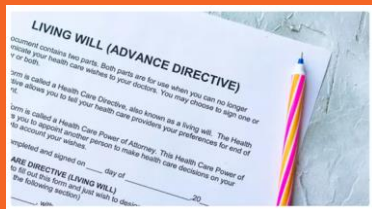


# Challenge: To Create Effective Advance Directives/Living Wills for Late-Stage Dementia

Dr. Stanley Terman & Dr. Karl Steinberg • 8/24/20 • DrTerman@CaringAdvocates.org

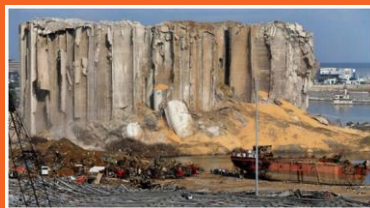
**Advance Directives/Living Wills are the last resort to prevent a prolonged dying with suffering**



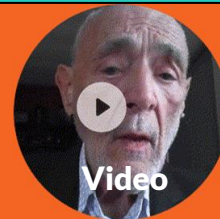
- A. No medications effectively prevent, delay, or treat advanced dementia symptoms**
- B. Medical Aid in Dying is not available to dementia patients**
- C. Physicians, judges, and others can require clear & consistent evidence in order to honor proxies/agents' instructions**

**Opponents to stop assisted feeding can refuse—if an advance directive has even one (of 24) types of flaws**

**Four types of flaws let Advance Directives/Living Wills fail & give a false sense of security**



- I. Process flaws as planning principals complete advance directives**
- II. Content flaws as drafters selected and described conditions and interventions**
- III. Inherent qualities that make advance directives unacceptable so that implementation is *not* likely**
- IV. Omitting strategies designed to compel physicians to write honoring orders, and to prevent third parties from sabotaging physicians' orders**



**Video**

**Flaws can violate the 4 Principles of Bioethics**




**Example: To honor requests to stop assisted feeding, physicians can require patients meet physicians' clinical criteria in addition to patients' criteria in their advance directives, which then violates**

**AUTONOMY**      **BENEFICENCE**  
**NONMALEFICENCE**      **SOCIAL JUSTICE**

**What Challenges Must Be Overcome?**

- ➡ Physicians' behavior can respect patients—and even be seen as noble—but still cause harm if they do not honor advance directives promptly**
- ➡ Physicians' behavior can appear well-meaning—but be selfish & cause harm**
- ➡ Physicians' behavior can insult patients so that physicians can be comfortable in their preferred roles—if they practice "hard" paternalism**

# The Challenge: to create an effective advance directive/living will for late stage dementia

- A. Advance directives/living wills are the last resort**
- B. Four types of flaws make advance directives/living wills fail**
  - I. Process flaws as planning principals complete their advance directives**
- C. Ethical Considerations** 

- 1) Doesn't Allow Refusal of Oral Nutrition = DARON**
- 2) Descriptions of Interventions & Conditions Not Understandable = DICNU**
- 3) Provides Inadequate Informed Consent = PIIC**
- 4) Presents Other Conditions Inconsistently = POCI**
- 5) Doesn't Offer Workable Irrevocability = DOWI**
- 6) Fails to Ask for Verbal Explanations = FAVE**

## Contact Information

Stanley Terman, M.D., Ph.D.      Karl Steinberg, MD, HEC-C  
[DrTerman@CaringAdvocates.org](mailto:DrTerman@CaringAdvocates.org)      [karlsteinberg@MAIL.com](mailto:karlsteinberg@MAIL.com)  
(760) 704-7524      (760) 473-8253

Return to Poster

# The Challenge: to create an effective advance directive/living will for late stage dementia

**A. Advance directives/living wills are the last resort**

**B. Four types of flaws make advance directives/living wills fail**

**II. Content flaws based on the conditions and interventions that drafters selected and how they are described**

**C. Ethical Considerations** 

- 7) Descriptions are Ambiguous, Vague, or Inconsistent = DAVI
- 8) Opponents Criticize Individual Conditions = OCIC
- 9) Doesn't Insist on Severe Enough Suffering = DISES
- 10) Condition Reached; Is Still Content = CRISC
- 11) Condition Reached; Is Possibly Treatable = CRIPT
- 12) Fallacy of Composition = FALCOM
- 13) Omits Conditions Often Dreaded = OCOD

## Contact Information

Stanley Terman, M.D., Ph.D.

[DrTerman@CaringAdvocates.org](mailto:DrTerman@CaringAdvocates.org)

(760) 704-7524

Karl Steinberg, MD, HEC-C

[karlsteinberg@MAIL.com](mailto:karlsteinberg@MAIL.com)

(760) 473-8253

Return to Poster

# The Challenge: to create an effective advance directive/living will for late stage dementia

**A. Advance directives/living wills are the last resort**

**B. Four types of flaws make advance directives/living wills fail**

**III. Inherent qualities render the advance directive arguably unacceptable--so opponents can refuse to implement them**

**C. Ethical Considerations** 

**14) Intervention Not Clinically Effective = INCE**

**15) Intervention Not Acceptable To Authorities = INATA**

**16) Limited Ability to Combine Conditions Causing Only Moderate Suffering = LACOMS**

**17) Who is the Authority to Determine If It Is Time = WADIT**

**18) How Authority Determines If It Is Time = HADIT**

**19) Format Incompatible with Physicians Order = FIPO**

## Contact Information

Stanley Terman, M.D., Ph.D.

