

Guardian of the Person - Video 13

End-of-Life Decision-Making

(Introductory music and images)

Speaker appears in comfortable, neutral setting. At times words and pictures will appear next to them or in place of them to support the dialogue.

This is the third of four videos about being a guardian of the person. In this video, we will discuss a responsibility sometimes faced by a guardian of the person, end-of-life decision-making for the incapacitated person.

It can be difficult to make decisions regarding end-of-life care on behalf of an incapacitated person and can be particularly challenging when the incapacitated person is your loved one.

To make these decisions, you must first look to any advance planning documents for health care decisions that the incapacitated person prepared before they became incapacitated. These may include an advance directive, sometimes called a living will, or Pennsylvania Orders for Life Sustaining Treatment, or POLST. You should review the documents to help you understand the preferences of the incapacitated person, which will help you advocate for their preferences.

If the incapacitated person is diagnosed with a terminal condition, they may need additional or different services. It is important for you to share any advance planning documents with their doctors.

Also consider any preferences the incapacitated person communicates after a diagnosis of a terminal condition, and what you know of their prior values or religious beliefs. Remember, you must honor their wishes to the extent possible, even if they conflict with your own beliefs or preferences.

As a court-appointed guardian of the person, you should confirm whether the court that appointed you requires you to seek court approval for any end-of-life decisions you must make. A guardian may only make decisions to withhold or withdraw medical treatment if the incapacitated person is determined to be in an “end-stage” medical condition. This means that the medical condition affecting the incapacitated person is incurable, irreversible and terminal, and in an advanced stage.

If the incapacitated person has close family members who are able and willing to make end of life decisions, they may be the best people to do so, and the Court may agree and grant an order either ending the guardianship, or recognizing that the family members, as Health Care Representatives, are the best decision-makers for any end-of-life medical decisions. To clarify who should have the authority to make end-of-life medical decisions, it may make sense to petition the Court to hold a review hearing.

When and if it becomes necessary to make decisions about withdrawing or withholding life-sustaining treatments, you must first abide by the incapacitated person’s written or spoken preferences stated prior to their incapacity, including those documented in advance planning documents.

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If there are no written documents stating their preferences, and you do not know what they would likely choose based on their beliefs and situation, then you must base your decision on what a “reasonable person” would do given the incapacitated person’s specific circumstances. You should make sure that you understand the medical condition and the options for any proposed treatment, and that you have adequate time to confer with doctors and medical providers. You may be required to seek court approval prior to acting. Ask the Court that appointed you whether court approval is required.

The opinions of the incapacitated person’s loved ones should be considered as well. In many cases even where loved ones initially express resistance or disbelief that their loved one may be dying, providing information, an opportunity to talk and ask questions and an opportunity to talk with the medical providers will result in all parties coming to terms and coming together about decisions in the best interest of the incapacitated person.

If there is disagreement among family members, or if you sense that one or more family members may have a conflict of interest or an improper motivation, as the guardian of the person, ultimately you have the responsibility of making the decision even if it is not the preferred option of some or all family members.

In some circumstances, you may also want to get a second opinion from another doctor, discuss the situation with the incapacitated person’s nursing and direct care staff, and consider opinions of an ethics committee or review board, if possible.

For information on the important topics of intellectual disabilities and mental health disorders, watch the final video of the Guardian of the Person series.

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