

Must We All Die With Forced Hand-Feeding?

American Society for Bioethics and Humanities
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Margaret Bentley

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By Arthur Caplan, Ph.D. COMMENTARY
Special to MSNBC
Updated 4/8/2004 1:12:34 PM ET

→ "All" is an eye-catching word. While great for headlines, it's admittedly an over-statement. The directive to which Dr. Caplan referred 10 years ago was meant to apply ONLY to patients in a permanent coma or "vegetative" state.



Outline

Clinical synopsis of Margaret Bentley's course of dementia. Her Living Will, proxy/agent designation, and verbal expression of her end-of-life wishes.

How administrators of her assisted living facility responded: It's elder abuse and illegal to honor them.

Judge's reasoning based on the evidence presented.

Strategic steps Margot could have taken to make it more likely others would honor her wishes. (—From which we can learn what will work for patients and us.)

Direct and unintended consequences of the Judgment.

Margaret Bentley ("Margot") was born in 1931. Her nursing career afforded her extensive clinical experience with patients who taught her what it is like to live with Advanced Dementia.

Affidavits of her husband, two daughters, a son, and a personal friend of 30 years who served as her treating physician for the last 3 years (Dr. Andrew Edelson) were all consistent: After she received the diagnosis of early dementia—Margot passionately, repeatedly and consistently stated that she did **not** want to endure a prolonged dying in the advanced stage of dementia. For example: "I'm worried. Please, please... Don't let this happen to me." Her (brief) chronology →



1991: Completed a Living Will ("Declaration of Wishes") that expressed her wishes and designated husband and daughter as first and alternate surrogate decision-makers. Signed, witnessed.

1999: Given the diagnosis of early dementia, probable Alzheimer's type. Restated her wishes orally to several people.

2005: Began residing in an assisted living facility.

2009-2010: Reached Advanced Dementia. **Cannot... recognize family members**, communicate or ambulate. Is... incontinent and dependent on others for **oral** hand-feeding/drinking.

Nov. 2011: Husband and daughter requested the honoring of Margot's "particular" instructions in her Living Will: "**No nourishment or liquids.**" Director of Care and treating physician agreed *initially*; but 3 days later, the administrative answer: NO!

Family endured a year of meetings, and evaluations, then another year of legal proceedings →

Comment on videos:

These two short clips are from August, 2013.
 Experts on both sides agreed:
 Margot manifested all criteria of the
 Functional Assessment Staging Tool—Stages 6 and 7.

FUNCTIONAL ASSESSMENT STAGING TOOL
 © 1984 Barry Reisberg MD

- 6a Difficulty putting clothing on properly without assistance.
- 6b Unable to bathe properly; may develop fear of bathing. Will usually require assistance adjusting bath water temperature.
- 6c Inability to handle mechanics of toileting (i.e., forgets to flush; doesn't wipe properly).
- 6d Urinary incontinence, occasional or more frequent.
- 6e Fecal incontinence, occasional or more frequent.
- 7a Ability to speak limited to about half a dozen words in an average day.
- 7b Intelligible vocabulary limited to a single word in an average day.
- 7c Nonambulatory (unable to walk without assistance).
- 7d Unable to sit up independently.
- 7e Unable to smile.
- 7f Unable to hold head up.

IN THE SUPREME COURT OF BRITISH COLUMBIA

Citation: *Bentley v. Maplewood Seniors Care Society*,
 2014 BCSC 165

Date: 20140203
 Docket: S135854
 Registry: Vancouver

Between:

Margaret Anne Bentley,
 by her Litigation Guardian Katherine Hammond,
 John Bentley and Katherine Hammod
 Petitioners

And

Maplewood Seniors Care Society,
 Fraser Health Authority and
 Her Majesty the Queen In Right of the Province of British Columbia
 Respondents

Before: The Honourable Mr. Justice Greycell

Reasons for Judgment

On Feb. 3, 2014, the Supreme Court of British Columbia issued a 44-page “Reasons for Judgment.”

Hand-feeding/drinking must continue as long as it is feasible. (Tube-feeding will **not** be started after.)

