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## Legal Fundamentals of Surrogate Decision Making

Thaddeus Mason Pope

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## Legal Fundamentals of Surrogate Decision Making

Thaddeus Mason Pope, JD, PhD

The four previous articles in this series have traced the history of patient autonomy and have identified its ethical and legal foundations. Patient autonomy is highly valued in the United States to the extent that the patient does not lose the right of self-determination when he or she loses the capacity to make health-care decisions for him or herself. The law has devised several tools to promote “prospective autonomy.” One mechanism is the instructional advance directive or living will. But most of us do not write such directives. Another mechanism is the proxy directive or durable power of attorney for health care, designating another person, a surrogate, to direct the course of our medical treatment upon our incapacity. But most of us do not do that either. Therefore, the most common mechanism by which our prospective autonomy is protected and promoted is through the informal selection of surrogates based on statutory priority lists. These “default” surrogates are the most numerous type of surrogate. This article explains the importance and legal fundamentals of surrogate decision making. It first describes five basic types of surrogates. The article then looks at the role of these surrogates and how they are supposed to make decisions on the patient’s behalf. Unfortunately, surrogate performance is often mediocre or poor. There are significant and persistent obstacles to good surrogate decision making. After explaining these problems, the article concludes by identifying several solutions. *CHEST 2012; 141(4):1074–1081*

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—Constantine A. Manthous, MD, FCCP, Section Editor, *Medical Ethics*

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self-determination when she loses the capacity to make health-care decisions for herself. The law has devised several tools to promote “prospective autonomy,” the right to control, before losing decision-making capacity, one’s future medical treatment.

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This article explains the importance and legal fundamentals of surrogate decision making. It first describes five basic types of surrogates. The article then looks at the role of these surrogates and how they are supposed to make decisions on the patient’s behalf. Unfortunately, surrogate performance is often mediocre or poor. There are significant and persistent obstacles to

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## IMPORTANCE OF SURROGATES

Essential to an understanding of patient autonomy is an understanding of decision-making capacity. If the patient has capacity, then there is no need to rely upon either advance directives or surrogates. Adult patients (both those  $\geq 18$  years of age and emancipated minors) are presumed to have capacity until determined otherwise. This presumption is rebutted only after the attending physician, often with confirmation from a second physician, determines that the patient lacks one or more of the three essential attributes of capacity. First, the patient must have the ability to understand both her own condition and the recommended treatment's significant benefits, burdens, risks, and reasonable alternatives. Second, the patient must be able to reason and deliberate about her treatment choices. Third, the patient must be able to make and communicate a decision.<sup>5</sup>

Capacity is decision specific. This means that a patient lacking capacity to make a complex decision might still have capacity to make other decisions. It also means that incapacity is not a status-based judgment. Being elderly or diagnosed with dementia does not automatically make one incapacitated.

Although autonomy is important in all clinical circumstances, legal attention has heavily focused on end-of-life treatment decisions. In the ICU, the patient almost always lacks capacity.<sup>6,7</sup> But losing capacity does not mean losing autonomy. For example, in the seminal *In re Quinlan* case,<sup>8</sup> the New Jersey Supreme Court ruled that Karen did not lose her right to choose when she lost capacity. That right could be exercised on her behalf by her family. Our society's individualistic norms place "such a strong emphasis on the value of the patient" that medical decisions should "continue to be guided by that voice as much as possible."<sup>9</sup>

Arguably, if patients left sufficiently clear and complete instructional advance directives (living wills), there would be no need for surrogates. Providers could simply consult the patient's own *ex ante* instructions for guidance. But  $> 3$  decades of experience shows that it is difficult to effectively implement this form of "directed decision-making."<sup>10</sup> Most individuals do not complete advance directives. Most of those that are completed are not available when needed. And, even when completed and available, instructional advance directives are often insufficiently clear and detailed to obviously apply to the patient's current situation.<sup>11</sup> Accordingly, prospective autonomy is

usually promoted not through instructional advance directives but through substitute decision makers collectively known as "surrogates."

## FIVE TYPES OF SURROGATES

There are five types of surrogates, corresponding to the five ways through which surrogates get their decision-making authority. First, the patient himself or herself can formally designate his or her surrogate in an advance directive. Second, the patient can informally designate a surrogate by informing his or her provider. Third, the court can appoint a surrogate (typically referred to as a "guardian"). Fourth, if none discussed here are available, the health-care provider can designate a surrogate pursuant to default rules. Finally, for those "unbefriended" patients with no other type of surrogate, certain special surrogates may be authorized.

