Give Good Care and Avoid "IJ"s:

Results From an Empirical Study

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Conflicts of Interest, and conflicting interests:

- I have no financial conflicts of interest to disclose, but,

- David Hoffman, JD:
- Serves as Clinical Ethics Consultant for VNS of NY, Hospice Program
- Provides legal, ethical and compliance advice to Hospitals and Long Term Care Facilities
- Holds teaching appointments at Columbia University and the Albert Einstein College of Medicine
- Serves on the Board of Directors of The Faith Sommerfield Family Foundation, Inc
- Serves on the Board of Directors of The Completed Life Initiative, Inc

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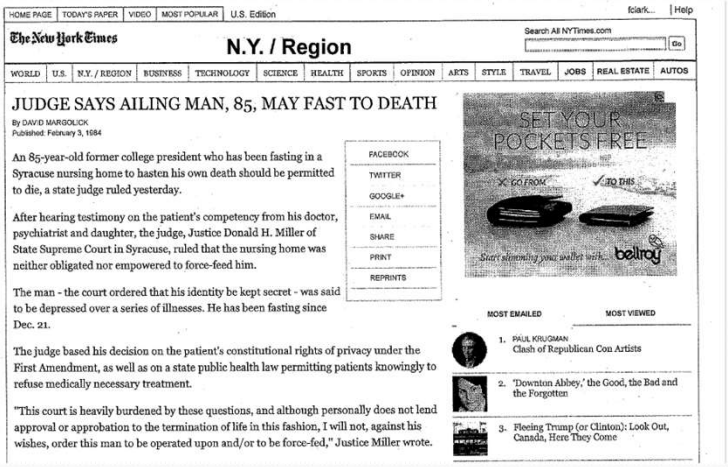
Why are we here?



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JUDGE SAYS AILING MAN, 85, MAY FAST TO DEATH

By DAVID MARGOLICK
Published: February 3, 1984

An 85-year-old former college president who has been fasting in a Syracuse nursing home to hasten his own death should be permitted to die, a state judge ruled yesterday.

After hearing testimony on the patient's competency from his doctor, psychiatrist and daughter, the judge, Justice Donald H. Miller of State Supreme Court in Syracuse, ruled that the nursing home was neither obligated nor empowered to force-feed him.

The man - the court ordered that his identity be kept secret - was said to be depressed over a series of illnesses. He has been fasting since Dec. 21.

The judge based his decision on the patient's constitutional rights of privacy under the First Amendment, as well as on a state public health law permitting patients knowingly to refuse medically necessary treatment.

"This court is heavily burdened by these questions, and although personally does not lend approval or approbation to the termination of life in this fashion, I will not, against his wishes, order this man to be operated upon and/or to be force-fed," Justice Miller wrote.

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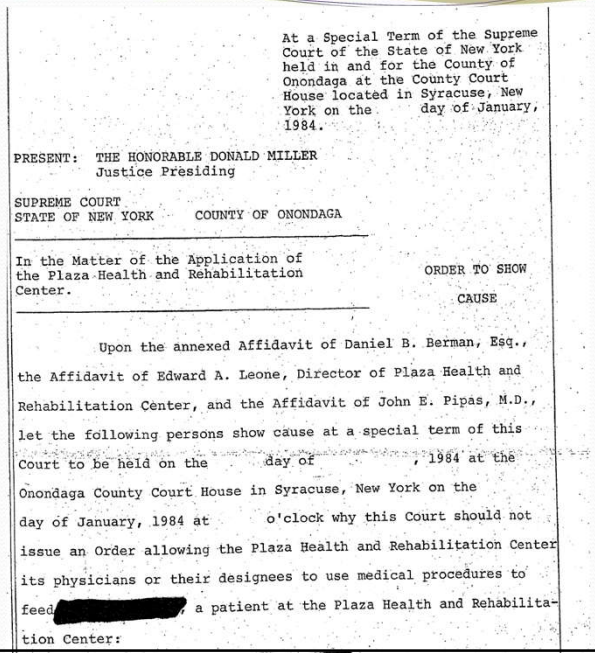
MOST EMAILED | MOST VIEWED

1. PAUL KRUGMAN Clash of Republican Con Artists
2. 'Downton Abbey,' the Good, the Bad and the Forgotten
3. Fleeing Trump (or Clinton): Look Out, Canada, Here They Come

3

1984:



At a Special Term of the Supreme Court of the State of New York held in and for the County of Onondaga at the County Court House located in Syracuse, New York on the day of January, 1984.

PRESENT: THE HONORABLE DONALD MILLER
Justice Presiding

SUPREME COURT
STATE OF NEW YORK COUNTY OF ONONDAGA

In the Matter of the Application of the Plaza Health and Rehabilitation Center.

ORDER TO SHOW CAUSE

Upon the annexed Affidavit of Daniel B. Berman, Esq., the Affidavit of Edward A. Leone, Director of Plaza Health and Rehabilitation Center, and the Affidavit of John E. Pipas, M.D., let the following persons show cause at a special term of this Court to be held on the day of , 1984 at the Onondaga County Court House in Syracuse, New York on the day of January, 1984 at o'clock why this Court should not issue an Order allowing the Plaza Health and Rehabilitation Center its physicians or their designees to use medical procedures to feed [redacted], a patient at the Plaza Health and Rehabilitation Center:

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And Mary Northern:

State Dept. of Hum. Serv. v. Northern

563 S.W.2d 197 (1978)

STATE of Tennessee, DEPARTMENT OF HUMAN SERVICES, v. Mary C. NORTHERN.

Court of Appeals of Tennessee, Middle Section.

February 7, 1978.

Certiorari Denied March 14, 1978.

*201 William B. Hubbard, Patricia J. Cottrell, Asst. Attys. Gen., Gregory M. Galloway, Nashville, for State of Tennessee.

Carol L. McCoy, Nashville, for Guardian Ad Litem.

Ames Davis, Nashville, for amicus curiae.

Certiorari Denied by Supreme Court March 14, 1978.

TODD, Judge.

OPINION

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Risk Management ....

OR

risk avoidance?

That is the question

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The New York Times

Pope Says a Strong U.S. Faction Offers a Backward, Narrow View of the Church

In unusually sharp remarks published this week, Pope Francis said some conservative American Catholics wrongly ignore much of the Church's mission and reject the possibility of change.

Share full article 1.2K

Pope Francis arriving for the weekly general audience in Paul VI hall at the Vatican on Tuesday. Filippo Monteforte/Agence France-Presse — Getty Images

By Jason Horowitz and Ruth Graham
Reporting from Rome and Dallas

Published Aug. 30, 2023 Updated Aug. 31, 2023, 10:17 a.m. ET

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Plan for today – Discuss:

- In this session we will explore the ethical tension between organizational obligations to provide all necessary and appropriate care on the one hand, while simultaneously respecting the right of patients and residents to refuse care, even when it is medically indicated and efficacious.

