

FRED FRIENDLY SEMINARS, INC.
ETHICS IN AMERICA II
THREE FAREWELLS: MEDICINE & THE END OF LIFE
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FINAL TRANSCRIPT
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ANGELL: Hope has no best interest at this point. No higher brain function means no best interest.

DELAHOYDE: My baby does have a best interest. My baby has a right to life. My baby has equal protection under the law.

CONNOR: She's not disqualified as a member of the human family simply because she's profoundly disabled.

TUCKER: If I need to obtain medication to let me hasten my death in a peaceful and dignified way, I want to know I'm in the hands of a doctor who will respect that.

BROOKOFF: I don't think a treatment aimed solely at hastening death is a medical treatment.

FRANK: I think you have the absolute right to decide the conditions in which death comes and at what point it is appropriate.

ANGELL: This isn't a matter of life or death. It's a matter what kind of death.

VOICEOVER: The situations are hypothetical but the dilemmas are real.

From the boardroom to the bedroom; from the court room to the classroom. Men and women put their values to the test as they struggle with the kinds of decisions we face everyday. Fred Friendly Seminars presents “Ethics in America.” This hour: Three Farewells: Medicine & the End of Life.

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VOICEOVER: Ethics in America is a presentation of the Fred Friendly Seminars at the Columbia University Graduate School of Journalism.

MILLER: Our story begins with Hope. Hope is the name that Faith and her husband have given to their child who is about to be born. It’s been a perfect pregnancy. But something happens on the way to the hospital. There's a prolapse of the umbilical cord. Dr. Campbell, what is that?

CAMPBELL: The cord slips between the baby and the cervical opening so that the cord is compressed. The baby is deprived of oxygen and nutrients.

MILLER: And, here's Hope. No movement. No breathing. Very weak heartbeat. Now what does she look like?

CAMPBELL: She will, really be limp. Be quite ashen looking. But would be perfectly formed and look like any other newborn.

MILLER: Another baby.

CAMPBELL: Correct.

MILLER: Well, the parents obviously are waiting. Art? You're the father. Melinda, you're the mother. What do you tell them at this point?

CAMPBELL: Hope is quite ill. We are supporting her breathing with the aid of the tube in her windpipe, as well as doing the breathing for her. We've given her medications to try and help her heart work more efficiently and establish her body functions.

MILLER: Do you think they understand what you just said to them?

CAMPBELL: No.

MILLER: No.

CAPLAN: What I think you're saying is that things are gonna be okay. You're just gonna do everything. And, you know, we've been trying--

DELAHOYDE: For a long--

CAPLAN: A long time. I-- you have the technology. I know you do.

MILLER: Dr. Campbell, deep in your soul, what's your expectation?

CAMPBELL: That I'm not gonna be able to solve it.

MILLER: They want aggressive treatment. You don't have any difficulties with that, do you?

CAMPBELL: Not-- not at the start. I mean, I think that you need some time to be able to assess and get a sense of exactly--

MILLER: Well, that time passes. What you find is severe brain damage, a swollen brain, and, a very, very low level of brain waves. The baby is still motionless. So now, it's time to talk to the

parents again.

CAMPBELL: How many days old is she first?

MILLER: Well, let's say a week.

CAMPBELL: OK. Hope is now a week old. She's not able, on her own, to take any spontaneous breaths. Without the ventilator, she's not breathing.

DELAHOYDE: She would not breathe.

CAMPBELL: She would not breathe.

DELAHOYDE: Without the machine.

CAMPBELL: Without the machine.

CAPLAN: Is she dead?

CAMPBELL: She's fully dependent on-- on the machine.

CAPLAN: This can't be happening.

DELAHOYDE: So--

CAPLAN: When we came, you said you would do everything.

CAMPBELL: And, we have--

DELAHOYDE: But, they are trying. They've--

CAMPBELL: We have done everything. We have her on the most advanced respirators. We're supporting her blood pressure. We're giving her intravenous nutrition. We're treating the seizures.

MILLER: What are their options given a baby of this description?

CAMPBELL: Their options are to continue the level of care that we're providing, which is aggressive maximal care. In terms of withdrawing care or withholding care, I think we would still need a little bit more information to be able to definitively say the true level of-- of brain functioning.

MILLER: All right. You've had your time. The baby is not changing in any material way. So, one of their options, if I heard it correctly, is to take the baby off the ventilator.

CAMPBELL: Correct.

CAPLAN: It's not an option.

DELAHOYDE: It's not an option.

CAPLAN: Is that an option--

MELINDA: Our baby's not dead.

CAPLAN: It's not an option in our faith. It's not an option from my personal point of view. It-- it's just not an option.

MILLER: I have a suggestion for you. Dr. Rodgers took care of you during the pregnancy.

CAPLAN: That was a good doctor. (LAUGHTER)

MILLER: Do you want-- do you want to talk to Dr. Rodgers about this situation?

DELAHOYDE: We trust our doctors, but we hear these terrible reports. We don't know. Does she have brain function at all? All these technical terms. What-- what do you suggest we do to help get the information we need about her future?

RODGERS: I think that some of the answers you want, we actually can't provide. We don't know exactly what the baby's long-term outlook will be. Although everything I'm hearing from Dr. Campbell suggests to me that it's going to be very bleak potentially, the baby's outlook.

CAPLAN: Since this all started, I go home. I-- I-- I get on the internet. I see-- people say that babies get better. That doctors aren't always right.

RODGERS: Yes.

MILLER: Dr. Rodgers, why is shutting the ventilator down even suggested as an option?

