

OVERCOMING CHALLENGES to Voluntary Refusal of Food & Fluid

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Right to refuse treatment

- 1) Your right of informed consent includes ALL your legal options.**
- 2) Your right to decide what happens to your own body, which includes refusing treatment that is potentially life-saving.**

Based on common law, Constitutional law, statutes, and case law—from the UK, US, and Australia.

(See T. M. Pope's article, and the slides posted at: www.CaringAdvocates.org/presentations.php.)

VOLUNTARILY STOPPING EATING AND DRINKING: A LEGAL TREATMENT OPTION AT THE END OF LIFE

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ABSTRACT

Despite the growing sophistication of palliative medicine, many individuals continue to suffer at the end of life. It is well settled that patients, suffering or not, have the right to refuse life-sustaining medical treatment (such as dialysis or a ventilator) through contemporaneous instructions, through an advance directive, or through a substitute decision maker. But many ill patients, including a large and growing population with advanced dementia who are not dependent upon life-sustaining medical treatment, do not have this option. They have the same rights, but there is simply no life-sustaining medical treatment to refuse.

In June 2010 the Supreme Court of South Australia: Court **granted** an elderly woman's wish to die after she clearly asserted her right to refuse to take food and medication. The Court case was instigated by the Nursing Home in which she resided, because of concerns that her carers might face prosecution for assisting in a suicide.

In Western Australia in 2009, the Chief Justice of the Supreme Court held that Christian Rossiter, a quadriplegic, be **allowed** to withdraw nutrition and medication. Where the advance directive is clear and unambiguous, there is no need to apply to the Court.

The fundamental principle: a person of adult years and sound mind has the right to consent to, or refuse medical treatment, and to determine what shall be done with his own body.

Hunter & New England Area Health Service v. A [2009] NSW SC 761, decided by McDougall J of the Supreme Court of New South Wales on 6 August 2009: the Area Health Service sought a declaration from the Court as to whether it would be justified in withholding treatment from Mr A in accordance with an advance directive he had signed a year earlier.

McDougall J: As long as there is **no doubt** as to a person's capacity to make his or her own decision as to medical treatment, and no factor such as misrepresentation that might vitiate that consent, the **wishes** of a competent adult patient **must be respected**. The Court must feel "*a sense of actual persuasion that the individual acted freely and voluntarily, and intended his or her decision to apply to the situation at hand*".

The problem: Some powerful groups are more interested in promoting their own agenda than in respecting patients' choices.

Three **examples** of “groups”:

A) US Catholic Bishops: *Ethical and Religious Directive # 58* (revised); and,

B) *For-profit* skilled nursing homes who use a Medicare/Medicaid Guide to strive for a “Five-Star” rating.

C) Your relatives—who may wish to influence the kind of end-of-life care you receive.



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Ethical and Religious Directives for Catholic Health Care Services

Fifth Edition



United States Conference of Catholic Bishops

PART FIVE

Issues in Care for the Seriously Ill and Dying

Introduction

The Church's teaching authority has addressed the moral issues concerning medically assisted nutrition and hydration. We are guided on this issue by Catholic teaching against euthanasia, which is “an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated.”³⁸ While medically assisted nutrition and hydration are not morally obligatory in certain cases, these forms of basic care should in principle be provided to all patients who need them, including patients diagnosed as being in a “persistent vegetative state” (PVS), because even the most severely debilitated and helpless patient retains the full dignity of a human person and must receive ordinary and proportionate care.

58. In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care.⁴⁰ Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.”⁴¹ For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.

**Design for *Nursing Home Compare*
Five-Star Quality Rating System:**

Technical Users' Guide

July 2010



Table 5
MDS-Based Quality Measures

Measure	Comments
Long-Stay Measures:	
Percent of residents whose need for help with daily activities has increased ¹	This is a change measure that reflects worsening performance on at least 2 late loss ADLs by one functional level or on one late loss ADL by more than one functional level compared to the prior assessment. The late loss ADLs are bed mobility, transfer, eating, and toileting. Maintenance of ADLs is related to an environment in which the resident is up and out of bed and engaged in activities. The CMS Staffing Study found that higher staffing levels were associated with lower rates of increasing dependence in activities of daily living.
Percent of residents whose ability to move about in and around their room got worse ¹	This is a change measure that reflects a worsening of locomotion self-performance by at least one functional level compared to the prior assessment. Residents who lose mobility may also lose the ability to perform other activities of daily living, like eating, dressing, or getting to the bathroom.



