Pitfalls and Limitations of Current Advance Directives

Introduction to a New Paradigm for Advance Care Planning
(Hint: It’s All about the Conversation)

Charles R. Nolan, MD
Medical Director, Lifelong Intensive Family Emotional (LIFE) Care Support Team
Guadalupe Regional Medical Center; Seguin, Texas
Texas Kidney Foundation Spring Symposium
April 28th, 2017
In January 1983, a 25 year-old Missouri woman named Nancy Cruzan, on her way to work on an icy road, lost control of her car which had no seat belts, was ejected from the vehicle and landed face down in a water-filled ditch.

Paramedics found her without vital signs but were able to resuscitate her.

Despite aggressive care in the ICU, she remained in a persistent coma and was eventually diagnosed as being in a persistent vegetative state.

She was extubated and able to breath on her own and surgeons inserted a feeding tube for her long-term care.

Her husband and parents hoped for her eventual recovery, but after 4 years accepted that there was no hope of substantial improvement.

The family sought to end Nancy’s suffering by removing the feeding tube and allowing natural death to ensue.
The Missouri Supreme Court refused to grant the parents’ request to withdraw the feeding tube, stating that without clear and convincing evidence of Nancy’s preferences for medical care, her real wishes were unknown.

In 1989, the case eventually went to the U.S. Supreme Court, the 1st time the court agreed to hear a right-to-die case.
The U.S. Supreme Court decided in favor of the State of Missouri (refusing to grant the families’ request to remove the feeding tube).

But most importantly, in this landmark decision, the Court ruled that a person with capacity did have the right to dictate in advance the type of medical care that they would want in the event of a future life-threatening illness or injury.

The Court affirmed that a person with capacity has the right to refuse any treatment, even treatments that in the opinion of the treating physicians would most likely be beneficial.
In the aftermath of the Supreme Court decision, the Cruzan’s lawyers went back to the Missouri Court with new evidence of Nancy’s wishes based on conversations she has had with coworkers about not wanting to be kept alive as a “vegetable”.

The state of Missouri withdrew from the case, paving the way for the family to remove the feeding tube.

12 days later, on December 26th, 1990 Nancy Cruzan died at the age of 33, seven years after her accident.
The Patient Self-Determination Act

- Passed by U.S. Congress in 1990 in the aftermath of the Nancy Cruzan case

- Effective 12/1/1991, the law required as a condition of Medicare/Medicaid participation, that hospitals, nursing homes, home health agencies, hospice providers and HMOs provide information about advance health care directives to all adult patients upon admission to the health care facility.
Patients must be given written notice of their decision-making rights and the policies about advance healthcare directives in their state.

Patient rights include:
1. The right to facilitate their own healthcare decisions
2. The right to accept or refuse any medical treatment
3. The right to make an advance healthcare directive
Types of Advance Directives

- Medical Power of Attorney
- Living Will or Directive to Physicians
- Out-of-Hospital Do Not Resuscitate Order
- Medical Order of Scope or Treatment (MOST) or Physician Order for Life-Sustaining Treatment (POLST)
What if an Incapacitated Person has No Medical Power of Attorney?

In the absence of a Guardian or Medical Power of Attorney, the Legal Next of Kin shall be authorized to make medical decisions.

1. Spouse
2. Reasonably available adult children
3. Parents
4. Siblings
5. Nearest living relative
Advanced Directives
Don’t Work !!!
Effectiveness of the PSDA

- Study of hospitalized seriously ill patients, focusing on the impact of advance directives on decision-making regarding resuscitation.
- Observational cohort study conducted 2 years before PSDA (Pre) and 2 years after PSDA (Post).
- In pre and post cohorts 21% of patients had AD.
- The existence of an AD was mentioned in the medical record more often in Post (36%) than Pre (6%) patients.

Effectiveness of the PSDA

- No significant differences were found in post-PSDA patients without AD and with AD concerning:
  - Documentation of discussions about resuscitation in the medical record (33% vs 38%).
  - DNR orders among those who wanted to forgo resuscitation (54% vs. 58%).
  - Attempted resuscitation at death (17% vs. 9%).

- Only 12% of patients with AD had talked with a physician when completing their advance directive.

- Only 42% of patients reported ever having discussed their advance directive with their physician.

