

Voluntary Stopping of Eating and Drinking (VSED)

BY CATHY SUSKIN

The question of how to respond to intractable suffering in patients with debilitating and life-limiting illness has no easy answers. For those whose suffering is primarily physical, good palliative care is often the best choice. Others qualify for hospice care as well. Some have the option to stop or not start unwanted life-sustaining treatments, and for others, Physician-Assisted Dying (PAD) is now an option.

But not all who suffer from debilitating or progressive illness have these options. Some people suffer from a devastating illness or from multiple chronic ailments that seriously compromise quality of life but are not terminal. Others have a terminal diagnosis, but there are no treatments to decline or machines to disconnect. Maybe the illness is not yet far enough advanced to qualify for hospice or PAD, or there is little pain but great suffering at the prospect of future decline. In this category are illnesses such as ALS (Lou Gehrig's Disease), Huntington's, AIDS, quadriplegia, dementia and cancers not yet at end stage, to name a few. While palliative care is available to all who suffer from serious illness, it is not a panacea. Sometimes despite a physician's best efforts to address the sources of the patient's suffering, a satisfactory solution cannot be found. For these patients, as well as those with advanced illness, Voluntary Stopping of Eating and Drinking (VSED) is an available option.

While not widely discussed in the medical or legal literature, this method of hastening death is legal in Vermont and in all other states.¹ Often overlooked in physician-patient conversations about end-of-life options, VSED is nonetheless practiced here,² sometimes in combination with other end-of-life care.

VEN is receiving increasing inquiries about VSED. Possibly, this is attribut-

able to legalization of Physician-Assisted Dying (PAD) in Vermont, as people seek alternatives. Possibly it is a consequence of Vermont's Patient's Bill of Rights, which now requires that patients with terminal illness be informed of "all available options for terminal care," regardless whether they make an inquiry.³ Because VSED is an available option, physician disclosure and discussion of its availability may be both necessary and appropriate for fully informed decision-making.

Because of the growing interest in VSED and because there are many unanswered legal, ethical and practical questions about it, we discuss this practice in some detail below.

VSED Defined

For many years, it has been a settled issue in both law and ethics that an adult with decision-making capacity who is unable to take food and fluids by mouth has the right to refuse nutrition and hydration by medical means (usually a feeding tube), even if doing so will hasten death.⁴ Less attention has been paid to the question of when an adult with decision-making capacity who *is* capable of eating and drinking on his or her own may refuse to do so. This is VSED.

In VSED, the patient is capable of ingesting food and drink by mouth, but chooses not to in order to hasten death.⁵ He or she deliberately refuses all food and fluids save for small amounts of fluid needed for mouth comfort or to swallow medications. Death by dehydration ordinarily follows in several days to three weeks.⁶ A growing body of clinical literature suggests that with good palliative support, VSED results in a relatively comfortable and peaceful death. (See EXPERIENCE OF VSED, below.)

It is important to distinguish VSED from the natural loss of appetite that often occurs when a patient is close

to death. The loss of appetite as death approaches is a normal consequence of the shutting down of body functions that accompanies advanced illness. By contrast, with VSED a patient intentionally refuses food and drink to bring about death before the underlying disease progresses to the end stage. The patient chooses to die from dehydration rather than from the underlying illness.⁷

VSED is also distinguishable from anorexia nervosa, which is a form of mental illness in which the patient irrationally values weight loss over the risk of death that follows from refusing food and drink. The choice of a grievously ill person to stop eating and drinking rather than endure pain and suffering as the illness progresses is not irrational and does not by itself indicate mental illness.⁸

VSED also differs from Physician-Assisted Dying (PAD) in important ways. While both VSED and PAD intentionally hasten death, in VSED the physician does not provide the means for the patient to hasten death. Both the decision to refuse nourishment and the means for carrying out that choice – i.e. fasting – are inherently in the patient's hands. The physician's role is to discuss the available options and, if a patient seeks hastened death, to explore the sources of suffering, seek ways to ameliorate it and support the patient regardless whether or not he or she chooses VSED.⁹

The Experience of VSED

As noted above, in VSED the patient dies not from starvation, but from dehydration. Many people fear that death by dehydration is terribly painful and some argue that permitting it denies basic humane care.¹⁰ However, the available evidence, while limited, is to the contrary.¹¹ Independent studies of hospice nurses' experience with VSED and a