C **“But they just want to save me.”**

(From: The *BEST WAY* to Say Goodbye: A Legal Peaceful Choice at the End of Life, page 226-7.)

Recently I learned that a family member felt compelled to fight my Advance Directive.

I trust my doctors to HONOR my Advance Directive—as long as I can still express myself.

But once I fall asleep, I will suddenly be fair game for a whole host of individuals who want to make a “cottage industry” of my fate.

→ Learning point: Even if you start VOLUNTARILY competent, you must have an Advance Directive and Physician’s Orders in place—if you want to make sure you will have a timely, peaceful transition.

“Plan Now; Die Later—ironclad strategy” can overcome challenges from others

- 1. My Way Cards** (*Informed + Selection*) →
- 2. My Way Cards—Living Will**
(*Clear and convincing specific expression*) →
- 3. Natural Dying Advance Directive**
(*validation by notary/witness*) →
- 4. Natural Dying Physician’s Orders**
(*consent NOW + doctor implementation LATER*) →
- 5. Natural Dying DNR Medallion**
(*when worn: notifies all—including registry*)
- 6. Natural Dying Agreement + Affidavit**
(*Will strengthen the strategy, if needed*)

1 My Way Cards use plain, straightforward language with almost no medical jargon. Sorting expresses your “Known Wishes” *clearly and convincingly* to future decision-makers/doctors/courts re: WHAT *specific* treatment you DO/do NOT want for *specific* conditions.

RECORDING (audio or video) your explanations as you sort the cards, or later as you explain your My Way Cards—Living Will, can be evidence to prove you had decisional capacity: Understood the alternatives’ potential benefits/risks; Appreciated their consequences to you and others; and used Reasoning to Express a choice, which was Consistent overtime. (U-CARE).

The RECORDING can also demonstrate that your emotions were stable and that your choices were made with *solemnity* and *diligence* since you considered each item 3 times. Resorting in a month proves *consistency*.


**Example: One of the 47 My Way Cards.
This one plays a key role in VRFF.**

**I forget to swallow.
Food stays in my
mouth. Others place
very soft food at the
back of my tongue.
They want me to
swallow by REFLEX.
But I do NOT want
them to feed me
this way.**


[8.3] ←



My **Date of Birth** is: ___ / ___ / _____. I know what **Natural Dying** means.* On this Living Will, “**YES**” means **I DO** want the people who will make decisions for me to consider this item along with other items—as they decide if the time has come to Permit Natural Dying; “**NO**” means I do **NOT** want them to consider this item. “**COL**” (for **My Checkout List**) means this “YES” item—*by itself*—is enough to Permit Natural Dying. I will sign these pages in front of a notary or two qualified witnesses. They will sign on a separate “Signature Page.” I

- (8.3)  : I forget to swallow. Food stays in my mouth. Others place very soft food at the back of my tongue. They want me to swallow by REFLEX. But I do NOT want them to feed me this way.
- (8.4) _____ : Others try to feed me but I turn my head away. Or I close my teeth tightly. Or I spit out food. I do NOT want others to try to force me to eat.
- (8.5) _____ : Food could go down the “wrong way.” If it enters my lungs I could get very sick (pneumonia). Feeding me through a tube will NOT lower the chance of this happening. I REFUSE tube-feeding.
- (8.6) _____ : First I can enjoy things like sing-a-longs, finger painting, eating, and being touched. But then I get very sick. Ask my doctor if I might have fun again. If the answer is “Yes,” then DO TREAT me.

** If I answered YES or COL to 6.6, I will discuss **Palliative Sedation** with my physician. I may then sign to give my **consent**. I will ask my physician to sign also. I can use the **Physician’s Orders to Permit Natural Dying**. This form turns the REQUESTS of my Living Will into a set of doctor’s ORDERS. Here are my **additional instructions**:

➔ Always place food & fluid near me—if I am awake. I previously agreed to **give up my right to object** to my proxy saying “No help eating/drinking” after I cannot make medical decisions. *(Cross out if does not apply.)* 

* **Natural Dying** means: 1) **No** medical treatment that might let me live; 2) **No** help with oral feeding or drinking; 3) **ALL** the Comfort Care I need. Based on my choices of “Yes” and “Checkout List” items, someday it will be time for my Natural Dying. Then I will be too ill to tell others exactly what I want. So I will be clear now:
➔ I want **No** medical treatment that might let me live. And, I want one of these four choices: *(I crossed out the*