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Plan for today – Discuss:

Methods for reconciling the competing demands of respect for patient autonomy and the duty of beneficence, which requires that we do what is right for the patient, even if they don't realize it, will be presented through data from an empirical study on resistance by long term care facilities to honoring the advanced directives of patients suffering from dementia.

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Plan for today – Discuss:

Participants will learn to distinguish between withdrawing/withholding care that is legally mandated due to a valid, patient choice, and circumstances that constitute neglect, which can result in findings of Immediate Jeopardy.

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What is VSED??

- VSED is a manner of deliberately hastening death by deciding to stop consuming food & fluids while still physically able to eat & drink
- It is an intentional & voluntary choice by a decisionally capable person who suffers intolerably from an incurable, progressive or terminal illness with the goal of hastening his/her death
- Distinct from frequently occurring diminished appetite often experienced by dying persons
- Rarely 1st choice but often ONLY legal option

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What is a **successful VSED outcome**?
How is success defined?

- VSED is legally available in all states IF person decisionally capable & makes voluntary (i.e. uncoerced) informed & contemporaneous choice
- A *'successful'* outcome = **peaceful death with minimum of discomfort occurring within a predictable period of days or weeks** (my definition)
- Cause of death is dehydration not starvation

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Four ingredients necessary for successful VSED death?

1. Decisionally capable, suffering pt who is VERY determined to hasten death by fasting

   - must understand the process, know what to expect & have concluded burdens of living consistently out-weigh benefits of continued life (This option is not for everyone!)

2. Must have both social & care-giving support
3. Must have access to hospice or palliative medical oversight
4. Must be able to be patient with the process

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Clinical challenges to peaceful VSED death

- For those with terminal illness, forgoing food usually not difficult as appetite often diminished
- Forgoing fluids **can** be challenging – but w good oral care, rinsing & spitting, fine spray etc help relieve feeling of dry mouth
- Also – use of small doses of opioids & anti-anxiety meds → sleepy state
- Usual length of fast 7–14 days [aver. is 10] if fluids significantly limited & pt terminally ill
- Pt often slip into coma during final days

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More challenges when patient **NOT** terminally ill

- Can be difficult to obtain palliative over-sight - sometimes long-time MD will order meds & provide palliative management or refer hospice
- Sometimes pt must fast for several days before considered eligible for home hospice support
- In absence of terminal illness – fasting can be more 'challenging' & last longer - up to 3 wks?
- Must be clear to all that patient's suffering is intolerable & their decision to 'escape' is voluntary, well considered & very determined

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Ethical issues re VSED support

- Some question whether providing VSED support morally equivalent to assisted suicide
- Those who believe always morally wrong for a person to hasten or cause own death may hold that providing information or support for VSED is also immoral
- Health care professionals are not obliged to provide care they find morally objectionable
- Claims of conscience permit withdrawing from case but NOT abandoning patient

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ANA position statement re VSED

- 2017 ANA published "Nutrition & Hydration at the End of Life"
- Statement supportive of patients' rights to make an informed choice to stop eating and drinking in order to hasten death

  (this was a **very big deal**)
- AMA has not yet addressed this practice.

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Dementia Data…

- 6 million Americans now have Alzheimer's - number is expected to ↑ 14 million by 2050
- Advanced dementia (including Alzheimer's) is 6th leading cause of death in US & the 5th leading cause for those > 65 yrs & 3rd for those > 85 yrs
- Although people can live well for several yrs w dementia – many want to avoid the final terminal stages
- There are SEVEN stages of declining abilities

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Functional Assessment Staging Test

- Stages 1-3 mild cognitive decline: decreasing organizational capacity & memory challenges
- Stages 4-5 = Moderate Decline: can't manage finances or complex tasks > can't choose appropriate clothes for season or occasion
- Stage 6 = moderate/severe: unable to dress or bathe or mechanics of toileting w/o assistance & begins to be incontinent of urine & stool
- Stage 7 = advanced/terminal: ↑ loss of speech unable to recognize loved ones, can't ambulate or sit up w/o assistance, CANNOT FEED SELF or smile
- This 'terminal' stage can last for months to years IF patient is hand fed

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Additional Alzheimer's factoids

- 10% of people 65 or ↑ have Alzheimer's disease (AZD) or another dementia disease
- Older African Americans are twice as likely to have AZD as older whites
- Older Hispanics are 1.5 times as likely to have AZD as older whites
- 2/3 of Americans living w AZD are women
- As # of elderly Amer ↑ so does # of those w AZD
- ↑ early diagnosis b/c of development of biomarkers for disease→ make EOL plans sooner

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1st West Coast Landmark Case

- Margot Bentley of Vancouver BC, Canada
- 1991 - retired RN completed/revised living will & sent to daughters
- Wrote refused "..nourishment & liquids if suffering from extreme mental disability"
- Then suffered from Alzheimer's > 17 years
- Spoon fed in nursing home for years despite family's efforts & multiple unsuccessful court cases
- One judge ruled she had 'changed her mind'
- Finally died 2015 @ age 83

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Margot Bentley

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2nd landmark case from Oregon

- Nora Harris, a research librarian
- 2009 'early onset' Alzheimer's at age 56
- Completed advance directive "to prevent her life from being prolonged when disease got worse"
- But - no mention of wishes about hand feeding & was spoon fed for years in nursing home
- Husband went to court twice stop feedings
- Judge said written directive **not** specific enough
- Finally died 2017 age 64

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Nora Harris

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Further West coast developments

- 2017 EOLWA developed "Instructions for Oral Feeding & Drinking"
- Form stated when dementia is 'advanced' - oral feeding to be limited to 'comfort-focused'
- Assisted feedings provided only while patient seems to enjoy or willingly participates in being fed
- Received with much enthusiasm in WA…

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WHEN to implement dementia feeding limitations

3 Triggering clinical criteria for dementia directive:

1. Health care agent consults w PCP & **agree** patient **now in** '**advanced**' stage of dementia (**stages 6-7** on **F**unctional **A**ssessment **S**taging **T**est) symptoms include: inability to speak comprehensively, ambulate, recognize family or be continent

And

2. Patient unable to make health care decisions **And**

3. Unable to feed self

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Two Options to limit assisted oral feeding when dementia advanced

- **Option A:** refuses all life-prolonging measures including CPR & **all nutrition & hydration** (N&H) whether provided medically **or** by assisted oral feeding **AND**
- Specifically - refuses oral feeding **even if** mouth opens when spoon touches corner
- Requests provision of excellent comfort care & symptom management with palliative or hospice care once feedings stopped

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2nd option limiting assisted feeding

- **Option B**: refuses all life-prolonging measures including CPR & **medically** provided N&H & **limits oral feeding** to **comfort focused - e.g:**
- Feedings provided only while pt shows enjoyment or positive anticipation re eating
- Only given foods & fluids seems to enjoy
- Feedings stopped once pt no longer appears interested or begins to cough or choke
- Pt not to be coerced or cajoled into eating
- Once feeding stopped – access to comfort measures & medications with palliative or hospice care

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Further IMPORTANT instructions

