

in a dead person. In non-donation circumstances, the precise moment separating alive from dead is usually inconsequential, because physicians declaring death have the luxury of time. In the circumstances of donation, timing is critical to minimize warm ischemic exposure of the organs being transplanted. Thus, a reasoned judgment must be made about the moment of death that is conceptually coherent, physiologically plausible, and socially acceptable.

Physicians should apply the circulatory criterion for death similarly whether or not organs are intended to be donated. When a dying patient with a do-not-resuscitate (DNR) order is not an organ donor, death is usually declared at the moment of asystole, a time when it still might be possible to resuscitate the patient if cardiopulmonary resuscitation (CPR) were attempted. Thus, physicians require only the permanent cessation of circulation in order to declare death. In DCDD donors, too, death is declared when circulation has permanently ceased. Permanence is established by two conditions: that sufficient time has elapsed after the occurrence of asystole to assure that circulation will not restart spontaneously (autoresuscitation) and that CPR will not be administered.⁵

Although public-survey data consistently reveal confusion over

the concepts of death and criteria for determining it in both DBDD and DCDD, reviews of professional and public opinion from several studies reveal strong support for the DDR.⁴ Indeed, the DDR is so clearly regarded as an axiom that survey questions assume its essential role and inquire whether the protocols for DCDD or DBDD violate it.⁴

I believe that the DDR is an indispensable ethical protection for dying patients who plan to donate organs and one that strengthens public trust and confidence in our voluntary system of organ donation. Public support for organ donation is broad but shallow. It remains precarious and can be shaken dramatically by highly publicized donation scares such as those following a BBC *Panorama* exposé in 1980, CBS's 1997 report on *60 Minutes* about the Cleveland Clinic's consideration of a DCDD protocol, and the story of the California transplant surgeon who allegedly wrote terminal care orders for an organ donor in 2006. Many people harbor a fear that physicians have a greater interest in procuring their organs than in their welfare. They need the reassurance provided by the DDR. In 2006, the Institute of Medicine supported the DDR as a protective standard necessary to instill public confidence.

I favor strategies to increase the organ supply such as improv-

ing donation consent rates by enhancing family education and communication, optimizing end-of-life care for donors while supporting grieving families, and developing state donor registries to authorize first-person donor consent. Recognizing that the harms of abandoning the DDR exceeded the benefits, John Robertson proposed a two-part prudential test for assessing proposed changes to the rule, asking what effect they would have on the protection of vulnerable persons and on preserving the public trust.² These essential questions need to be answered conclusively before our society considers abandoning the DDR.

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What Would You Do if It Were Your Kid?

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I know we're not supposed to have favorites, but Lizzy was one of mine. She was 8 years old. Her eyes still sparkled, even

though her curly brown hair had long since fallen out because of radiation and chemotherapy for a malignant brain tumor. When the

tumor recurred, her parents and I knew she would ultimately die of her disease. But she felt fine, and it was impossible not to give

second-line therapy a try. Things did not go well. Within 2 months, Lizzy had a worn and vacant stare, and her normally animated face was expressionless.

Then, during an MRI, she inexplicably went into respiratory distress and was whisked away to the emergency department. I saw her in the trauma bay, laboring to breathe, her eyes ablaze with fear and confusion. She would die if she wasn't intubated. But should she be? We went back and forth: she would ultimately die of her disease, and perhaps that was happening now. But it was so sudden, and what if the problem was something fixable — a pulmonary embolus or aspiration pneumonia? On the other hand, how much more should a dying child have to endure? Yet those of us who loved Lizzy were ill prepared to let her go.

To escape the chaos of the emergency department, I sat with Lizzy's parents squeezed into a storage room crowded with monitors and IV poles. We discussed the pros and cons of intubation, and through tears her mother asked me, "What would you do if it were your kid?"

