

Making Health Care Decisions for Others: A Guide To Being A Health Care Proxy or Surrogate

A Quick Reference for Physicians

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Ideally, the doctor-patient relationship is enriched by years of care and many discussions regarding personal values and treatment preferences. The clinical reality is that a physician often must address treatment options without benefit of either. When a patient becomes unable to make health care decisions, the physician is faced with a substitute decision maker who may or may not be familiar to the physician

This *Quick Reference for Physicians* is designed to provide information and guidance for physicians treating patients unable to make their own health care decisions. There are several types of substitute decision makers, whose responsibilities and authority depend on how they assume their roles. They all function as valuable resources in representing the wishes and best interest of the patient without decision capacity.

1. Why does a patient need someone else to make health care decisions?

Health care decision making is more complex than it used to be because there are more difficult decisions to be made. How clinical dilemmas are resolved almost always depends on who makes the decisions.

Health care decisions are usually made by adults who have the capacity to make them and caregivers are legally and ethically bound to honor these choices. **Decision-making capacity** is the ability of a person to understand his medical situation, weigh the benefits, burdens and risks of various treatment options, make a decision that is consistent over time and communicate it. The inability to make these decisions is known as **loss of capacity** or **incapacity**. A person is always presumed to have capacity and lack of capacity must be demonstrated before someone else assumes the responsibility for making substitute decisions.

When a person loses decision-making capacity, he also loses the opportunity to participate in deciding about the care goals or treatment plans. Even if he previously had very strong feelings about what he would or would not want in case of serious illness or injury, his incapacity prevents him from discussing his medical situation with his caregivers, expressing his wishes and making sure they are honored

A substitute decision maker fills that void. She steps in when the patient loses capacity and acts on his behalf, conferring with his caregivers, evaluating the information and making the decision she believes he would make if he were able or the decisions she thinks are in his best interest. Through her, the patient's voice is still heard in the care discussions and his wishes are respected in the decisions.

There are two types of substitute health care decision makers – the health care proxy and the health care surrogate.

2. What is a health care proxy and how is one created?

A **health care proxy** or **agent** is a competent adult over 18 years of age who has been chosen and legally *appointed by a patient* to make medical decisions when the patient is no longer able to make those decisions.

Even though it seems logical for next-of-kin to automatically assume decision making for patients, not all states clearly confer this authority. As a result, the people who know the patient best may be hindered in guiding treatment plans. This makes it especially important that, in advance of illness, patients elects and legally appoint the people they want to act on their behalf. The term “proxy” is often used to refer to both the person who is the substitute decision maker and the legal appointment document that patients sign.

Here, “proxy” refers to the *person* making health care decision for a patient.

3. What is a health care surrogate and how is one created?

A **health care surrogate** is a competent adult over 18 years of age who, although not specifically chose or legally appointed by a patient, assumes the responsibility for making health care decisions for a patient who has lost the ability to do so. A person may become a surrogate in two ways:

- **Surrogate by state law** refers to a person who authority to make health care decision for someone else is based on state statute or case law

- **Informal surrogate** refers to a person, usually someone close to the patient, who is asked by the medical team to participate in making treatment decisions because there is no one who has been specifically appointed or legally authorized.

4. How is a health care proxy or surrogate different from a living will?

Advance directives are legal authorizations that allow people to express their health care wishes while they are capable so that, when they are no longer able to make decisions, their wishes can still be communicated and honored. There are two types of advance directives – living wills and health care proxies.

A **Living will** is a *document* listing instructions about medical treatments the patient does or does not want, usually at the end of life. Because it is written in advance of illness and incapacity when the patient cannot anticipate his future health, the living will may not accurately reflect his medical condition when decision need to be made. The living will has the weaknesses of any piece of paper – it is static and inflexible, unable to respond to the patient's changing condition. The living will should be used as guidance in making decisions that reflect the patient's wishes.

A **health care proxy or surrogate** is a *person* who can make health care decisions at any time the patient cannot decide. Her decision-making authority commences when the patient loses decisional capacity and ends when the patient dies or regains capacity. Proxy and surrogate decisions are not limited to end-of-life matters and include any decisions that a capacitated patient would make. If the patient's prior instructions do not address his current condition, the proxy or surrogate can figure out what the patient would have chosen or help the doctors to determine what is in the patient's best interest.

The benefits of a proxy or surrogate to the patient is that a trusted persons can make decision as necessary, rather than having the medical team interpret a piece of paper. A particular advantage is that the proxy or surrogate can respond as the patient's condition gets better or worse. The proxy or surrogate can also confer with the care team, other family and/or friends who know the patient.

When the patient has created a living will *and* appointed a health care proxy, it should be made clear which is to control in the event they conflict. The best approach is for the documents to say that the interpretation of the proxy will prevail.

5. What is the benefit of a legally appointed health care proxy?

Physicians are able to interact with an appointed person who has both the patient's trust and the legal empowerment to make decisions in response to changing medical conditions and prognoses. While both the proxy and surrogate should receive the same resources, support and information as the patient, in many states the proxy has greater decision-making authority.

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- **Determine** if the patient has designated a healthcare proxy and review all documents that provide guidance about the patient's prior wishes. If there is no appointed proxy, determine who will be acting as the patient's surrogate in the event that capacity is lost.
- **Ensure** that all relevant information and documents are placed in the patient's medical record
- **Discuss** general treatment preferences with the patient prior to loss of capacity and note preferences in the medical record.
- **Encourage** patients to routinely articulate preferences and select a health care proxy proper to an admission or emergency situation
- With the patient's consent, include the proxy or surrogate in discussions with the patient
- Upon determination that the patient has lost capacity, provide the proxy or surrogate with the same medical information (diagnosis, prognosis, treatment options and recommendations) that a capacitated patient would receive in order to make informed decisions. The proxy or surrogate may rely on the patient's previously expressed wishes, knowledge of the patient's values, beliefs and attitudes, or on his/her own judgment as to what is in the patient's best interest. Remember the patient trusts the proxy and usually the surrogate to make the best decision possible under the circumstances.
- **Support** the proxy or surrogate in the process of deciding for another, which is often more difficult than deciding for one's self.
- **Alert** the proxy or surrogate to specific changes in the patients medical condition.

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- **Apply** patient confidentiality standards to information provided to the proxy or surrogate
- **Avoid** burdening the proxy or surrogate with "false" decisions (e.g., when a patient is to be transferred out of the ICU, do not present the issue to the proxy as a choice s/he must make).
- **Explain** that a DNR order does not mean do not treat. **Explore** palliative care options when cure is not longer the goal. **Assure** the proxy or surrogate that the patient will not be abandoned.
- **Advise** the proxy or surrogate of institutional resources, such as bioethics consultants, patient advocates, social workers, translators and spiritual advisors.
- **Use** institutional resources to support your relationship with the proxy or surrogate. **Request** a bioethics consultation or assistance from patient services and social services whenever there is confusion, uncertainty or conflict about decision making.

Physician Resources

For additional information about interaction with proxies, please consult:

- Bioethics staff of your hospital
- Risk Management staff of your hospital
- Patient Services staff of your hospital

For more information, please call
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