- Once dementia directive completed, discuss with: PCP, health care agent, family members, attorney & all other 'stakeholders' who care about patient
- Give copies of directive to all of above
- Patient should **make videotape** of personal values & **reasons why directive completed** & give copy to all of above
- Remind all you are trusting them to NOT disregard your wishes b/c you 'appear' comfortable or have 'adequate' quality of life

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Long term care considerations

- As dementia becomes advanced, long term care placement often becomes necessary
- In anticipation of such transfer - patients & families should explore whether LTC administrators will honor dementia directive BEFORE entering facility
- In-service education within LTC facilities will be necessary – particular among CNA's who provide most care & often know patients best (video very important for them)
- We anticipate judicial review

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Determining Success of Directive

- May be a some time before we learn if effective in limiting feedings; one current case in Ithaca
- EOLCNY has counseled ↑ number of persons with early dementia who have completed directive (most chose option "A")
- Many have said they don't want to have to wait until dementia becomes 'advanced'
- **VSED** always an option while still decisionally capable & DETERMINED to avoid final dementia stages – none yet

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The Legal Perspective

- Eating & Drinking and the Law
- How did we get here?
- Where are we going?

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Think about 1914

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Think about 1914

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Benjamin Cardozo:

"[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body,"

Schloendorff v. *Society of New York Hospital*
211 N. Y. 125, 129-130, 105 N. E. 92, 93 (1914)

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Delio v Westchester

View New York Official Reports version

129 A.D.2d 1
Supreme Court, Appellate Division, Second Department, New York.

In the Matter of Julianne DELIO, etc., Appellant,
v.
WESTCHESTER COUNTY MEDICAL CENTER, et al., Respondents.

June 1, 1987.

Synopsis

Wife of 33–year-old patient in chronic vegetative state with no hope of recovery petitioned to terminate patient's care. The Supreme Court, Westchester County, 134 Misc.2d 106, 510 N.Y.S.2d 415, Cerrato, J., denied the petition, and wife appealed. The Supreme Court, Appellate Division, Thompson, J., held that wife, as conservator of patient, was entitled to act in accordance with prior clearly expressed wishes of patient and have use of feeding and hydration tubes discontinued.

Judgment reversed; petition granted.

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Federal Regulation: 42 CFR 488.301

Title 42 Part 488 → Subpart E → §488.301

Title 42 → Chapter IV → Subchapter G → Part 488 → Subpart E → §488.301
Electronic Code of Federal Regulations e-CFR

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Federal Regulation Definitions:

§488.301 Definitions.
As used in this subpart—

***

Abuse is the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish. Abuse also includes the **deprivation by an individual, including a caretaker,** of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being. Instances of abuse of all residents, irrespective of any mental or physical condition, cause physical harm, pain or mental anguish. It includes verbal abuse, sexual abuse, physical abuse, and mental abuse including abuse facilitated or enabled through the use of technology. ***Willful,*** as used in this definition of abuse, means the individual must have acted deliberately, not that the **individual must have intended to inflict injury** or harm.

***

Immediate jeopardy means a situation in which the provider's **noncompliance** with one or more requirements of participation has caused, or **is likely to cause**, serious injury, **harm**, impairment, or death to a resident.

***

Neglect is the failure of the facility, its employees or service providers to provide goods and services to a resident **that are necessary to avoid physical harm, pain, mental anguish, or emotional distress**

***

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State Operations Manual
Appendix Q - Guidelines for Determining Immediate Jeopardy
(Rev. 102, Issued: 02-14-14)

Triggers	
Issue	**Triggers**
D Failure to protect from undue adverse medication consequences and/or failure to provide medications as prescribed.	1. Administration of medication to an individual with a known history of allergic reaction to that medication; 2. Lack of monitoring and identification of potential serious drug interaction, side effects, and adverse reactions; 3. Administration of contraindicated medications; 4. Pattern of repeated medication errors without intervention; 5. Lack of diabetic monitoring resulting or likely to result in serious hypoglycemic or hyperglycemic reaction; or 6. Lack of timely and appropriate monitoring required for drug titration.
E Failure to provide adequate nutrition and hydration to support and maintain health.	1. Food supply inadequate to meet the nutritional needs of the individual; 2. Failure to provide adequate nutrition and hydration resulting in malnutrition; e.g., severe weight loss, abnormal laboratory values; 3. Withholding nutrition and hydration without advance directive; or 4. Lack of potable water supply.
F Failure to protect from widespread nosocomial infections; e.g., failure to practice standard precautions, failure	1. Pervasive improper handling of body fluids or substances from an individual with an infectious disease; 2. High number of infections or contagious diseases without appropriate reporting, intervention and care; 3. Pattern of ineffective infection control precautions; or 4. High number of nosocomial infections caused by cross contamination from staff and/or equipment/supplies.

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State Operations Manual
Appendix Q - Guidelines for Determining Immediate Jeopardy
(Rev. 102, Issued: 02-14-14)

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State Operations Manual
Appendix Q - Guidelines for Determining
Immediate Jeopardy
(Rev. 102, Issued: 02-14-14)

E Failure to provide adequate nutrition and hydration to support and maintain health.

Food supply inadequate to meet the nutritional needs of the individual;

2. Failure to provide **adequate nutrition** and hydration **resulting in malnutrition; e.g., severe weight loss, abnormal laboratory values**;

3. **Withholding nutrition and hydration without advance directive**; or

4. Lack of potable water supply.

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State Operations Manual:

Example Case #2 (Continued): (Refer to B - Investigation) During the investigation, the surveyor finds that the chart does not include a copy of the patient's advance directive. The progress note does not contain any documentation of the patient ever stating a wish to have nutrition and hydration withdrawn at the end of life. The patient has a diagnosis of advance dementia with a documented history of refusal to eat in a long-term care facility. The patient had been admitted because of continued weight loss and dehydration related to the refusal to eat or drink. The patient has a daughter who actively

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§ 489.102 Requirements for providers.

(a) Hospitals, critical access hospitals, skilled nursing facilities, nursing facilities, home health agencies, providers of home health care (and for Medicaid purposes, providers of personal care services), hospices, and religious nonmedical health care institutions must maintain written policies and procedures concerning advance directives with respect to all adult individuals receiving medical care, or patient care in the case of a patient in a religious nonmedical health care institution, by or through the provider and are required to:

(1) Provide written information to such individuals concerning—

(i) **An individual's rights under State law (whether statutory or recognized by the courts of the State) to make decisions concerning such medical care,** including the right to accept or refuse medical or surgical treatment **and the right to formulate, at the individual's option, advance directives.**

- * * *

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§ 489.102 Requirements for providers.

- **(3) Not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive;**
- (4) **Ensure compliance with requirements of State law (whether statutory or recognized by the courts of the State) regarding advance directives.** The provider must inform individuals that complaints concerning the advance directive requirements may be filed with the State survey and certification agency;
- (5) Provide for education of staff concerning its policies and procedures on advance directives;
- * * *

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§ 489.102 Requirements for providers.

