

# Testimony before the Senate Health and Welfare Committee March 25, 2015

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## What is the difference between “competence” and “capacity”?

	Determined by	Scope
Competence	Court	Global (generally you’re either competent, or you’re not)
Decision-making capacity	Clinician	Decision-dependent (might have sufficient DMC for a simple, minor decision, but not for a complex, major one)

## How is decision-making capacity determined?

“An individual shall be deemed to have capacity to make a health care decision if the individual has a basic understanding of the diagnosed condition and the benefits, risks, and alternatives to the proposed health care.” (Vermont Statute Title 18 §9701)

DMC is *decision-dependent*, meaning that a patient needs to show greater evidence of DMC in specific situations:

1. Serious decision (e.g., where the consequences might be life-or-death)
2. Complex decision (i.e., multiple options/probabilities/risks)
3. “Unusual decision” (i.e., one where most other people would decide differently)
  - a. This doesn’t necessarily mean the patient lacks DMC (he could simply be unusual/exceptional), but we need to probe deeper to make sure he is really able to make the decision

## How are decisions made in the hospital setting for a patient who lacks decision-making capacity?

When a patient lacks DMC, the first thing we try to do is restore it. Many causes of impaired capacity are potentially remediable (such as delirium or electrolyte imbalances).

If full DMC cannot be restored, we still involve the patient as much as possible (i.e., to the degree to which their capacity allows). For instance, a patient may not have sufficient DMC to choose between multiple treatment options for a serious disease, but the patient may have enough DMC to identify the person to make decisions in his stead.

When a patient cannot make decisions and also cannot name a decision-maker, we seek substituted judgment from (in order of priority):

1. An **agent**, named in a Durable Power of Attorney for Health Care (which <25% of Americans have completed)
2. A **guardian** (which very few Vermonters have appointed to make decisions for them)
3. A “**surrogate**”

The issue here is that while the powers of an agent (Title 18 §9711) and a guardian (Title 14 § 3069) are clearly delineated in the law, the law is silent on the issue of surrogate decision-making for an incapacitated patient who has neither an agent nor a guardian.

Practically speaking, in those situations we attempt to identify the person who best knows the patient’s values and is able to advocate for them. This is expressed in S.62 as an “interested individual”: “Any adult who has exhibited special care and concern for the principal or patient and who is personally familiar with the principal’s or patient’s values.” (§9701 18B)

The surrogate is often a blood relative, but need not be. Often there is an obvious decision-maker, such as a spouse who is the practical (if not legally-mandated) choice. In situations where there are several “competing” decision-makers, we attempt to focus on the decision itself (and how it comports with the patient’s values), rather than the identity of the decision-maker. In the vast majority of cases consensus can be achieved (often through a great deal of discussion and hard work).

When consensus on the decision cannot be achieved, it often becomes apparent this is due to one or more “interested persons” not using appropriate substituted judgment. In other words, those parties are acting based on *their own* values, rather than the patient’s (which would violate §9731[e] of S.62). Often those “interested persons” can be helped to see the way their own values are influencing their position. At other times, a majority of “interested persons” decides to proceed with a treatment plan that reflects the patient’s values.

At any point in the process, involved parties have the right to petition for guardianship.

## So what's the problem?

The big problem is that, at present, there is no clear legal direction for surrogate decision-making for patients who have neither an agent nor a guardian. I believe we are currently acting in a thoughtful, ethical fashion, but the lack of a clear overarching surrogacy statute can lead to disagreement and uncertainty. (An example of such a statute is New York's Health Care Decisions Act, passed in 2010 [<https://www.nysba.org/FHCDA/>]).

The smaller problem which S.62 directly addresses is what to do for patients who lack capacity and have no agent or guardian, for whom it is currently unclear (legally) whether *any* person can give informed consent for a DNR/COLST order.

<b>Certification and signature for DNR</b>	<b>A-6 Clinician Certifications and Signature for CPR/DNR (required)</b>
	<b>I have consulted, or made an effort to consult with the patient and the patient's agent or guardian.</b>
	Patient's Agent or Guardian _____ Address or Phone _____
	<b>I certify that I am the clinician for the above patient, and I certify that the above statements are true.</b>
	Signature of Clinician _____ Printed Name of Clinician _____
	Dated: _____

Thus, according to Act 127: "The Department of Health shall adopt by rule on or before July 1, 2016, criteria for individuals who are not the patient, agent, or guardian, but who are giving informed consent for a DNR/COLST order. The rules shall include the following:

- (1) Other individuals permitted to give informed consent for a DNR/COLST order who shall be a family member of the patient or a person with a known close relationship to the patient." (Title 18, §9708)

There is precedent for the legislature—in lieu of an overarching surrogacy statute—to specifically authorize someone other than an agent or guardian to consent/refuse medical treatment for a patient. Act 127 specifically states: "A family member of a patient or a person with a known close relationship to the patient may elect hospice care on behalf of the patient if the patient does not have an agent or guardian or the patient's agent or guardian, or both, if applicable, are unavailable. Decisions made by the family member or person with a known close relationship shall protect the patient's own wishes in the same manner as decisions made by an agent."

