perhaps we can do that and post it on the website. Would that be okay, Stephanie?

Stephanie: Sure and I think another big thing that people should just consider is ask. Because of your individual coverage everyone has a different plan so you might ask that question of your provider and/or directly if you have insurance to find out exactly what your responsibilities are going to be if the patient does pass away. I think that's something that is more on an individual basis and I don't know that we're going to find an answer that's going to be a blanket answer.

Question #3: Are uro-oncologists receiving any training on how to have the goals of care or end-of-life conversation as part of their medical training? It seems as though some are much better at doing these kinds of conversations than others. From your experience, have you seen people be more aware?

Dr. Wittmann: I would say that there is definitely an awareness in medical education that this conversation requires skills training and it just depends on when a person trained, whether the skills training will have been in depth or not. Every physician I would say is aware that this is important to talk about and that it's important to talk about it during different phases. Again, I don't know that physicians get a lot of in-depth training so that some may become quite fearful of it and avoid it and may farm it out to the nurse or to a social worker.

Others are very, very good at that but there is definitely an awareness that this is important. Like many difficult conversations in healthcare, oftentimes, physicians feel not adequate and so there is a movement to make this be a much more in-depth training early in medical school and in residency.

Stephanie: Okay. Yes, I think that probably even within care team most patients would recognize that some doctors and even the healthcare team, some members are more likely to accept or bring up some of the questions relating to these end-of-life decisions than others. I think it is very much a personal thing just as it's very personal for us as patients and caregivers as to whether we're comfortable discussing this at all for all of the reasons that you spoke about in the beginning of your talk about loss of hope and so many other aspects. I think it really is the smorgasbord of different people with different skills in this space.

Dr. Wittmann: Can I just make a suggestion also? I think sometimes in this situation it's very, very difficult for patients and their caregivers to advocate for themselves but in the end, it sometimes just comes down to that. All physicians are trained about advanced directive, for example. Some will not bring it up until last minute. If you're having any kind of a concern like this and if your physician's not really good at talking about, just ask who would I best talk to about this? They may be relieved to indicate somebody else like one of their nursing or social work colleague. It's good to bring it up and if they don't think of it, we'll say, "Well, who can talk to me about it?" They will perhaps find somebody for you who can do it more effectively.

Question #4: "Should I shelter my kids from my diagnoses or keep them involved and updated even though these diagnoses can be difficult for a tween to deal with?"

Dr. Wittmann: Absolutely. It's best for adolescents to know what's going on. I think it helps them to feel included. They may be worried, they may cry, they may be sad. You can do a lot of reassuring at the time of treatment, that you're hopeful about the treatment and that you're doing everything you can to maintain your health. I think it's much harder when kids find out later on this stuff has been going on for a long time and they were never told.

It's much better to be included because if they have fears and worries they can tell you, you can hug them, you can say reassuring things about your own optimism or about your own hard work at this. That will definitely help them. If they have this happen, perhaps, then they can talk to their friends and get support or they can talk to other family members so you're opening up a possibility of their being able to cope with this better than when they find out much later on.

Stephanie: Right. Okay. Yes. They can also speak to a social worker or a therapist, couldn't they?

Dr. Wittmann: Absolutely, yeah.

Stephanie: There might even be in the particular instance of young adults or teenage adolescent children, there might even be some resources at the school perhaps.

Dr. Wittmann: Yeah, absolutely. Absolutely.

Question #5: "From your experience, what do you say to someone facing the end of life?" You know that somebody is nearing the end that they don't have a good prognosis and they're not expected to live longer. What do you say to them? How do you know what to do?

Dr. Wittmann: Okay. What people who are at the end of life are probably most afraid of is that other people will avoid them because they're afraid to talk to them about this. The best thing that you can say is, "How are things going today? How do you look towards what's going to happen next and what's most important and how can I be a part of what it is that you want?" Usually, people have some ideas about what they want and how they want to connect with other people. If you ask, "How are you feeling about the way things are going and what do you see for yourself in the future, and how can I be a part of it?" it gives them the feeling that you're not afraid of what they're facing, you want to face it with them.

You don't have to say anything kind or supportive because just having that conversation is the most important thing because there's nothing we can say to somebody who's facing death, right? Because we don't know what it's like but they can tell us, and so being interested and being caring is really what's most important.

Question #6: How do you decide to call it quits in fighting cancer and going to hospice and is there any guidance you can provide for patients that are really having a hard time even bringing up this discussion with their family members because they're [inaudible 00:47:17]. They know it and they don't want to fight anymore. How do you bring that up?

Dr. Wittmann: Okay. Find the person that you trust the most. If there's nobody that you feel totally comfortable with, again ask for social worker or ask for the person in your treatment team or in your family that you can speak to most honestly. Lay it out and have a discussion with the treatment team and visit with the family about where you are in your treatment, what the treatment can actually accomplish and what the side effects are, whether it's really worth it to go further and explain why is it you don't really want to go forward.

I think most people will be respectful. Sometimes family members have a hard time letting go but that's where the provider can really be helpful in saying, "Yeah, there is this experimental treatment that you can try but all we know is it can prolong life on average by three months at the expense of side effects." It may make sense that you want to have a peaceful end of life where you're not struggling with nausea or extreme itching or pain that you may want to just be peaceful and calm and be with your family and friends.

I think in the end everybody can get on board with that because nobody wants a person to suffer. Start with the person you trust the most and then get everybody together to let them know what you want and that's where hospice and palliative care also come in.

Question #7: What if your adult children don't want to talk about the diagnoses? They just say, "Everything's going to be fine," how do you get them to at least start a conversation about the gravity of the situation?

Dr. Wittmann: Well, in a sense use your parental authority and call them out and say, "Look, I know you want things to work out for me well and I want that too but it's not helpful for us to be pretending that things are going to be better than they're going to be. If you're having a hard time with your feelings then maybe you need some help to process what this means to you but I want us to be able to talk about it because I want to stay close to you and this is keeping us apart."

It takes a certain amount of courage to do that but it's important for people to face their denial and sometimes again, you can solicit the help of either your health care provider or social worker on the team to have that conversation because this is not uncommon. It's something that health care teams have experience with. Oftentimes, having that conversation means that the people who have not been wanting to face it get very sad and cry. It just loosens up the whole thing and then things can be more open and more honest.

Having that conversation is really critical. You can do it alone or you can invite somebody to help you.

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