In seriously ill patients, advance directives did not substantially enhance physician-patient communication or decision-making about resuscitation.

This lack of utility of advance directives didn’t change post-PSDA.

PSDA substantially increased documentation of advance directives.

Current practice patterns indicate that increasing the frequency of advance directives is unlikely to be a substantial element in improving the care of seriously ill patients.

Future work to improve decision-making should focus on improving the pattern of practice through better communication and ... more comprehensive Advance Care Planning.

Living Wills Don’t Work

• Often the chosen Healthcare Agent(s) are unaware of their role and haven’t had the conversation
• Living Will often locked away in a “Safe Place”
• Preferences for life-sustaining treatments not discussed with PCP ... Hospitalists
• Living Will and Directive to Physicians do not become effective until “someone” declares patient is “terminal” or in the last 6 months of life
• Living Wills and many MOST-POLST documents have the potential to limit choice (all or nothing type of approach)
DYING IN AMERICA

Improving Quality and Honoring Individual Preferences Near the End of Life

Key Findings and Recommendations
http://respectingchoices.org

**PBS Now Death Panel** (www.pbs.org/now/shows/541/index.html)

Hammes BJ, Rooney BJ. Death and end-of-life planning in a Midwestern Community; Arch Intern Med 158: 383-90, 1998

Healthy Adults (Ages 55 – 65)

Adults with Chronic, Progressive, Life-Limiting Illness with Frequent Hospitalization & ER Visits

Adults for whom it would not be a surprise if they died within the next 12 months
Stages of Advance Care Planning over the Life Time of Adults

- Healthy Adults (Ages 55 – 65)
- Adults with Chronic, Progressive, Life-Limiting Illness with Frequent Hospitalization & ER Visits
- Adults for whom it would not be a surprise if they died within in the next 12 months

This is the Focus of our LIFE Care --- Palliative Medicine Intervention

High-Cost Terminal Admission Often with ICU Care
### Advance Care Planning Facilitation

**Respecting Choices® Model**

#### Stages of Advance Care Planning over the Life Time of Adults

| Healthy Adults (Ages 55 – 65) | Adults with Chronic, Progressive, Life-Limiting Illness with Frequent Hospitalization & ER Visits | Adults for whom it would not be a surprise if they died within in the next 12 months |

**First Steps ACP**

*Create Power of Attorney for Healthcare*

(Consider when a serious neurological injury would change goals of treatment)
Advance Care Planning Facilitation
Respecting Choices® Model

Stages of Advance Care Planning over the Life Time of Adults

First Steps ACP
Create Power of Attorney for Healthcare

Consider when a serious neurological injury would change goals of treatment

Disease-Specific ACP
Determine patient goals of treatment if complications of chronic illness result in “bad” outcomes
Statement of Treatment Preferences

Healthy Adults
(Ages 55 – 65)

Adults with Chronic, Progressive, Life-Limiting Illness with Frequent Hospitalization & ER Visits

Adults for whom it would not be a surprise if they died within the next 12 months
“Making Sure Your Voice is Heard”
GRMC – LIFE Care Planning Program – Respecting Choices Model

Stages of Advance Care Planning over the Life Time of Adults

**First Steps ACP**
*Create Power of Attorney for Healthcare*

Consider when a serious neurological injury would change goals of treatment

**Disease-Specific ACP**
*Determine patient goals of treatment if complications of chronic illness result in “bad” outcomes – Statement of Treatment Preferences*

**Last Steps ACP**
*Establish a specific plan of care documented in medical orders using the POLST paradigm*

| Healthy Adults (Ages 55 – 65) | Adults with Chronic, Progressive, Life-Limiting Illness with Frequent Hospitalization & ER Visits | Adults for whom it would not be a surprise if they died within in the next 12 months |
**Physician Orders for Life-Sustaining Treatment (POLST)**

Follow these orders until orders change. These medical orders are based on the patient’s current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.

For more information on Oregon POLST visit: [www.opolst.org](http://www.opolst.org)

### A CARDIOPULMONARY RESUSCITATION (CPR):

- Patient has no pulse and is not breathing.

- [ ] Attempt Resuscitation/CPR
- [ ] Do Not Attempt Resuscitation/DNR

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

### B MEDICAL INTERVENTIONS:

- If patient has pulse and/or is breathing.