On Sept. 10, 2014, on behalf of Margot, her daughter Katherine Hammond filed an Appeal. (Hearing date?)

Even if the appeal is successful, Dec. 2014, will mark **three years** during which Margot was forced to endure the consequence of “protection”: **“To Delay is To Deny”** ...and her physical condition continues to worsen as she loses weight (and likely experiences hunger) and most likely suffers pain—as her daughter, Katherine Hammond, describes on the next video. →

Comments:

Immobility causes contractures that are extremely painful when joints are extended since moving stretches the now-shortened muscles beyond their ability. (Imagine an extremely painful muscle spasm of the whole body.)

Note: Nursing staff rarely attempt to extend the muscles of patients after they have progressed to the fetal position.

Dental caries are extremely likely to cause pain if X-rays show apical abscesses. (This evaluation could be done.)

(Why no poll regarding if Margot has pain.)

One-page
 “Living Will”
 1991

TO MY FAMILY, MY PHYSICIAN, MY LAWYER & ALL OTHERS WHOM IT MAY CONCERN

I, Margaret A. Bentley, of British Columbia, hereby declare that if the time comes when I can no longer take part in decisions for my future, I wish this statement to stand as an expression of my wishes.

IF AT SUCH A TIME THE SITUATION SHOULD ARISE THAT THERE IS NO REASONABLE EXPECTATION OF MY RECOVERY FROM EXTREME PHYSICAL OR MENTAL DEBILITY, I DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR “HERDIC RESOURCES”.

I DO ASK THAT MEDICATION BE MERCIFULLY ADMINISTERED TO ME TO ALLEVIATE SUFFERING EVEN THOUGH THIS MAY SHORTEN MY REMAINING LIFE.

I MAKE THIS STATEMENT AFTER CAREFUL CONSIDERATION AND IN ACCORDANCE WITH MY CONVICTIONS AND BELIEFS.

I HEREBY ABSOLVE ALL WHO FOLLOW THESE INSTRUCTIONS TO BE FREE OF ANY LEGAL LIABILITY. IN PARTICULAR, I WOULD REQUEST THE FOLLOWING INSTRUCTIONS TO BE CARRIED OUT:

A. NO ELECTRICAL OR MECHANICAL RESUSCITATION OF MY HEART WHEN IT HAS STOPPED BEATING.

B. NO NOURISHMENT OR LIQUIDS.

C. NO MECHANICAL RESPIRATION WHEN I AM NO LONGER ABLE TO SUSTAIN MY OWN BREATHING.

D. NO SURGERY.

E. OTHER THAN MEDICINE FOR PAIN RELIEF, I AM UNWILLING TO ACCEPT ANY INTERVENTION OF MY BODY.

I HEREBY DESIGNATE John Bentley OF British Columbia TO SERVE AS MY PROXY FOR THE PURPOSE OF MAKING MEDICAL DECISIONS ON MY BEHALF IN THE EVENT THAT I BECOME INCOMPETENT AND UNABLE TO MAKE SUCH DECISIONS FOR MYSELF. SHOULD John Bentley BE UNABLE TO CARRY OUT MY WISHES, I HEREBY APPOINT Katherine Hammond OF British Columbia AS AN ALTERNATE PROXY.

Two witness signed. (Copy truncated.)

I HEREBY ABSOLVE ALL WHO FOLLOW THESE INSTRUCTIONS TO BE FREE OF ANY LEGAL LIABILITY. IN PARTICULAR, I WOULD REQUEST THE FOLLOWING INSTRUCTIONS TO BE CARRIED OUT:
 A. NO ELECTRICAL OR MECHANICAL RESUSCITATION OF MY HEART WHEN IT HAS STOPPED BEATING,
 B. NO NOURISHMENT OR LIQUIDS.

Poll:

Is the term “No Nourishment or Liquids” **all encompassing**; that is, “NO” means “NO”?

OR

Is the term “No Nourishment or Liquids” vague so that others might misinterpret what Margot wanted?

Result: Of about 50 attendees, only 2 voted for vague so almost everyone considered it “**all encompassing**.” [Note: No claim is made for the validity or reliability of this result.]