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survey of 800 members of the American Academy of Hospice Physicians have found that VSED generally produces what is often referred to as a “good death.”¹² Typically, the patient remains conscious but comfortable for a period of days, with any feelings of thirst and hunger relieved by simply sucking on ice chips and any other symptoms managed by other simple palliative measures.¹³ Thereafter, there may be some disorientation, confusion and/or delirium and varying levels of consciousness, after which the patient slips into unconsciousness.¹⁴

Several physicians, including at least one from Vermont, have published accounts of their experience with VSED.¹⁵ They describe death by VSED as “peaceful” and as involving relatively little discomfort that could not be easily managed.¹⁶ In 2008, an experienced registered nurse documented in the Brattleboro Reformer his experience attending the death by VSED of an elderly man with advanced Parkinson’s. In it, the man’s family described the man’s death as comfortable and without pain.¹⁷

Paradoxically, it appears that near total abstinence from intake of food and drink may lead to a more comfortable death than partial abstinence. This is because total abstinence produces a physiological condition called ketosis that is often experienced as euphoric or analgesic,¹⁸ whereas continuing small meals may prevent ketosis from setting in.¹⁹ While a patient can undertake VSED on his or her own, to maximize comfort, provide guidance and safeguard the process, the support of a health care provider is advisable for all patients who consider this option.²⁰

Reasons for VSED

Reasons for choosing VSED vary. Often, patients seek it rather than endure the poor quality of life that often accompanies terminal illness, whether due to loss of independence, deterioration in physical or mental ability, extreme physical pain, or the prospect of losing control or dignity as a result of the illness. For many patients with terminal illness, maximizing control over the process of dying is the most important value.²¹

In this regard, it is important to note that few patients who are informed about VSED actually choose it.²² In the vast majority of cases where a patient seeks to hasten death, the sources of suffering that prompt the patient to seek death can be adequately addressed by good palliative and/or hos-

pice care.²³ For many, simply knowing that VSED is an available option relieves a major source of suffering. The awareness that they have “a way out” that remains within their control may allay the need to use it.²⁴

Ethics of VSED

As with the practice of Physician-Assisted Dying (PAD), there is a diversity of views about the ethics of VSED. Because VSED, like PAD, intentionally hastens death, some view it as violating the fundamental ethical principle of respect for the sanctity of life.²⁵ Others view it as an ethically permissible choice to forego an unwanted life-prolonging measure, no different from the right to refuse surgery, chemotherapy, or any other unwanted medical intervention.²⁶ Several authorities have argued that VSED is ethically preferable to PAD because it does not require physician participation in hastening death by prescribing lethal medication.²⁷ Others note that because VSED is a process that unfolds over days or weeks, it has the advantage of allowing the patient to change his or her mind about following through, whereas taking a lethal dose of medication does not.²⁸ VSED’s slower process provides something of a built-in buffer against impulsive decision-making.

Some clinicians ethically oppose VSED. In this situation, many of the same professional practice standards applicable to Physician-Assisted Dying (PAD) would appear to apply equally to VSED. As with PAD, clinicians are not required to act contrary to strongly held moral or religious beliefs. However, they are required to inform terminal patients of all legally available treatment options.²⁹ They are also ethically bound by the duty of non-abandonment. Therefore, before withdrawing from a case in which VSED may be an appropriate strategy, a physician who opposes the practice would be expected to refer the patient to another physician who is willing to provide the needed information and support.³⁰

Legal Issues in VSED

It is a fundamental principle of both law and medical ethics that “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.”³¹ For this reason, performing a medical procedure without a patient’s consent is a battery.³² The same principle governs the right to refuse unwanted medical care.³³ With respect to adults capable of making

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their own medical decisions, this right is virtually absolute,³⁴ applying even when refusing treatment means the patient will die.³⁵ The right to refuse unwanted treatment is recognized as part of the constitutional right to privacy, growing out of the core ethical values of respect for individual autonomy and self-determination.