RODGERS: It's suggested as an option because this baby is very unlikely to, first of all, ever get off a respirator.

CAPLAN: That would be okay. We could do that.

RODGERS: Yes. And, I think that that is an option, quite frankly. But, I think it's important to understand what life for this baby, chronically on a respirator, is potentially going to be like. It isn't that the baby will be on a respirator and life will go on.

The baby will develop pneumonias. The baby will potentially develop any number of other complications. Not the least of which is we have to make decisions about how to feed the baby.

CAPLAN: But if the baby's not on the respirator, what are the options?

RODGERS: The baby will die. There is no question. The baby will die.

CAPLAN: But, that's not an option.

RODGERS: I think given where you are right now, and given your beliefs, the baby will remain on the respirator.

MILLER: Dr. Brookoff?

BROOKOFF: I can't tell you what's gonna happen to your baby. Only God can predict the future. What I bring to the table is I know what's happened to other babies I've treated in this situation. That's what doctors bring, is we bring our experience. And, the fact that we want to promote their life. What I think from having seen babies like this is that they-- they don't live a very long time despite all of our efforts because of the pneumonias, because of being on a ventilator. At the same time, I owe it to you to give you the options.

I don't know if this baby's going to survive. I don't know. And, if I had to guess, I'm worried that the baby might not survive. The only--

DELAHOYDE: But--

BROOKOFF: I have-- I owe it to you to tell you that.

DELAHOYDE: I can't kill my baby. I can't--

BROOKOFF: Well, you can't--

DELAHOYDE: --unplug a respirator.

BROOKOFF: Exa-- let-- let me unburden you.

DELAHOYDE: Is my baby dying?

BROOKOFF: Let me unbur-- let--

DELAHOYDE: Am I-- am I just helping my baby to die? Or, am I actively--

BROOKOFF: No.

DELAHOYDE: --killing my baby?

BROOKOFF: No.

RODGERS: We're not-- we're not asking you to--

BROOKOFF: The decision of--

RODGERS: --to make that decision.

BROOKOFF: --life and death is not yours or mine. It's--

DELAHOYDE: But, it is mine if we decide to pull the plug on her--

BROOKOFF: I'm not-- I'm not telling you to pull the plug. I'm saying if the baby-- to be honest, if the

baby is dying, the baby is dying.

DELAHOYDE: But, is the baby dying?

BROOKOFF: I think she is. She shows no neurologic response and shows so much brain damage. I don't think things will be sustained.

MILLER: Father Paris.

BROOKOFF: But-- but, I don't know.

MILLER: Why is turning off the ventilator even an option here?

PARIS: I've known the Caplans a long time. I performed their wedding. They've been in my parish.

They're good Catholics. We have great emphasis on the sanctity of life and people think this requires that we do everything possible to sustain every life.

But, that's never been the Catholic teaching. We understand that God creates us. That we're created for the purpose of living this life and ultimately going back to God. And, that decision is God's, not ours to make.

It can be 80 years. It can be eight days. And the Catholic tradition in this and I've talked with both of the parents about this, is that if medicine holds out no realistic expectation that the child will improve, then there's no obligation to use it.

And, the cause of death is the underlying disease that's created this problem, not in the removal of the ventilator. So, this isn't killing. This is letting die.

CAPLAN: But I don't want to stop. I don't want to give up.

MILLER: Even though Father says all that's happening is you are allowing her to die as God might have?

CAPLAN: I'll never allow her to die.

MILLER: Ken Connor? What do you think about this situation?

CONNOR: Well, I think it is a very important distinction morally for the mother and dad as to whether or not they're going to take active steps to cause the death of their child or whether or not they're simply going to let their child die.

MILLER: I take it you think that shutting that ventilator down is an active step.

CONNOR: This baby would die obviously without the benefit of the ventilator which means arguably she would die from an underlying medical condition. I don't think that's the same as actively taking her life if the parents decide. I think it's a very difficult decision. I would have less apprehension about removing the ventilator than I would say, depriving the baby of food and fluids in which case she would die arguably from dehydration or-- or malnutrition before she would die of her underlying condition.

MILLER: Marcia A-- Angell?

ANGELL: Well, you know we haven't been talking about the baby as much as we should have. And, that's what I would like to get to. I do think that the parents have the right to make this very difficult decision. I would not stampede them into doing it in the first week or the first two weeks even. I would let them live with it for a while. But, what I would try to get them to understand is that there is no higher brain function here. This baby, fast forward months, years, decades. This baby, even if it could be kept alive that long, would have no feelings, no awareness. None of the things we associate with being a human being. I would try to make them understand what it's like from the baby's point of view,

which is nothing. There is nothing in this baby.

ANGELL: But, that will take time.

MILLER: --this is in the best interest of Hope.

ANGELL: Hope has no best interest at this point. No higher brain function means no best interest.

DELAHOYDE: How can you say that--

ANGELL: (OVERTALK) The parents--

DELAHOYDE: --about a baby? How can you say--

ANGELL: That--

DELAHOYDE: --about our baby?

ANGELL: That is what I would--

DELAHOYDE: Our baby does have a best interest.

ANGELL: --wait to say to you. I would say that to the doctors maybe. I would say that to Arthur Miller. I would not say that to you just yet. (LAUGHTER)

DELAHOYDE: But why would you not say it to me? I am the parent. My baby does have a best interest. My baby has a right to life. My baby has equal protection under the law. All those things that babies have, whether I believe my baby has it or not. Whether there's a higher brain function or not. Unless you can tell me my baby is dying.

CAPLAN: And, you know, doc, medicine changes. Things improve.