The Honourable Mr. Justice Greycliff’s Judgment paragraph numbers are in [brackets].

I HEREBY ABSOLVE ALL WHO FOLLOW THESE INSTRUCTIONS TO BE FREE OF ANY LEGAL LIABILITY. IN PARTICULAR, I WOULD REQUEST THE FOLLOWING INSTRUCTIONS TO BE CARRIED OUT:
 A. NO ELECTRICAL OR MECHANICAL RESUSCITATION OF MY HEART WHEN IT HAS STOPPED BEATING,
 B. NO NOURISHMENT OR LIQUIDS.

[111] The most likely interpretation appears to be that Mrs. Bentley did not want artificial delivery of nourishment or liquids through measures like a feeding tube. I do not believe many people would consider eating with a spoon or drinking from a glass, even when done with assistance, “artificial”. While “heroic measures” may be a commonly used expression, it does not communicate with any degree of clarity what a particular adult considers “heroic”. As Ms. Duthie’s Clinical Ethics Consult report states, there is consensus in the medical community that assistance with oral nutrition and hydration is neither artificial nor heroic.

How could Margot have made her Living Will clear and specific so misinterpretation would very unlikely?

Simply add one four-letter word:

oral

so that it modifies “nourishment or liquids.”

TO MY FAMILY, MY PHYSICIAN, MY LAWYER & ALL OTHERS WHOM IT MAY CONCERN

I, Margaret Bentley, do hereby declare that at the time I signed this statement to stand as an expression of my wishes:

IF AT SUCH A TIME THE SITUATION SHOULD ARISE THAT THERE IS NO REASONABLE EXPECTATION OF MY RECOVERY FROM EXTREME PHYSICAL OR MENTAL DISABILITY, I DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR “HEROIC MEASURES”.

I DO ASK THAT MEDICATION BE MERCIFULLY ADMINISTERED TO ME TO ALLEVIATE SUFFERING EVEN THOUGH THIS MAY SHORTEN MY REMAINING LIFE.

I MADE THIS STATEMENT AFTER CAREFUL CONSIDERATION AND IN ACCORDANCE WITH MY CONVICTIONS AND BELIEFS.

I HEREBY ABSOLVE ALL WHO FOLLOW THESE INSTRUCTIONS TO BE FREE OF ANY LEGAL LIABILITY. IN PARTICULAR, I WOULD REQUEST THE FOLLOWING INSTRUCTIONS TO BE CARRIED OUT:
 A. NO ELECTRICAL OR MECHANICAL RESUSCITATION OF MY HEART WHEN IT HAS STOPPED BEATING,
 B. NO NOURISHMENT OR LIQUIDS,
 C. NO MECHANICAL RESUSCITATION WHEN I AM NO LONGER ABLE TO SUSTAIN MY OWN BREATHING,
 D. NO SURGERY.

E. OTHER: *In the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.*

I HEREBY APPOINT *John Bentley* AS AN ALTERNATE PROXY.

WITNESSED: *John Bentley* SIGNED: *Margaret Bentley*
 WITNESSED: *[Signature]* DATE: *10/21/14*

E. OTHER: *In the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.*

E. Other. In the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.

Pros:

Her own handwriting is consistent with this request being her personal, specific wish & is more convincing than checking a box.

Listing an emergent specific symptom can help provide a “time line” to guide others on **WHEN** to implement her Living Will.

The request also clarifies her intent: “I ask that I be euthanized” is clearly consistent with wanting to be **allowed to die** after she has reached the stage of Advanced Dementia—**not** to wait until she requires, but does not receive, tube-feeding if oral is not feasible.

Are there any problems with this request?

E. Other. In the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.

In 2012, the staff of Margot’s assisted living facility responded by involving Adult Protective Services... The result was that neither husband nor daughter were allowed to take their loved one home—even though they were also her designated proxies/agents. Police would physically prevent husband or daughter from removing Margot—based on the suspected threat that husband and daughter would **withhold** food and fluid to bring about Margot’s death, as evidenced by their repeated requests.