VSED is morally and legally consistent with the right to refuse unwanted care. However, VSED has not been the subject of high-profile court cases in the way that other so-called “right to die” issues have been.³⁶ Possibly, the reason VSED has received so little attention is that few clinicians and fewer patients are even aware that VSED is an option. Possibly, it is because the alternative to honoring a gravely ill or dying patient’s informed choice to refuse food and drink is to force-feed him or her, a prospect repugnant to courts and clinicians alike.³⁷

A key case in this area is a 1986 case, *Bouvia v. Superior Court*.³⁸ In *Bouvia*, a 28 year old woman who suffered from quadriplegia, cerebral palsy and chronic pain but who was not terminally ill sought a court order to be allowed to die in a hospital by refusing to eat or drink, while also receiving morphine to relieve any pain symptoms she might suffer as she died. Finding Ms. Bouvia to be both intelligent and decisionally capable, the court granted her request and turned back a request by the facility where she lived to insert a feeding tube.

Still, there remain many unanswered legal, ethical and practical questions about how and when a VSED request can and should be honored. The boundaries for honoring a VSED request aren’t always clear, as for example when the requester suffers from multiple chronic conditions, but is not terminal, or when the requester is terminal, but has a life-expectancy of more than six months.³⁹ A common question for nursing homes and other health care facilities is whether honoring a VSED request might violate state and federal laws protecting patients against abuse and neglect. Some facilities assume, incorrectly, that it would.⁴⁰ Another area of uncertainty is whether a person can request VSED in an advance directive.⁴¹

While it is ultimately a competent individual’s choice to stop eating and

drinking,⁴² health care facilities need to respond to VSED requests in an organizationally coherent and clinically consistent fashion and to develop clear policies and procedural guidelines for handling VSED requests. Educating patients about VSED can empower them to make fully informed choices about whether this choice is right for them. Concerned patients and facilities should seek legal advice.

