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Dying Well

Encouraging the Difficult Conversations

January 24, 2024

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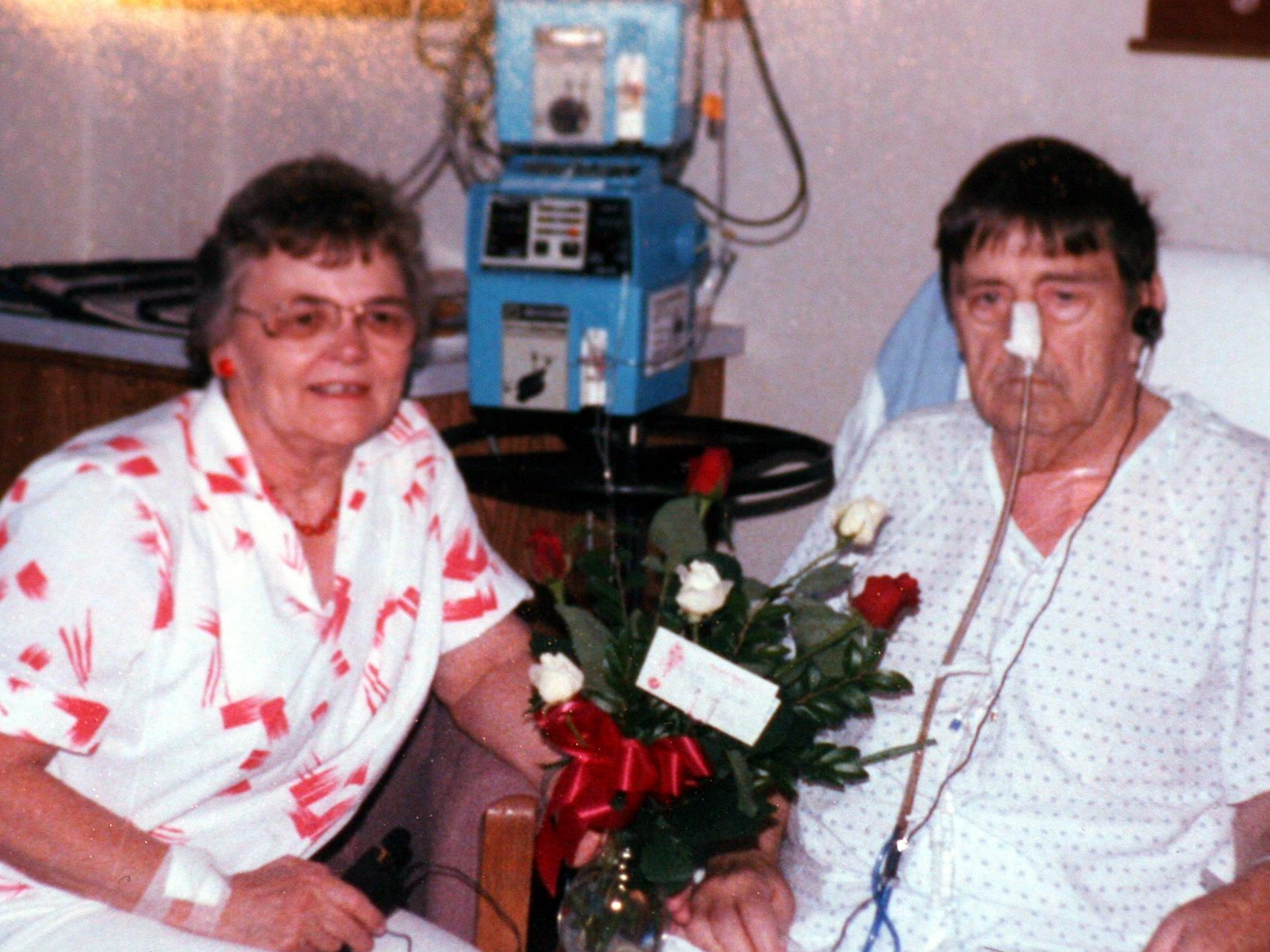