### *Patient-Designated Surrogates: Proxies, Agents, and Attorneys-in-Fact*

Every state has established a process that allows competent individuals to appoint an agent to decide about health care in the event that they become unable to decide for themselves.<sup>12</sup> Although terminology varies from state to state, this type of surrogate is normally referred to as a "proxy," an "agent," or an "attorney-in-fact."

This appointment can be made through a legal form typically referred to as an advance directive or a durable power of attorney for health care. Although short and simple, these appointment forms require the strict observation of certain formalities. For example, many states require the individual to sign the form before a notary public or in the presence of two witnesses who are neither related to the individual nor employed at a facility where the individual is a patient or resident.

The agent's power is often referred to as "springing," because it is triggered when the patient loses capacity, and it vanishes when the patient regains capacity. Whenever authorized to act, the agent typically has the right to make all health-care decisions that the patient could have made for himself or herself, unless the patient has explicitly limited the agent's authority. Providers must comply with decisions made in good faith by an agent to the same extent they would have to comply with decisions made by the patient himself or herself. Although ordinarily an obligation only under state law, providers also have a duty to honor advance directives under the federal Patient Self Determination Act,<sup>13</sup> its implementing regulations,<sup>14</sup> and Joint Commission accreditation standards.<sup>15</sup>

### *Patient-Designated Surrogates: Informal and Orally-Designated Surrogates*

Although completing an advance directive ordinarily does not require an attorney, most individuals have not completed one.<sup>11</sup> For some individuals, like long-term care residents, it may be difficult to comply with the mandatory execution formalities. These individuals are surrounded by facility employees who can neither serve as agent nor witness an appointment.

But, in many states, these residents and patients can still designate a surrogate informally.<sup>12</sup> The individual makes the designation directly to the supervising provider in the presence of a witness. The provider then confirms the designation on the medical record and has that signed by the witness.<sup>16</sup>

### *Court-Designated Surrogates: Guardians and Conservators*

In cases of conflict among potential surrogates or where no previously designated surrogate is reasonably available, it is sometimes necessary to petition a court to appoint a surrogate. A court-appointed surrogate is typically referred to as a “guardian” or “conservator.”<sup>12</sup> The petition is usually filed by a relative or by the administrator of a long-term care facility where the patient resides. The court-appointed guardian may be a family member, a friend, a disinterested stranger, a nonprofit or for-profit agency, or a public program. Since the appointment is usually not directed by the patient herself, judicial appointment is sometimes referred to as “displaced decision-making.”<sup>10</sup>

After the appointment, the court is supposed to supervise and monitor the guardian’s choices on behalf of the patient, to ensure that the patient is getting appropriate medical care.<sup>17</sup> Because this entire process can be cumbersome and expensive, comparatively few surrogates are guardians. Moreover, the guardianship system is currently the subject of significant scrutiny and reform.<sup>18,19</sup>

For example, although capacity is decision specific, guardianship is typically all or nothing. Once the patient is assessed as “incompetent,” the guardian has full power to make most, if not all, decisions for the patient, even if the patient retains capacity to make some decisions or even all decisions some of the time. Policymakers are working to encourage the use of less restrictive alternatives; more limited, tailored guardianship orders; and more procedural due process protections.

### *Physician-Designated Surrogates: Default Surrogates*

If there is no court-appointed guardian, no formal patient-appointed agent, and no informal patient-

designated surrogate, then the health-care provider can select the surrogate. This is sometimes referred to as “devolved decision making.”<sup>10</sup> The provider makes the designation pursuant to default surrogate statutes in almost every state.<sup>20</sup>

These statutes specify a priority list of individuals whom the physician should or must designate. Typically, at the top of this hierarchy are the patient’s spouse, adult child, parent, and adult sibling.<sup>21</sup> The hierarchy prioritizes those relatives who are typically more likely to know the convictions and beliefs of the patient and more likely to be concerned for the patient.

Default surrogates are the most numerous type of surrogate.<sup>22</sup> Therefore, the sequence and manner in which they are designated from the list has great significance. But there are material differences among the states. For example, because “spouse” is near the top of the list, a patient’s spouse is usually designated as surrogate. But < 20 states have same-sex-inclusive statutes that list “domestic partner” as an equivalent alternative to “spouse.”<sup>23</sup> In some states, same-sex partners might qualify as “close friend” near the bottom of the list. In other states that lack such a category, same-sex partners might not qualify at all.

A second variation among default surrogate statutes is that a handful of states do not require strict adherence to the statutory sequence.<sup>24</sup> In Tennessee, for example, the ordered list is merely a guideline to which “consideration may be given in order of descending preference for service as a surrogate.”<sup>25</sup> In some cases, the best-qualified surrogate might be lower ranked.