- 1 Paula Span, *The Right to Choose a Fatal Fast*, New York Times, August 30, 2011. In patients with terminal illness, VSED is not generally considered suicide. See Ira Byock, *Patient Refusal of Nutrition and Hydration: Walking the Ever-Finer Line*, Am. J. Hospice & Palliative Care, Mar.-Apr. 1995, at 8, 8 (1995). And See Thaddeus Pope, et al., *Voluntary Stopping of Eating and Drinking: A Legal Treatment Option at the End of Life*, Widener Law Review, Vol 17, 363 (2011).
- 2 See Zail Berry, *Responding to Suffering: Providing Options and Respecting Choice*, Journal of Pain and Symptom Management, Vol 38 No 5 November 2009, 797-800.
- 3 18 V.S.A. § 1852
- 4 See *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990). This right applies as well to those who cannot make decisions for themselves, but in more limited circumstances. *Ibid*.
- 5 See Pope, supra note 1
- 6 Emily Rubin and James Bernat, “*Voluntarily Stopping Eating and Drinking*,” in *Palliative Care and Ethics*, Quill, T., and Miller, Franklin, Editors, Oxford University Press (2014), at 233
- 7 Pope, supra note 1 at 384
- 8 Rubin, supra note 6 at 236-237
- 9 Berry, supra note 2 at 798-799. As one authority has noted, physicians also play an important role in safeguarding against coercion and uninformed or impulsive decision-making. Rubin, supra note 6 at 240-241.
- 10 See, e.g., Wesley J. Smith, *Starving Patients Who Eat Next Stop on Slippery Slope*, National Review Online, June 29, 2014, accessible at <http://www.nationalreview.com/human-exceptionalism/381493/starving-patients-who-eat-next-stop-slippery-slope-wesley-j-smith>
- 11 See Byock, supra note 1; Pope, supra note 1 at 389-399; Rubin, supra note 6.
- 12 Linda Ganzini et al, *Nurses’ Experience with Hospice Patients who Refuse Food and Fluids to Hasten Death*, N Engl J Med, Jul 24 2003;349(4):359-65; James Bernat, *Ethical Issues in Neurology* (3rd Ed 2008) at 215. See also Robert J. Miller & Patricia G. Albright, *What is the Role of Nutritional Support and Hydration in Terminal Cancer Patients?*, Am. J. Hospice Care, Nov.-Dec. 1989, at 33
- 13 See Berry, supra note 2.
- 14 *Ibid*. Because VSED often follows this pattern, it is important for the patient and his caregivers to discuss in detail in advance the patient’s specific wishes for care through the VSED process. For example, does the patient want caregivers to offer food and drink? If so, how often and in what form? Does the patient want to be asked “Do you want food and drink?” Or does he want food to be placed within reach, leaving it to him to ingest it or not? How often? Three times per day? Once a day? Not at all? It is important for all to know in advance what the patient wants and to have a plan for how the care team should respond.
- 15 Berry, supra note 2; see also David M. Eddy, *A Conversation with my Mother*, 272 JAMA 179 (1994)
- 16 *Ibid*.
- 17 Richard Davis, *The Death of Joshua Segar*, Brattleboro Reformer, May 23, 2008, available at homepages.sover.net/~asegar/The Death of Joshua Segar.html
- 18 Byock, supra note 1 at 11; Rubin, supra note 6 at 239
- 19 Pope, supra note 1 at 400; Byock, supra note 1 at 11
- 20 See Rubin, supra note 6 at 239; Ganzini et al, supra note 12 at 360
- 21 Pope, supra note 1 at 368-69; Judith K. Schwarz, *Hospice Care for Patients Who Choose to Hasten Death by Voluntarily Stopping Eating and Drinking*, Journal of Hospice and Palliative Nursing, 2014;16(3):126-131
- 22 Berry, supra note 2
- 23 Berry, supra note 2; see also Schwarz, supra note 21 at 130
- 24 Berry, supra note 2; see also Schwarz, supra note 21 at 130
- 25 See, e.g. Wesley J. Smith, *The Ethics of Food and Drink*, The Weekly Standard, Jul 28, 2014, Vol. 19, No. 43
- 26 Pope, supra note 1; Rubin, supra note 6 at 236
- 27 Rubin, supra note 6 at 237-238
- 28 Pope, supra note 1 at 383; Berry, supra note 2 at 799
- 29 18 V.S.A. § 1852
- 30 See Schwarz, supra note 21
- 31 *Schloendorff v. New York Hospital*, 211 NY 125, 105 NE 92, 93 (1914)
- 32 See e.g., *Hershley v. Brown*, 655 SE 2d 671, 676 (Mo. App. 1983)
- 33 See *Cruzan*, supra note 4.
- 34 Pope, supra note 1 at 407
- 35 *Cruzan*, supra note 4
- 36 Pope, supra note 1; Schwarz, supra note 21; Rubin, supra note 6
- 37 Pope, supra note 1; Rubin, supra note 6
- 38 *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. App. 1986)
- 39 Rubin, supra note 6 at 242. Customarily, end-of-life options apply to individuals with a life expectancy of six months or less. *Ibid*. For those who do not have a terminal prognosis at the time of requesting VSED, eligibility for hospice is sometimes possible, but uncertain. The determination is made on a case-by-case basis. Email communication between Zail Berry, MD and Cindy Bruzzese, December 11, 2014; email communication between Kristin Barnum, Area Director, BAYADA Hospice and Cindy Bruzzese, December 12, 2014.
- 40 Nursing home residents have the same right to refuse unwanted care as anyone else. In fact, feeding a patient over his or her objection could constitute abuse. See Pope, supra note 1 at 418. The crucial distinction is that in VSED, the patient is voluntarily choosing not to eat, whereas in cases of abuse and neglect, the facility is failing to offer a choice. *Ibid*.
- 41 See Paula Span, *Complexities of Choosing an End-Game for Dementia*, New York Times, January 19, 2014. VSED ordinarily refers only to the refusal of food and drink by a person who currently has decision-making capacity. Since an advance directive ordinarily becomes effective only when the person has lost decision-making capacity, it is unclear whether a desire to refuse oral nutrition and hydration expressed in advance directive can be honored. While the Vermont advance directive statutes confer a broad right to direct future health care, see 18 V.S.A. Chapter 231, questions remain about the validity and appropriateness of not assisting an incapacitated person with eating and drinking.
- 42 Rubin, supra note 6 at 240