➔ The problem: Margot’s Living Will asked others to commit an act that was **illegal**, which they might view as conflicting with the teachings of their religion or as not conforming to their view of their professional, ethical, or moral duty.

E. Other. In the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.

How could Margot have expressed her wishes WITHOUT INVITING CONFLICT and provoking such a draconian response?

Simply add six words :

...if by then, euthanasia is legal.

(Note: Her wishes would still be clear, but she would not be asking anyone to commit an illegal act.)

What is the **best way** for Margot to express her end-of-life wishes clearly, specifically, and convincingly—after she has lost the ability to speak for herself?

To memorialize her wishes on a **recorded video**.

Advantages:

At best, Margot's direct statement would require no interpretation. Conflict of interest need not be considered (as could be suspected with proxies/agents).

The interview process is not simple since Margot was in the early stage of dementia. Ideally, she should be interviewed by a clinician who can give his/her opinion on whether or not she possessed decisional capacity.

Margot's **video** could make these points:

A) State what she knows about Advanced Dementia and why she refuses treatment to prolong dying in this stage;

B) Explain why she wants to refuse **oral** food and liquid; e.g., "My treatment goal is a peaceful and timely dying";

C) Passionately ask others to honor her wishes (as she did).

D) Note: Others can view this recorded statement later to decide if she **did, or did not possess capacity to give her "informed refusal."** (The interviewing clinician can also record his/her contemporaneous opinion about capacity.)

The goal of a clear and specific Living Will and recorded video statement is to resolve conflicts about her wishes...

Promptly, and thus avoid
Privately, and **"To Delay is To Deny."**
Peacefully;

The means: Present evidence of Margot's wishes that is so convincing that potential objectors will predict they will be embarrassed by losing. Instead of escalating the conflict to the courts, they will **refer** the patient to other providers.

Diligence in completing Living Wills and video statements is thus **necessary**—if one requests withdrawing assistance for hand-feeding/drinking in Advanced Dementia—so one can attain a dying that is both **timely** and **peaceful**.

In your opinion, is the completion of a Living Will and a video statement **sufficient** to attain this goal: to honor the patient's wishes?

Poll:

Yes, **sufficient**.

OR

No, **NOT sufficient**.

Result: About the same number of people voted for sufficient as for not sufficient. [Note: *No claim is made for the validity or reliability of this result.*]

My opinion: **NOT sufficient**.

Before explaining why and presenting two of several remaining challenges that require effective strategies,

Consider how to attain the goal,

A timely and peaceful dying.

The Living Will and video address "**Timely**."

This end-of-life intervention accomplishes "**Peaceful**":

NATURAL DYING *withdraws* another's help to put food and fluid in the patient's mouth (stops hand-feeding/drinking)—but **never withholds food and fluid** since vital substances are always placed in front of the patient. This allows patients to die of the underlying disease, dementia.

The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death

Linda Ganzini, M.D., M.P.H., Elizabeth R. Goy, Ph.D., Lois L. Miller, Ph.D., R.N., Theresa A. Harvath, R.N., Ph.D., Ann Jackson, M.B.A., and Molly A. Delorit, B.A.
N Engl J Med 2003; 349:359-365

Overall Quality of Death (alert patients) with Voluntary Refusal of Food and Fluid (VSED)

0 1 2 3 4 5 6 7 8 9
Very bad death Very good death

Hospice Nurses' Perceptions of VRRF

- Pain 0 1 2 3 4 5 6 7 8 9
No pain Severe pain

- Suffering 0 1 2 3 4 5 6 7 8 9
No suffering Severe suffering

- Peacefulness 0 1 2 3 4 5 6 7 8 9
Very much at peace Not at all peaceful

Two examples of why a diligent, clear and specific Living Will and a video recording are **NOT sufficient**:

Example 1:
 One self-righteous staff member can submit a request to investigate possible elder abuse that could take a **long** time to resolve, so that... **To Delay is To Deny**.

➔ To avoid an elder abuse investigation that may be prolonged, Attorney/Social Worker **Michael S. Evans** and I created a strategic "advance refusal to an elder abuse investigation" that is now part of the patient's affidavit that she can swear is true and correct before a notary.