- [ ] Comfort Measures Only (Allow Natural Death). Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, 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. Treatment Plan: Maximize comfort through symptom management.

- [ ] Limited Additional Interventions In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: Provide basic medical treatments.

- [ ] Full Treatment In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. **Transfer to hospital and/or intensive care unit if indicated.** Treatment Plan: Full treatment including life support measures in the intensive care unit.

### C ARTIFICIALLY ADMINISTERED NUTRITION:

- Offer food by mouth if feasible.

- [ ] No artificial nutrition by tube.
- [ ] Defined trial period of artificial nutrition by tube.
- [ ] Long-term artificial nutrition by tube.

### D DOCUMENTATION OF DISCUSSION:

- [ ] Patient (Patient has capacity)
- [ ] Parent of minor
- [ ] Court-Appointed Guardian

- [ ] Health Care Representative or legally recognized surrogate
- [ ] Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)
- [ ] Other

**Signature of Patient or Surrogate**

- Signature: ________________
- Name (print): ________________
- Relationship (write "self" if patient): ________________

This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check opt out box

### E SIGNATURE OF PHYSICIAN / NP / PA

My signature below indicates to the best of my knowledge that these orders are consistent with the patient’s current medical condition and preferences.

- Print Signing Physician / NP / PA Name: ________________
- Signer Phone Number: ________________
- Signer License Number: ________________

- [ ] Physician / NP / PA Signature
- Date: ________________

Send Form with Patient Whenever Transferred or Discharged, Submit Copy to Registry

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La Crosse Advance Directive Studies (LADS I & II)

The Prevalence, Availability and Consistency of Advance Directives over a 10-year period following implementation of the Respecting Choices© Advance Care Planning Program
Prevalence, Availability and Consistency of Advance Directives in La Crosse County after Implementation of the Respecting Choices ACP Program

<table>
<thead>
<tr>
<th></th>
<th>LADS I † Data Collected 1995-1996 (n=540)</th>
<th>LADS II ‡ Data Collected 2006-2007 (n = 400)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedents with AD Number (%)</td>
<td>459 (85.0%)</td>
<td>360 (90.0%)</td>
<td>0.023</td>
</tr>
<tr>
<td>AD found in medical record</td>
<td>437 (95.2%)</td>
<td>358 (99.4%)</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Treatment decisions consistent with AD</td>
<td>98%</td>
<td>99.5%</td>
<td>0.13</td>
</tr>
</tbody>
</table>

† Hammes BJ, Rooney BJ. Death and end-of-life planning in on Midwestern Community Arch Intern Med 158: 383-90, 1998
• 67% of decedents had a POLST document
• 98.5% of POLST Forms were in the medical record of the health organization where the person died
• The most recent POLST form was completed on average 4.5 month prior to death
• 96% of decedents (n = 400) had either an AD or POLST form at the time of death

“MAKING SURE YOUR VOICE IS HEARD”
GUADALUPE REGIONAL MEDICAL CENTER
LIFE CARE PLANNING
• In general, there is inadequate training of clinical professionals in discussing end-of-life issues.
• Many clinicians remain uncomfortable and are unprepared for end-of-life discussions. Lack of adequate time and reimbursement are also issues.
• ACP is a process of communication ... of understanding, reflection and discussion (It’s all about the conversation).
• ACP requires that clinicians gain patient-centered communications skills.
### First Steps ACP

**Create Power of Attorney for Healthcare**

Consider when a serious neurological injury would change goals of treatment.

**First Steps Directive to Physicians** *(for healthy adults)*

<table>
<thead>
<tr>
<th>Healthy Adults (Ages 55 – 65)</th>
<th>Adults with Chronic, Progressive, Life-Limiting Illness with Frequent Hospitalization &amp; ER Visits</th>
<th>Adults for whom it would not be a surprise if they died within the next 12 months</th>
</tr>
</thead>
</table>
First Steps ACP Interview Tool  
(Meeting with individual and agent)

**Note to Facilitator:** Information in yellow boxes is for Facilitators only and not intended to be read out loud.

This interview is for individuals who have selected a healthcare agent or is with an individual who may be willing to take this role. The goals of this planning session are to:

1. Review the three decisions for First Steps ACP;
2. Promote understanding of the role of the healthcare agent; and
3. Complete an advance directive as appropriate.