Clinicians do not routinely interview all potential surrogates to identify the best-qualified surrogate. But they do, usually with the help of nonphysicians, engage in due diligence once it appears that a higher-ranked surrogate does not know the patient or is uninvolved in the patient’s life. In identifying the patient’s surrogate, the physician is primarily looking for an “adult who has exhibited special care and concern for the patient, who is familiar with the patient’s personal values, who is reasonably available, and who is willing to serve.”<sup>25</sup>

Generally, a default surrogate can make any health-care decision that the patient could have made for herself. But because these surrogates were not personally chosen by the patient, many states impose more limitations on default surrogates. These vary from state to state and are usefully cataloged in an annually updated chart prepared by the American Bar Association.<sup>26</sup> Here are four key variations.

First, some states do not allow surrogates to consent to extraordinary interventions, such as abortion, sterilization, electroshock therapy, psychosurgery, experimental treatments not approved by an institutional



review board, or voluntary admission to a mental health facility. Second, some states authorize surrogates to consent to withholding or withdrawing life-sustaining treatment only when the patient is not pregnant and has a “qualifying condition,” such as terminal illness or permanent unconsciousness. Third, many states restrict the ability of surrogates to withhold or withdraw oral and/or clinically assisted nutrition and hydration unless specifically authorized by the patient. Finally, some states require surrogates to produce “clear and convincing” evidence that foregoing life-sustaining treatment is what the patient would have wanted.<sup>27</sup>

### *Surrogates for Unbefriended Patients*

Some patients have no family or friends to make health-care decisions on their behalf. Not only is there no formally or informally designated surrogate but also there is no one reasonably available on the default list. For some of these patients, providers may seek a court-appointed guardian. But this is time consuming and expensive. And guardians, who sometimes earn fees from the patient’s estate, may suffer from a financial conflict of interest.<sup>28</sup>

Consequently, some states have developed special mechanisms for authorizing treatment decisions on behalf of unbefriended patients. For example, a new law in Oregon permits a hospital to “appoint a health care provider who has received training in health care ethics.”<sup>29</sup> Other states have authorized other decision makers to consent to health-care services on behalf of incapacitated patients for whom no other surrogate is reasonably available. These decision makers include: temporary guardians, social workers, clergy, ethics committees, and regional surrogate decision-making committees.<sup>30</sup> But such mechanisms are available in only a few states and often for only certain treatment decisions or certain patient populations.<sup>10</sup>

## THE ROLE OF SURROGATES

A surrogate is an “extension of the patient”<sup>31</sup> and stands in the shoes of the patient. Accordingly, the surrogate is “obligated to suppress his or her own judgment in favor of ‘channeling’ what the [patient] would have done.”<sup>32</sup> The surrogate “must make the medical choice that the patient, if competent, would have made and not one that the surrogate might make for himself or herself.”<sup>33</sup>

Although applied with different frequency, the standards for surrogate decision making are basically the same for all five types of surrogates. These standards are usually specified in state statutes, and there is substantial uniformity across the country. There is generally a three-step hierarchy.<sup>12</sup> Surrogates should

apply these standards sequentially in the following order: (1) expressed wishes, (2) substituted judgment, and then (3) best interest.<sup>34</sup> Obviously, to apply any of these standards, the surrogate must be reasonably available and must consult with providers, so that she understands the patient’s clinical situation.

### *Subjective Standard: Implement the Patient’s Instructions*

Sometimes, before losing capacity, the patient might have spoken directly to the treatment decision at hand, for example in an instructional advance directive or living will. Although rare, if it is sufficiently clear to the clinician, the advance directive can become a “self-initiating consent document,”<sup>35</sup> and the surrogate’s role is no longer that of decision maker so much as that of “reporter” or “enforcer.”<sup>36</sup> Unless the patient has expressly given the surrogate discretion, the surrogate must implement what the patient has already “actually decided.”<sup>12</sup> The agent, after all, is only a second-best means to protecting patient autonomy. Almost always preferable is subjective first-hand evidence of the patient’s very own decisions about her health-care treatment.<sup>37</sup>

### *Substituted Judgment: Decide in Accord With the Patient’s Preferences and Values*

Although theoretically the most straightforward standard, the circumstances rarely provide for application of the subjective standard.<sup>38</sup> Consequently, surrogates usually must instead apply the substituted judgment standard, by engaging in some speculation and “inferring” the patient’s wishes from her prior statements and conduct.<sup>31</sup>