ANGELL: That's true.

CAPLAN: Someday they might find something.

ANGELL: That's true. And as I said, this is your choice. This is ultimately your choice. And, I would have the doctors and the hospital do what you wanted to do. But I would let you know that the things that we associate with being human, the capacity to form attachments, to love, to feel, to think, even if it isn't Albert Einstein thinking, that this will never happen to a child with no higher brain function.

CONNOR: But, this baby is alive. This baby is a human being. She's not excluded from the human family simply because her-- thought processes may not be the same as others. For Heaven sakes, lots of folks with dementia in the nursing homes can't form attachments, aren't aware of their surroundings. She's not disqualified as a member of the human family simply because she's profoundly disabled.

BROOKOFF: None of the doctors here have talked about withdrawing support, if you'll notice. It's only the lawyers that have said that. And (LAUGHTER) the thing is, you love your baby things will unfold. And there is time. There's no rush to death. And if I'm gonna make a mistake, I'm always gonna err on the side of life.

MILLER: General-- General Satcher?

SATCHER: I think from the beginning I would've been concerned about these parents. And, I don't know if I would've dealt with them in isolation. I would've wanted to know more about their support system. These parents need to be prepared for the fact that this baby may not survive. I

would've started that preparation in the beginning. But I would've sought some help in terms of dealing with them because they're in a very difficult situation.

ANGELL: I think it's important to tell these parents the-- the truth, even while you acknowledge that it's now the parents who are your patients in a sense. And, that they really do have the final decision.

MILLER: So, this-- this is to me beginning to sound rather holistic.

MILLER: Now, Elder Oaks, they're not Catholic. They're members of your church.

DELAHOYDE: What happened?

MILLER: And, they come in-- (LAUGHTER)

CAPLAN: You met Elder Oaks, that's what happened.

MILLER: They come in and they say, "These people are looking at the potential of success. They're looking at benefits, burdens. Isn't this just simply about sanctity of life?"

OAKS: I think it's about the source of life and the purpose of life. Sanctity of life is kind of a political term. And you know the teaching of our church that when death becomes inevitable, it should be looked on as a blessing, and a purposeful part of eternal existence. I'm not telling you what to do or when to do it. But I am urging you as my-- my friends and fellow believers to see what has happened to Hope as something that's happened to a daughter of God who loves her as much as you do. And who in the great eternal scheme of things is going to see that she is not denied any advantage in the eternities. And while I think you surely should not give up hope if I can say it in that way-- in-- in the short-term, take the long view, and seek guidance through your prayers and your personal consultation with one another.

CAPLAN: But, Elder Oaks, just tell me, you know we tried to have a baby a long time.

OAKS: Yes.

CAPLAN: We've listened to the church on the desire to have children.

OAKS: Yes.

CAPLAN: If-- if we do this now, are we going to kill her? Will that be on our hands if we say yes to that withdraw-- turning off that machine?

OAKS: No, because you will be dealing with a situation that's known to your Heavenly Father, and he does not guarantee any of us unlimited existence. As I've heard some other people of other faiths say, we're sent here with a certain period of time. And perhaps her period is short. And you could not realistically expect to sustain her life by heroic measures through a lifetime. And I don't think that's expected of you by a Heavenly Father who understands the conditions of this circumstance.

MILLER: Dr. Campbell, unfortunately, as a result of the prolapse, Hope has now experienced renal failure. They want dialysis.

CAMPBELL: The concern for Hope is that even with maintaining full support for her, her organs would begin to fail, and we're seeing that now. We could initiate dialysis, but it's-- it's really forestalling an inevitable process for her. She is dying.

DELAHOYDE: She is dying.

CAPLAN: I don't care, honey.

DELAHOYDE: No, she is dying. That-- that presents a different situation.

CAPLAN: Why?

DELAHOYDE: A medical opinion has been given to us by a doctor whom I trust because when others said think of cost benefits and think of quality of life, and think of all these things, she said, "No. Let's-- let's keep Hope alive and see what's happening." She saw Hope as that person regardless of what her potential or quality of life was. But now, this same doctor is saying to me, "Your baby is dying."

CAPLAN: Will this dialysis hurt?

MILLER: He obviously wants the dialysis.

BROOKOFF: You can't do anything that's futile. We do have a standard. We're not gonna do anything that we know is not going to be helpful. We won't do a sham treatment.

CAPLAN: Will the dialysis be helpful?

BROOKOFF: From the point of view of the renal failure, it'll stop the renal failure from killing her. But it's unfolding. We have to face reality. And-- and there's a reality test here. And--

DELAHOYDE: If the reality here is that our baby, from all medical indications, not quality of life indications, not cost indications, not any other indications, but if the medical indications are that our baby is dying, then I think that's a case where we say what-- what is the benefit here to Hope of-- of putting her through a treatment like that when we know that we are looking, from a medical perspective, at her death?

PARIS: The kidney specialists say, "We won't do it." And, this would now be a clash between the parents' desires and at least one segment of the medical community's insistence that it's not appropriate. Then it goes to the ethics committee.

MILLER: And you're it.

PARIS: And I'm it. And what we ask is what is the potential benefit to the person? To Hope? Not to her kidneys as isolated organs. Because we don't just deal with kidneys and hearts and livers and spleens. We deal with this whole person.

Against the horizon of her eternity, what's the benefit that we can offer to her? We listen to the doctors. Dr. Campbell tells us this is a cascade of incidents she's going down. We're unable to reverse these. This is the first of the multiple organs that has failed, but others are surely going to fail. And the ethics committee would rule there's no obligation to provide an intervention that doesn't offer a realistic medical expectation of significant restoration to the patient.

