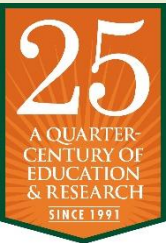




What I Really Wanted "Before" May Not Be What I want "Now"

Presentation of
a Hasting's Center Report
March-April 2014



UNIVERSITY OF MIAMI
MILLER SCHOOL OF MEDICINE
INSTITUTE FOR BIOETHICS



Raul de Velasco, MD
Ethics For Lunch Series
August 23, 2017



What I Really Wanted “Before” May Not Be What I Want “Now”

- **Mrs. F** was diagnosed as having Alzheimer's disease at 75 years of age. After knowing her diagnosis and conversations with her husband and children, she became adamant and made her husband promise that when she couldn't recognize herself, her husband or her children, she would like to die in the manner of her choosing, which was to stop drinking and eating.
- She, under any circumstance, would like to become a burden to her family or spend the last years of her life in a nursing home.



What I Really Wanted “Before” May Not Be What I Want “Now”

- As the disease progressed and **Mrs. F** became more impaired, she decided one the day to carry her decision to die by not drinking or eating. She reminded her husband that if she ever wavered on her decision not to drink or eat, it was his responsibility to remind her of the reasons she had expressed her decision to die.
- Hospice did not accept her as she was not close enough to dying from her Alzheimer’s.



What I Really Wanted “Before” May Not Be What I Want “Now”

- As she became weaker, the husband arranged for professional caretakers to assist him in her care. She began to ask for food and fluids from the professional caretakers...
- Her husband and family reminded her of her decision not to eat or drink if she requested it, that she did not want to be a burden to the family, and above all, she did not want to be in a nursing home, she wanted to die with dignity.

What I Really Wanted “Before”
May Not Be What I Want “Now”



The Fable of Ulysses and the Sirens

UNIVERSITY OF MIAMI
MILLER SCHOOL OF MEDICINE
INSTITUTE FOR BIOETHICS





What I Really Wanted “Before” May Not Be What I Want “Now”

Mrs. Lack-of-decision-making-capacity was not absolute and there were times that she appeared to be capacitated with respect to eating and drinking and looked like she had forgotten the decision she made.

What should the caregivers do?

- a. Give Mrs. F the food she wanted or
- b. Listen to her husband who knew her best?



Ross Fewing

Director of Ethics

St. Joseph Medical Center

- **Mrs. F** has now a different identity.
- At the present state she is now, she is not ready to die; is this because she is now having seconds thoughts about her previous decision or because she just forgot she made them?
- If we believe she is different person .
–otherwise why ask what she wants- reminding her of her previous wishes is a kind of coercion.
- If her request is strong enough, bring her food and let her decide.



Timothy Kirk

Assistant Professor of Philosophy
City University of New York

- It is legal in all 50 states to make and follow through with the deliberate decision not to eat or drink.
- The main problem in **Mrs. F** case is that this act requires a sustained and voluntary effort to refuse hydration and nutrition; she lacked both.
- The husband was promoting her previous decision but she now can't understand him; if she could, the reminders from the care givers or **Mr. F** are not coercive.
- In its truest form, autonomy is an expression of self. At the present time, her current wishes and preferences should be respected.



Alan Meisel

Professor of Bioethics and Law
University of Pittsburgh

- This event is complex, and it will become more frequent in the future now that the ‘conversation’ is happening more often.
- Don’t expect help from the law to provide guidance in particular cases of this kind, yet...



What I Really Wanted “Before” May Not Be What I Want “Now”

- ✓ Have the conversation any way – but do not expect every care taker to buy into your wishes.
- ✓ Document your wishes with videos and audio and give clear directives with your reasons to hopefully avoid misinterpretations.
- ✓ Consider having a “Ulysses Contract” prohibiting change in the future or allowing it in very special circumstances.



What I Really Wanted “Before”
May Not Be What I Want “Now”

It Is Very Complicated!

UNIVERSITY OF MIAMI
MILLER SCHOOL OF MEDICINE
INSTITUTE FOR BIOETHICS





What I Really Wanted “Before”
May Not Be What I Want “Now”

DISCUSSION

UNIVERSITY OF MIAMI
MILLER SCHOOL OF MEDICINE
INSTITUTE FOR BIOETHICS