Natural Dying Advance Directive (NDAD): to refuse all life-sustaining treatment

The **Natural Dying Advance Directive** is the *pivotal* form of the “Plan Now; Die Later” ironclad strategy. It is for *only* those who wish to refuse *all* life-sustaining treatment if their future mental or physical condition ever meets *their criteria*. This **NDAD** is the basis for *actionable* **Natural Dying Physician’s Orders (NDPO) 1 - 4**. In the event of a *conflict* with other Advance Care Planning forms, **NDAD/NDPO** will prevail if these forms are most recently dated.

Signatures to “PLAN NOW”:

3

Did you express your specific wishes for Advanced Dementia by creating a My Way Cards–Living Will? Yes/No.

List any individuals you **DISQUALIFY** from making medical decisions for you:



Natural Dying Physician’s Orders (NDPO): For Emergency First Responders (EMTs); healthcare providers in hospitals, nursing homes & hospices; family members; & others.

First follow my orders to withhold the interventions below; then contact me.
Safeguard: Competent patients can revoke any order to accept treatment that is potentially life-sustaining. To verify this order call: 1-888-765-7876.

My “NATURAL DYING Physician’s Orders” (NDPO) are based on the patient’s “NATURAL DYING Advance Directive” (NDAD), attached, and on discussions that led to my understanding of his/her end-of-life preferences.

Patient’s full name:

Patient’s date of birth or patient number:

4

Patient’s address and phone:

DO NOT HOSPITALIZE (DNHOSP) *unless Comfort Care cannot be provided in current setting*; eg, to pin a hip fracture or provide **Palliative Sedation**. If transfer is necessary, **list** physical risks eg, fragility of bones; psychological factors, eg, delusions, delirium, combativeness. List **facilities NOT desired**:



Natural Dying Physician's Orders (NDPO): For Emergency First Responders (EMTs); healthcare providers in hospitals, nursing homes & hospices; family members; & others.

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Patient's
full name:

Patient's date of birth & patient number:

4

Patient's address and phone:

D
N
A
E
D

4 DO NOT ASSIST EATING & DRINKING (DNAED) BUT OFFER FOOD & FLUID.

Always place food and fluid near the patient, if awake. Respect patient's decision if repeatedly refused. Never force oral ingestion if patient turns head away, bites down on the straw or spoon, or spits out food. Respect patient's wish for Natural Dying and his/her prior authorization/agreement to empower Proxies to refuse all food & fluid over his/her objection. **Unless** patient explicitly indicated otherwise when competent, **fulfill patient's request for food & fluid even if s/he is mentally unable to make medical decisions.**

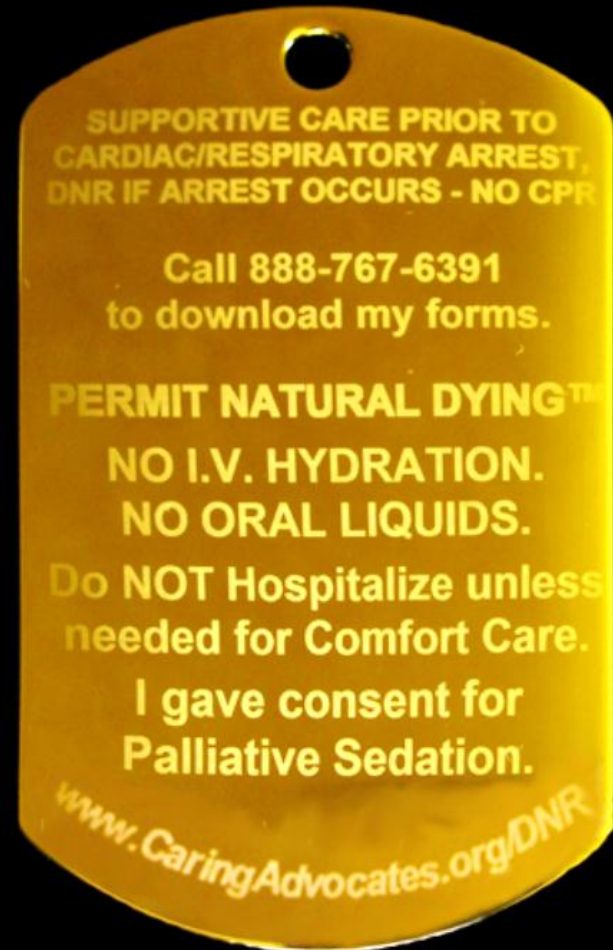
MD initial



Patients can cross out the bolded words with a thin line, to indicate they DID explicitly indicate otherwise when competent. They sign in the margin and have a notary acknowledge signing for this important, additional end-of-life preference.