MILLER: And that's what she should tell them.

PARIS: That's what the ethics committee will tell the physicians because we're only asked about the ethics of it.

MILLER: All right. Let me give you an alternative world. It's still baby Hope. She has severe brain damage. But she can see. She can feel. She can hear. But she has a defect in her intestines. And, of course, Dr. Campbell, you'd be ready to do the procedure. Now here's the rub: When you talk to the parents, the parents say no. And you know this baby will die without the operation. And, you know what they're thinking about. Some of these children never talk. They never get out diapers. They're a burden. These parents don't want that burden. Does their will control?

CAMPBELL: We do need to elicit from parents their views, their values and that does have to factor

into our discussions in terms of-- of--

MILLER: Yes, yes, yes, yes, yes. But--

CAMPBELL: --what we offer babies.

MILLER: The parents are a brick wall. We do not want the operation on the child.

CAMPBELL: Actually in the-- in the context of a-- of a baby who you're describing as neurologically very compromised, but able to feel pain and able of suffer, it's adding another burden on this baby without potential benefit beyond just correcting the problem.

MILLER: Dr. Rodgers?

RODGERS: I agree with Dr. Campbell.

MILLER: Nothing you can do? And he's shaking his head again. Every time you talk he shakes his head. (LAUGHTER)

BROOKOFF: If this baby is going to live a life and it's-- it's gonna be ended because I'm withholding what would be normal medical care for any other baby in this situation, I have to ask myself am I being complicit in terminating this baby's life unnecessarily?

MILLER: But can you impose that--

BROOKOFF: (OVERTALK) I'm just--

MILLER: --set of values on those parents?

BROOKOFF: I'm not imposing anything. I'm just tell-- I'm bringing that set of values. At the same time, if you're in my hospital in my ICU, am I gonna withhold a routine procedure that I've done to other babies because this is a baby you don't want to take home? This procedure will keep the baby alive.

MILLER: How can you ignore the wishes of the parents?

BROOKOFF: Who's my patient? That's-- here we're gettin' discordant. Before we were all on the same--

MILLER: Do you have consent for this operation? No.

BROOKOFF: Well, I have to ask myself--

MILLER: I'll sic the lawyers on you.

BROOKOFF: Well, I'll get my own lawyers and protect the baby 'cause the baby's interests and the parents' interests are now becoming divergent and my-- my patient is this baby. That-- that's--

CONNOR: I'll represent him pro bono.

MILLER: Oh, I knew you'd pop in. (LAUGHTER)

ANGELL: I-- you know, this-- this case is very different from the other one. In the other case, we're presuming there was no higher brain function.

BROOKOFF: Right. (UNINTEL)

ANGELL: The first baby was incapable of suffering. So it was beyond suffering in a sense. And so, it

had no best interest in that narrow definition.

Here you have a baby who presumably is capable of suffering. So, once again, what I'm asking is that we look at it from the baby's point of view. Not just the baby's intestine, but fast forward months, years. What will be the condition of this baby? How much suffering will this--

BROOKOFF: (UNINTEL PHRASE)

ANGELL: --baby endure?

BROOKHOFF: Well, that's not the whole thing.

ANGELL: And, if-- if the baby endures terrible suffering for the rest of his or her life, then I would side with the parents.

BROOKOFF: This was a baby--

ANGELL: If that were not an issue, then I think I would think about going to court and getting guardianship. But that's the key issue. What does this mean to the baby? Not to the baby's intestine, but to the degree of suffering that will be a part of this baby's life.

BROOKOFF: This is a baby that's gonna see, and feel, and hear. This is a baby who's gonna know things.

ANGELL: (OVERTALK) Is it gonna feel pain? Is it gonna feel misery? Or, is it--

BROOKOFF: (OVERTALK) It's gonna feel the love of its mother--

ANGELL: --gonna feel--

BROOKOFF: It's gonna hear things. And, as far as I know, this is a baby that can relate with the world somehow at least--

ANGELL: You know--

MILLER: I'm-- I'm-- I'm getting the strange feeling that it's a complete crapshoot which doctor you get.
(LAUGHTER)

BROOKOFF: It sure is.

FEMALE VOICE: It is a little bit.

MILLER: I mean, congressman, shouldn't there be a law about this?

FRANK: About-- yes, there are laws that say, but the laws won't decide the specific cases. If in fact-- there is gonna be some significant benefit-- that the baby later be a hum-- a-- an adult, can survive independently, the fact that the parents see it as a burden shouldn't be a problem.

BROOKOFF: But, where do you draw the line then? What if the baby can't walk and they don't want it?
I mean--

DELAHOYDE: I mean, isn't it a crapshoot what parents you get?

FRANK: Maybe I wasn't clear. Then that-- the-- the baby can't walk-- I'm saying the fact that the parents see it as a burden is irrelevant.

PARIS: If they see it as a burden on themselves, that's irrelevant. But if they see this as Marcia puts it, as a horrendous burden--

FRANK: I agree.

PARIS: --on the baby, it's very different.

FRANK: If you're talking about someone who is gonna only breathe, have no other element of life, that's an easy one. But if you are then saying, "Well, on balance is this individual gonna suffer more pain than pleasure?" that's not a calcul-- calculation the law would make. I would say if you-- you're talking about someone who will be able to exist off a respirator, a sentient being, I would put a heavy burden of proof on keeping that baby alive.