The law across the several states is substantially similar. Alabama, for example, provides that the surrogate must make decisions “that conform as closely as possible to what the patient would have done or intended under the circumstances.”<sup>39</sup> The surrogate must take into account “any evidence of the patient’s religious, spiritual, personal, philosophical, and moral beliefs and ethics.”<sup>39</sup>

### *Best Interests Standard: Promote the Patient’s Welfare*

Sometimes, there is no reliable evidence of the patient’s expressed wishes, values, or preferences. For example, court-appointed guardians, who often do not know the patient, lack this information. In such cases, the surrogate can apply neither the subjective nor the substituted judgment standards. Therefore, the surrogate must shift her focus from the autonomy of the patient to the welfare of the patient. In the absence of subjective evidence about patient

wishes, the surrogate must rely on more objective grounds, on “the outcome that would best promote the patient’s well-being.”<sup>31</sup> This decision-making criterion is referred to as the “best interest standard.”<sup>12</sup>

Typical factors used to guide a surrogate’s application of the best interest standard include: (1) the patient’s present levels of physical, sensory, emotional, and cognitive functioning; (2) the quality of life, life expectancy, and prognosis for recovery with and without treatment; (3) the various treatment options and the risks, side effects, and benefits of each; (4) the nature and degree of physical pain or suffering resulting from the medical condition; (5) whether the medical treatment being provided is causing or may cause pain, suffering, or serious complications; (6) the pain or suffering to the patient if the medical treatment is withdrawn; and (7) whether any particular treatment would be proportionate or disproportionate in terms of the benefits to be gained by the patient vs the burdens caused to the patient.<sup>40</sup> Although seemingly objective, application of these factors is necessarily somewhat mediated by the surrogate’s own values and attitudes.

#### PROBLEMS WITH SURROGATE DECISION MAKING

Although surrogate decision making is an important and valuable tool for protecting patient autonomy, surrogates often perform rather poorly. There are five basic types of problems. First, surrogates often do not know patient preferences. Second, surrogates themselves often have impaired capacity. Third, surrogates often fail to follow patient preferences. Fourth, surrogates do not know patient best interests. Fifth, surrogates often disagree with each other.

##### *Surrogates Do Not Know Patient Preferences*

Both the subjective and substituted judgment standards require that the surrogate make treatment decisions that reflect the patient’s preferences and values. But numerous studies confirm that the choices surrogates make for patients are often not the same choices that patients would make for themselves.<sup>41–43</sup> A meta-review of sixteen studies indicated that, overall, surrogates predict patient treatment preferences with just 68% accuracy.<sup>44</sup> A more recent study found even lower accuracy.<sup>45</sup>

None of this evidence is surprising given the widely observed failure of patients to discuss end-of-life planning with their prospective surrogates.<sup>46</sup> Patients themselves often do not reflect on their end-of-life care, so it is unclear whether they have even formed preferences to communicate to surrogates. This is only exacerbated by the fact that patient preferences change over time.<sup>47</sup>

Furthermore, surrogates often “cannot distinguish their own preferences from those of the patient.”<sup>48,49</sup> There are two leading psychologic explanations for this tendency. A surrogate may act on “assumed similarity” by assuming that she and the patient hold similar preferences and thus allowing her own preferences to guide the decision.<sup>50</sup> Surrogates may also be affected by “projection bias,” because they have difficulty disregarding their current preferences formed under current circumstances, even though they are irrelevant both to the patient and to the patient’s condition.<sup>50</sup>

##### *Surrogates Have Impaired Capacity*

Although surrogate knowledge of patient preferences is a necessary condition, it is hardly a sufficient condition for application of the subjective and substituted judgment standards. Surrogates must also be willing and able to make decisions on the basis of that knowledge. As with patients, clinicians should presume that surrogates have capacity.<sup>51</sup> But, occasionally, “a serious question arises about the surrogate’s fitness to serve.”<sup>12</sup>

In such cases, clinicians should explore surrogate capacity. Some surrogates have clinically diagnosable conditions, such as stress, depression, and anxiety.<sup>52–55</sup> These psychologic problems sometimes impair the surrogate’s own decision-making capacity. The surrogate may fail to exercise sound and informed judgment or will find it too difficult to accept personal responsibility for carrying out the patient’s wishes.

##### *Surrogates Fail to Follow Patient Preferences*

Even when surrogates know patient preferences and have capacity, they may base their decisions on factors external to the patient. Although most surrogates are trustworthy and act in good faith, some may have dubious motives in that they are looking out for their own interests rather than the patient’s interests.

