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The Importance of Bioethics for Post-Acute Care:

Compliance and Risk Management Benefits

AHLA Long-Term Care and the Law 2018

New Orleans, LA

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Edited to now start with primer, synopsis

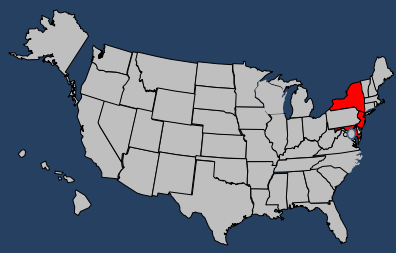
AHLA has and will post these too

Importance of Bioethics for Post-Acute Care

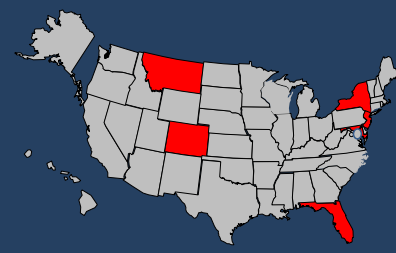
Prevalence

Bioethics is **rare** in PAC

Some statutory mandates



Some statutory roles



But usually **not** required

Consequently

Bioethics still **rare** in PAC

Geriatric Nursing Volume 25 Number 6

Ethics Committees in Long-Term Care Facilities

Mildred O. Hogstel, PhD, RN, Linda C. Curry, PhD, RN, Charles A. Walker, PhD, RN, and Paulette G. Burns, PhD, RN

17 facilities responded to survey

5/17

Ethics support in institutional elderly care: a review of the literature

Sandra van der Dam,[1] Bert Molewijk,[2,3] Guy A M Widdershoven,[3] Tineke A Abma[3]

To cite: van der Dam S, Molewijk B, Widdershoven GAM, *et al*. *J Med Ethics* 2014;**40**: 625–631.

"CECs are still an **uncommonly** used tool of nursing homes"

Caring for the Ages

When There Is No Ethics Committee

By Jeffrey Nichols, MD

Some exceptions

Does **your** client have a bioethics committee?

Functions

Education

Policies

Consults

Case consults

"main" function

Usually **prospective**

also retrospective

Issues

What does a PAC bioethics committee **do**?

Resolve conflicts

Navigate uncertainty

About what?

4 areas

End of Life
Surrogates
Other healthcare
Everyday

1

End of Life

Advance directives

- Completing
- Interpreting

DNR / POLST

DNH

Stop dialysis

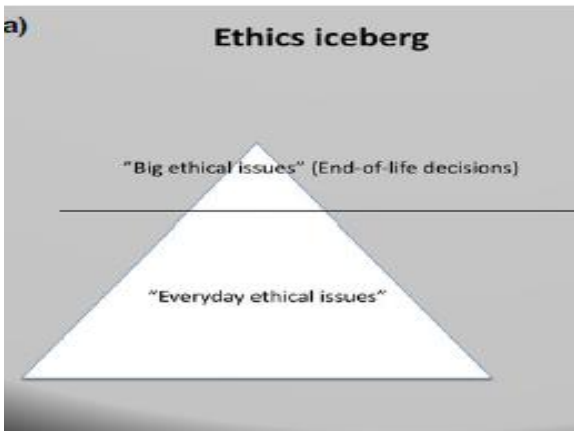
PEG / CANH

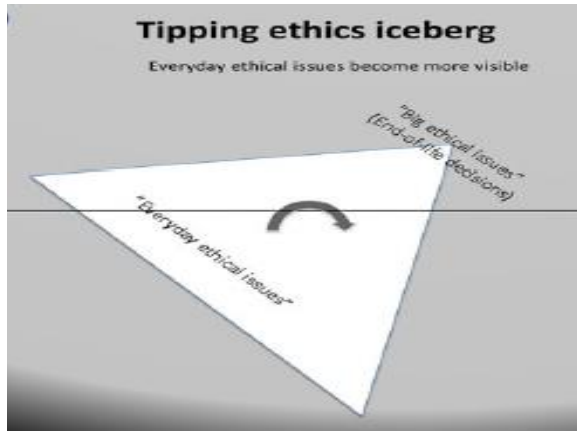
Other refusals

- Antibiotics
- Etc.