I suppose we've all been asked that question: What would you do if it were your child, your mother, your brother, your husband? Sometimes I've asked people what they mean by this question — and been answered by puzzled looks saying, "What do you mean what do I mean? I just want to know what you would do if it were your kid!" People may ask this question because they reasonably assume that the option we'd choose for those we love the most is the best option and therefore the most appropriate for them. They may also be seeking to humanize

us, to make our involvement personal. They're entreating us to approach them or their relative not just as another case, but as a human being with as much value as our own sons and daughters, mothers and fathers. It's another way of asking for guidance, a plea to share with them, as a partner, the heavy burden of decision making.

They may not appreciate, however, that when it comes to making medical decisions for our own families, we may draw on our emotions at least as much as the objectivity required for sound medical decisions. In addition, medical decisions, particularly regarding goals or limits of care, are seldom straightforward and depend on the medical scenario, the patient, the family, and their culture and philosophy of care. What I might want for my daughter (and what she might want) may be very different from what Lizzy and her family want.

So how do we answer? How do we balance our professional judgment with the very personal judgments that such a question asks us to make? We could avoid answering altogether, explaining that since we're not in the same situation we cannot possibly know what we would do. But though there may be truth in that answer, it denies our patients an important piece of information that may help them make an agonizing decision. Another option is to answer as honestly as possible.

I often combine these approaches, explaining that I would be presumptuous to think I could say with confidence what I would do if it were my child, because when it comes to my child, my thinking is more emotional than rational. In that situation, I'm a father more than a physician,

and not ever having stood where my patient's family stands, I'm not certain how I'd react. Then I say, "But here is what I *think* I would do" I thus acknowledge the extraordinarily stressful decision they're wrestling with, while providing some guidance by answering their question. Families deserve an answer, however difficult it may be for us to provide it.

But what if what we're recommending for our patient is different from what we would do for our own child or spouse? Do we share that information? Or is it acceptable to be less than truthful? I recall meeting with the parents of a 9-month-old with a progressive neurodegenerative disorder who was beginning to cough and choke when fed. The discussion centered on whether a G-tube should be placed in this infant whose prognosis would be very poor either way. The parents, of a noninterventionist bent, were inclined to let things take their natural course. But the feeding issue was hard for them. My sense was that they didn't want to have the G-tube inserted and were looking for permission not to do it. Then the father asked, "What would you do if it were your kid, doc?"

My mind raced: "What would I do, what would I do . . . ?" If this were my child, I thought, I would want the G-tube. But isn't that the father in me, making a decision based on my own family, culture, philosophy, values, and emotions? Is this man seeking the physician's recommendation or the father's — or is he even considering that distinction? If I tell him what I would do if it were my kid, might I inadvertently put some pressure on this family to do what their instinct tells

them not to do? Or should I lie? Should I tell them what I think they were hoping to hear, knowing there is no clear right or wrong, no single standard of care? The father must have seen panic in my eyes, because he didn't push me to answer, mercifully moving on to something else.

Had he pushed, I probably would have said, "If this were my child, I would decide on the basis of comfort. If I could ensure that he'd get enough to eat and drink to remain comfortable, I would forgo the G-tube. But if he continued to cough and choke and seemed irritable and hungry despite his medical team's best efforts, I would consider the G-tube."

In Lizzy's case, answering the question was not so much hard as tragic. If she'd been my daughter, I would have wanted her to

be intubated, and I told her parents so. That was clearly their wish as well, and it made the most sense to all involved. We hoped that if we had a little more time to figure out the problem, her condition might be stabilized long enough for her to say goodbye. And that's what happened. Lizzy briefly rallied, the tube came out, and she and her family said their goodbyes before she died. Her parents still hold onto that rally as their gift from Lizzy.

The "What would you do?" question is daunting but common. Though sometimes the personal and professional answers converge, other times the question creates conflict for clinicians. Perhaps before we discuss difficult decisions with patients or families, we should ask ourselves how we would answer that

question. We should remember that our patients ask it because they're seeking guidance, not a menu of options, and I believe we should answer as honestly as possible. Perhaps it's not such a bad thing if our perspective as a parent or a spouse is a part of our answer. Sharing a little piece of ourselves with patients and families humanizes us at a time when they need us to be human and sends the message that we are all in this together.

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