

Discussing Do-Not-Resuscitate Status

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A 53-YEAR-OLD woman is admitted to the hospital because of lower-extremity swelling and pain. She has a history of breast cancer, metastatic to bone and liver. She has been treated with several different courses of combination chemotherapy. There is no record of existing advance directives or evidence of any discussion about advance care planning in the medical record. The diagnostic work-up reveals an extensive deep vein thrombosis.

Scenario One

A resident physician, looking preoccupied, enters the room.

MD: Mrs B, according to hospital rules, I need to discuss your code status with you. Do you wish to be a full code or a no code?

Mrs B: (*looking pensive*) Oooh, I don't know I've never thought about this before I don't want to die. I still have relatively young children.

MD: So, you want to be a full code?

Mrs B: Yes, I guess so

MD: Okay.

The physician leaves the room.

Scenario Two

A resident physician, looking uneasy, enters the room.

MD: Mrs B, umm, uh, if anything were to happen, do you want us to do everything?

Mrs B: (*tentatively, after a pause*) I don't understand.

MD: (*speaking quickly*) Well, if your heart and lungs were to stop, would you want us to use shocks to start your heart and put you on a breathing machine?

Mrs B: Yes, I guess so

MD: (*with increased volume and forcefulness*) You mean you want us to jump up and down and break your ribs and put a big plastic tube down your throat and do a lot of aggressive and invasive measures only to have you die in the intensive care unit?!

Mrs B: (*meekly and seeming a bit frightened*) Oh, I guess not.

MD: (*in original tone of voice*) OK, so you want DNR status.

The physician leaves the room.

The clinical situation described above is one in which virtually all knowledgeable health care providers would recommend a do not resuscitate (DNR) order. The patient has advanced chemotherapy-resistant metastatic cancer with a limited life expectancy (months). Were the patient to have a cardiopulmonary arrest, there would only be the remotest of chances for the patient to have any substantial survival after the resuscitation attempt.¹

In the United States, when a patient is hospitalized, it is generally recommended that a DNR order be discussed with the patient and that the discussion be documented. The scenarios above represent composites of discussions that I've witnessed or that I've heard described by both physicians and patients. The medical literature suggests that these are common approaches to this discussion.²⁻⁵

Let's analyze these two scenarios. In both, the physician fails to place the conversation in the context of a larger discussion of goals of care.⁶ In neither case does the physician engage in a discussion about the issues that are most pertinent to decision making or important to the patient. The physician does not educate the patient about what "full code" and "no code" mean relative to her overall medical condition. Both physicians ask the patient to provide an answer to a question about which the patient is not properly informed. In short, the physicians fail to communicate well. Not surprisingly, they came up with different "answers" to the same question.

The physician in the first scenario presumes that because the patient does not want to die, she would like to be resuscitated. Yet, cardiopulmonary resuscitation (CPR) will not provide the longevity that she expects. In fact, most would consider CPR in this setting to be futile medical care.¹ Unfortunately, the end result is a patient with a "full code" order in her hospital orders who mistakenly thinks her "choice" will have an impact on whether she lives or dies.

The physician in the second scenario started by asking the patient if she wanted everything. This was the first mistake. The physician used the term in the medically colloquial way. "Doing everything" is euphemistic jargon that has one meaning to the physician but another for the patient. The implied alternative to "everything" for the patient is "nothing." The issue of abandonment is implicit in any discussion

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of DNR status. It is essentially explicit when DNR status is discussed using this “all or none” framework.

In general, most patients want “everything.” More precisely, patients want everything done that will be of benefit to them. There’s a critical distinction between “everything” and “everything that will be of benefit.” The issue is what is likely to be beneficial. That determination can only be made in the light of specific circumstances. The error in this scenario is that no groundwork for a mutual understanding of those circumstances was laid.