More controversial

- VSED
- MAID





2

Surrogate Decisions

Capacity

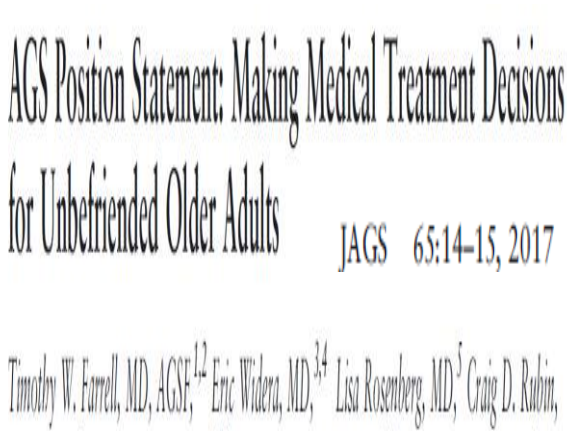
Identify surrogate

Support surrogate

Conflict among surrogates

"Bad" surrogates

No available surrogate


AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults

JAGS 65:14–15, 2017

Timothy W. Farrell, MD, AGSF,[1,2] Eric Widera, MD,[3,4] Lisa Rosenberg, MD,[5] Craig D. Rubin,

3

Healthcare

Covert medication

Coercion/restraints

Lack of time

4

Everyday ethics

Sex

Noncompliance

Racist requests

Value

Little direct research, measurement

Extrapolate research from **hospital** setting – where there is more research

Outcomes of Ethics Consultations in Adult ICUs: A Systematic Review and Meta-Analysis

Au, Selena S. MD, FRCPC, MSc[1]; Couillard, Philippe MD, FRCPC[1,2]; Roze des Ordons, Amanda MD, FRCPC, MMEd[1,3]; Fiest, Kirsten M. PhD[1,4,5,6]; Lorenzetti, Dianne L. PhD[4]; Jette, Nathalie MD, FRCPC, MSc[2]

Critical Care Medicine: February 1, 2018 - Volume Online First - Issue - p
doi: 10.1097/CCM.0000000000002999

Meta-review looked at 16 studies 1988 to 2015

Assessed **outcomes** after clinical ethics consultations in the ICU

5 main benefits

Higher surrogate & patient satisfaction

Consensus **more** often achieved

Less litigation

But even if so, courts **defer** to HEC

Lower resource utilization

Lower staff moral distress

That's **ICU**

where most bioethics consults go

There are **some** PAC-specific studies

show **same** benefits

Scandinavian Journal of Caring Sciences

EMPIRICAL STUDIES

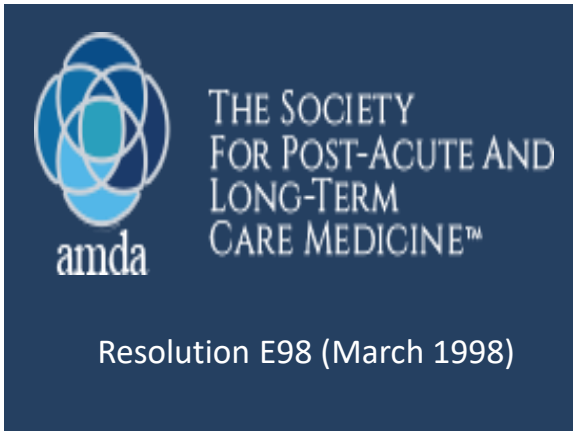
doi: 10.1111/scs.12213

Ethical challenges in nursing homes – staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives

Georg Bollig MD, MAS (PhD Candidate, Consultant)[1,2,3], **Gerda Schmidt** RN, MAS (Ward Manager, Nursing Manager Representative)[4], **Jan Henrik Rosland** MD, PhD (Professor, Director, Chief Physician)[1,2,5] and **Andreas Heller** PhD, MA (Professor)[6]

"lead to **consent** on acceptable decisions . . . **agreement** acceptable for all involved parties"

Value for PAC recognized **exactly** 20 years ago



Back to **originally** posted materials

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Health Care Decision Making in Long-Term Care

What Comes to Mind?