AÉROPOSTALE
A87
VARSITY ATHLETICS

The Reality

Approximately 2.5 million deaths in America each year

- 49% die in the hospital
- 22% die in the nursing home
- 23% die at home
- 6% die elsewhere

National Center for Health Statistics, 2001 in *Hospice in the Nursing Home* AAPHM Medical Directors Course, Aug 2006

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The Reality

"Most people in acute care hospitals are not able to die with dignity, with adequate pain relief, or with realistic and compassionate communication with their physicians"

-- Christine Cassel

Cassel CK, Caring for the Dying. ABIM,1998;pp. 2.

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The SUPPORT Trial

Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment

30-million-dollar study commissioned by Robert Wood Johnson Foundation

5 Teaching hospitals; 8 critical diagnoses

Two Phases

- Phase One: Observation and identification of problems in EOL care (two years)
- Phase Two: Test an intervention designed to address the problems in phase one (two years)

The SUPPORT principle investigators. *JAMA* 1995;2741591-1598.
Phillips RS, et al. Findings from SUPPORT and HELP: an Introduction. *JAGS* 2000;48:S1-S5.

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SUPPORT: Phase One

Only 47% of physicians knew when their patients preferred to avoid CPR

46% of DNR orders were written within two days of death

38% of patients who died spent at least 10 days in an ICU

50% of conscious patients who died in the hospital reported moderate to severe pain at least half the time

The SUPPORT Principle investigators. *JAMA* 1995;2741591-1598.

SUPPORT: Phase Two

Goal: improve deficiencies found in phase one

Hypothesis: better communication would improve deficiencies

Intervention: intense multi-disciplinary effort

Skilled nurse specialist acted as liaison between patient and physician

The SUPPORT principle investigators. *JAMA* 1995;2741591-1598.

SUPPORT: Phase Two

Nurse collected information, convened family meetings

Physicians were given:

- Current patient symptoms and pain levels
- Estimates of likelihood of 6-month survival
- Information on future functional ability
- Patient preferences for EOL care

The SUPPORT Principle investigators. *JAMA* 1995;2741591-1598.

SUPPORT: Phase Two

No improvement in any of the targeted outcomes

Physicians were no more likely to know preferences for CPR

DNR orders were not written any earlier

Patients spent no less time in the ICU

Patients reported no better pain control

No difference in resource use (excluding the cost of the intervention)

The SUPPORT principle investigators. *JAMA* 1995;2741591-1598.

Current Views on End-of-Life Care

87% felt patients and families should have a greater say in decisions about which treatments to pursue for patients near end of life.

88% wanted doctors to be completely honest about prognosis, even if there is little chance of recovery.

49% felt patients have too little control over medical decisions. Among individuals in poor health, that number rose to 63%.

71% felt the top priority at end of life should be relief of pain and stress.

19% felt the top priority should be preventing death and extending life as long as possible.

Hamel L., Wu B., Brodie M. Views and Experiences with End-of-Life Medical care in the U.S. Kaiser Family Foundation. April 27, 2017. Kff.org.

Current Views on End of Live Care

56% of respondents report having conversations with loved ones about end-of-life medical care.

92% stated they would be comfortable discussing end of life wishes with their doctors.

11% report having such a discussion.

27% of respondents had a written document with their wishes for end-of-life care

Of the 72% who did not,

49% haven't gotten around to it

27% have never considered it

Hamel L., Wu B., Brodie M. Views and Experiences with End-of-Life Medical care in the U.S. Kaiser Family Foundation. April 27, 2017. Kff.org.

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How do we bridge the gap?

