

**Options for End-of-Life Treatment and Care in Florida:
Helping Patients and Families Make Difficult Medical Choices**

End of Life Scenario & Questions to Panel

Scenario:

John Smith is a bed bound 88 year old patient with moderate to high dementia and has been diagnosed with metastatic lung cancer. He has been admitted to palliative care services in hospice. The patient has an advance directive and has designated his daughter as his health care surrogate. The patient's daughter lives out of state, but has come to Florida to be with her father. Due to his dementia it is not always clear whether the patient understands what is happening around him. While the patient has a "do not resuscitate" order and an advance directive that says he does not want to be kept alive through artificial means, he cannot effectively communicate his wishes at the current time.

Questions to Panel: (not all questions were asked)

What medical considerations do you take into account when you develop a diagnosis and treatment plan for this patient?

Are there medical procedures that you would not recommend although they may prolong Mr. Smith's life by days, maybe even weeks?

If you are talking to the patient's daughter, how do you explain the options for treatment and care to her, given the fact that the patient has an advance directive that expresses his wishes for treatment?

What are your goals for this patient?

Is there a way to bring some comfort to her that she is making the right decisions?

How much of what you do when providing care for these patients is protocol and how much is instinctual?

Is it your experience that people do make sound, informed end-of-life decisions or do you see a lot of unnecessary suffering?

What is your entry point in this scenario? When and how will this patient and his daughter first meet you?

If there was ever a time when someone would be spiritually in need this would be it. A daughter having to make decisions for her dying father and a father that at some level knows he is leaving his daughter to fend for herself. How do you comfort them?

Are fear and sadness the overwhelming emotions you are dealing with or are you able to find something positive and life affirming in this experience?

Advance directives allow patients to express their wishes for end-of-life care. In your experience, how important is it for someone to have an advance directive and other documents expressing their treatment choices?

Are advance directives always honored and what steps can be taken to increase the chances that they will be?

How common is it for dementia or even Alzheimer's disease to be a factor in end-of-life care?

How does serious dementia or Alzheimer's complicate what you're trying to accomplish with your patients?

Aspiration pneumonia is a common cause of death in people with late-stage dementia. What are the issues surrounding care for patients with this condition?

Is there a point at which simply being alive is no longer a reason for living?