- End of Life Care
- Advance Directives
- POLST
- Withdrawal of Nutrition/Hydration

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Questions Raised

- "Irreversible"
- "Incurable"
- "Terminal"
- "Dementia" or "Alzheimer's"

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Advance Directives

- Some studies show that 50% of LTC residents may have
  Galambos, C., Starr, J., Rantz, M. J., & Petroski, G. F. (2016). Analysis of advance directive documentation to support palliative care activities in nursing homes.
- Even then, what has been discussed directly with the agent?
- Family members may differ regarding resident's wishes
- Can the agent be found?
- Is the agent willing?

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Ethics Iceberg

Bollig, G., Schmidt, G., Rosland, J. H., & Heller, A. (2015). Ethical challenges in nursing homes – Staff's opinions and experiences with systematic ethics meetings with participation of residents' relatives. *Scandinavian Journal of Caring Sciences, 29*, 810-823. doi:10.1111/scs.12213

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AUTONOMY:
A Legal As Well As An Ethical Concept

"No right is held more sacred or is more carefully guarded by the common law than the right of every individual to the possession and control of his own person, free from all restraint or interference of others unless by clear and unquestionable authority of law."

Union Pacific Railway Co. v Botsford, 141 U.S. 250, 251 (1891).

Meet Jane

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- Jane has difficulty swallowing
- Jane is considered a **"choking risk."**
- Dietician recommends a pureed diet.

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- But Jane finds pureed food to be unappetizing.
- Jane requests a **regular diet.**

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- Jane has decision-making capacity.
- She understands the risks of choking, including death

Traditional risk management approach

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- Find a superficially credible reason to **decline** Jane's request.
- Risk management concerns:
  - If Jane chokes and dies, will the facility get stuck with a **multi-million dollar verdict**?

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Manor Care v Douglas, 234 W. Va. 57, 763 S.E. 2d (2014).

Jury awarded $11.5M in compensatory and $80M in punitive damages; These were later reduced to $6.5M compensatory and $32M punitive. [Note: Entirely different set of facts]

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The average settlement amount paid to nursing home plaintiffs is **three times** the amount typically paid to medical malpractice plaintiffs.

Stevenson, D.G. & Studdert, D.M. (2003) The rise of nursing home litigation: Findings from a national survey of attorneys. *Health Affairs* 22(2), 219-229.

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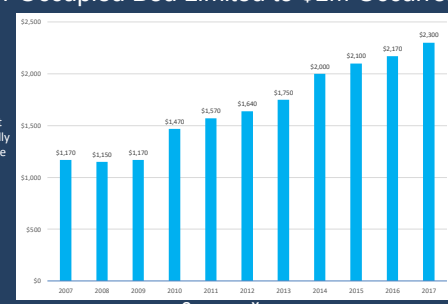
LTC Loss Rates
per Occupied Bed Limited to $1M Occurrence



Loss Rate: the amount paid annually by insurance to settle claims

AON Risk Solutions (2017). *Long term care general liability and professional liability actuarial analysis.*

2016 CMS Regs. "Person-Centered" Care

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- 42 CFR 483.5

Focus on the resident as the locus of control and support the resident in making his or her own decisions and having control over his or her daily life.

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- 42 CFR 483.10(c)(2)

Resident or representative right to participate in development and implementation of person-centered plan of care.

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- 42 CFR 483.10(b)(3)

Unless adjudged incompetent, the resident has the right to appoint a representative.

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More regulations that bioethics resources support

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General Residents' Rights
42 CFR 483.10, F-550

Right to Be Fully Informed
42 CFR 483.10(c), F-552

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Right to Refuse: Formulate Advance Directives

42 CFR 483.10(c)(6), F-578

Personal Privacy

42 CFR 483.10(h), F-583

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Dignity

42 CFR 483.10(a)(1), F-550,557

Self-Determination-Right to Make Personal Choices

42 CFR 483.10(f), F-561

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Fundamental Principles of Health Care Ethics

- Respect for Autonomy
- Beneficence
- Non-Maleficence
- Justice

L.F. & Blustein, J. (2015). *Handbook for Health Care Ethics Committees, 2nd ed.* Johns Hopkins University Baltimore, MD

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"Culture Change"

An intentional transformation of LTC settings

- To become less institutional
- To provide care centered on and directed by residents
- To be more empowering of care workers

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"Culture Change"

For example:

- Honor a resident's wake and sleep times, dietary choices, and right to decline recommended medical treatments.
- Culture change has been shown to positively impact quality improvement