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Palliative Care

- A team approach
  - Physician, nurse, social worker, chaplain
- Care for the whole person
  - Physical, emotional, spiritual, social
- Improving quality of life for patient and family
- An extra layer of support

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Patient and Family Benefits

- Aggressive treatment of pain and other symptoms
- Close communication about the care plan
- Care coordination and smoother transitions
- Support for caregivers
- Sense of safety and continuity

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Staff and Hospital Benefits

- Improved patient satisfaction scores
- Time saving
  - Assistance with coordinating care
  - Handling time-intensive discussions
- Improved quality of care, lower cost of care
- Specialty-level assistance to attending physicians for difficult physical symptoms
- Supports the Commission on Cancer Accreditation

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Could Your Loved One Benefit From Palliative Care?

- New diagnosis of life-limiting illness
- Two or more hospitalizations for chronic illness in three months
- Difficult-to-control physical symptoms
- Uncertainty regarding prognosis
- Uncertainty regarding appropriateness or treatment options

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Could Your Loved One Benefit From Palliative Care?

- Code status conflicts with patient's prognosis or reflects disparate goals
- Conflicts regarding use of non-oral feeding or hydration
- Patient or family in need of psychosocial or spiritual support
- Patient with rapidly deteriorating condition, including imminent death

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Could Your Loved One Benefit From Palliative Care?

- Requests for potentially futile care
- Metastatic cancer with evidence of progression despite treatment; or metastatic cancer not believed likely to benefit from cancer-directed therapy

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Palliative Care vs. Hospice

Palliative care

- No prognostic requirement
- Can be concurrent with curative treatment
- Still sees the treating physician(s) and can be hospitalized again if needed

Hospice

- Six month prognosis
- Patient declines curative treatments
- Minimal clinic or inpatient treatment

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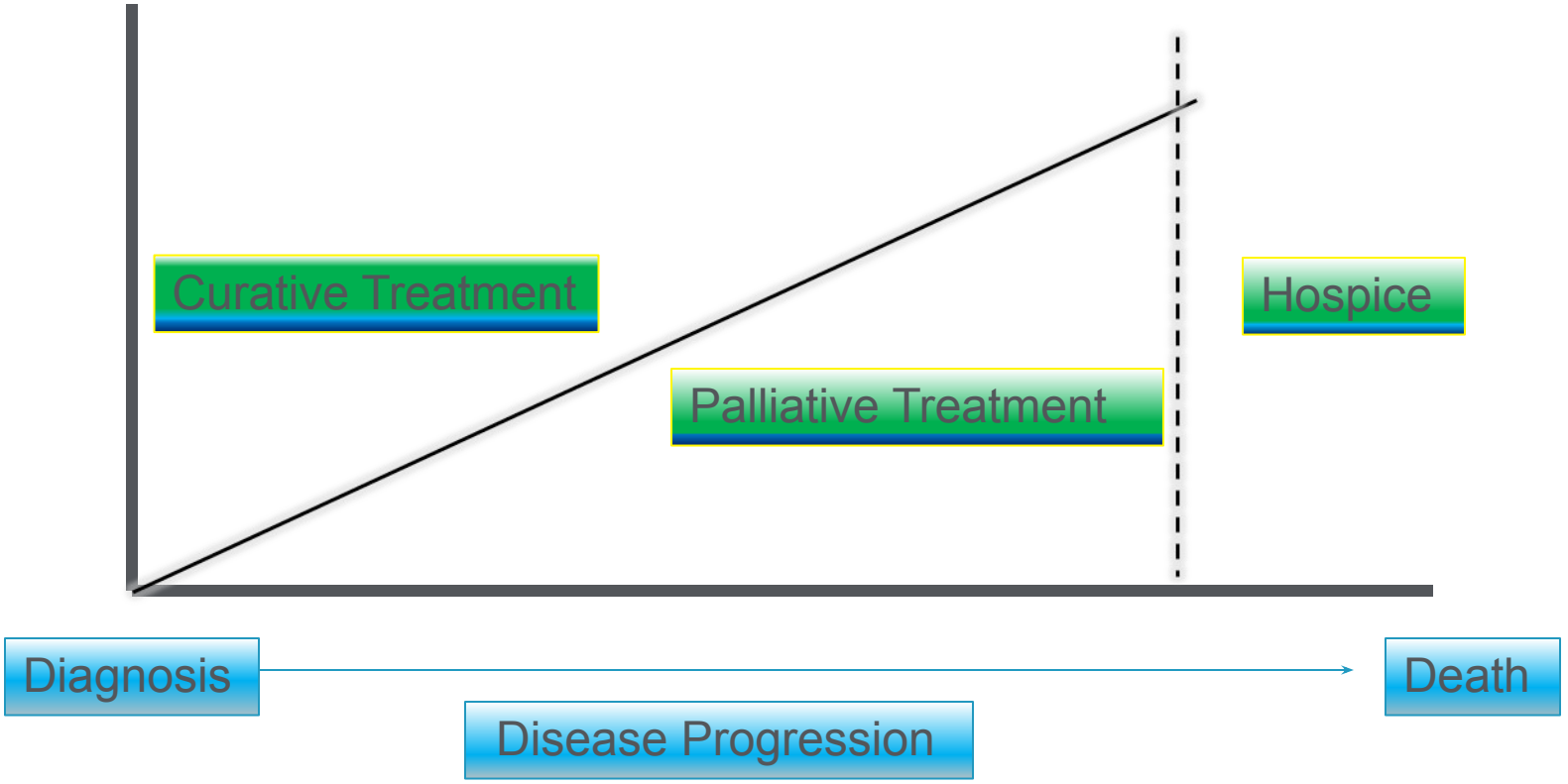
Putting the Pieces Together