- **(c) The providers listed in paragraph (a) of this section—**
- **(1) Are not required to provide care that conflicts with an advance directive.**

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All of which,

lead me to my research project . . .

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Original Study design

Planned as a randomized in-person interview study.

Then COVID -19 HAPPENED!

Switched to an on-line survey of AMDA membership.

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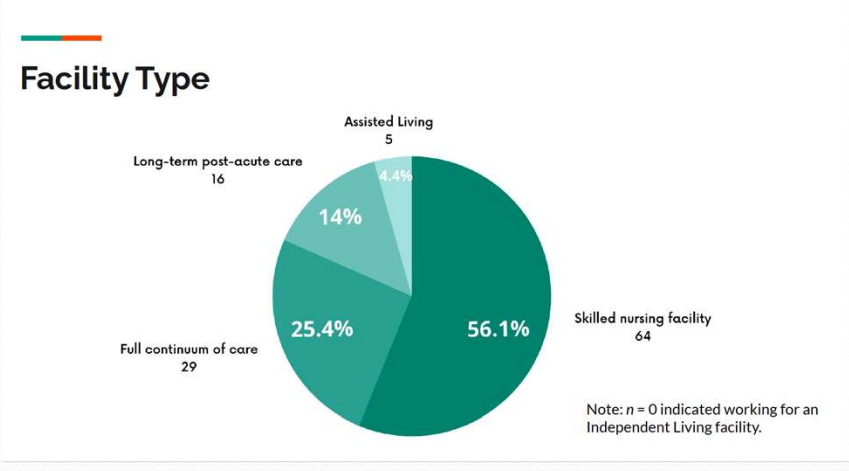

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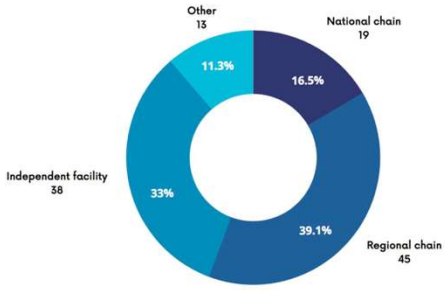
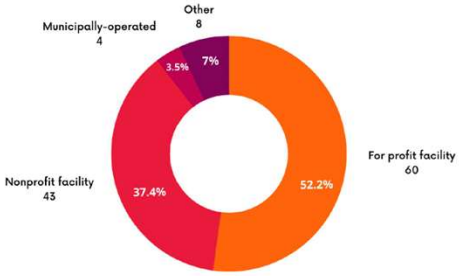
Facility Type & Funding





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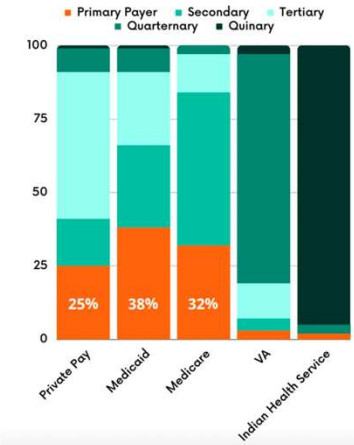
Payer Structure

25% of respondents indicated that private pay made up the largest proportion of their payer base.

38% and **32%** indicated the same for Medicaid and Medicare, respectively.



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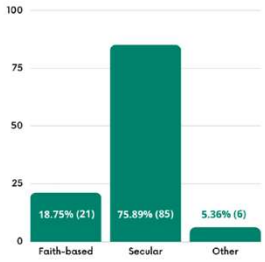
Facility Detail



Total # of beds:
Average: 171.79, Range: 24-500
Standard deviation: 120.05

Bed Type	Minimum	Maximum	Mean	SD
Independent living	0.00	400.00	**25.06**	79.31
Assisted living	0.00	349.00	**17.22**	43.73
Memory care	0.00	150.00	**16.45**	28.13
Skilled nursing	0.00	500.00	**111.17**	81.49

Enter facility with dementia

Develop dementia at facility

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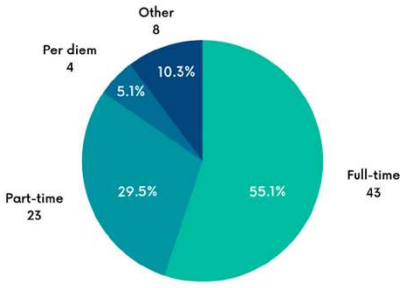
Personal Job Role + Practitioner Staffing



Number of practitioners in facility:

52

When do staff ask patients and their families about advance directives/care wishes?

The bulk of facilities assess on admission.

Among 87 respondents, **advance documentation rates at their facilities ranged from 5-100%.** The **mean rate was 59.49%** with a standard deviation of 24.33%.

At least **31%** of respondents (*n* = 23) indicated their facility does not conduct swallow tests on admittance, and at least **35%** (*n* = 26) do not discuss handling of oral feeding and hydration with families.

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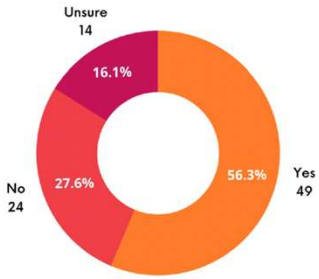
Use of CMS Code 99497



VSED Awareness

84 respondents estimated that of the patients entering their facilities with advance directives, **8.76% on average specified VSED at some juncture** (standard deviation of 18.62%, with a range between 0-90% – so a lot of variability here).

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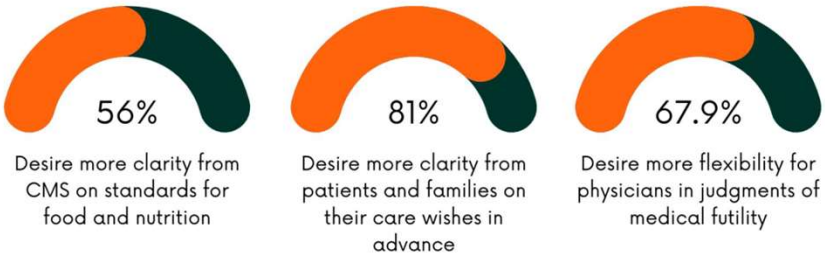
What would assist your facility in managing end of life issues for those of your patients with dementia?



Desire more clarity from CMS on standards for food and nutrition

Desire more clarity from patients and families on their care wishes in advance

Desire more flexibility for physicians in judgments of medical futility

88.46% (*n* = 69) of respondents indicated that their facility did have specific procedures and practices for assisting patients with dementia in oral feeding.

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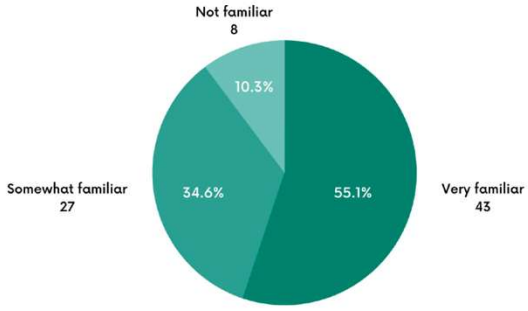
Immediate Jeopardy Concerns



64.10% (*n* = 50) of respondents indicated that their facility had specific protocols/rules in place for preventing IJ.