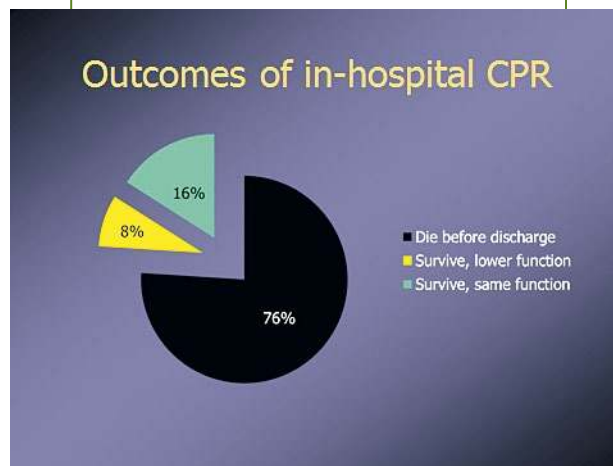
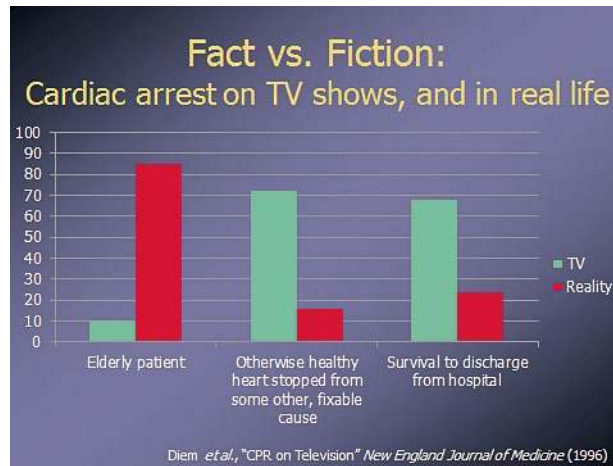
The Ethics of Cardiopulmonary Resuscitation (CPR)

BY ROBERT MACAULEY, MD

When it comes to medical treatments, cardiopulmonary resuscitation (CPR) is unique. First of all, unlike other procedures that involve risks and benefits and thus require the patient's informed consent, consent for CPR is *assumed*. In other words, unless you say no to it in advance, you're going to get it if you qualify for it (i.e., you're experiencing cardiac arrest). Second, it doesn't require medical licensure to provide, as reflected by community training courses and exhortations from groups like the American Heart Association that everyone receive training. And, third, if you qualify for it and don't get it, you have essentially no chance of surviving.

In addition, compared to other medical procedures, CPR is perhaps the most familiar to the public. Each year there are over half a million cardiac arrests in the United States. By virtue of training courses and depictions in television and movies, people are generally acquainted with the basic elements of CPR. And given that it is the default response to cardiac arrest, CPR has become something of an end-of-life ritual. In the opinion of many, a person shouldn't be "allowed" to die without at least trying to resuscitate them.

But while the public may be familiar with the concept of CPR, there are common misunderstandings about its efficacy and indications. A major reason is that many people's knowledge of CPR is based on depictions on television and in movies, which bears little resemblance to reality. On television, most patients who undergo CPR are young, have intrinsically healthy hearts that are affected by some non-cardiac disease (such as electrolyte imbalances), and end up surviving. In reality, though, most patients who undergo CPR are elderly, have some



degree of heart disease, and *don't* survive.¹

According to the American Heart Association's most recent statistics, less than a quarter of hospitalized patients – and less than 10% of non-hospitalized patients – who undergo CPR survive long enough to ever leave the hospital.² And of those who do survive, approximately one-third have diminished level of function, such that they require additional assistance at home. Of course, those statistics need to be applied to individual situations, so that a young, otherwise-healthy person with an arrhythmia will have a better chance of a good outcome than an elderly person with several other medical problems. In general, though, if a patient has a cardiac arrest in the hospital, the odds of them going home in roughly the same state of health as when they came in are approximately 1-in-6.

But even if the odds of survival after CPR aren't as good as they are on TV, the odds of surviving cardiac arrest *without* CPR are zero. Some, therefore, claim that there's "nothing to lose" in receiving CPR. If it works, then you're glad to be alive. And if it doesn't work, then you haven't lost anything because the end result is the same.

I don't agree. First of all, there are medical complications of CPR. Studies have shown that approximately 1-in-3 non-survivors sustain rib fractures, and 1-in-7 have a fractured sternum.³ One might respond, however, that a fracture is a small price to pay for survival.

More profound than physical complications are the personal and emotional ones. The ultimate end-point of both unsuccessful CPR and withheld CPR may be death, but the manner of those deaths is extremely different. One involves an emergent response to a medical condition, including chest compressions, IV

medications, and frequently lots of shouting and chaos. The other can be very peaceful, with loved ones in attendance, a sacred private moment with family and friends. In that respect, I believe there is something to be lost in attempting CPR: the opportunity for a peaceful, comfortable, and companioned death.