Advanced Directives

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Advanced Directives

Power of Attorney for Health Care

- Chosen representative for decision-making
- Able to navigate gray areas
- Requires detailed communication with decision-maker
- Does not take effect while patient is decisional

Living Will

- Expressed written preferences for health care
- Allows patient to “speak for themselves”
- Can leave room for interpretation
- Patient can change mind at any time

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Power of Attorney for Health Care

Durable Power of Attorney *for Health Care*

Fill out this document carefully. You may want to seek professional help to make sure the form does what you intend and is completed without mistakes.

This document will be in effect unless or until you revoke it. You may change or revoke this document at any time by telling your doctor and other healthcare providers. You should give copies of this document to your family, your doctor and your health care facility. This form is optional. If you choose to use this form, the form has a signature line for you and a notary.

I,_____, _____appoint _____
(Principal/Patient) *(Birthday)* *(Decision Maker/Agent)*

as my Attorney-In-Fact for the purpose of making healthcare decisions on my behalf. In the event the person named above is unable or unwilling to act as my Attorney-In-Fact, I appoint

(Optional) _____as my Attorney-In-Fact. In the event both of the previously named persons are either unable or unwilling to act as my Attorney In Fact, I appoint

(Optional) _____ as my Attorney-In-Fact. This Power of Attorney shall become effective upon my disability as authorized by SD Codified Law §§ 59-7-2.1-2.8.

I grant my Attorney-In-Fact the power to:

(Initial) _____Make any and all health care decisions on my behalf, including each of the powers identified in items 1-7 below:

OR

I only grant my Attorney-In-Fact the power to (initial each power granted):

1) _____ Consent to healthcare on my behalf.
2) _____ Withdraw consent for healthcare.
3) _____ Reject care or treatment recommended by a healthcare provider in accordance with my previously stated wishes.
4) _____ Authorize a healthcare provider to withhold care or treatment when such care or treatment would prolong my suffering.
5) _____ Authorize artificial nutrition to be withheld or withdrawn.
6) _____ Authorize artificial hydration to be withheld or withdrawn.
7) _____ Other /Additional Instructions (specify): _____
_____

Dated this, the_____day of _____, 20 _____. _____
(Principal/Patient)

State of South Dakota)
) ss
County of Pennington)

On this _____ day _____,20_____, _____, known to me or satisfactorily proven to be the person named above, personally appeared before me, a Notary Public with the State of South Dakota, and acknowledged that he or she executed the same for the purposes stated herein.

