



Pathways to Health Care Decision-Making

What Are the Preferred Ways to Make Health Care Choices?

Health-care decision-making authority follows one or more of six legal pathways. The Pathways are listed below in a suggested order of priority for their use, although they are not necessarily mutually exclusive. They may overlap in practice, and depending on the circumstances, may augment or conflict with each other.

HEALTH CARE DECISION PATHWAYS: SIX PATHWAYS IN ORDER OF PREFERENCE¹

1. **Individual Decision-Making.**

The first option should always be for the individual to make decisions in consultation with health care providers. Few decisions are as personal as health care. When working with persons with diminished or limited capacity, special efforts should be made to enable these individuals to make health care choices independently.

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make decisions. The role of the supporter, surrogate or health care agent is to communicate with the individual in ways the person can understand, to describe the health care challenges, the options, the consequences, and to make a recommendation, and to ask the individual to make a choice or express a preference that the supporter then helps to implement.

SDM is both person centered and person driven, with the person always being offered the opportunity to make a choice or offer a preference. SDM rests on the assumption that as long as a person can communicate in a meaningful way, they have a right to participate in making decisions about their life. The decision-making model of SDM should be used across the pathways.

3. **Delegated Decision-Making.**

If the person is unable to make health care choices, an agent that the person has selected and empowered as the person they most trust to make health care choices is the third-choice. This is most effective if the selection has been carefully considered and the agent understands the values, health care goals and beliefs of the individual and has agreed to make the health care choices they believe the individual would make. This works best if the agent has had the opportunity to work with the individual in SDM, learning what the person believes is important and how the person makes choices allowing the agent to follow that model. The strength of this pathway is that the person is able to select and empower the agent of their choice. The potential weaknesses include its dependency on the quality of guidance the agent has been given on how health care

¹Four of the pathways are based on "Death in the Legislature," by Charles Sabatino, published in the *New York University Review of Law and Social Change*, 1992.

decisions should be made; the possibility that a named agent is unavailable or unwilling to act; and the possibility that agent will not follow the known values or wishes of the patient.

4. **Directed Decision-Making** is when the individual leaves written directions about the care that they want or do not want. This is the fourth-choice option. The most common form of directed decision making is a “living will directive.” The best examples of this type of directive describe the individual’s beliefs and personal values. The strength of this model is that, it offers a way to control some decisions, at least in part, even when capacity is lost. This type of directive paints with a broad brush, covering a wide array of conditions. The limitation of the typical living will or other direction-specific advance directive is that it fails to address the thousands of illness and treatment needs that may arise. The scope of direction is limited and can only address hypothetical future decisions. Instructions won’t likely offer guidance on many real-time decisions that need to be made, and the instructions are frozen in time. They may not reflect changes in wishes based on the progression of life, health status and treatment experience.

5. **Devolved Decision-Making** is done by a person designated in a state statute.² Thirty-seven states use a hierarchical model, where the highest-ranking person available makes health care decisions. Five state statutes provide a list of permissible surrogates and ask the group to select a spokesperson from among them. Twenty-nine states include a close friend as a permissible surrogate but normally of the lowest priority. Nine states have no default surrogate law that applies to health decisions in general, although some of these have limited statutes applicable to specific decisions such as consent to medical research. The statutes and accepted medical practice focus primarily on family and legal next of kin. There is nothing in these laws that focusses on whom the individual most trusts to make health care decisions. The person named may have no idea, until asked to make health care decisions, that the responsibility will fall to them. Laws vary in the scope of family members recognized, the extent of their authority, and whether they recognize close friends or other non-family as default surrogates. The person given priority in the statute may not be the person most trusted by the patient. Health care providers are more likely to ask next of kin to make health care decisions than they are to be aware of the laws authorizing them to do so. Even in the few states without these laws, health care providers typically ask next of

kin for consent as a matter of custom and practice.

6. **Displaced Decision-Making.** This pathway is the last resort option, where a court appoints a guardian or conservator to make health care decisions. The court may appoint someone who knows the individual well and can make decisions based on the beliefs, values and goals of the person, but the court may also appoint a total stranger as guardian or conservator. In an ideal world, a guardian would not be appointed unless all the alternatives for enabling the person to name a surrogate or make decisions were exhausted. Guardians are expected to decide as the individual would have decided to the extent that can be ascertained, but that depends on the guardian’s knowledge of the individual and their diligence in investigating the person’s values, beliefs, and priorities. Beyond that, the guardian is asked to make choices “in the best interest” of the person. Many adults make choices that are not what others may think is in their best interest, so while the best interest standard is meant to protect the person, it may result in decisions that do not reflect their beliefs, values or goals.

² Default Surrogate Consent Statutes, American Bar Association Commission on Law and Aging, January 2018 available at https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.pdf