Only **28%** of this subgroup (*n* = 14) could definitively say that these policies include guidance on withholding assisted oral feeding.

67.53% (*n* = 52) respondents said they had not had the chance to discuss VSED concerns around immediate jeopardy with any colleagues.

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Immediate Jeopardy Attitudes

Were aware of any institution that was penalized for withholding nutrition or hydration pursuant to an advance directive

Cited Immediate Jeopardy as a primary institutional concern over implementing VSED by advance directive

Think Immediate Jeopardy is a correct designation for facilities that accommodate VSED by advance directive

11.69% (*n* = 9) were unsure.

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Immediate Jeopardy Experience

25.97% of respondents (*n* = 20) affirmed their institution had held trainings or briefings on avoiding Immediate Jeopardy in clinical practice, and **45.45%** (*n* = 35) reported having had meetings with their facility administrators on the topic.

Of the 35 participants who responded to the question, **45.17% (*n* = 16) indicated their facility had faced an Immediate Jeopardy investigation.**

5.6% (*n* = 4) later indicated that their facility had been the subject of an investigation into patient neglect. (Next step: investigate these subgroups?) **23.94%** (*n* = 17) cited the potential for investigation of neglect as a significant concern in considering VSED (larger than the proportion who were concerned about immediate jeopardy).

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VSED Attitudes

37.7% (*n* = 26) see informing patients and surrogates about the option of VSED as part of their institution's clinical responsibility.

31.9% (*n* = 22) do not, and **30.4%** (*n* = 21) are unsure.

Opens us up to the possibility of subgroup analyses.

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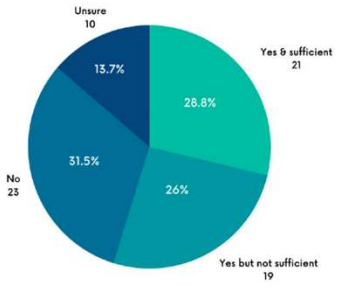
Training Needs

Does the institution provide trainings on managing symptoms from patients declining assisted oral nutrition and hydration?



Participants were most interested in:

- Trainings on **VSED Policy 50.7%** (*n* = 37)
- Trainings on **palliative care and oral care during VSED 41.1%** (*n* = 30)
- Trainings on advance directive screening at intake **32.9%** (*n* = 24).
- *Comparable numbers also indicated interest in the ethical obligation to respect advance directives, though others indicated this question was a sign of our researcher bias, a valid concern.*

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Managing Conflict

Participants were no stranger to family conflict, with **70%** (*n* = 49) indicating experience at their facility with managing family conflict around provision of nutrition and hydration to patients.

53.6% (*n* = 37) have a process for resolving disputes between prior expressed patient wishes and surrogate wishes.

60.9% (*n* = 42) reported rejecting surrogate instructions based on knowledge of advance care planning wishes.

61

Where do we go from here?

Residents must appoint an agent who knows, **and will follow**, your wishes regarding oral feeding.

And appoint an alternate agent or two!

And leave behind clear written instructions that describe your values and preferences

62

David's advance directive:

- I do not want to be a potted plant.
- If I am unable to express myself **and** show signs of experiencing joy, I want all but pain care withheld, so that my passing can come quickly.
- Organs to the living, body to science, then to the sea.
- Smile and Breathe.

D.N.H.

63

Why does this matter?

64

Like your teeth,

If you ignore your rights
They will go away!

65

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SECTION 2

Decisional Capacity and the Right to Refuse Treatment

State of Tennessee Department of Human Services v. Mary C. Northern

Court of Appeals of Tennessee, Middle Section, Feb. 7, 1978

On January 24, 1978, the Tennessee Department of Human Services filed this suit alleging that Mary C. Northern was 72 years old, with no available help from relatives; that Miss Northern resided alone under unsatisfactory conditions as a result of which she had been admitted to and was a patient in Nashville General Hospital; that the patient suffered from gangrene of both feet which required the removal of her feet to save her life; that the patient lacked the capacity to appreciate her condition or to consent to necessary surgery.

Attached to the complaint are identical letters from Drs. Amos D. Tackett and R. Benton Adkins, which read as follows:

> Mrs. Mary Northern is a patient under our care at Nashville General Hospital. She has gangrene of both feet probably secondary to frostbite and then thermal burning of the feet. She has developed infection along with the gangrene of her feet. This is placing her life in danger. Mrs. Northern does not understand the severity or consequences of her disease process and does not appear to understand that failure to amputate the feet at this time would probably result in her death. It is our recommendation as the physicians in charge of her case, that she undergo amputation of both feet as soon as possible.

On January 24, 1978, the Chancellor appointed a guardian ad litem to defend the cause and to receive service of process pursuant to Rule 4.04(2) T.R.C.P. On January 25, 1978, the guardian ad litem answered as follows:

> The Respondent, by and through her guardian ad litem, states as follows:
>
> 1. She is 72 years of age and a resident of Davidson County, Tennessee.
> 2. She is presently in the intensive care unit of General Hospital, Nashville, Tennessee, because of gangrenous condition in her two feet.
> 3. She feels very strongly that her present physical condition is improving, and that she will recover without the necessity of surgery.
> 4. She is in possession of a good memory and recall, responds accurately to questions asked her, is coherent and intelligent in her conversation, and is of sound mind.
> 5. She is aware that the Tennessee Department of Human Services has filed this complaint, knows the nature of the complaint, and does not wish for her feet to be amputated.
>
> . . .

On January 26, 1978, there was filed in this cause a letter from Dr. John J. Griffin, reporting that he found the patient to be generally lucid and sane, but concluding:

> Nonetheless, I believe that she is functioning on a psychotic level with respect to ideas concerning her gangrenous feet. She tends to believe that her feet are black because of soot or dirt. She does not believe her physicians about the serious infection. There is an adamant belief that

EDITORS' NOTE: The suit was filed under the state "Protective Services for the Elderly" Act, which permits a court to appoint a guardian for the purposes of consent to medical treatment if an elderly person is in imminent danger of death without treatment and lacks capacity to consent to it.

her feet will heal without surgery, and she refused to even consider the possibility that amputation is necessary to save her life. There is no desire to die, yet her judgment concerning recovery is markedly impaired. If she appreciated the seriousness of her condition, heard her physicians' opinions, and concluded against an operation, then I would believe she understood and could decide for herself. But my impression is that she does not appreciate the dangers to her life. I conclude that she is incompetent to decide this issue. A corollary to this denial is seen in her unwillingness to consider any future plans. Here again I believe she was utilizing a psychotic mechanism of denial.

This is a schizoid woman who has been urged by everyone to have surgery. Having been self-sufficient previously (albeit a marginal adjustment), she is continuing to decide alone. The risks with surgery are great and her lifestyle has been permanently disrupted. If she has surgery there is a tremendous danger for physical and psychological complications. The chances for a post-operative psychosis are immense, yet the surgeons believe an operation is necessary to save her life. I would advise delaying surgery (if feasible) for a few days in order to attempt some work for strengthening her psychologically. Even if she does not consent to the operation after that time, however, I believe she is incompetent to make the decision.