Miller, S. C., Lepore, M., Lima, J. C., Shield, R. & Tyler, D. A. (2014). Does the introduction of nursing home culture change practices improve quality? *Journal of the American Geriatrics Society, 62*, 1675-1682. doi:10.1111/jgs.12987

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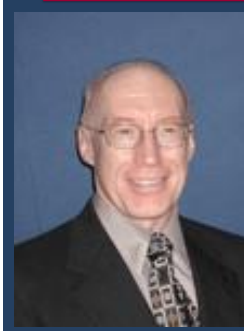
"Culture Change"



Thomas Hamilton

Director,
CMS Survey & Certification
2003-2016

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"Culture Change"

Noted the positive aspects of "culture change" in nursing homes and said that surveyors would help providers to incorporate culture change into regulatory compliance.

Pioneer Network. (2007, March 22). *Culture Change and CMS* [Video File]. Retrieved from https://www.youtube.com/watch?v=El35aaByvY0&t=1s

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Regulatory Interpretation

The Devil is in the Details

"Sometimes the greatest barrier to nursing home culture change is not the actual wording of the regulations or [CMS] interpretive guidelines, but instead the often inconsistent and incoherent manner in which those words are interpreted and enforced at the ground level by state employees who regularly survey facilities and issue them citations for perceived noncompliance."

Kapp, M. B. (2012). Nursing home culture change: Legal apprehensions and opportunities. *The Gerontologist, 53*(5), 718-726 p. 724.

Back to Jane

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Back to Jane

A Person-Centered Care Plan

- Will this be enough if Jane comes to harm?
- Realistically, will this case likely even go to trial?
- What else might support her autonomy and her care plan?

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What About An Ethics Committee?

- Healthcare providers and others who:
  - Consider and discuss medical ethical issues
  - Educate facility staff
  - Mediate disputes related to patient care among family members
- Purpose: To support the decision-making process using ethical principles

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What About An Ethics Committee?

- Frequently available in hospitals
- **Not** commonplace in post-acute care

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Ethics Consultation

"[A] set of services provided by an individual or group in response to questions from patients, families, surrogates, healthcare professionals or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care."

American Society for Bioethics and Humanities. (2011). *Core competencies for healthcare ethics consultation* (2nd Edition, p. 2) Chicago, IL.

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Characteristics of Effective Ethics Committees

- Multi-Disciplinary
  - Not just MDs
  - Other professionals such as nurses, social workers and others
- Ethicist
  - Individual with some formal background
  - Conversant with ethics literature
  - Educational resource

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Typical Ethics Committee Members

- Physicians (at least one not involved in care)
- Administrator
- Nurses (including DON)
- Social workers
- Ethicist
- "Outside" perspectives: former patient, family members, others interested in bioethics
- Clergy member
- Attorney for facility

Table 2. Member of Ethics Committees in Long-Term Care Facilities (LCTFs) Surveyed (n = 5)

Members	1	2	3	4	5	%
Physician	x	x	x	x	x	100
Registered nurse	x	x	x	x	x	100
Social worker	x	x	x	x	x	100
Chaplain or clergy	x		x	x	x	80
LTCF administrator			x	x		40
LTCF resident				x		20
Community member	x					20
Admissions coordinator				x		20
Activities director			x			20
Ethicist						0
Attorney						0

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Characteristics of Effective Ethics Committees

- Confidentiality
- Meaningful deliberation from all members
- Focuses upon relevant ethical principles and application to the case presented

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Ethics Committee Responsibilities (1)

- **Seek information** from patients, their friends or family members, and the facility
- **Ask** relevant questions

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Ethics Committee Responsibilities (2)

- **Educate** facility staff, patients, and their families about bioethics and the role of the committee

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Ethics Committee Responsibilities (3)

- Review cases
- Make policy recommendations
- Be accessible and available to physicians, staff, residents and families

Meet Dorothy

WEDNESDAY, JAN. 1, 2014 NEWS LONG BEACH REGISTER 3

Samuel Benardo dances with his mother, Kirsten Benardo, of Los Angeles, at the Waterfront in Long Beach.

Getting a jump on the new year

Downtown Long Beach celebrations began early New Year's Eve.

THE REGISTER

The New Year's celebrations started early Tuesday in downtown Long Beach before the big Pine Avenue party began.

At Auld Dubliner Irish Pub and Restaurant, 71 S. Pine Ave., revelers rang in the Irish new year at 4 p.m., celebrating with those a continent away.

