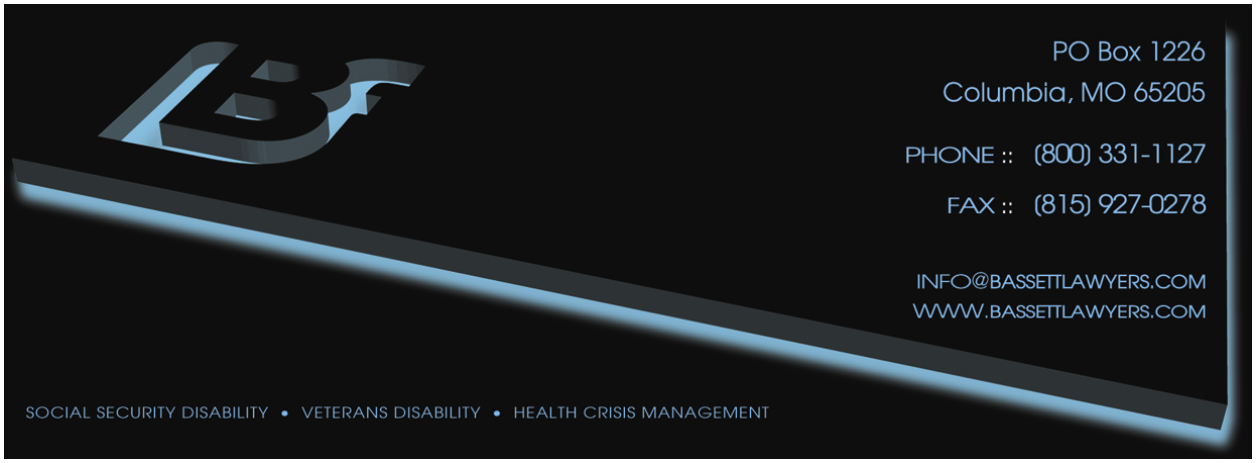

Designated to Decide: How to Help a Loved One Finish Well

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In the video, "When Surrogates Override the DNR," a woman who was appointed to be her mother's healthcare agent explains why she directed emergency room doctors to intubate her mother against her mother's wishes.

It is a compelling video especially in light of the upcoming April 16th National Healthcare Decisions Day and growing discussion about aggressive healthcare at the end of life. The video is a sad story of loss that teaches important lessons about choosing and agreeing to be chosen as a healthcare agent.

A loving daughter agrees to be her mother's healthcare agent. A thoughtful mother completes a DNR (Do Not Resuscitate) and DNI (Do Not Intubate) forms. The mother even goes so far as to wear a bracelet to alert paramedics not to resort to heroic measures to save her life. The mother also has a form on her refrigerator door alerting others of her wishes. Then the day comes which is most feared – her loved ones get a call from an emergency room. Upon arrival, they discover their beloved mother is gravely ill. Emergency room personnel tell them only support through intubation will continue her life. In light of all the mother's preparations, the end should have come quickly as daughter and medical staff honored her explicit desire not to be intubated and then put on a respirator. Instead the mother is intubated by the emergency room physician and put on a respirator in the ICU. The family gathers and watches as the mother suffers in ICU. She dies 22 days later after what everyone agrees was a great deal of terrible suffering.

As the video plays, the daughter who was appointed healthcare agent and another daughter explain why events unfolded as they did. Their explanations illustrate the truth that documents don't take care of people – people take care of people.

The daughter who was the appointed healthcare agent explained that when she arrived at the emergency room, her mother was hardly able to breath, not able to speak and gray in color. At one point the healthcare agent was asked, "Do you want your mother intubated?" In the video, she tells of how she allowed the emergency room doctors to intubate her mother even while her mother shook a protesting finger at her.

What was the healthcare agent's explanation for allowing this to happen to her mother against her obvious protest? She explained she felt she "did not have time to think," "things were happening so quickly," and that "the doctors and family" were all so vocal and all at once. The healthcare agent also revealed that every time she visited her mother in the ICU, she felt her mother's eyes were shouting out her displeasure at being put on life support. Despite this continual feeling, the healthcare agent did not agree to withdraw life support from her mother until three weeks later.

The other daughter defended putting her mother on life support by explaining her view that she was not convinced that the mother understood what was meant by DNR or DNI. The other daughter was not convinced that her elderly mother had received sufficient explanations of the forms that she had signed or the bracelet on her wrist or the form on her refrigerator. All of these indications of her mother's wishes not to be place on life support were meaningless to the non healthcare agent daughter because her mother had never spoken to her about such things. In her mind, little weight could be given to choices that had not been discussed with the whole family. Also the other daughter felt it was only right to wait until all of the extended family had arrived to say whatever goodbyes were necessary. This daughter insisted that the mother would have wanted life support measures, at a minimum, to keep her alive for all of the family to be present at her bedside.

The story ends when finally they asked the mother to blink if she wanted the life support measures to end. When those blinks happened, the family authorized the withdrawal of life support measures. There was a lot of grief in that moment. There was also a lot of guilt because, in that moment, when both daughters understood and accepted their mother's wishes, they accepted and understood their part in the mother's suffering.