The other two things that S.62 does is (1) permit the surrogate to access confidential health information and (2) provide immunity for decisions reached in good faith. These are both critical, because how can a surrogate make an informed decision for an incapacitated patient without all relevant information, and when concerned about legal liability?

## **Why not just get every incapacitated patient a guardian?**

Studies have shown that up to 40% of hospitalized patients lack DMC (Raymont *et al.*, “Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study,” *Lancet* 364 [2004]:1421-7), but this is often not recognized by clinicians and families.

As an example: the UVM Medical Center has over 20,000 admissions annually. Assuming (generously) that 30% of those patients have either an agent or a guardian, that would leave 14,000 patients who have neither. If the above study is representative, 40% of those (a total of 5600, or 15/day) would lack DMC. Seeking guardianship for each of those would unnecessarily delay important medical decision-making, while also overwhelming the Probate Court system.

In addition, many of these patients do not even *qualify* for a public guardian. (Unless an “interested individual” were willing to function as a private guardian—which is not always the case—a public guardian would be the only other option.) Only patients who (1) have developmental disabilities (which must arise before the age of 18 [Title 18 §9302]), or (2) are mentally disabled and at least 60 years of age (<http://www.ddas.vermont.gov/ddas-programs/programs-guardianship/programs-guardian-addl-webpages/programs-guardianship-adult-public>) qualify for a public guardian.

## **What does S.62 not change?**

All S.62 does is permit a surrogate to provide or refuse to provide consent for a DNR/COLST. It does not specifically address decisions beyond DNR/COLST where an incapacitated patient has neither an agent or a guardian.

It does not change the medical response to emergency treatment where there is no time to get consent. In those situations—unless there is clear instruction from an Advance Directive—we proceed with treatment, as we simultaneously attempt to determine patient goals.

It also does not change the response to an “unbefriended” patient, as this would mean that there are no “interested persons” who could function as surrogate decision-makers (and thus a guardian would be required).

## **What sort of patient is this act designed to serve?**

The patient I imagine when I think of S.62 is an elderly patient with advanced dementia who did not complete an Advance Directive (and thus does not have an agent), is at the end of his life, and whose loving family want him/her to die a peaceful death. Without a guardian—which would take time to appoint, burden the grieving family, and use valuable court resources—at present the patient would be forced to undergo unwanted procedures (such as CPR). S.62 would allow the people who love this patient and know his values to be his voice.

## What's so important about a DNR/COLST?

Many people don't understand that even if a patient *has* an Advance Directive (which most patients don't), the Advance Directive requires interpretation and thus isn't relevant in emergent, out-of-hospital situations. In other words, even if a patient has written "Don't do CPR" all over their Advance Directive, if someone calls 911 the paramedics will perform CPR until receiving a physician's order to stop.

A DNR/COLST is such an order, and thus prevents unnecessary treatment. And unlike the old "DNR" form which was limited to CPR, the COLST permits a clinician to give instructions related to other treatments such as intubation, antibiotics, IV fluids and nutrition, and hospital transfer. This has been shown to prevent a great deal of unwanted treatment.

## A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program

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**RESULTS:** Residents with POLST forms were more likely to have orders about life-sustaining treatment preferences beyond cardiopulmonary resuscitation than residents without (98.0% vs 16.1%,  $P < .001$ ). There were no differences between residents with and without POLST forms in symptom assessment or management. Residents with POLST forms indicating orders for comfort measures only were less likely to receive medical interventions (e.g., hospitalization) than residents with POLST full treatment orders ( $P = .004$ ), residents with traditional do-not-resuscitate orders ( $P < .001$ ), or residents with traditional full code orders ( $P < .001$ ).

*Journal of the American Geriatric Society* (July 2010)

Note: Most other states use the term "POLST" to describe our "COLST" form.

## If the DNR/COLST is so important, why allow surrogates to make decisions about it, when they can't make other (less important) medical decisions?

It is precisely because the DNR/COLST addresses critically important, time-sensitive decisions at the end of life that regulatory hurdles should not prevent loving family and friends from speaking for a patient who can't speak for himself.