Some surrogates make decisions to avoid the guilt from making a death-hastening decision or to avoid criticism from other family members for having made the decision. Other surrogates, suffering from material conflicts of interest, make deliberately and intentionally selfish decisions.<sup>56</sup> Again, clinicians have no obligation to investigate surrogates unless or until evidence raising suspicion is brought to their attention.

##### *Surrogates Do Not Know Patient Best Interest*

On the best interest standard, surrogates must be willing and able to make a decision on the basis of what will best promote the patient’s wellbeing. Unfortunately, surrogates are often not up to the challenge.

They do not understand the clinical status of the patients whom they represent.<sup>56-59</sup> “Less than one-half, regardless of educational level, had adequate knowledge of what was going on and what would happen [to the patient].”<sup>60</sup> Sometimes, surrogates are unwilling to accept or do not understand the patient’s prognosis.<sup>61</sup> But to accurately determine best interests, the surrogate must comprehend the clinical information and the consequences of the options presented.

### *Surrogates Disagree With Each Other*

With significant frequency there is conflict between surrogates or potential surrogates. One type of conflict is between surrogates of the same class, for example, parent vs parent, sister vs sister. Another type of conflict is when the surrogate is identified (eg, spouse), but potential surrogates lower on the list (eg, child) challenge the surrogate’s decision.

In many states, the physician is not tied strictly to the priority list. The physician may select someone who is not highest on the list if that person best: (1) knows the patient’s wishes, (2) knows the patient’s best interest, (3) has regular contact with the patient, (4) demonstrates care and concern for the patient, (5) visits the patient regularly, (6) participates in the decision-making process, and (7) is available and willing to serve. But if conflict should persist, the American Medical Association<sup>31</sup> and some state laws<sup>62</sup> recommend the use of ethics committees before resorting to courts.

## SOLUTIONS TO SURROGATE PROBLEMS

Some risk of bad surrogate decision making is the inevitable consequence of forgoing potentially burdensome safeguards and permitting the quick and easy identification of surrogates. Still, there are practicable ways to mitigate problems with surrogates. The most obvious is improving clinician-surrogate communication.<sup>63</sup> Three others are better advance care planning, surrogate education and training, and surrogate replacement.

### *Better Advance Care Planning*

Substantial efforts are being made to increase and improve advance care planning and the accuracy of surrogate decision making. One key development is the shift from a “legal transactional approach” to a “communications approach.”<sup>64</sup> Instead of focusing on legal forms, this approach emphasizes iterative discussions with family members and physicians, often facilitated by increasingly sophisticated toolkits, workbooks, and interactive applications.<sup>64</sup> More and better advance care planning will inform and guide surrogate decision making.

### *Surrogate Education and Training*

Although an appreciation of the patient’s values, goals, and preferences is necessary for good surrogate decision making, it is not sufficient. The surrogate must also understand how she is supposed to use this information. Surrogates are performing a new role, for the first time, under difficult circumstances. Understandably, they often do not understand the responsibilities and duties of a good surrogate.<sup>65</sup>

In response, a number of organizations and medical facilities have developed materials to educate and train surrogates.<sup>66</sup> These efforts are increasingly bolstered by state law. California conservators, for example, must file a seven-page form acknowledging their duties as described in a 300-page handbook developed by the state Judicial Council.<sup>67</sup>

### *Surrogate Replacement*

Providers normally have immunity for complying in good faith with a decision made by one whom they believe authorized to decide for the patient. But there are limits to the scope of this immunity. In one California case, a family member sued the provider for complying with a rogue surrogate. The court denied the provider immunity protection, observing that “compliance with an agent’s decision that is at odds with the patient’s own expressed decision, in her AHCD [Advance Health Care Directive], would probably not qualify as in good faith.”<sup>68</sup>

This case is but one example of a broader principle: Providers have an ethical and legal obligation to resist surrogate decisions that materially deviate from applicable standards. If the mediation of such conflict fails, providers should get a new surrogate. Some states permit the physician to unilaterally recognize the authority of a new surrogate. Others authorize the ethics committee to adjudicate disputes between and among surrogates.<sup>69,70</sup> But physicians usually need (or want) a judicial determination. Increasingly, US providers have successfully petitioned courts to replace surrogates who demand treatment contrary to the patient’s wishes or best interest.<sup>71,72</sup>

## CONCLUSION

The current vehicles for promoting and protecting patients’ prospective autonomy are imperfect. Still, the benefits of surrogate decision making outweigh its risks. Surrogates, after all, are still more accurate than physicians.<sup>73</sup> Prevailing ethics and public policy value patient self-determination even when patients lose capacity. Although there is significant room for improvement, surrogate decision making remains the best method of safeguarding prospective autonomy.



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