MILLER: All right. All right. As this debate rages, sadly, in the ICU, baby Hope passes away. Now, as one might imagine, the death of the baby has devastated the parents. Even more than you, Faith, somebody who is devastated and distressed is your mother. In other words, Hope's grandmother. Name of Charity. (LAUGHTER)

Time passes. Maybe a year later. And sadly, Charity is beginning to show signs of early Alzheimer's. She's in her 50s. You're still the family doctor.

RODGERS: Charity, from everything we can gather, it's likely that you have the early stages of Alzheimer's Disease. What this means is that over time, you're going to have more and more difficulty remembering things.

You're going to eventually get to a point where you may not be able to live on your own as you do now. And you may need more and more support throughout the rest of your life. And it's important now to do those things that perhaps you said, "Three years from now. Four years from now I think I'll do this." It's important now for you to make those connections or reconnections with people that you kept putting off because you've got a limited period, and I think now is the-- this is the time.

MILLER: Well, that's a lot to think about. So I think about it. Then I want to talk to my husband. Barney, will you be my husband? (LAUGHTER)

FRANK: In Massachusetts. (LAUGHTER)

MILLER: I want to talk to you about something serious. When the time comes that I can't remember things, that I don't recognize you, that I don't recognize Hope-- see? I said Hope. I meant Faith. I still think about Hope. I don't want to be put on a machine. I don't want to have tubes. I don't want to be in pain. But Barney, let me die. Don't give me a cough drop. And I need your word on this. When that time comes, let me die.

FRANK: Absolutely. I completely agree with you. I think it would be useful for us now to write this out because there may or may not be some legal issue. But whether there is or there isn't, I love you and I respect you. And I think you have the absolute right to decide the conditions in which death comes and at what point it is appropriate, particularly when we talk about a complete loss of all the things that have meant life to you. And yes, you have my absolute word, and no matter what the consequences, I will honor that.

MILLER: And by the way, no artificial hydration or nutrition.

FRANK: Absolutely, and I--

MILLER: No tubes. No tubes.

FRANK: I will honor that--

MILLER: I watched Hope. No tubes.

FRANK: I will fight for that. I will do everything that is legally possible to accommodate that and to keep you from a situation in which that would be imposed upon you against what I now know to be your will.

MILLER: Thank you. Bless you, my love. And Barney and Charity get the best medical care, best medication, but she deteriorates. And it's now five years later. And she doesn't recognize Barney.

Now, I-- I-- I have my good days and I have my bad days. They're about equal.

And you know, friend brings a little dog, a little terrier to the house a couple times a week. And I pat it, and it licks my face.

Then I have a stroke. Charity has a stroke. Now her attitude toward life and her ability to enjoy and-- or to be confused, that doesn't seem to have changed as a result of the stroke. But two things have changed.

First, she no longer can speak. Second, she cannot swallow. So that the only way to receive nutrition is through a tube.

FRANK: My answer would be first, I would feel obligated to try to get a response as to whether or not she had changed her mind. It may be that that's beyond hope. If I got no positive indication that she had changed her mind, my answer would be that she should be allowed to die. And that having clearly as an adult made clear what she wanted to be done, that my obligation is to honor those instructions.

CAPLAN: But she did say, "Let me die." Not, "Cause me to die."

BROOKOFF: And not "kill me." I mean--

RODGERS: She said--

FRANK: (OVERTALK) Oh, I think you are quibbling. You didn't know her.

MALE VOICE: No.

FRANK: She-- she-- when she said, "No tubes and no--"

PARIS: No tubes means no tubes.

FEMALE VOICE: That's right.

FRANK: I mean, I-- that's why you have to be very clear she said no tubes. By the way, knowing her--

MILLER: Any tubes? I mean, you take that literally?

FRANK: --knowing her--

FEMALE VOICE: Yes. Yes, she--

FRANK: Knowing her-- a tube-- well, a tube stuck in her permanently? Yes, no-- I would think that's--
what did she think she was-- what-- what did you think she was worried about? An air hole?

MALE VOICE: I would've thought (OVERTALK) she was worried about--

CAPLAN: She was at death's door.

MALE VOICE: No, but that's what she--

MALE VOICE: So, to--

FRANK: But, not-- she didn't say that.

MALE VOICE: I mean--

FRANK: She didn't say--

MILLER: We're not dying, Barney. She's not dying.

FRANK: She didn't-- she didn't say, "When I'm at death's door." She did not say, "Oh, if I'm dying, don't stop me." She said, "If I reach this point where there is no quality of life, where I have no ability to enjoy and-- and-- and-- and have any of that, then don't put tubes in."

CAPLAN: Not there yet. Not there yet.

FRANK: Well, my-- but, she is. And, she said no tubes. She's had a stroke. She can't speak. She was--

TUCKER: Well, she can't swallow. And so, the reality is--

FRANK: And, she can't speak. And, before the--

TUCKER: She will die--

FRANK: Also, before the--

TUCKER: --unless a tube is inserted.

FRANK: --before the stroke, she was already deteriorating rapidly. A good day was a day in which a dog licked her face. Now by my standards, a day in which a dog licked your face, if that's the highlight, you're not in great shape. She having made clear to me what she wanted done with her life, she continues to govern.

MILLER: Father?

PARIS: I've been down this road many times with my mo-- truly, with my grandmother, my mother, my sister, and my brother. All of them said no tubes and no tubes were ever given.

When my aunt-- my great aunt-- tell this story regularly. Aunt Moll has a stroke. My grandmother takes care of her. She bathes her, feeds her as she grows weaker, sips of tea.

Weaker still, nothing.