But they meant well. They had argued that they knew their mother best. They knew her better than some piece of paper that said not to intubate her or put her on life support. They knew her better than some bracelet that indicated to paramedics where to draw the line at treatment. They knew her better than some form on the refrigerator.

But they didn't.

They acted the way they did, in part, because they did not know and, in part, because they were not prepared. Everyone's suffering could have been lessened if they had understood their mother's preferences better. Such an understanding would have been gained from family conversations about her wishes. As the video makes clear, no such conversations were held. Interestingly, the daughter who was appointed healthcare agent revealed her mother had "told" her that she did not want to be on life support. In a sentence or two, the mother had told her that she did not want to be put on a respirator. But "telling" others of such wishes is not necessarily the conversation needed to make sure those wishes are heard and honored.

The National Healthcare Decisions Day organization encourages families to have a "conversation" about advance care planning. This is the kind of planning needed to ensure a preferred course of healthcare is provided (or not provided) in the event of incapacity. Incapacity occurs when a person cannot speak because of illness or injury. Because incapacity can occur for many reasons that have nothing to do with advanced age, adults of all ages need to engage in such planning.

One definition of "conversation" is "the informal exchange of ideas by spoken words." The daughter appointed to be healthcare agent "heard" her mother say not to put her on life support. The other daughter and the rest of the family never heard anything. No one ever had a "conversation" with the mother so that they would know her "ideas" about life support and her attitude toward dying. There was never an exchange of concerns, wishes or attitudes that helped the family understand whether their matriarch would have agreed to life support until the arrival of all family members**,** although the wagging of the protesting finger in the ER would have suggested otherwise. But without conversations about such matters families can often project their wishes onto their loved one. Besides, such discussions are hard ones. They are vulnerable discussions about values and intimately held (possibly not shared) beliefs.

Some try to avoid the conflict or disclosure involved in such conversations by documenting their wishes in advanced directives. They figure if it is there in black and white, then they can count on their wishes being honored. But documents don't take care of people. People take care of people. A person's advanced directive is not going to become a flesh and blood person, materialize on the side of the road, or in the ER or in the ICU, and assert its contents. A person does that. A live feeling person with their own ideas, values and attachments does that.

Thus, the video offers a twofold lesson. First, the person engaging in advance care planning must understand that it is more about the people than the papers. When choosing a healthcare agent, a person should be sure to have a conversation with their person of choice so that they understand their wishes are not the products of

deception, confusion or manipulation. It must be clear to the proposed healthcare agent that their wishes are not just the mood of the day. The healthcare agent may need multiple conversations to understand and accept choices based on the appointee's values and attitudes about life and death. The video showed there is much to consider in choosing a healthcare agent such as their temperament, place in the family dynamics, and their own feelings about life and death. Thus, the person choosing a healthcare agent and the person being asked to be a healthcare agent, should <u>together</u> identify obstacles and possible sources of resistance that could be faced by the proposed healthcare agent in carrying out the advanced directives

The second lesson is for the person who agrees to be a healthcare agent – the person designated to decide. That person needs to understand that they have two decisions before a health crisis even arises.

First, the person who is asked to be a healthcare agent must decide if they are willing to make the choices he may be asked to make. He or she needs to examine oneself to decide if they have a moral, emotional or other issue that would make it impossible to carry out the choices of the advanced directive – whether that is to withheld life support or order it. The second decision is whether one has the personality or temperament to carry out an advanced directive in the worst circumstances. In the video, the daughter who was appointed healthcare agent often said that she did not have time to decide and that they (ER) wanted a "quick" decision. Also she explained how overwhelmed she felt with the insistent voices of the medical personnel and anxious voices of family coming at her.

Resistance by family members should be considered by both the appointee and the person proposed as healthcare agent. The other daughter, who was not the healthcare agent, repeatedly said that she told the ER personnel that she "did not want to hear" anything negative about her mother's condition. She had decided that she would be a force to be reckoned with to save her mother. This illustrates that even when the appointed healthcare agent, intellectually, morally and emotionally, agrees with the course of care that a loved one has indicated, they may be, by personality or temperament, unable to deal with family dynamics that resist such a course of care. It cannot be overemphasized that the choice of a healthcare agent or the choice to be a healthcare agent involves more than deciding who is smartest or who loves the most. Consider whether what is trusted about the proposed healthcare agent is what will stand in the worst of situations.

Yet it is important to understand that agreeing to be a healthcare agent does not always mean a heart wrenching scene in an ER or in an ICU. Healthcare agents regularly agree to far less dramatic interventions. Healthcare agents can agree to surgeries or procedures for a loved one too upset to think through even a non-life threatening situation. But because people drive through red lights, accidents happen and fatal diseases can make an ugly announcement of their presence,

people who agree to be a healthcare agent need to be emotionally and intellectually ready, willing and able for anything. Being ready and able is more likely if the person choosing a healthcare agent engages that person in open and honest conversations. From a true dialogue, the person choosing a healthcare agent can gain a finish of life of their own choosing and the person chosen as the healthcare agent will gain the peace of having helped a loved one "finish well."

This video is found at www.geripal.com, *A Geriatrics and Palliative Care Blog*

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