Example 2:
 Margot opens her mouth sometimes but not other times. There is "some" (weak) evidence she thereby indicates her preference for different kinds of food.

How did the Judge interpret Margot's behavior?

[54] "All adults are **entitled to change their mind** subsequent to creating written instructions.... This Court must consider the possibility that Mrs. Bentley's previously expressed wishes are not valid in the face of **her current consent.**" {Bold emphasis added.}

Consent, of course, requires **capacity**...

The Judgment quotes the relevant section of British Columbia Act regarding criteria to determine capacity:

"(e) the health care provider **gives** the adult the **information** a reasonable person would require to **understand** the proposed health care... including...

- (i) the condition...,
- (ii) the nature of the proposed health care,
- (iii) the risks and benefits... and
- (iv) alternative courses of health care, and

(f) the **adult** has an opportunity to **ask questions** and **receive answers** about the proposed health care."

Poll:

Margaret Bentley **does** possess capacity.
OR
 Margaret Bentley does **not** possess capacity.

Unanimous: Margot does **NOT** possess capacity.
 [Note: *No claim is made for the validity or reliability of this result.*]

Also: No professional attending raised his/her hand to indicate s/he had ever seen a FAST Stage 6 or 7 patient who possessed capacity for making this decision.

As demonstrated in the video, Margot is not alert enough to respond by saying “Hello.”

Nevertheless, the Honourable Mr. Justice Grezell used this line of reasoning:

[53] “...until the contrary is demonstrated, every adult is presumed to be **capable** of making decisions.”

[55] “Communicating her decisions and preferences through **non-verbal** means... **does not mean** that she is **mentally incapable** of making this decision.”

[59] “Based on the evidence before me, I am of the view that the **petitioners have not met their onus of rebutting the legislative presumption** that Mrs. Bentley is capable of making the decision to accept or refuse to eat and drink. The preponderance of the evidence demonstrates that **she has the capacity to make this decision.**”

Unfortunately Petitioners for the patient never asked the court to consider this relevant bioethical point: →

Attorney/philosopher Ronald Dworkin taught:

Even if Margot clearly indicated her **experiential desire** to enjoy puree and liquids, her **precedent autonomy** should prevail. Her Living Will is her last expression of her competent autonomy and of her long-standing **critical interests** that are consistent with her life-narrative. Critical interests include not wanting a prolonged dying in Advanced Dementia and its associated harms and burdens.

[Dworkin RM. *Life's Dominion*. New York: Alfred A. Knopf; 1993]

Rebecca Dresser and others have argued, based in part on the “Disability Paradox,” that the principal who created an Advance Directive does not have “standing” to impose her judgment on the middle stage dementia patient she has become—since this patient now has different values and different treatment preferences.

But Dresser’s view arguably does not apply to patients in Advanced Dementia whose brains are so diseased that they **cannot have new values**. This includes Margot.

Thanks to **Dr. Guy Micco** (UC Berkeley) and to **Dr. Tony Hope** (Oxford University) for many discussions on these and related issues.

Suppose Margot’s behavior was actually clear to indicate that she **did want help to put food and fluid into her mouth?**

Then the question would be, to whom should her health care providers listen...

1) To Margot’s Living Will—created with capacity?

Or

2) To the person she is now, who has dementia and who lacks capacity—but can still express current desires—assuming her decision really means she wants to preserve her life?

How could Margot have resolved this conflict herself?

She could have decided and then memorialized her own decision—**before** she lost capacity.

→ Margot could have created an effective, **irrevocable, Ulysses contract** that empowered her proxies/agents to make sure her “future demented self” would **not** have the power to sabotage her goal to attain a peaceful and timely dying. (Thanks to Professor **Ronald B. Miller** (U C Irvine), who introduced me to the “Ulysses contract.”)