Into the scene comes young Dr. Miller. He says, "We can put a rubber tube right down Aunt Moll's nose and feed her isocal." My grandmother says, "Glory to be God, Arthur. Have you lost your senses?" (LAUGHTER) "What is your tube gonna do for that?" And then she'd tell you where to put your blessed tube. (LAUGHTER)

MILLER: Elder Oaks?

OAKS: I'm addressing a question to the doctors. When you put the tube down a person's throat because they cannot swallow, how many inches of-- of treatment are we talking about? I'm suspicious that this case fits in the category of-- of what we should do to sustain life in a reasonable, non-intervention way.

ANGELL: But does that matter? People have a right to refuse medical treatment for any reason whatsoever. It's a battery if you force medical treatment on someone. So here you have a person who knows that she won't be able to exercise this capacity. But who then says to her husband, her proxy, "Do it for me."

That transfers her rights to him. He has the right to act as he believes she would want him to act. And I don't see any reason to get into how long the tube is.

MILLER: While you people are conducting this very interesting seminar, Faith has come into the room. And I'm Faith now. (LAUGHTER) Faith says, "Dad, what are you doing? Mom doesn't want to die. Don't you remember about six, seven months ago she had pneumonia? And I took her to the hospital because she was having trouble breathing? And all the way to the hospital she kept-- she-- she just kept gasping, 'Don't let me die. Don't let me die. Do something.' That was mom.

And, the woman who is here today, that's mom. That was mom. Not five years ago." Which Charity are we talking about? Which Charity are we talking about?

DELAHOYDE: Well, that's there's two. That's the point. You can't know who you're talking about. And when I listen to my father over here making decisions about when mom's quality of life wasn't what she would want, well, how do you know? On what particular day? Under what circumstance?

MILLER: Do you think we have a lawsuit here?

CONNOR: Yeah, we got a lawsuit.

MILLER: Do you want to represent Faith?

CONNOR: I'll represent Faith. And I'll maintain that what Charity's decision would be today under the circumstances is what controls.

MILLER: Diane?

HOFFMANN: I'll represent Barney.

MILLER: You want to represent Barney?

HOFFMANN: Absolutely.

MILLER: Want to be a judge? I have some recollection that you used to be a judge. Now you can make an argument. And you can be amicus curiae. Argue to the judge.

CONNOR: Your Honor, we're here today to decide what decision Charity would make today under the

circumstances. We have admittedly a previously executed living will that identified that she didn't want to have any tubes. That was done five years ago.

But more recently confronted with her own mortality, staring the possibility of death in the face, she urged her daughter in the strongest of terms to preserve her life, to protect her, to provide her with the care that she needed. And we-- we think that-- it-- it doesn't matter what Barney's wants. It doesn't even matter for that matter what Faith wants.

The issue here is what would Charity want today under these circumstances? And, we think the most recent evidence available indicates that she would want to live. She's not dying. All she needs is the provision of nutrition and hydration. And respectfully we would urge the court to provide her with the basic-- stu-- sustenance of life in order to preserve her.

MILLER: Diane?

HOFFMANN: Your Honor, we-- we strongly disagree with this characterization of the facts. The patient expressed to her husband in very clear terms when she was competent that she would not want to live under these circumstances. That she did not want any tubes. She made that as clear as she possibly could.

Any comments or remarks that she's made there's a question of-- of whether she was competent to make those-- to make-- those comments at this point. She has Alzheimer's. She had a stroke. They do not appear that they would reflect what she would want.

CONNOR: Judge, she has a right to change her mind. We make decisions far removed from the eventuality that we're gonna face. But here most recently, just a few months ago when-- when-- when Charity was faced with the imminence of her death, if there wasn't intervention, she plead that she would be protected. That her life would be saved.

MILLER: We've granted some time to an amicus who would like to speak.

TUCKER: Your Honor, I'd like to frame the issue in terms of what is the right of the patient that's at

stake here. And when Charity made her wishes known in the advanced directive, she was looking forward to an eventuality such as we confront today. At that time, with all of her values and beliefs in mind, she decided then that should this day arrive, she did not want a tube. And the nature of the right, Your Honor, which has been recognized by our United States Supreme Court in the Cruzan Case, is that this is one of the most fundamental, deeply personal decisions an individual will make in their lifetime. And that kind of a decision is reserved to the individual.

And we must respect that here. Now it's appropriate to make sure the document was executed at a time she had decision making capability. And that it's a valid document. And that the husband is also speaking from knowledge of the patient's wishes and beliefs. But we've done that here, Your Honor. And we must respect that patient's wishes because these are her most deeply held beliefs.

OAKS: There's another consideration if I may that-- that a judge has to think about. Not only the case before him, but the effect of the ruling upon the whole field of the law. As a judge, I would be saying to myself, if I rule against the document and the stated regular intent of the individual, what is that going to do to the validity of such documents in this jurisdiction generally?

MILLER: So you see footprints in the sand.

OAKS: Yes. A judge is responsible to do that.

MILLER: General, what do you think of the way the law approaches this and decides cases?

SATCHER: I certainly agree in this case that given what we know about Alzheimer's, we would think that once she made the earlier decision, she was at her highest competency. And so, I would hope then that-- that the law would see it that way.

And obviously, it's not easy to resolve family conflicts. And you have one here. And so, this is now in the hands of the court. And, they have to rule based on judgment about her competency

at that time.

MILLER: Well, as the case is being heard, Charity passes away. So now, we have Faith. Hope is gone. Charity is gone. Faith, you're going through a tough period and you've been experiencing some physical symptoms. And, you've gone to your doctor, Dr. Brookoff. And, he reports to you that it looks as if you have pan-- pancreatic cancer. Doctor, talk to her.