When the patient said she didn’t understand, the physician responded mechanistically about CPR and advanced cardiac life support (ACLS) procedures. This was the physician’s second error. The physician talks about body parts as if they were isolated entities with no relationship to each other or to the rest of the body. If the heart stops, shall we try to start it? If the lungs stop, shall we breathe for you? The conversation could just as well be about a car. If your battery stops, do you want us to jump-start it? If your carburetor doesn’t work, do you want us to blow gas into it?

For the purposes of discussing DNR status, it is unwise to begin the discussion with the inference that the heart “just stops” or the lungs “stop working.” Unless there is a shared understanding of what might cause them “to stop,” or what could be done after their function is restored, the inevitable (and understandable) response will be the one this patient gave.

Introducing a DNR discussion this way unintentionally implies that the impossible is possible. A false sense of reversibility is conveyed. This reductionist approach fails to acknowledge the context in which CPR would be administered to a patient who is dying of cancer or its complications. In the case of advanced cancer, circulation and breathing generally stop because of the relentless progression of the cancer.

The physician in the second scenario then replies with what some might call the “aggressive gambit.” Rather than engaging her in a discussion of her overall situation and sharing an opinion about the medical efficacy of CPR in her case, the physician described CPR and ACLS procedures in the most frightening way possible. It seems likely that the physician was hoping that the patient wouldn’t want such aggressiveness and would decline the intervention. One could imagine that, if the patient continued to say yes, the physician would have provided a more detailed portrayal of the horrors of the resuscitation attempt itself as well as of dying in an intensive care unit (ICU). Alternatively, the physician could have left having not “gotten” the DNR and told his colleagues that she “wants everything.”

Table 1. Recommended Steps for Discussing a DNR Order

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1. Establish an appropriate setting for the discussion.
 2. Ask the patient and family what they understand.
 3. Find out what they expect will happen.
 4. Discuss a DNR order, including context.
 5. Respond to emotions.
 6. Establish and implement the plan.
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RECOMMENDED STEPS

A step-wise approach to discussing DNR status is helpful, particularly for those who are inexperienced or who are early in their training where this has generally not been demonstrated.⁵ A multistep protocol has been suggested to guide the discussion of treatment preferences, particularly when considering withholding or withdrawing a life-sustaining therapy.⁷ Discussing DNR status is but one element of such a discussion. In this sense, it is an example of the interview in which important medical information needs to be conveyed.⁸ Over the course of many years, I have adapted these approaches to teach this skill to house staff, physicians, and other trainees.⁹ The steps are summarized in Table 1.

Establish the Setting

First, arrange to have the conversation in a place that ensures comfort and privacy for everyone. Be sure to sit down in order to be at eye level with the patient. Ask the patient if family members or others should be present. Be prepared to postpone the discussion if this is true. Introduce the subject with phrases like the following:

- I’d like to talk with you about possible health care decisions in the future.
- I’d like to review your advance care planning. Would you like your daughter to be here with you?
- I’d like to discuss something I discuss with all patients admitted to the hospital.

What Does the Patient Understand?

Second, ask an open-ended question to elicit what the patient understands about his or her current health situation. This is an important question, and one that many clinicians skip. It is important to get the patient talking about how he or she sees the current health situation. If the doctor is doing all the talking, it is unlikely that the rest of the conversation will go well. Consider starting with phrases like these:

- What do you understand about your current health situation?
- Tell me about how you see your health.
- What do you understand from what the doctors have told you?

If it becomes clear that the patient does not have the same understanding that you have about his or her overall health, this is the time to determine whether the patient wants to discuss the real picture or not. I remember a patient who had extensive pancreatic cancer. I was called as a consultant because she “wouldn’t be DNR.” When I asked her this question, she said, “The doctors think I have cancer.” I answered with the obvious follow-up question, “What do you think you have?” She said, “I think I have some indigestion.” Clearly, we needed to establish a more common understanding of her situation before we could talk about future medical decisions.

What Does the Patient Expect?

The third step, for patients who understand the status of their disease, is to ask the patient to consider the future. Use this step to determine or reconfirm general goals of care. Examples of ways to start this portion are as follows:

- What do you expect in the future?
- Have you ever thought about how you want things to be if you were much more ill?
- What are you hoping for?