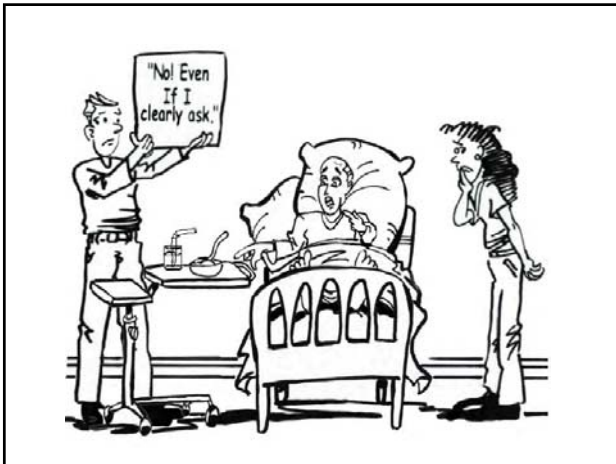
To implement an effective strategy, Professor **Thaddeus Mason Pope** (Hamline U. School of Law) and I created a form that waives patients' right to object to their proxies/agents' future instructions—thus empowering proxies/agents to make sure the patient does not sabotage her own goal. (We modified a section of the Vermont Advance Directive, long form.) Note: To override Margot's contemporaneously expressed desires requires that two clinicians have determined the patient lacks capacity.

To include this in Advance Care Planning, patients must obtain additional signatures, then sign and swear that the affidavit is true and correct before a notary.

This line drawing illustrates how this strategy works:

Patient points both to food and fluid and to his mouth, then grunts—to indicate clearly, his desire for another person to help hand-feeding/drinking.

The proxy overrides the patient as per the affidavit.



Comments:

The man pictured in the cartoon does not look like patients living in the advanced stage of dementia.

Some patients want a strategy that ensures Natural Dying since they know it is likely they will have “No Plug To Pull.”

Such advance decisions are totally voluntary and can be changed as long as the patient has decisional capacity.

Dying within two weeks of medical dehydration can be considered kind—not cruel—compared to the alternative of chronic suffering in Advanced Dementia.

While some may be offended by this counter-cultural patient choice, it respects patients. It does not violate their bodily integrity after food

Since the staff at Margo's assisted living facility routinely tapped on her lips or check or chin as many as 6 times (subsequently reduced to 2 times, as recommended)—to get Margot to open her mouth...
Petitioners are now appealing on the basis of **battery**.

They argue staff is **prodding** or **prompting** Margot to eat and drink. This, they claim, is **battery** because Margot did not give her prior consent.

Poll:

Do you agree staff has been committing **battery**?

Yes: About one-third; some spiritedly spoke out “Yes.”

No: Much fewer. (In this poll, many did not vote.)

Clearly, this sad case had good intent on both sides.

Society treasures the goal, to preserve life.

The doctrine of *parens patriae* demands the state act to protect its vulnerable citizens.

But the AMA Code of Ethics states [2.20]: “The social commitment of the physician is to **sustain life** and **relieve suffering**. Where the performance of one duty conflicts with the other, the **preferences of the patient should prevail**. The principle of patient autonomy requires that physicians **respect the decision to forgo life-sustaining treatment** of a patient who possesses decision-making capacity.” {Bold emphasis added.}

The Judgment of Honourable Mr. Justice Greuell is having at least 1 direct result and 2 unintended consequences:

1. Increases the length and intensity of Margot's suffering as well as the suffering of members of her family.
2. Decreases others' faith in, and therefore completion of Advance Care Planning... so more patients will reach Advanced Dementia without expressing their wishes... so many will then suffer unwanted, prolonged dying.
3. Increases the intensity of the "Dementia Fear" that makes it more likely patients like Janet Adkins (Kevorkian's 1st patient) and Gillian Bennett (a B. C. patient) will commit suicide in the early stage of dementia to avoid getting "stuck" in advanced stage.

The "**Dementia Fear**" is the *realistic* fear of losing control in the advanced stage of dementia, when others—who likely mean well—will force them to endure an unwanted, prolonged dying with its associated suffering and burdens.

Fear may lead to daily, intense anticipatory anxiety. To avoid prolonged dying in Advanced Dementia, *some* patients may hasten their dying or commit suicide—to die months to years earlier than they would prefer.