[DrTerman@CaringAdvocates.org](mailto:DrTerman@CaringAdvocates.org)

(760) 704-7524

Karl Steinberg, MD, HEC-C

[karlsteinberg@MAIL.com](mailto:karlsteinberg@MAIL.com)

(760) 473-8253

Return to Poster

# The Challenge: to create an effective advance directive/living will for late stage dementia

**A. Advance directives/living wills are the last resort**

**B. Four types of flaws make advance directives/living wills fail**

**IV. Implementation fails due to omitting strategies designed to compel physicians to write honoring orders and to prevent third parties from sabotaging their orders**

**C. Ethical Considerations** 

## Contact Information

Stanley Terman, M.D., Ph.D.

[DrTerman@CaringAdvocates.org](mailto:DrTerman@CaringAdvocates.org)


(760) 704-7524

Karl Steinberg, MD, HEC-C

[karlsteinberg@MAIL.com](mailto:karlsteinberg@MAIL.com)

(760) 473-8253

**20) Strategies to Compel Orders by Treating Physicians = SCOTP**

**21) Physicians Require Additional Clinical Criteria = PRACC** 

**22) Undermining Planning Principals' Authority = UPPA**

**23) Undermining Proxies/Agents' Power = UPAP**

**24) False Interpretation of Behavior Observed = FIBO**

Return to Poster

# The Challenge: to create an effective advance directive/living will for late stage dementia

- A. Advance directives/living wills are the last resort**
- B. Four types of flaws make advance directives/living wills fail**
- C. Ethical Considerations**

## What challenges must be overcome?



Physicians' behavior can respect patients—and even be seen as noble—but still cause harm if advance directives are not honored promptly



Physicians' behavior can appear well-meaning—but still be selfish and cause harm




Physicians' behavior can, at worst, insult patients to allow physicians to be comfortable in their preferred roles—if they practice “hard” paternalism

Example: A flaw that violates the four principles of bioethics 

[Return to Poster](#)

# The Challenge: to create an effective advance directive/living will for late stage dementia

- A. Advance directives/living wills are the last resort
- B. Four types of flaws make advance directives/living wills fail
- C. Ethical Considerations 

**IV. The flaw, “Physicians Require Additional Clinical Criteria” violates the four principles of bioethics**

**Physicians, or organizations, can insist patients not only meet the criteria in their advance directive, but also meet physicians’ additional criteria in order to honor patients’ requests to stop assisted feeding.**

- 1) AUTONOMY 
- 2) BENEFICENCE 
- 3) NONMALEFICENCE 
- 4) SOCIAL JUSTICE 

# The Challenge: to create an effective advance directive/living will for late stage dementia

A. Advance directives/living wills are the last resort

B. Four types of flaws make advance directives/living wills fail




C. Ethical Considerations 

IV. “Physicians Require Additional Clinical Criteria” violates the bioethical principle of...

**Autonomy**

Unilaterally changing the advance directives of patients who cannot give their informed consent due to their current incapacity does not respect patients’ right to self-determination.

So imposing additional clinical criteria violates the principle of *autonomy*.

BENEFICENCE   
NONMALEFICENCE   
SOCIAL JUSTICE 

[Return to Poster](#)



# The Challenge: to create an effective advance directive/living will for late stage dementia

A. Advance directives/living wills are the last resort

B. Four types of flaws make advance directives/living wills fail

C. Ethical Considerations 

IV. “Physicians Require Additional Clinical Criteria” violates the bioethical principle of...

**Beneficence**

The relentless downward trajectory of advanced dementia eventually makes patients completely unable to enjoy life. Imposing additional criteria prolongs patients’ process of dying without improving their lives.

So imposing additional clinical criteria violates the principle of *beneficence*.

NONMALEFICENCE 

SOCIAL JUSTICE 

# The Challenge: to create an effective advance directive/living will for late stage dementia

A. Advance directives/living wills are the last resort

B. Four types of flaws make advance directives/living wills fail

C. Ethical Considerations 

IV. “Physicians Require Additional Clinical Criteria” violates the bioethical principle of...

**Nonmaleficence**

Various types suffering usually increase as the process of dying is prolonged; and some go unrecognized, undertreated, or untreated.

So imposing additional clinical criteria violates the principle of *nonmaleficence*.

SOCIAL JUSTICE 

[Return to Poster](#)

# The Challenge: to create an effective advance directive/living will for late stage dementia

A. Advance directives/living wills are the last resort

B. Four types of flaws make advance directives/living wills fail

C. Ethical Considerations 

IV. “Physicians Require Additional Clinical Criteria” violates the bioethical principle of...

**Social Justice**

The longer advanced dementia is prolonged, the greater the cost of care and the lower the benefit to patients. Incapacitated patients will *not* be able to appreciate the sacrifices their family is making. They will consume scarce medical resources that could be allocated to provide benefit with less harm to patients who are not suffering from a terminal illness.

So imposing additional clinical criteria violates the principle of *social justice*.

# **The Challenge: to create an effective advance directive/living will for late stage dementia**

## **CONCLUSION**

**Reducing the suffering of millions of dementia patients and their family members is important, but this contentious area also inspires such profound questions as:**

**Do some flaws violate any of the four principles of bioethics?**

**Will patients' personal freedom, autonomy, and self-determination be respected by responsive, even noble, physicians' actions?**

**Or will patients' wishes be thwarted by self-serving, even insulting, paternalistic physicians' actions?**

**Contact information: [DrTerman@CaringAdvocates.org](mailto:DrTerman@CaringAdvocates.org) 800 647 3223**

**Return to Poster**