BROOKOFF: Well-- I-- I have to tell you we-- we saw in the cat-scan advanced pancreatic cancer. And-- it-- it's a terrible cancer.

TUCKER: That's an especially bad kind.

MILLER: You should know that it-- it's fairly early.

BROOKOFF: Oh, okay. Well, then--

MILLER: It's fairly early and maybe there is a 20 percent chance.

BROOKOFF: Well, if it's-- if it's surgically removable, we're very aggressive. And, like I said, you know what? There's no 20 percent chance. Your chances are zero or 100. Probabilities relate to other folks. And all I care about is you. And I think if there is any kind of reasonable chance that we can get you through this and past it, we want to do that. I want to know what you want. And, I-- I want to work with you to outline a plan so that we're both on this page. The one thing I can promise you is I'm sticking with you.

TUCKER: Well, let me tell you what I want. I'm willing to pursue curative therapy. So, if you think surgery has a chance, I'd be willing to do that and/or chemotherapy. Or any other therapy that might give me a good chance of a cure.

But I do know that if that's not successful and I am approaching death, that I want to know that

I can have a measure of control over the time and manner of my death. And, for me, based on who I am and my values and beliefs, it would be important for me to know that if my dying process is prolonged and horrific, that you will assist me in bringing about a comfortable and peaceful death when I feel my dying process is intolerable.

BROOKOFF: What I'm gonna do --

TUCKER: And I need to know if you would do that.

BROOKOFF: What I'm gonna do is I'm gonna keep you comfortable. And just like you're willing to take risks to fight the cancer, and I-- I'm gonna tell you, the chemotherapy can be dangerous. There are dangers that we might accept. I'm gonna do everything I can to keep you comfortable.

TUCKER: Right. But I want to push you a little bit further, doctor, because it's-- it's early enough that I could change doctors. And what I need to know from you is if my dying process becomes intolerable to me, despite your best efforts, and I say, "It's time for me to have a peaceful and dignified death," I want to know that you'll help me with that. And if you can't make that commitment to me now, then I do want a-- a referral.

BROOKOFF: I don't think death is a treatment for anything. And there are-- there are certain things that we might encounter 'cause we're going through this together. There's pain that we can treat. There's sadness and depression we can treat. There are other things that are not medical, but come up. There's abandonment. There's despair. There's anger. And those are all things that have treatments. And--

TUCKER: Well, let me tell you a little bit more--

BROOKOFF: --I want your life to be wonderful even--

TUCKER: --about me, and that is I've been a person that's always exercised a lot of control and autonomy in my life. And I know as I approach death, I'll-- I'll want to be feeling that I'm still an autonomous person. And if I need to obtain medication to let me hasten my death in a peaceful and dignified way, I want to know I'm in the hands of a doctor who will respect that. And so, maybe--

BROOKOFF: Right--

TUCKER: Dr. Angell, do you need a-- a patient? (LAUGHTER) Because maybe that-- I need to look for a different doctor.

MALE VOICE: Don't-- don't blow him off like--

BROOKOFF: No, no. I-- I mean, we-- we're-- we're coming to the issue, which is I don't think a-- a-- a-- a treatment aimed solely at hastening death is a medical treatment.

TUCKER: Well, that's gonna be my decision.

BROOKOFF: Right. That is your decision. But I'm just saying, I don't think that's part of medicine. And I want to get down to brass tacks. I don't want to jerk around and deceive you--

TUCKER: I don't hear a commitment from you that you would honor my request though to make available to me medications that I could take at the time I felt I was ready to--

BROOKOFF: That are aimed-- that are--

TUCKER: --have a peaceful death.

BROOKOFF: --aimed at terminating your life.

TUCKER: Yes. Mm-hmm (AFFIRMING), yes.

BROOKOFF: Not-- not relieving pain or other symptoms.

TUCKER: Well, I appreciate you being so candid.

MILLER: Would it make any difference to you, doctor, if this were taking place in a state like Oregon. That had a statute that under certain conditions a doctor could assist--

BROOKOFF: A doctor could --

MILLER: --a death?

BROOKOFF: --but that doesn't mean he has to. And like I said, I know why I'm here and it's to promote your life.

TUCKER: I-- I think I would look for a physician who would give me that commitment.

MILLER: How about Dr. Campbell?

TUCKER: Well, I don't know. Dr. Campbell, would you be in a-- in a position to make that commitment to me if we traveled that path together--

MILLER: And, assume we're in a state like Oregon, and that the conditions of the statute could be a-- complied with.

CAMPBELL: Under the-- those circumstances-- if-- again, therapy was not beneficial, the patient was not responding, the cancer was spreading, the patient was in the process of dying and it was

acceptable, again within the construct of a societal stamp of approval, if one will, to provide comfort so that the patient could make that final decision--

BROOKOFF: That's not what she said. I'm-- we're willing to give her comfort. She wants us to poison her.

CAMPBELL: She's not asking you to poison her.

FEMALE VOICE: (OVERTALK) (UNINTEL PHRASE) making the decision.

CAMPBELL: She's saying that the decision-- once it is clear she is dying and that there are no other options, she's asking for the control to be able to limit the dying process.

MALE VOICE: What-- what--

MILLER: It's a prescription, doctor.

MALE VOICE: Are you asking (UNINTEL)--

MALE VOICE: That's all it is. A prescription.

MALE VOICE: No, but it's a prescription for what?

MALE VOICE: A vial--

MALE VOICE: For what?