Strategic Advance Care Planning is the "antidote" to the Dementia Fear because it can give patients confidence that others will honor their end-of-life wishes.

(Thanks to **Karl Steinberg** (Editor-in-Chief, *Caring for the Ages*) and to **Ron Hamel** (Catholic Health Association) for their many suggestions on appropriate phrasing.)



Gillian Bennett (in 2013). She committed suicide in 2014 in the early stage of dementia because she feared getting stuck in Advanced Dementia.

video
→

Video of Katherine Hammond commenting on Gillian Bennett and on premature dying.

While nothing in this presentation is meant to imply that Gillian Bennett knew about or was influenced by the Judgment of Honourable Mr. Justice Greuell regarding Margaret Bentley...

Similar patients who perceive their risk to be high that they will reach Advanced Dementia are more likely to actively commit suicide or to passively hasten their dying—if they cannot trust their health care institutions or the judicial system to honor the wishes they expressed in their Living Wills. (Patients need strategies.)

Summary of Discussion

Is the motivation of proxies/agents always for the benefit of the patient?

Lynnette Cederquist (UCSD) asked: Was the patient referred to Hospice?

David Unger, Providence Health System, British Columbia: The Honourable Mr. Justice Greuell did the best he could. Margot possibly did want to eat and drink. The Judgment was **not** influenced by religious views.

Neil Wenger (UCLA): "What happened to this unfortunate woman in British Columbia would not happen in Los Angeles."



Margaret Bentley (2013, part of the court record, as exhibits to the affidavit evidence.)
How much beyond three years must she suffer—based on Judge Greuell's ruling that she did have decisional capacity to prefer 1 dessert over 1 main dish at 1 meal by 1 observer?

Concluding Remarks

Recall the title's use of the word "**ALL**." The policies of some faith-based health care institutions require **all** ways of continuing nutrition and hydration for **ALL** patients.

Pope John Paul II's 2004 statement was about patients in a coma or a Permanent Vegetative State. Note: If the diagnosis is accurate, these patients cannot feel pain.

A **compelling reason not** to apply this statement to Advanced Dementia patients: Most can, and many do experience **pain**—pain their physicians fail to recognize and thus under-treat. If this point becomes better known, it may increase the Dementia Fear and the number of premature suicides. We should **ALL** consider this possible harm as we apply the Principle of Proportionality—in addition to whether an intervention can benefit our patients (or ourselves). THANK YOU!

Must We All Die With Forced Hand-Feeding?

American Society for Bioethics and Humanities

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Slightly shortened ABSTRACT submitted to the American Society for Bioethics & Humanities:

Must We All Die with Forced Hand-Feeding? Patient Strongly Wanted to Avoid Prolonged Dying in Advanced Dementia but British Columbia's Supreme Court Ruled Her Living Will not Valid. Stanley A. Terman, Ph.D., M.D., *Caring Advocates*.

In Feb. 2014, British Columbia's Supreme Court ruled that hand-feeding must continue indefinitely for Margaret Bentley (born, 1931). This former nurse cared for Advanced Dementia patients. Her 1991 Living Will stated—as strongly as possible—her wish to avoid a prolonged dying in the advanced stage of dementia. She received the diagnosis of dementia (1999). It progressed to "advanced" by 2010. In late 2011, her husband and daughter (designated surrogates) began a repeated series of verbal and written requests to implement one of Ms. Bentley's instructions: "No nourishment or liquids." The nursing home refused to comply, refused to reveal their legal justification, and threatened to report husband or daughter for elder abuse if either attempted to remove Bentley from their facility. We will review the actual Living Will and ask: What did Margaret Bentley do wrong? What could she have done differently so others would have honored her request? While it is harder (but not impossible) to argue hand-feeding is medical treatment, does not the same bioethical conclusion apply? Is it not cruel and disrespectful to force someone to endure any unwanted invasion of their bodily integrity? The court's ruling has great implications given the escalation of the dementia epidemic: In addition to increasing individuals' suffering, it may overwhelm society's emotional, financial and manpower caring capacities.