Notary Public_____ Seal
My commission expires_____

Produced by
Regional Health
Learning & Development Department
353 Fairmont Boulevard, Rapid City, SD 57701

004656-20150218EDU

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Living Will

HEALTH CARE DIRECTIVE (LIVING WILL)

I, _____ want everyone who cares for me to know what health care I want, when I cannot let others know what I want.

SECTION 1:

I want my doctor to try treatments that may get me back to an acceptable quality of life. However, if my quality of life becomes unacceptable to me and my condition will not improve (is irreversible), I direct that all treatments that extend my life be withdrawn.

A quality of life that is unacceptable to me means (check all that apply):

- Unconscious (chronic coma or persistent vegetative state)
- Unable to communicate my needs
- Unable to recognize family or friends
- Total or near total dependence on others for care
- Other: _____

Check only one:

- Even if I have the quality of life described above, I still wish to be treated with food and water by tube or intravenously (IV).
- If I have the quality of life described above, I do NOT wish to be treated with food and water by tube or intravenously (IV).

SECTION 2: (You may leave this section blank.)

Some people do not want certain treatments under any circumstance, even if they might recover.

Check the treatments below that you do not want under any circumstances:

- Cardiopulmonary Resuscitation (CPR)
- Ventilation (breathing machine)
- Feeding tube
- Dialysis
- Other: _____

SECTION 3:

When I am near death, it is important to me that: _____

_____

_____

_____

(Such as hospice care, place of death, funeral arrangements, cremation or burial preferences.)

BE SURE TO SIGN PAGE TWO OF THIS FORM

If you only want a Health Care (Medical) Power of Attorney, draw a large X through this page.
Talk about this form with the person you have chosen to make decisions for you, your doctor(s), your family and friends. Give each of them a copy of this form.
Take a copy of this with you whenever you go to the hospital or on a trip.
You should review this form often.
You can cancel or change this form at any time.

FOR MORE INFORMATION CONTACT HEALTH CARE DECISIONS, (602) 222-2229 OR WWW.HCDECISIONS.ORG

SW 0229 | JUL 05

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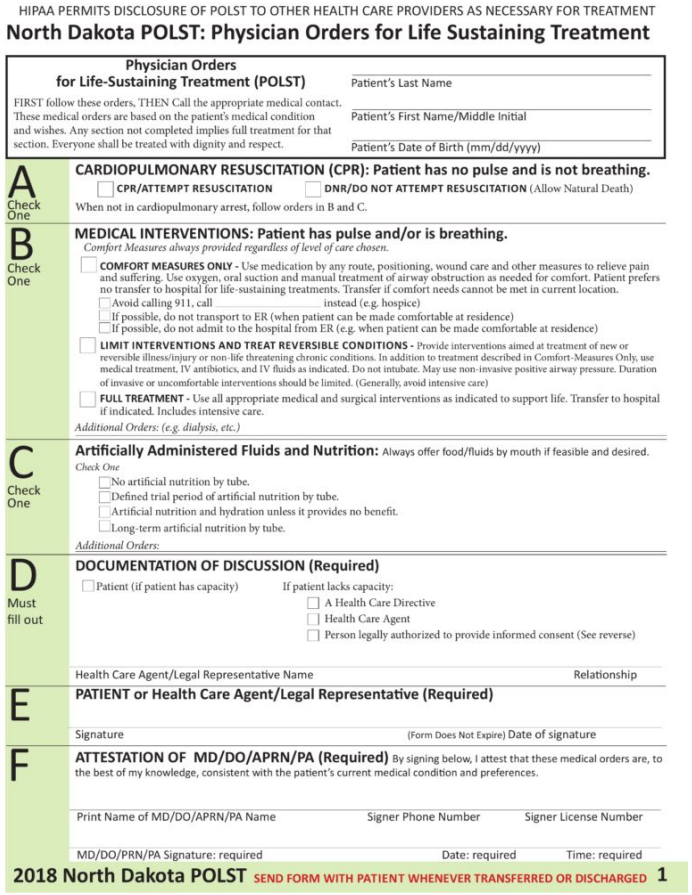
Advanced Directives