MILLER: A bottle of pills.

CONNOR: What's the act we're asking for? Do-- do-- do we want to the doctor to hasten the death?

TUCKER: I'm asking for medication that I could consume when my suffering become intolerable and my death is impending so that I can gather my family at my bedside in my home, looking out at the Willamette River, say my goodbyes and take that medication knowing that it will bring me a peaceful and dignified death.

MALE VOICE: But, wait--

CONNOR: So, we're asking-- we're asking for assisted-- physician assisted suicide. Chan-- changing the name--

MALE VOICE: --assisted suicide--

CONNOR: --to make us feel better about it doesn't change--

MALE VOICE: But, (UNINTEL PHRASE) suffering in another way.

CONNOR: --the essential nature of the act.

FRANK: Who cares if--

MILLER: All Right, hol-- hold-- hold. Arthur, you may recall that you are Faith's husband. And it so happens that in the shortness of this story telling, you have become a bioethical expert.

CAPLAN: This is fictional. (LAUGHTER)

MILLER: This is your life. That's your wife.

CAPLAN: I don't want her to leave me. I heard the story from the doctor. I understand what the cancer is. And I know she's a fighter. So I know she'll do what can be done. And she'll try it. But, I do support her if she tells me that she can't go on. Not because of what these doctors say about what's the quality of life for her. But if she says to me, "I've now come to the point where it's unacceptable to me," I'm gonna do what I can to give her the means to-- to end it.

MILLER: Now, Barney, you may recall that you are Faith's father. Talk to her.

FRANK: I admire your dignity. I admire the fact that you remain committed to your autonomy and integrity. And I think you are dealing with this terrible situation as sensibly as possible. We didn't ask for it, but you are dealing with it well. And I will do everything I can to facilitate your desires.

MILLER: Now Ken, you also are a relative. This is a family gathering. What do you say to her?

CONNOR: I'd say, well, I respect and understand the importance of her right to autonomy. But we're also part of a community. And our decisions have impact on others. I'm worried about the implications of Faith impressing into service one who is trained in the healing arts to hasten and facilitate her death. I'm worried about the implications that has on the confidence of other people when they learn that this physician was willing to assist a suicide. And I would say there are some things really that-- that are not our decision to make. The time and manner of our death is not something that we can bring someone else in ethically, I think, to facilitate.

MILLER: Melinda, you are also a member of this family.

DELAHOYDE: Because I love her, I understand how much she hurts and I don't want to see her suffer. But at the same time, I cannot get out of my mind the fact that she's asking the doctor to help her kill herself. And-- and, that bothers me on the inside because-

CAPLAN: If I get the pills on--

DELAHOYDE: --what, you know--

CAPLAN: --the internet and give 'em to her, is that all right with you?

DELAHOYDE: No, it's the thought that-- that we don't-- what like-- like Ken was saying, we don't have control over our life all the time.

CAPLAN: But, forget the doctor--

DELAHOYDE: But, it's not--

CAPLAN: What if I gave her the medicine?

DELAHOYDE: No, it's not the doctor. It's the idea that she is actively doing something to take her life. And I think, you know, wait a minute. She-- suppose this is a situation where she wants to take her life, whether the pills are on the internet or from the doctor, because it's her personal choice. But suppose that we were a family where, gosh, we are so sick of this situation. And all the money it's taking. And all the time away from our own family to take care of her. And she's gonna die anyway. Why don't we go to the doctor and get the pills? And, why don't we hasten-- I-

FRANK: Because that's not her choice.

DELAHOYDE: But, how-- but--

FRANK: There's a difference between her choice and your choice.

DELAHOYDE: (OVERTALK) --what difference-- what different does a choice make if the actual circumstances are--

FRANK: About my-- my-- the individual-- autonomy of the individual--

DELAHOYDE: --that her life isn't what she what she wants it to be.

FRANK: Oh, there's a qualitative difference between your deciding and she deciding--

MILLER: As the head of this family, as dysfunction as it is-- (LAUGHTER)

FRANK: Perfectly functional (UNINTEL)

MILLER: I have the prerogative of having people speak in turn. Now Father, you're a member of this family.

PARIS: Well, I've consulted with Elder Oaks. (LAUGHTER) And Faith, we're coming to you now in the issue of faith. Not of autonomy. You didn't create yourself, and you're not fully autonomous. One of the problems in this contemporary world is we just act as if we're absolutely isolated automatons, created ourselves, paint the picture of our own life, and paint it according to our own design. But it's God who created us. And it's to God whom we go. And we'll be judged on fidelity to God's design in all of eternity. So it's not really this life. But the next life that we consider as well.

MILLER: Marcia? Aunt Marcia?

ANGELL: Aunt Marcia? I'm also Dr. Angell, and I would be happy to be your doctor, Faith. And, I would give you the commitment that you're asking for. My obligation is to take care of you. To relieve your suffering. To further your sense of autonomy. To make your last days better.

This isn't a matter of life or death. It's a matter what kind of death. And what I'll do is give you a prescription for some pills that you can keep at your bedside table.

TUCKER: That would give me such comfort --

ANGELL: And that will give you peace of mind. You may never use them. In fact, I imagine that you won't. But I don't want you to think that I'm gonna abandon you at the end of your life, or impose my religion or my philosophy on you.

And I will do everything I can to take care of you as you want to be taken care of. I know that the issue is usually not pain. The issue is usually this sense of growing loss of control over bodily functions, of weakness, of dependence, of hopelessness. And I know that those things are not necessarily treatable. I will do what you ask me to do.

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