5

Medallions for emergency medical personnel (paramedics)



“Natural Dying Agreement” between you and your proxy: You agree to waive your right to request or to object to treatment after you cannot make healthcare decisions.

6

EXCERPT from the Natural Dying Agreement:

I hereby give my proxy [print name:] _____ the authority to consent to or refuse the following treatment(s) **over my objection** if two clinicians determine that I lack capacity to make healthcare decisions at the time such treatment or type of care is considered.

I do NOT want **Manual Assistance with Oral Feeding and Drinking**—even if I clearly request help with feeding and drinking. **Always** place food and fluid closely in front of me, but no one should use their hands to put food or fluid in my mouth.

Available from www.PlanNowDieLater.org

“NATURAL DYING” AFFIDAVIT

I, _____, hereby declare as follows:
(Print your full name on the line, above.)

5. I instruct my proxy to seek declaratory or injunctive relief to effectuate my originally expressed, competent wishes to receive NO nutrition and hydration.
6. I instruct my proxy to sue any person, health care provider, institution, or any other entity who fails to honor my Known Wishes, or who accedes to requests by my “future incompetent self” for assistance to eat or to drink. (I allocate using funds from my estate for this purpose, if necessary.)

Patient’s signed name: _____

State of _____ County of _____

(Notary Public’s seal)

Subscribed and sworn to (or affirmed) before me

on this ___ day of ____, 20___,

by (patient’s printed name) _____,

proved to me on the basis of satisfactory evidence to be the person(s) who appeared before me.

Signature of Notary _____

Summary: the underlying premise of the “Plan Now; Die Later—Ironclad Strategy”:

Do you want to be sure no person/institution will try to sabotage your plan for a timely and peaceful transition? The strongest way to express your conviction may be to disqualify your “future demented self.” Then, a third party challenge is very unlikely. How can another claim s/he knows what is *really* in your “Best Interest” when even the new “you” is bound by your previous wishes?

This is ironic: the more obvious it is your strategy will be effective, the less likely anyone will challenge you, to test the strategy in court. So no case will set a legal precedent or be reported by the media. Good news: dying can be private. Bad news: many may remain uninformed, suffer long and needlessly, or risk punishment for acts they do not need to commit because they did not know they could plan ahead to use this legal alternative.

PEACEFUL TRANSITIONS

A Successful, Compassionate
Strategy for Life's Final
Challenge



STANLEY A. TERMAN, PhD, MD

with Michael S. Evans, MSW, JD; Guy Micco, MD; Ronald B. Miller, MD; Thaddeus M. Pope, PhD, JD; and Karl E. Steinberg, MD, CMD

For 14 million US baby boomers and 1 of 3 of those over 65: Plan *now* to avoid lingering for years in late-stage Alzheimer's dementia. For all: Plan *now* to prevent prolonged end-of-life pain & suffering. Includes an introduction to a new tool to help create your **effective** Living Will: **My Way Cards**.

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www.CaringAdvocates.org (has this presentation)

www.MyWayCards.org (video, sample forms)

www.PlanNowDieLater.org (Ironclad Strategy)

Dr. Barbara Hayes of the Center for Health and Society, U. Melbourne, at “Respecting Patient Choices”—excerpt from her talk on “Trustworthiness,” Ethics session, International Conference on Advance Care Planning , April, 2010:

“Victorian legislation would say you have to feed the person by hand. It is a recognized part of palliative care. Our legislation says you have to provide reasonable fluids and food—meaning you have to offer food. You don’t have to use PEG or NG tubes. I would be required to feed the person, REGARDLESS OF PREVIOUSLY EXPRESSED WISHES.”

“I would also see this as unacceptable to have a hungry patient in front of me, wanting to eat something, and say, “Well, no, you said before you didn’t want this. I’m not going give you any. I could not do that. I think that would be wrong.”

{*Comment: Is this “Respecting Patient Choices”?*}