POLST Forms

Physician Orders for Life Sustaining Treatment

- Signed by physician/provider and patient
- Works as written order throughout the healthcare system
- Expresses preferences in writing with ability to leave sections blank if undecided

POLST Forms



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT

North Dakota POLST: Physician Orders for Life Sustaining Treatment

Physician Orders for Life-Sustaining Treatment (POLST)

FIRST follow these orders, THEN Call the appropriate medical contact. These medical orders are based on the patient's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Patient's Last Name

Patient's First Name/Middle Initial

Patient's Date of Birth (mm/dd/yyyy)

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.**

☐ CPR/ATTEMPT RESUSCITATION ☐ DNR/DO NOT ATTEMPT RESUSCITATION (Allow Natural Death)

When not in cardiopulmonary arrest, follow orders in B and C.

B Check One — **MEDICAL INTERVENTIONS: Patient has pulse and/or is breathing.**

Comfort Measures always provided regardless of level of care chosen.

☐ **COMFORT MEASURES ONLY** - Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.

- ☐ Avoid calling 911, call _____ instead (e.g. hospice)
- ☐ If possible, do not transport to ER (when patient can be made comfortable at residence)
- ☐ If possible, do not admit to the hospital from ER (e.g. when patient can be made comfortable at residence)

☐ **LIMIT INTERVENTIONS AND TREAT REVERSIBLE CONDITIONS** - Provide interventions aimed at treatment of new or reversible illness/injury or non-life threatening chronic conditions. In addition to treatment described in Comfort-Measures Only, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Duration of invasive or uncomfortable interventions should be limited. (Generally, avoid intensive care)

☐ **FULL TREATMENT** - Use all appropriate medical and surgical interventions as indicated to support life. Transfer to hospital if indicated. Includes intensive care.

Additional Orders: (e.g. dialysis, etc.)

C Check One — **Artificially Administered Fluids and Nutrition:** Always offer food/fluids by mouth if feasible and desired.

Check One

- ☐ No artificial nutrition by tube.
- ☐ Defined trial period of artificial nutrition by tube.
- ☐ Artificial nutrition and hydration unless it provides no benefit.
- ☐ Long-term artificial nutrition by tube.

Additional Orders:

D Must fill out — **DOCUMENTATION OF DISCUSSION (Required)**

☐ Patient (if patient has capacity) If patient lacks capacity:

- ☐ A Health Care Directive
- ☐ Health Care Agent
- ☐ Person legally authorized to provide informed consent (See reverse)

Health Care Agent/Legal Representative Name Relationship

E — **PATIENT or Health Care Agent/Legal Representative (Required)**

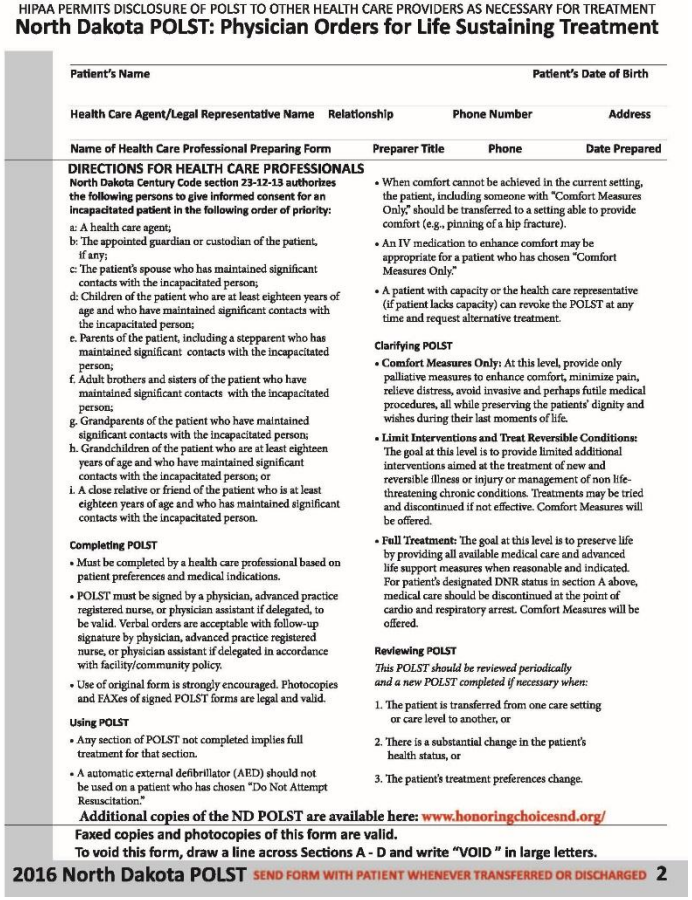
Signature (Form Does Not Expire) Date of signature