This step allows you to listen while the patient describes a real or imagined future. In my experience, most patients with advanced cancer describe their thoughts about dying when guided this way. It creates an opportunity for the physician to clarify what is likely or unlikely to happen. Don’t hesitate to ask follow-up questions in order to clarify his or her vision of the future. If there is a sharp discontinuity between what you expect and what the patient expects, this is the time to discover it. In other words, be sure you share the same understanding of the overall goals of care. This step will also give you a sense of the person’s values and priorities.

Discuss a DNR Order

Now that you have set the stage with a joint understanding of the patient’s present and future, you can discuss resuscitation, the fourth step. You can use your insight into the patient’s values and priorities to structure the conversation. Use language that the patient will understand, and give information in small pieces. Stop frequently to check for reactions, to ask for questions, and to clarify misunderstandings. You may want to offer your assessment that a DNR order would be appropriate.

Be sure to establish the context in which resuscitation would be considered. This is another important aspect that physicians miss in DNR conversations that don’t go well. The classic misstatement on the part of a well-meaning physician is, “Do you want us to do everything?” This highly euphemistic and misleading question fails to ac-

knowledge context. When are we talking about? Today, when the patient is ill but expecting therapy to reverse the illness, or at the very end of his or her life when medical therapy has failed to reverse the underlying disease? “Everything” is much too broad and is easily misinterpreted by patients and families. This is especially true when they feel “everything,” in fact, has not been done. Consider starting with questions like these:

- If you should die despite all of our efforts, do you want us to use “heroic measures” to bring you back?
- How do you want things to be when you die?
- If you were to die unexpectedly, would you want us to try to bring you back?

Using the word “die” helps to clarify that CPR is a treatment that tries to reverse death. To a layman, when the heart and/or lungs stop, the patient dies. I don’t start discussing resuscitation by introducing CPR as “starting the heart” and “putting on a breathing machine” because of the inaccurate implication of the independence of body parts or vital organs.

Listen carefully to the response. Many patients with cancer have thought a lot about dying. They only need permission to talk about what they have been thinking. My experience is that the majority of patients describe goals of comfort, being with family, and avoiding unnecessary medical treatment. Setting up the conversation in this way permits the physician to respond with clarifying and confirming comments, such as:

- So what you’re saying is, you want to be as comfortable as possible when the time comes.
- What I hear you saying is you don’t want it to be like your friend. You don’t want us to “call a code” if it won’t do any good.
- What you’ve said is you want us to do everything we can to fight this cancer, but when the time comes, you want to die peacefully.

If the patient and family respond to this portion of the discussion with, “Can you explain more about what you mean?” you can then move to more specific descriptions depending on the circumstances. You may want to discuss specific CPR and ACLS procedures in more detail at this point in the discussion.

Another way to approach this part of the discussion is to begin by offering your own recommendation. After all, CPR is a medical therapy with indications and contraindications. In that sense, it is not different from other possible therapies offered to patients with cancer. You can offer your suggestion, just as you would for other therapies, and elicit the patient’s response. Examples of this approach are:

- From what you’ve told me, I think it would be best if I put a DNR order on the chart.

- I recommend that we put a DNR order on the chart.
- Most patients who have expressed such opinions have a DNR order.

Reasonable physicians may argue that it is unnecessary and potentially confusing to patients and families to ask them to decide about CPR if it will be unsuccessful. Research shows that patients with cancer who have an unwitnessed cardiopulmonary arrest in the hospital do not survive to discharge.¹ Patients and families are ill served if physicians regard the principle of autonomy as meaning that physicians must offer all possible therapies from which patients and families choose, as though they were choosing items from a menu in a restaurant. However, it is useful to discuss and recommend withholding CPR in light of the general or overall goals that have previously been established by the patient. Furthermore, many health care institutions have policies that require evidence of a discussion before a DNR order is entered.