. . .

On January 28, 1978, this Court entered an order reciting the following:

From all of the above the Court finds:

1. That the respondent is not now in 'imminent danger of death' in the extreme sense of the words, but that her present condition is such that 'imminent danger of death' may reasonably be expected during her continued hospitalization.
2. That both feet of respondent are severely necrotic and affected by wet gangrene, an infection which probably will result in death unless properly treated by amputation of the feet.
3. That the probability of respondent's survival without amputation is from 5 percent to 10 percent and the probability of survival after amputation is about 50 percent, with possible severe psychotic results.
4. That, with or without amputation, the prognosis of respondent's condition is poor.
5. That respondent is an intelligent, lucid, communicative, and articulate individual who does not accept the fact of the serious condition of her feet and is unwilling to discuss the seriousness of such condition or its fatal potentiality.
6. That, because of her inability or unwillingness to recognize the actual condition of her feet which is clearly observable by her, she is incompetent to make a rational decision as to the amputation of her feet.
7. That respondent has no wish to die, but is unable or unwilling to recognize an obvious condition which will probably result in her death if untreated.

This Court is therefore of the opinion that a responsible individual should be named with authority to consent to amputation of respondent's feet when urgently recommended in writing by respondent's physicians because of the development of (symptoms) indicating an emergency and severe imminence of death.

. . .

[Appellant's first assignment of error states:]

Such actions by the Court were injurious to the appellant because they deprived her of her right to make her own decisions—regardless as to whether death might be a probable consequence—as to whether she was willing to surrender control of her own person and life.

This controversy arises from the fact that Miss Northern's attending physicians have determined that all of the soft tissue of her feet has been killed by frostbite, that said dead tissue has become infected with gangrene, and that the feet must be removed to prevent loss of life from spreading of gangrene and its effects to the entire body. Miss Northern has refused to consent to the surgery.

The physicians have determined, and the Chancellor and this Court have found, that Miss Northern's life is critically endangered; that she is mentally incapable of comprehending the facts which constitute that danger; and that she is, to that extent, incompetent, thereby justifying State action to preserve her life.

As will be observed from the bill of exceptions, a member of this Court asked Miss Northern if she would prefer to die rather than lose her feet, and her answer was "possibly." This is the most definitive expression of her desires in this record.

The patient has *not* expressed a desire to die. She evidences a strong desire to live and an equally strong desire to keep her dead feet. She refuses to make a choice.

If the patient would assume and exercise her rightful control over her own destiny by stating that she prefers death to the loss of her feet, her wish would be respected. The doctors so testified; this Court so informed her; and this Court now reiterates its commitment to this principle.

The appellant has filed three supplemental assignments of error, of which the first is:

> 1. The statute, T.C.A. §§ 14-2301, *et seq.*, is impermissibly vague; and, therefore, void and unconstitutional. The two phrases used in the statute, 'imminent danger of death' and 'capacity to consent' have not been defined in the statute nor is the Court given any assistance to determine when either standard has been met in the legal context, rather than a medical context.

In the judgment of this Court, the words "imminent danger of death" are no more vague than is consistent with the nature of the subject matter.

. . .

The words, "imminent danger of death" mean conditions calculated to and capable of producing within a short period of time a reasonably strong probability of resultant cessation of life if such conditions are not removed or alleviated. Such is undoubtedly the legislative intent of the words.

"Imminent danger of death" should be reasonably interpreted to carry out the purposes of the statute. For an authorization to mildly encroach upon the freedom of the individual, a relatively mild imminence or danger of death may suffice. On the other hand, the authorization of a drastic encroachment upon personal freedom and bodily integrity would require a correspondingly severe imminence of death.

In the present case, the Chancellor was not called upon to act until the imminence of death was moderately severe. By the time of the hearing before this Court, the imminence of death had lessened somewhat but remained real and appreciable. Accordingly this Court, recognizing a present real and appreciable imminence of death, made provision for drastic emergency measures to be taken only in event of severe and urgent imminence of death.

Appellant also complains of vagueness of the meaning of "capacity to consent." Capacity means mental ability to make a rational decision, which includes the ability to perceive, to appreciate all relevant facts, and to reach a rational judgment upon such facts.

Capacity is not necessarily synonymous with sanity. A blind person may be perfectly capable of observing the shape of small articles by handling them, but not capable of observing the shape of a cloud in the sky.

A person may have "capacity" as to some matters and may lack "capacity" as to others.

In 44 C.J.S. Insane Persons § 2, pp. 17, 18, partial insanity is defined as follows:

> *Partial insanity.* Although it is hard to define the invisible line that divides perfect and partial insanity, the law recognizes a state of mind called 'partial insanity,' that is, insanity on a particular subject only, sometimes denominating it 'insane delusion' or 'monomania.' The use of the term, however, has been criticized. Partial insanity has been said to be the derangement of one or more of the faculties of the mind, which prevents freedom of action. Ordinarily it is confined to a particular subject, the person being sane on every other. The degree of insanity, as partial or total, is to be measured by the extent and number of the delusions existing in the mind of the person in question. . . .

In the present case, this Court has found the patient to be lucid and apparently of sound mind generally. However, on the subjects of death and amputation of her feet, her comprehension is blocked, blinded, or dimmed to the extent that she is incapable of recognizing facts which would be obvious to a person of normal perception.

For example, in the presence of this Court, the patient looked at her feet and refused to recognize the obvious fact that the flesh was dead, black, shriveled, rotting, and stinking.

The record also discloses that the patient refuses to consider the eventuality of death which is, or ought to be, obvious in the face of such dire bodily deterioration.

As described by the doctors and observed by this Court, the patient wants to live and keep her dead feet, too, and refuses to consider the impossibility of such a desire. In order to avoid the unpleasant experience of facing death and/or loss

of feet, her mind or emotions have resorted to the device of denying the unpleasant reality so that, to the patient, the unpleasant reality does not exist. This is the "delusion" which renders the patient incapable of making a rational decision as to whether to undergo surgery to save her life or to forgo surgery and forfeit her life.

The physicians speak of probabilities of death without amputation as 90 to 95 percent and the probability of death with surgery as 50–50 (1 in 2). Such probabilities are not facts, but the existence and expression of such opinions are facts which the patient is unwilling or unable to recognize or discuss.

If, as repeatedly stated, this patient could and would give evidence of a comprehension of the facts of her condition and could and would express her unequivocal desire in the face of such comprehended facts, then her decision, however unreasonable to others, would be accepted and honored by the Courts and by her doctors. The difficulty is that she cannot or will not comprehend the facts.

The first supplemental assignment of error is respectfully overruled.

