

End of Life Experiences: “I Felt Like I Couldn’t Do What She Wanted”

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SCENARIO 1

- You are the guardian for an 83 yo woman with multi-organ system failure who is dying and on life support. Based on earlier conversations the clinical staff had with her, they are convinced that she would want no further life support. Her husband of 65 years insists that life support be continued, saying that he can't bear to lose her, and that he believes there is a chance she may still recover. She has no advance directive and the doctors are looking to you for a decision.
- What would you do?
- Does your state law give guidance for a situation such as this?



SCENARIO 2

- You are the newly appointed guardian for a 70 yo man with advanced dementia living in a nursing home where he is happy and content. He completed an advanced directive prior to being diagnosed with dementia 8 years ago. In the advance directive he stated that he would not want any life sustaining treatment at the end of his life but would want to pass peacefully. You receive a call from an emergency room doctor informing you that he was sent there due to difficulty breathing from underlying pneumonia. The doctor states that the pneumonia was caught early and is easy to treat with a round of antibiotics and he will be allowed to return to the nursing home with no issues and continue with his life as before. Choosing not to treat the pneumonia will mean placing him on comfort care measures. The doctor is looking to you for a decision to treat with antibiotics.
- What would you do?
- Does your state law give guidance for a situation such as this?

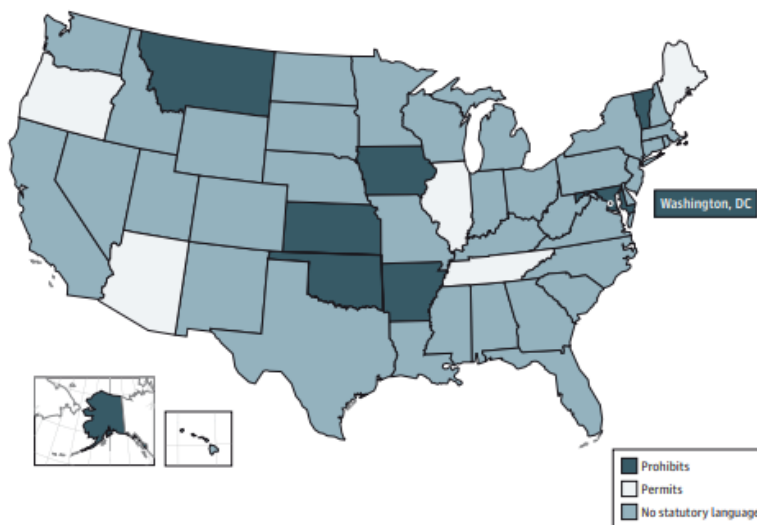


SCENARIO 3

- You are the guardian for a woman who has long avoided medical care. She is now hospitalized with sepsis, respiratory failure and peritonitis and is in need of further life sustaining treatment to continue living. She has no family and no evidence of any written preferences for medical treatment. In an initial conversation involving you and the ICU staff, her parish priest stated that if she could speak for herself she would refuse life support, even if she would otherwise die.
- What would you do?
- Does your state law give guidance for a situation such as this?



Figure. Language About Guardian's Authority to Make End-of-Life Decisions



Permits

- Arizona
- Indiana
- Maine
- Tennessee
- Washington

Prohibits

- Alaska
- Arkansas
- Iowa
- Kansas
- Maryland
- Montana
- Oklahoma
- Vermont
- Washington, DC

Cohen, A. B., Wright, M. S., Cooney, L., & Fried, T. (2015). Guardianship and end-of-life decision making. *JAMA internal medicine*, 175(10), 1687-1691.

METHODS

- 20 open-ended interviews of Massachusetts guardians
- Convenience sample from two publicly available lists (MA Guardianship Association, National Guardianship Association)
- Iterative process of coding and question development
- Three major research questions



THEMES IDENTIFIED BY SUBJECTS

- Unclear whether guardians have authority for EOL
- Reluctance of courts to expand authority
- Impact of delays
- Recommendations



AUTHORITY IS UNCLEAR

I think there's a lot of confusion out there as to when I need to get court authority and when I don't. And I think that that's hard and that's a hard thing for practitioners to be managing day in and day out.



SOME BELIEVE GUARDIAN HAS AUTHORITY

I think the law says as long as there is no controversy, a guardian can do it. As long as family members don't object. As long as there's a medical consensus.



SOME BELIEVE GUARDIAN DOES NOT

End of life decisions ... so now, as you know, we would never be allowed to just go ahead and sign a DNR, DNI, DNH whatever. So, prior to the MUPC it was a little bit easier of a road, the judges that are like a generation, two generations ago were also kind of more practical and less wrapped up in the statutory requirements. Doesn't matter anymore, whatever is happening now is happening now, so it's very procedural.



COURTS ARE RELUCTANT TO CHANGE CODE STATUS

In this one case we went in, it seemed to be clear that this person is really reaching a point where she's not able to eat. She's barely able to breathe because of underlying degenerative disease. I go into court and say we're filing this emergency petition and the clerk said, "The judge is not going to approve that. She never approves these DNR's. She had a case where she allowed a DNR authority and then the person got up the next week and walked out of the hospital. It's gonna be a prolonged process."