As a consultant who is often called in for patients who “won’t be DNR,” I have frequently found that the root issue is confusion about the overall goals. Patients may need help to see that a decision about DNR status is not necessarily related to decisions about the intensity of the effort to cure or control the cancer. In fact, they may need reassurance about “continuing to fight.” It can be stated that a DNR status does not mean that the medical team will not fight for the patient to live “as well as possible, for as long as possible.” Resuscitation in the event of a cardiopulmonary arrest after “everything that can be done, has been done” appeals to very few people who have confidence that this is so.

Respond to Emotions

Patients, families, and surrogates may experience profound emotions in response to a discussion of CPR when conducted in this way. It shouldn’t be surprising that patients, when considering the end of their life, might cry. Parents, if the patient is a child, are likely to be very emotional and need support from the physician and other members of the health care team. Usually, the emotional response is brief.

The fifth step is to respond sympathetically. The most profound initial response a physician can make may be silence and offering facial tissues. Consider using phrases like:

- I can see this makes you sad.
- Tell me more about how you are feeling.
- You seem angry.

In teaching the skills described here to house staff, the most common barrier they describe is not wanting to precipitate emotion that they don’t feel prepared to handle.

Consequently, they either avoid these conversations entirely or structure them in such a way as to minimize the chance of the patient being “out of control.”

The best way to overcome this barrier is to learn how to sympathetically respond to the patient who has an emotional response.^{7,8} As with most aspects of being a physician, a sense of competence leads to a willingness to engage in the challenge. The most important message is that emotional responses are usually short-lived. The vast majority of patients have good coping skills and appreciate the presence of the doctor while they work through the experience and emotions of their illness.

Establish a Plan

Sixth, establish and implement a plan that is well articulated and understood. Depending on your judgment, and the institutional policies under which you work, you may want to describe the orders, such as DNR, that you will write. Written consent is required in some settings. You can also clarify the orders and plans that will accomplish the overall goals of care that relate to the cancer, other medical conditions, symptom control, and so on. Your plans might include convening a family meeting to discuss the patient’s preferences or to assure that a key family member living out of town is notified about the patient’s status and treatment plans.

Discuss treatment preferences with other health care professionals so that the plans may be carried out in a straightforward and organized fashion. In health care institutions, this involves discussing the plan with nursing and other house staff at a minimum.

Write appropriate orders. Some have advocated a do not attempt resuscitation (DNAR) order in preference to a DNR order to try to avoid the unintended implication of reversibility that DNR holds. Others have advocated orders like “permit natural death to occur,” particularly when death is expected, to better indicate the overall treatment plan.

Be sure to write orders in addition to the DNR order. A DNR order does not address any aspect of care other than preventing the use of CPR. Include all positive orders that relate to symptom control and those that guide intensity of care. Some institutions have special forms to facilitate communication and documentation of orders. It will be rare that only a decision about DNR status is the result, if this step-wise approach is used. In fact, engaging in a discussion that focuses only on DNR status may leave the patient and family confused and anxious. Additionally, it is unwise and poor practice to use DNR status as a proxy for other life-sustaining therapies. For example, in the case that began this discussion, a DNR order will not address decisions about the use of antibiotics in the event of cellulitis,

orthopedic intervention for a fracture, or management in the event of an acute pulmonary embolus. Put the discussion of resuscitation into the context of all the life-prolonging therapies that may need to be decided and affirm what therapies will be continued even if others are foregone. Consider describing various scenarios and eliciting the patient's preferences. Consider using the following language:

- We will continue maximal medical therapy. However, if you die despite everything, we won't use CPR to bring you back.
- We'll continue the intravenous antibiotics and white-cell growth factors, but we won't plan to move you to the ICU if things worsen.
- It sounds like we should move to a plan that maximizes your comfort. Therefore, in addition to a DNR order, I'd like to ask my hospice colleagues to come give you some information.