Nearby, family-friendly festivities began at 5 p.m. at the waterfront amphitheatre and ended with fireworks at 9 p.m.

Meanwhile, a street party with live bands took over Pine Avenue for the annual New Year's event, as raucous crowds rang in 2014.

PHOTOS: ANIBAL ORTIZ, THE REGISTER

Dorothy Dresser of Carson celebrates the Irish new year with friends at Auld Dubliner in Long Beach on Tuesday.

Dorothy & daughter in Ireland

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Who was Dorothy?

- Loved Irish music and often seen at the pub singing along with a drink in her hand
- Loved by her family and had many friends with a wide variety of ages
- "Terminal" diagnosis – wanted "no heroics" at the end but not there yet!

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Dorothy & NPO Order

- Came out of surgery "NPO"
- Order continued based upon speech pathology assessment of some swallowing risk

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Dorothy & NPO Order

- Transferred to SNF with order still in place
- SNF MD **refused to change** order even after swallowing test at SNF and again at hospital both supported trial of fluids and soft foods

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No Meeting of the Minds

- MD
- Dorothy
- Dorothy's family

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No Meeting of the Minds

- **MD:** As long as there is some risk, she might aspirate or choke.
- This could lead to pneumonia or death. Not on my watch.

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No Meeting of the Minds

- **Dorothy**: Hey, I'm realistic about my new diagnosis and I've had a good life.
- But I'm not ready to go yet! I want to give treatment a try first.

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No Meeting of the Minds

- **Dorothy's Family**: We can't help but sneak mom some protein shakes and she is doing well so long as we feed her slowly.
- We can't get the doctor to change his mind and we don't want to get caught and have him raise a ruckus.
- Communication has already broken down.

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How Could An Ethics Committee or Ethics Consultant Have Helped Dorothy?

- Basic principles: Autonomy, beneficence, non-maleficence and justice
- **Autonomy:** Facilitate by giving her the opportunity to discuss risks and benefits and make her own choice
- **Beneficence/Non-Maleficence**: Even if not and potentially risky psychological benefit may be substantial
- **Justice**: resident rights and recognition of her interests

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How Could An Ethics Committee or Ethics Consultant Have Helped Dorothy?

- Support for her decision beyond the care plan
- Possibly recommend transfer to a new physician
- Mediate issues between physician and patient on an equal playing field

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Ethics Committees & Resources in Long-Term Care

It's Time!

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Questions

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Two more cases

Meet John

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John is a long-term custodial nursing home resident who has intact decisional capacity.

Nursing staff are required by policy to check on him **every two hours** during the night.

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But because John is a light sleeper, this wakes him up.

John offers to sign a waiver of liability if the facility will agree to **leave him alone** for 8 hours of uninterrupted sleep

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Meet the Lawyers

Although John is competent, if there is an **adverse outcome**, then we will be on the defensive to prove this in hindsight.

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Meet the Lawyers

What about the **regulatory authorities**?

Will failing to check on him translate to neglect?

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Meet the Lawyers

If he is in the facility because he requires 24-hour care, how can we justify ignoring him for **one-third** of the time?

Meet Arturo

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Arturo has advanced Alzheimer's Disease.

He has progressed to the point where he is unable to take food and fluids orally.

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The only medical alternative to provide nutrition would be **artificial feeding by G-tube**.

But the medical benefit of this procedure in end stage Alzheimer's is known to be marginal, and there are also significant risks.

Arturo has no advance health care directive.

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Arturo has **two children.**

One child says that "my father would **never have wanted** to have an artificial feeding tube under these circumstances."

The other says "my father was **devoutly religious** and would believe that forgoing artificial nutrition and hydration is tantamount to the sin of suicide."

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Meet the Lawyers

Both children are involved in their father's care

There doesn't seem to be **any evidence** as to what Arturo actually wanted, or which child he would want to speak for him were he to become incapacitated.

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Meet the Lawyers

One child says he would **not have wanted** artificial nutrition and hydration

But the other makes a serious and credible argument allegedly based upon their father's **religious beliefs.**

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Meet the Lawyers

This is very difficult situation but, when in doubt, we ought to "**err on the side of life"**

The child who is opposed to tube feeding can **go to court** and we will, of course, advise the facility to comply with any court order.

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