The second supplemental assignment of error is as follows:

> 2. The Chancellor erred by denying the Appellant her rights to substantive and procedural due process. The entire legal proceedings involved in this case and on appeal are unprecedented; the order of the Chancellor granting the appeal but refusing the automatic stay of thirty days allowed by the Rules is one example of the procedural wrongs which was not in accordance with the established legal practice, and contrary to the expected procedure to be followed. The proposed amputation will not only permanently deprive the Appellant of her two limbs, but most likely will significantly and irreparably alter her personality for the worse, and make her mentally and physically dependent upon the State.

Whatever the propriety or impropriety of the action of the Chancellor in attempting to effectuate his action in spite of the appeal, the error, if any, has been rendered harmless by the action of this Court, after appeal, in reviewing and modifying his actions.

This Court does not recognize that it has been guilty of any improper deviation from correct procedure. The gravity of the condition of the patient and the resultant emergency in time required the unusual action of the Court under § 27-327 T.C.A. and the unusual acceleration of hearings and actions taken.

This Court is painfully and acutely aware of the possible tragic results of amputation. According to the doctors, the patient has only a 50 percent chance of surviving the surgery; and, if she survives, she will never be able to walk and may suffer severe mental and emotional problems.

On the other hand, the doctors testified, and this Court finds, that the patient's chances of survival without amputation are from 5 percent to 10 percent—a rather remote and fragile chance. Moreover, as testified by the doctors and found by this Court, even if the patient should survive without amputation, she will never walk because the dead flesh will fall off the bones of her feet leaving only bare bones.

IT IS, THEREFORE, ORDERED, ADJUDGED AND DECREED that

1. Mary C. Northern is in imminent danger of death if she does not receive surgical amputation of her lower extremities and she lacks the capacity to consent or refuse consent for such surgery.
2. That Honorable Horace Bass, Commissioner of Human Services of the State of Tennessee or his successor in office is hereby designated and authorized to act for and on behalf of said Mary C. Northern in consenting to surgical amputation of her lower extremities and of exercising such custodial supervision as is necessarily incident thereto at any time that Drs. Amos D. Tackett and R. Benton Adkins join in signing a written certificate that Mary C. Northern's condition has developed to such a critical stage as to demand immediate amputation to save her life. The previous order of this Court is likewise so modified.

As modified, the order of the Chancellor is affirmed. The cause is remanded for further appropriate proceedings.

. . .

Modified, Affirmed, and Remanded.*

*On May 1, 1978, Mary Northern died in a Nashville hospital as a result of a clot from the gangrenous tissue migrating through the bloodstream to a vital organ. Because of complications rendering surgery more dangerous, the proposed surgery was never performed.

Transcript of Proceedings: Testimony of Mary C. Northern

January 28, 1978

Testimony of Mary Northern: [The following interview took place at the bedside of Mary Northern in the Intensive Care Unit of the Nashville General Hospital. Present were Judge Todd, Judge Drowota, and the Reverend Palmer Sorrow, a friend and frequent visitor of the patient. Eds.]

JUDGE TODD: Now, Mrs. Mary, you know that there have been some proceedings in court about you, and that's the reason why the judges are here. And we wanted to see you and talk to you.

MISS NORTHERN: Yes.

JUDGE TODD: And give you a chance to talk to us.

MISS NORTHERN: Yeah.

JUDGE TODD: I understand that you had a little problem of getting too cold out there at your house.

MISS NORTHERN: Yes.

JUDGE TODD: That's right.

MISS NORTHERN: Yes. Well, now, it's a point of this, the swelling of my foot was—was very dangerous looking.

JUDGE TODD: Yes ma'am.

MISS NORTHERN: And so that's what caused most of the trouble, and the—it's starting to go down. Give it a chance, it is starting to go down, and it's almost . . . Well, these—these ankles and the—along on these legs have gone down wonderfully.

JUDGE TODD: Yes, now, Mrs. Mary, these doctors have been talking to us at great length about the condition of your feet.

MR. SORROW: I think it's okay.

MISS NORTHERN: Okay.

JUDGE TODD: —and they tell us this about your feet. Now, mind you . . . we don't know whether it's so or not, but I want you to know what they have told us. . . . They tell us that your feet have been frostbitten before, and that they got well.

MISS NORTHERN: Yes.

JUDGE TODD: What they tell us, that your feet were frostbitten a great deal worse this time than they were . . . before.

MISS NORTHERN: Yes.

JUDGE TODD: And they tell us this,—now I am going to say some things to you that might be a little uncomfortable, but I want—I don't believe these doctors have told it to you just like they told it to us.

MISS NORTHERN: Yeah.

JUDGE TODD: So I want to give it to you just like they have given it to us. They tell us that this time every bit of the flesh on your two feet is completely dead.

MISS NORTHERN: I know—No, it isn't, it will revive.

JUDGE TODD: I understand.

MISS NORTHERN: Four or five days ago it started to go down.

JUDGE TODD: All right. Now they tell us this, that when you came in . . . here that your feet were swollen. . . . And they tell us that the swelling has gone down.

MISS NORTHERN: Yes.

JUDGE TODD: But they tell us that your feet are shriveling up like a dead person's feet—

MISS NORTHERN: Unh-unh.

JUDGE TODD: —rather than a live person's feet.

MISS NORTHERN: No, no. . . . I can get and walk all the way down to the shopping places.

JUDGE TODD: Now they tell us—We questioned them very, very thoroughly about this thing, and they tell us that you can move your toes. And then I asked them how could a person move his toes if his foot was dead? You see? And here's what they tell us. They tell us that the ligaments that move the toes . . . are dead, but they are still just like strings,—

MISS NORTHERN: Yeah.

JUDGE TODD: —and that the muscles that move the toes are up here where they are still alive, and therefore a dead foot can move its toes.

MISS NORTHERN: Well, they are not going to—they are not going to take my legs away. They are not going to take my legs away from me, you understand this?

JUDGE TODD: Yes, ma'am.
MISS NORTHERN: And they are not going to—I think it's rather silly, because they all—all of em have gotten viable.
JUDGE TODD: Yes, ma'am. Yes, ma'am. Now here is the thing that disturbs us. The doctors tell us that you have a very heavy infection which they are keeping in control by antibiotics, but that your temperature has started to rise, that you have a hundred and one temperature . . . which indicates that the infection is increasing. And we questioned them very closely now, we have been a long time—
MISS NORTHERN: You understand they are going to do it. Now, does this have something to do with the Metropolitan Government, has it not? Well, the Metropolitan Government can't take anything—do me this way, you know?
JUDGE TODD: Yes, sir. Now, here is what I want to present to you. You are a very intelligent woman for your age. I want to compliment you on that, you really are. I said you were like my mother, but you do circles around my mother as far as talking and thinking.

