

MODULE: END-OF-LIFE DECISION-MAKING

Detailed Case Scenario

Mrs. Linda Scott is a 70-year-old widowed woman with Alzheimer's disease. She worked as a bookkeeper so when she started having problems balancing her checkbook 4 years ago she became concerned and came to visit you. You eventually diagnosed her with Alzheimer's disease. In the last year and a half, her health has continued to deteriorate and while she still lives at home, she requires 24-hour care to help her with activities of daily living. This care is provided by her long-time friend Martha, a 65-year-old woman.

You have been Linda's doctor for the last 10 years. In this time you have come to know her as an extremely independent, intelligent woman. Widowed for 7 years she overcame the grief of her husband's death and eventually developed an extensive circle of friends with whom she would travel across the country. She became very close to one of these friends, Martha Watling, who eventually moved in with her 5 years ago. Linda is extremely well read and you always have lively discussions on topics as wide ranging as philosophy to the latest murder mystery. She has no children. Both of her brothers are dead. Her only family is two cousins who live in the United States who she has not seen for 7 years.

At the time of her diagnosis, Linda told you and Martha that she would "never want to go on a respirator" and, furthermore, did not want "any artificial feeding contraptions inserted" should she come to need them. You have not discussed these decisions with her since.

In the last few days Martha noticed that Linda seems to be having more trouble with her speech and seems to choke when she swallows. When Martha brings her to the hospital, a CT scan is done which shows evidence of a new stroke. After a few days, it becomes evident that Linda's swallowing difficulties are not improving. Furthermore, since the stroke, Linda has not been able to communicate or to understand any information. Martha discusses Linda's previously expressed wishes with the medical team and they agree to make her DNR. The medical team wants to insert a NG but Martha objects.

Martha did have Power of Attorney for Health Care at the time of diagnosis however, she did not feel comfortable fulfilling this role – said that she did not think she "would be strong enough to tell the doctors not to treat Linda". After discussing it with Linda her power of attorney was revoked a year ago and Linda had not found someone to assume this role since then. As her family doctor, you have not had any further discussions with Linda regarding feeding tubes since the time of her diagnosis. Knowing Linda, you do not think she would have changed her mind and you convey your opinion to the team.

Feeling strongly that feeding is a necessary to live, the medical team asks for a bioethics consult. The bioethicist tells them that since Linda expressed these wishes regarding feeding 4 years ago, they may not reflect her current wishes. These, he feels, are not known since a lot can happen in 4 years. The bioethicist therefore recommends that her family in the United States be contacted and feeding discussed with them. The cousins say that while they have not seen or talked to Linda for 7 years, they do not think she “would want to starve to death.”

Teaching Tips:

1. Distribute the case scenario. Allow participants a couple of minutes to read the information or have one of the participants read the scenario
2. Ask participants what issues in end-of-life decision-making are raised in this case scenario and what learning issues they would identify. Write these down on a flip chart, overhead or blackboard
3. The participants should identify a number of issues including:
 - ❑ The importance of discussing expected course of Alzheimer's
 - ❑ The role and importance of advance care planning
 - ❑ Importance of patient's goals, values and beliefs, perception of quality of life
 - ❑ What counts as an advance directive (legal standing of expressed wishes as advance directives)
 - ❑ Role of substitute decision-maker and who can act as substitute decision-maker
 - ❑ The use of artificial nutrition and other life-sustaining treatment near the end of life
 - ❑ Role and meaning of DNR orders
 - ❑ The importance of informed consent
 - ❑ The effect of physician's personal values and beliefs on decision-making
 - ❑ Role of a bioethics consult
 - ❑ What to do if there is conflict between health care providers, health care providers and bioethicist, health care providers and substitute decision-makers
4. Participants should move on to request more background information about her advance care planning and expressed wishes and discuss role of advance care planning, what counts as an advance directive, who can act as substitute decision-maker

TIP: Again it may be useful to ask participants to reflect on their past experiences with substitute decision-makers and advance directives. What did they find helpful? What problems did they encounter: How did they resolve these problems?

5. Ask participants to reflect on the medical team's acceptance of Martha's request that Linda be made DNR and their failure to accept her in role of substitute decision-maker when it came to providing artificial nutrition.

TIP: Ask participants to reflect on the opposite scenario: have they ever had a patient who wanted either to be resuscitated, or to go on life support or to be given any treatment when they, as physicians, thought the benefits of such treatments were very questionable? What happened in these situations?

6. Ask them to comment on the role of bioethics consult and the recommendations of the bioethicist. Was this good advice?
7. Move on to ask how participants would respond to the cousin's comment "Linda would not want to starve to death".
8. Ask participants what they would do now as Linda's doctor. What would they say to Martha? To the team? To the bioethicist?

TIP: Ask participants to reflect on situations in which they have doubts whether the substitute decision-maker was truly expressing the values of the patient. What did they do in these situations?

9. Review the learning issues that have not been dealt with and assign tasks.