COURTS ARE RELUCTANT TO CHANGE CODE STATUS

I think a horrible, horrible situation is that the court's very reluctant to grant changing code status unless the person's on death's door, which I think is horribly disrespectful. I'm grossly offended by that. Me, I can change my code status any time I want, because I have capacity, and nobody can tell me not to. That's how it ought be, I should have the right to do that. I think so, too, should people who are disabled have their rights to do that. Certainly all the due process in the world, but if that's something that they want, I think it's horrible that they're not given that right. If a person under guardianship says, "I don't want to be full code," then I say, "Judge, he doesn't want to be full code, can you help me make this not full code?" The judge says to come back when they're on death's door, and at that point they could get all kind of treatment, which is horrible. It's brutal. That's horribly disrespectful to people with disabilities, I think.



RESULTS IN CRISIS

If you've got an 89-year-old woman who weighs 90 pounds, and she's got pneumonia for the third time, she has dementia, are we going to resuscitate her? Are we going to intubate her? At what point do we stop aggressive medical procedures? They will ship her off to the hospital, and they'll attempt to resuscitate her. She'll be on life support for a few days, and it'll be horrible, a horrible death.



RESULTS IN CRISIS

We recently had a case where it was a poor gentleman, DMH, who we had for years. Perfectly, physically healthy. Got just sick overnight, hospitalized. Went into multi-organ failure. There was ... He was in a coma. He had a massive stroke. He was not coming back. They gave him time, they watch him. They did everything. He's got a whole slew of family members. They all went to visit him. They're all there. They're all talking to the physicians. They all want him extubated, because he has absolutely zero quality of life. We had to go back to court and they were so frustrated that it took so long for us to go through this process. They couldn't understand why this decision could not be made for their brother.



RESULTS IN CRISIS

I got a call from one of my facilities Monday morning, the whole staff was going nuts, 89 pounds, she coded, didn't have the instructions. She bled to death internally and she goes, "I am losing [staff]. I am losing people because this was so shattering." She was such a sweet and little thing.



GUARDIANS FEEL IT IS A BAD LAW

[A panel of judges] all had a differing opinion. One says, it is substituted judgment. It's extraordinary authority. No, it's not. Continue as usual. If that's how you did it, do it. I left there saying, "I'm more confused now, then ever." I came back and sent an email to the staff and said, "They couldn't answer it."



GUARDIANS FEEL IT IS A BAD LAW

This is horrible. I've always thought, what do I do? Do I call the Boston Globe? This is a travesty, what's going on. I want to not wait until someone is in the process of dying or dead, to make these decisions. Literally, it can happen. I once missed a phone call, called the doctor back less than 5 minutes later, and in that time the person had to be intubated.



SO THEY MAY GO AROUND THE COURT

I think there has probably been a couple circumstances that [the client had advance directives] signed and I said, "You're honoring that. I'll sign everything else, but you're going to honor that. Have them sign for that."



SO THEY MAY GO AROUND THE COURT

I'll tell you, you know what I did recently ... I allowed a code status change while he was in the hospital. Then when he was going back the nursing home wouldn't accept the code change. I said, "I'm gonna take liability for this." I did change it while he was in the hospital. They will accept it because they're not under the same guidelines as nursing homes.



HONORING WISHES

It was definitely a frustrating circumstance in guardianship that I wasn't able to do what she wanted.

I think maybe a person should just be allowed to die the way they want to die.



BEST CASE SCENARIO

Some people already have their advance directive spelled out. I'll say, "You know, I'm looking at your advance directives. What do you think about these?" If they're able to tell me, being asked an open-ended question like that, sometimes they're not, they'll either confirm or say, "Rip it up." I had one woman rip hers up. If they can't answer an open-ended question, just say, "I see here that you have said X, Y, and Z in your advance directive. How do you feel about that?" I'll try to use the simplest language as possible. "If your heart stops beating and you're clinically dead, do you want to be brought back? Do you understand what it means to be resuscitated? Would you ever want to be on life support?" It depends. I try to be really sensitive to the person I'm talking with.



BEST CASE SCENARIO

I used to go in whenever people are aging and in order to avoid a crisis I used to go in on a petition for authority to enter end of life orders. I would try to do that ahead of time so that there wasn't a crisis at the time ... and also because I could get hospice involved and I could do all this better planning and supporting.



SOLUTIONS: TRAIN JUDGES

That's what they don't get. They think with DNR you're killing them. Training with the judges, training with DPH. The legislature has to be involved and physicians.

Poor woman is 93 years old who they had to do CPR on while she was dying. Why? So we have to go into court, file a whole new petition, file an affidavit regarding DNR, DNI, medical certificate, the whole thing. Get citation, serve notice. It takes so long... It's just horrible. To me it's one of the worst – judges need training.



SOLUTIONS: CHANGE THE LAW

I respect the judge's role. I really do, but I think it's a statutory mistake. There's a lot of them in the MUPC. We'll leave it at that.

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EXERCISE

In MA we're concerned about this problem and we would like to recommend some clarification to the legislature.

- Under what circumstances would you recommend guardians have the authority to make EOL decisions?
- Is there a tool that you have used to delineate the circumstances in which guardians can make these decisions?
- Is there currently anything going on in your state around this issue and if so what is being proposed?