F — **ATTESTATION OF MD/DO/APRN/PA (Required)** By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's current medical condition and preferences.

Print Name of MD/DO/APRN/PA Name Signer Phone Number Signer License Number

MD/DO/PRN/PA Signature: required Date: required Time: required

2018 North Dakota POLST SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED 1



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT

North Dakota POLST: Physician Orders for Life Sustaining Treatment

Patient's Name **Patient's Date of Birth**

Health Care Agent/Legal Representative Name **Relationship** **Phone Number** **Address**

Name of Health Care Professional Preparing Form **Preparer Title** **Phone** **Date Prepared**

DIRECTIONS FOR HEALTH CARE PROFESSIONALS

North Dakota Century Code section 23-12-13 authorizes the following persons to give informed consent for an incapacitated patient in the following order of priority:

a. A health care agent;
b. The appointed guardian or custodian of the patient, if any;
c. The patient's spouse who has maintained significant contacts with the incapacitated person;
d. Children of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person;
e. Parents of the patient, including a stepparent who has maintained significant contacts with the incapacitated person;
f. Adult brothers and sisters of the patient who have maintained significant contacts with the incapacitated person;
g. Grandparents of the patient who have maintained significant contacts with the incapacitated person;
h. Grandchildren of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person; or
i. A close relative or friend of the patient who is at least eighteen years of age and who has maintained significant contacts with the incapacitated person.

Completing POLST

- Must be completed by a health care professional based on patient preferences and medical indications.
- POLST must be signed by a physician, advanced practice registered nurse, or physician assistant if delegated, to be valid. Verbal orders are acceptable with follow-up signature by physician, advanced practice registered nurse, or physician assistant if delegated in accordance with facility/community policy.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid.

Using POLST

- Any section of POLST not completed implies full treatment for that section.
- A automatic external defibrillator (AED) should not be used on a patient who has chosen "Do Not Attempt Resuscitation."
- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort Measures Only," should be transferred to a setting able to provide comfort (e.g., pinning of a hip fracture).
- An IV medication to enhance comfort may be appropriate for a patient who has chosen "Comfort Measures Only."
- A patient with capacity or the health care representative (if patient lacks capacity) can revoke the POLST at any time and request alternative treatment.

Clarifying POLST

- **Comfort Measures Only:** At this level, provide only palliative measures to enhance comfort, minimize pain, relieve distress, avoid invasive and perhaps futile medical procedures, all while preserving the patients' dignity and wishes during their last moments of life.
- **Limit Interventions and Treat Reversible Conditions:** The goal at this level is to provide limited additional interventions aimed at the treatment of new and reversible illness or injury or management of non life-threatening chronic conditions. Treatments may be tried and discontinued if not effective. Comfort Measures will be offered.
- **Full Treatment:** The goal at this level is to preserve life by providing all available medical care and advanced life support measures when reasonable and indicated. For patient's designated DNR status in section A above, medical care should be discontinued at the point of cardio and respiratory arrest. Comfort Measures will be offered.