Given the stakes and complexities involved in CPR, the decision of whether to withhold it can be extremely difficult. But it is precisely the unique aspects of CPR (especially the assumption that it will be performed, and the stakes for not attempting it) that make it necessary to address it preemptively. So how is a person to decide whether or not to decline CPR?

First of all, it's important to start with the patient, not with the procedure. Rather than delving into the

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statistics related to CPR, it's better to start with the patient's goals. If a patient can identify what's most important to them, what odds of achieving that goal is acceptable, and how much they're willing to go through to get there,⁴ the decision about whether to be DNAR should become more clear. A patient for whom any life is better than no life – and who is willing to bear significant burden to survive – should clearly be “Full Code.” A patient who's unwilling to accept any decreased function and who does not want to undergo burdensome procedures should not receive CPR. And for the many folks who are somewhere in the middle, the act of identifying goals can assist in working through the specific decisions that follow.

Once the goals are clarified, it's important to understand the facts in order to make an informed decision. Too often in my work I hear conversations between health care professionals and patients regarding CPR, when they're using the same term in different ways. The health care professional is referring to the often-burdensome procedure that works a minority of the time, while the patient envisions a non-traumatic intervention that succeeds more often than not. So when the patient “consents” to CPR, it's not actually *informed* consent, because so many misunderstandings are present. In order for patients to make truly informed decisions, they have to fully understand what they're saying “yes” to, and what they're saying “no” to.

To reinforce the uncertain benefit of CPR, it is wise to replace the abbreviation DNR with *DNAR*. The term DNR (“Do Not Resuscitate”) implies that we could resuscitate someone if we tried, when in fact all we can really do is *attempt* to resuscitate the patient. More and more the term DNAR (“Do Not Attempt Resuscitation”) is being used to convey the uncertain outcomes of CPR.

It's also important to be clear that DNAR *only* refers to cardiopulmonary resuscitation. In other words, as long as a patient has a pulse, it doesn't make a difference whether they're “DNAR” or “Full Code.” Some patients may

want life-prolonging treatments like antibiotics or mechanical ventilation, while drawing the line at CPR. In lay language, they want to be treated as long as they're alive, but if their heart stops they want to be allowed to die in peace. A DNAR order is reasonable for such a patient, along with the explicit understanding that other treatments will not be limited.

And that brings us to the question of documentation. Many patients (and physicians) believe – erroneously – that an Advance Directive stating that the patient does not want CPR is enough to prevent CPR from occurring. That isn't true, at least outside a health care facility. The reason is that an Advance Directive is long and nuanced and often involves “if/then” statements, like “if I won't regain consciousness, then I don't want certain treatments.” That isn't very helpful in an emergent situation (like paramedics being called to a patient's home), especially when there's no way to be sure if the patient will ever regain consciousness or not. So unless a patient has a DNAR Order from a clinician, CPR is the appropriate response to a cardiac arrest.

But if a patient is absolutely sure that under no circumstances would s/he want CPR, s/he should speak with a clinician to get a DNAR

Order, which in Vermont is known as a COLST (Clinician Order for Life Sustaining Treatment⁵). A COLST allows the clinician to specify that a patient shouldn't receive CPR and/or mechanical ventilation and/or antibiotics and/or medically administered nutrition and hydration, depending on the patient's goals. It's the only way to be sure that a patient doesn't receive CPR, and for patients who've reached that thoughtful conclusion, it's a critically important element of advanced care planning.

- 1 Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television. Miracles and misinformation. *The New England Journal of Medicine* 1996; 334:1578–82.
- 2 Cardiac arrest statistics. 2014. (Accessed November 17, 2014, at http://www.heart.org/HEARTORG/General/Cardiac-Arrest-Statistics_UCM_448311_Article.jsp.)
- 3 Black CJ, Busuttill A, Robertson C. Chest wall injuries following cardiopulmonary resuscitation. *Resuscitation* 2004; 63:339–43.
- 4 Bernacki RE, Block SD, for the American College of Physicians High Value Care Task F. Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices. *JAMA Internal Medicine* 2014.
- 5 Clinician orders for life sustaining treatment. (Accessed November 17, 2014, at http://vtethicsnetwork.org/forms/dnr_colst_instructions%20and%20Form%2009.pdf.)

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