Now, you are educated, and you know this business of "if," and I want to ask you an "if" question. If your feet, the flesh of your feet, really is dead, and if you have one chance in ten of living without surgery, that it is, if—if the feet are left on, that nine chances to one that you will not live, it will kill you,—
MISS NORTHERN: I am not going to have—
JUDGE TODD: —would you still say, "I want that one chance?"
MISS NORTHERN: Well, of course,—
JUDGE TODD: Ma'am?
MISS NORTHERN: —this is not going to do anything like this. All—All of these thing,—
JUDGE TODD: Yes, ma'am.
MISS NORTHERN: —and my feet have gone down.
JUDGE TODD: Yes, ma'am.
MISS NORTHERN: My ankles are—
JUDGE TODD: Yes, ma'am. Now, let me ask you one more question.
MISS NORTHERN: I am not going to—Let me tell you something. I am not going to argue any more with you, because I know you have a multiple of opinions.
JUDGE TODD: No, I haven't formed any opinions, that's the reason I came up to talk to you. I haven't decided.
MISS NORTHERN: It's an opinion you formed, and I am not going to let you tell me—
JUDGE TODD: I am just telling you what they told me. Now let me ask you one more little thing.

If the time comes that this infection gets so bad that you are practically unconscious and can't talk to anybody, would you then be willing for the doctors to go ahead and do what they think should be done? . . .
MR. SORROW: That's an "if"—That's an "if" question.
JUDGE TODD: "If."
MISS NORTHERN: I think that's an understandable idea.
JUDGE TODD: Yes, ma'am.
MISS NORTHERN: An amongst your—your own opinion former—opinion former.
JUDGE TODD: Yes. Now, if the time comes that you are so sick that you can't make the decision, are you willing for the doctors to make the decision for you then?
MISS NORTHERN: Well, I think that that's an unreasonable way to look at it because you want an opinion.
JUDGE TODD: Yes, ma'am.
MISS NORTHERN: And you see, that's—that—Groundhog Day and the—all the weather and everything else, now, it's an opinion.
JUDGE TODD: Judge, is there anything you would like to ask?
JUDGE DROWOTA: Well, I have the same questions, though, with the "if." And as Reverend Sorrow has said, if in fact at some day there is a feeling that—and you are unconscious and we can't ask you—
MR. SORROW: It's a question of whether to let you die.
JUDGE DROWOTA: —should we let you die, or would you rather live your life without your feet?
MISS NORTHERN: I am giving my feet a chance to get well.
MR. SORROW: Right, right. Okay. Let's say we have given it a chance to get well, and if the infection didn't get out of your system and you became unconscious, he is saying, would you rather—
MISS NORTHERN: I am not making any further . . . statement.
JUDGE TODD: In other words, you are not willing to admit that you might get unconscious?

MISS NORTHERN: No.
JUDGE TODD: I see. All right.
MISS NORTHERN: You are pretty handsome; it's rather nice to have all you handsome men come at you this morning.
MR. SORROW: Can they look at your feet?
MISS NORTHERN: No, no. Can you see me?
JUDGE TODD: I think maybe you better see your feet.
MISS NORTHERN: You know where they are? . . . They are there.
JUDGE TODD: I need to ask you this, Miss Mary. . . . When have you seen your feet?
MR. SORROW: Have you seen them recently? Have they let you see your feet real close?
MISS NORTHERN: They let me see my feet. I can see my feet.
JUDGE TODD: When did you see them, do you remember?
MISS NORTHERN: I seen them two or three times. Don't look at the feet. Let's don't look at the feet.
JUDGE TODD: I tell you what let's do.
MISS NORTHERN: Don't look at the feet.
JUDGE TODD: Let's don't look at the feet. I tell you what let's do. . . . Let's you and I look at them together at the same time and see what we can.
MISS NORTHERN: They are down there.
JUDGE TODD: I want you to look at them with me. Would you do it?
MISS NORTHERN: Isn't—I just don't understand, it's sadism about it. I can't understand it.
A NURSE: Let's all look at your feet.
MISS NORTHERN: Okay. All right, General.
A NURSE: All of us together. Let's get your gown down. There we go. Now—
MISS NORTHERN: That's all peeling off of that. It's all getting well. It's all going down.
JUDGE DROWOTA: Do you have feeling in your feet?
MISS NORTHERN: Oh, yes, they were knocking all around, and they're banging up against this thing and everything.
MR. SORROW: Can you feel it when you do that?
MISS NORTHERN: Yeah.
MR. SORROW: Is there feeling?
MISS NORTHERN: Yeah. . . .
JUDGE TODD: —Would you—would you just bear with us just for one more thing?
MISS NORTHERN: You want to establish your point.
JUDGE TODD: No, we don't. I am asking you—
MISS NORTHERN: You got your points all in writing and established it, according to your own—
JUDGE TODD: Yes, ma'am. If the time comes that you have to choose between losing your feet and dying, would you rather just go ahead and die than lose your feet? If that time comes?
MISS NORTHERN: It's possible—It's possible only if I—Just forget it. I—You are making me sick talking.
JUDGE TODD: I know. I know. And I am sorry. Would you be willing to say to me that you just don't want to live if you can't have your feet? Is that the way you feel?
MISS NORTHERN: I don't understand why it's so important to you people, why it's so important. . . .
JUDGE TODD: Mrs. Mary, you see a judge has to see both sides of the thing, and these people have come and told us something, and now we want you to tell us what you want to tell us so we can decide.
MISS NORTHERN: A billion of you have been here.
JUDGE TODD: I understand. And that's the reason we came out to see you, so we could let you—
MISS NORTHERN: I don't want to discuss it any more. I made my point.
JUDGE TODD: I believe, Mrs. Mary, that you have made your point that you would rather—that you don't want to live if you can't have your feet; isn't that about it?
MISS NORTHERN: That's possible. . . . It's possible to see it that way, to have that opinion. I don't want you all to change your opinion.
JUDGE TODD: No. I want you to tell me if you really feel that way. Tell me because I want to know it. I want to consider how you feel.
JUDGE DROWOTA: Or if you would rather live and have your feet. I mean, without your feet. See, you have got me confused, Miss Mary.
JUDGE TODD: She wants to live and have her feet.
MR. SORROW: That's exactly what she wants.
MISS NORTHERN: This is ridiculous. I am tired. And ridiculous, you know it is.
MR. SORROW: I think they are trying to look at your side of it and understand how you feel, and, of course, somebody else in your position, we don't know what we would do, and so I guess they are saying so many people have told these judges so much they want to see Miss Mary and say, "How do you feel, how do you feel?"
MISS NORTHERN: It's gotten a little roll.

MR. SORROW: Like a snowball.
MISS NORTHERN: This is—Let's leave it alone. Let's leave it alone. And you keep your opinions. I am through with it.
JUDGE TODD: I wish I could be through with it. Let me leave you with a little thought, Miss Mary.
MISS NORTHERN: All right. . . .
JUDGE TODD: Did you ever read the Sermon on the Mount?
MISS NORTHERN: Yes.
JUDGE TODD: You remember one thing the Good Lord said?
MISS NORTHERN: What?
JUDGE TODD: If thy eye offend thee,—
MISS NORTHERN: Oh, yes, take the eye out.
JUDGE TODD: —cast it out. If thy hand offend you, cut it off. Now, if and when your feet begin to offend you, maybe, maybe, you will remember that little verse.
MISS NORTHERN: I thank you.