Reviewing POLST

This POLST should be reviewed periodically and a new POLST completed if necessary when:

1. The patient is transferred from one care setting or care level to another, or
2. There is a substantial change in the patient's health status, or
3. The patient's treatment preferences change.

Additional copies of the ND POLST are available here: www.honoringchoicesnd.org/

Faxed copies and photocopies of this form are valid.

To void this form, draw a line across Sections A - D and write "VOID " in large letters.

2016 North Dakota POLST SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED 2

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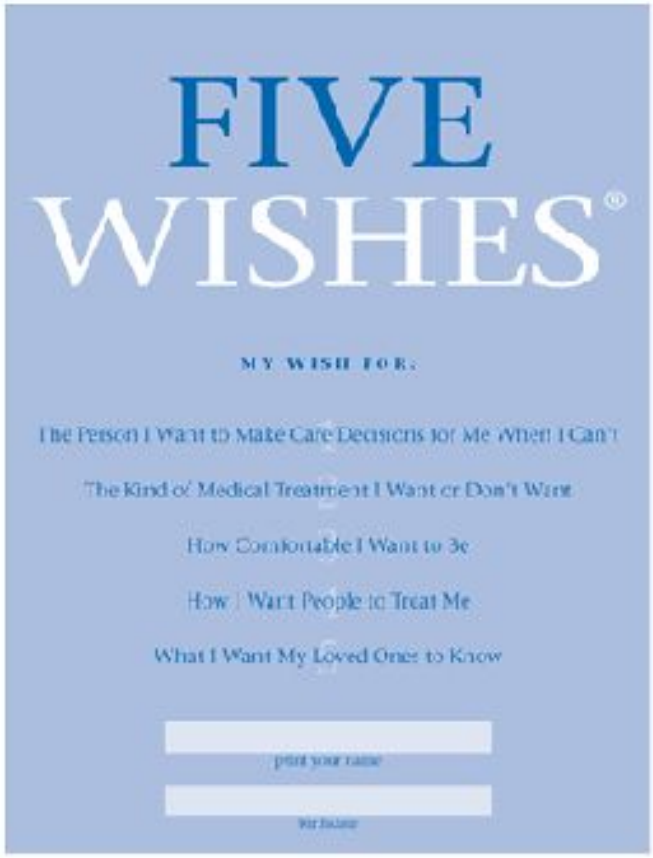
Five Wishes



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Five Wishes

1. The person I choose as my health care agent
2. My wish for the kind of medical treatment I want or don't want
3. My wish for how comfortable I want to be
4. My wish for how I want people to treat me
5. My wish for what I want my loved ones to know

Signature and witness needed

No notary required in North Dakota

Includes wallet card

Fivewishes.org

Not free

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Case Study #1

A 78 year old male presented with a large acute hemorrhagic stroke. He has been on the ventilator for the past 2 weeks. He remains minimally responsive despite being off all sedation. The ICU team is discussing trach and peg.. Patient has an advanced directive and has told his wife specifically that he would not want a trach and peg in this situation. A palliative care consult is requested to help his wife address goals of care.

Points to Consider

"Quality of life"

Patient's value system

Benefits and burdens

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Ethical and Religious Directives

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. 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.

—Ethical and Religious Directives for Catholic Health Care Services

6th edition; United States Council of Catholic Bishops; 2016; Part 3, paragraph 58

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Case Study #2

A 58-year old woman is admitted for gastric outlet obstruction due to widely metastatic ovarian cancer. She has malignant ascites. Her disease has progressed despite treatment. She is not a candidate for surgery to resolve the obstruction. The palliative care team has been consulted to discuss benefits and burdens of artificial nutrition.

Points to Consider

Overall prognosis

Goals of care

Benefits and burdens

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Ethical and Religious Directives

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.

—Ethical and Religious Directives for Catholic Health Care Services

6th edition; United States Council of Catholic Bishops; 2016; Part 3, paragraph 57

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Questions