ADDITIONAL NOTES

What if the patient continues to want CPR in the event of expected death from cancer? My own approach is to ask them what they are expecting to happen. Usually patients or families describe the hope for a miracle or not wanting to "give up." In these situations, I try to identify the underlying emotions and express my understanding. For example, I might say the following:

- I want to give you the best medical care possible.
- I would do anything I knew how to do to make the cancer better.
- I do believe in miracles, but they are rare and by definition not in my power to bestow.

Some patients focus on the aspect of the "last chance" that CPR seems to hold out for them. In these cases, I ask them to tell me what they think would be done differently after the resuscitation that wasn't being done before. They usually describe a hope for a new treatment. I use the opportunity to describe my earnest conviction that I would be doing everything in my power to prolong their life before a cardiopulmonary arrest. I wouldn't be "saving something" to do after they had died.

Finally, some patients persist in wanting CPR. In those cases, I ask the patient to engage in a discussion about care if they survive the resuscitation attempt. While I reassure patients that, if there is a chance for recovery, full care will continue, I tell them, nonetheless, that I need guidance because it will be most likely that they will be unable to communicate after CPR. I usually indicate that, if someone is on life support in the ICU, it becomes clear in a few days if they will be able to recover, or whether life support is prolonging an inevitable death. I ask for them to help me

determine what the guidelines will be for deciding whether to remain on life support or not if they are unable to participate.

CASE REVISITED

Let's revisit the case presented at the beginning of this article. What might the conversation look like if the above steps had been followed?

A resident physician enters the room, unhurried and comfortable.

MD: Mrs B, I'd like to talk with you about something that I discuss with all my patients. Is this a good time?

Mrs B: *(pause)* Yes.

Physician puts a chair beside her bed, adjusts the curtain around the bed, and sits down.

MD: Now then, tell me what you understand about your health.

Mrs B: *(pause)* Well, you know I have cancer. It started in my breast, but now it's in my bones and in my liver. We've done lots of chemotherapy. Now I'm in the hospital because of this blood clot.

MD: Hmm. That's what I understand, too. What are you expecting?

Mrs B: *(looking a little puzzled)* I'm not sure what you mean. In the hospital?

MD: I'm sorry. I don't mean to confuse you. I was wondering what you see for yourself in the future.

Mrs B: *(looking thoughtful)* Well . . . I'm hoping I'll get over this blood clot and feel a little stronger. *(pause)* I know you can't cure this cancer. I know I'll die from it at some point. I'm hoping that they can give me enough time to see my daughter graduate from college. *(longer pause, a little tearful)* But I know that isn't likely. *(pause, then smiling)* I do know I'd rather not be in this hospital very often *(with a snort of laughter)*.

MD: *(smiling)* I know what you mean. So many patients feel that way. *(pause)*

Mrs B: My mother died in the hospital. I don't want it to be like that for me.

MD: How do you want it to be?

Mrs B: Well, I'd like it to be peaceful . . . and without any pain. I don't want to be a burden to my kids. I'd like to just fall asleep.

MD: So what you're saying is that when the time comes for you to die, whenever that is, you don't want heroic efforts to bring you back.

Mrs B: *(quickly and firmly)* Oh no. When it's my time, I want to go.

MD: I think that is a wise choice. So let me summarize what I've heard you say. You're expecting this blood clot to get better, and you're hoping that we can keep this cancer

under control for as long as possible. But, if you die despite our best therapy, you don't want us to try to resuscitate you.

Mrs B: That's right.

MD: I'd like to put a DNR order in the chart in order to be sure we follow your wishes. Of course, we'll still be doing everything we can to get your blood clot treated and try to get you feeling better and back home.

Mrs B: I know you're doing your best to help me. I think that would be a good idea.

MD: Okay. That's what I'll do. What other questions do you have for me before I leave?

Mrs B: Nothing right now.

MD: Right. I'll see you again in the morning.

The physician leaves the room.

Successful discussions about DNR orders begin with communication about overall goals of care before focussing

on the narrow instance of whether or not to administer CPR. Like most skills, it is easier when it is practiced and when there is a structure to guide the beginner. Working to help patients and families achieve their goals and understand the limits of modern medical care can be rewarding when this skill is mastered.

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