1. **Assess the motivation, knowledge, and beliefs of the individual**

   "Hello. My name is __________. I am an Advance Care Planning Facilitator. I help people and their families learn how to plan for future healthcare decisions. This often takes more time than people expect. I will start with a few questions."

   "Tell me what brings you here today?"

   "You may have received information about advance care planning. Tell me what you understand about this type of planning."

2. **Provide the following information ONLY for clarification on ACP or AD as needed. For example:**

   **Advance Care Planning**

   "Advance care planning is for all adults. It is thinking and talking about future healthcare decisions if you had a sudden event, like a car accident or illness, and could not make your own decisions. A person close to you would need to make choices for you. We call this person a healthcare agent. This conversation will help your agent understand your goals and values. This will help him or her to make decisions for you, if needed."
First Steps Directive to Physicians for healthy adults

This legal, Advance Directive document is designed for you to indicate your wishes should you find yourself receiving intensive care treatment with life-support measures as a result of sudden illness or catastrophic injury. This document provides a mechanism whereby you express your wishes in advance of the crisis. The attending physicians, along with your family, will refer to your wishes documented here, thus allowing you to participate in the decisions made on your behalf. This directive should be based on your personal values; this would include considering what burdens or hardships you would accept to obtain a particular benefit if you were seriously ill or injured. If you develop a chronic, life-limiting illness you may want to complete the Advanced Steps Directive to Physicians. Texas Health and Safety Code chapter 155

Federal law protects these rights of patients: the right to facilitate their own health care decisions, the right to accept or refuse medical treatment, and the right to make an advance health care directive. Federal Patient Self-determination Act of 1990 42 U.S.C. 1395cc (a)

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A

MEDICALLY ASSISTED BREATHING: I have suffered a sudden illness or catastrophic injury and I am receiving life support in an intensive care unit including intubation and mechanical ventilation (breathing machine).

☐ I would accept long-term intubation and mechanical ventilation with the following goals of treatment:

☐ If I have severe or permanent brain injury: If I am not expected to have a meaningful recovery, i.e. I will not be able to know who I am, where I am, or who I am with, then I authorize my MPOA or surrogate to decide to compassionately withdraw medically-assisted breathing measures such as intubation and mechanical ventilation and to focus on symptom control, dignity, and allowing gentle, natural death should it occur.

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B

ARTIFICIALLY ADMINISTERED NUTRITION AND HYDRATION: If I develop difficulty swallowing I will be offered treatment with artificial nutrition and hydration administered intravenously or via a feeding tube.

☐ I would accept artificially-administered nutrition and hydration with the following goals of treatment:

☐ I do not want artificially administered nutrition and hydration; i.e. feeding tube or parenteral nutrition.

---

C

☐ I HAVE A MEDICAL POWER OF ATTORNEY. I have designated a medical power of attorney (healthcare agent) and have/intend to inform that individual(s) of my wishes in the event that I suffer a sudden illness or a catastrophic injury. Refer to my legally completed Medical Power of Attorney document.

MPOA name/phone contact: ___________________ Relationship to patient: ___________________

MPOA Alternate name/phone contact: ___________________ Relationship to patient: ___________________

☐ I HAVE NOT COMPLETED A MEDICAL POWER OF ATTORNEY

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D

☐ I wish to be considered as an organ and/or tissue donor candidate. If you select to be a donor candidate then you are encouraged to register at www.donatelife.netnow.org

☐ I do not wish to be a an organ or tissue donor.

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E

DOCUMENTED CONVERSATION: Note - This form should not be completed without the assistance of a trained facilitator. Refer to Section E on back.

First Steps LCP* Facilitator (Print name/Sign): ___________________ Date: ___________________

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F

I direct that the above selections be applied to my care in each of the appropriate situations as defined above. By signing this directive I revoke all prior directives to physicians. This directive does not revoke any prior medical power of attorney.

Signature: ___________________ Print Name: ___________________ Date: ___________________

Witness #1

Signature: ___________________ Print Name: ___________________ Address: ___________________

Witness #2

Signature: ___________________ Print Name: ___________________ Address: ___________________

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Revision date: 4/6/17
The Continuum of LIFE Care Services at GRMC

Progression of Chronic Illness

Percent Palliative Care Involvement

100% 100%

Home Hospital Nursing Home Home Hospice

Disease-Directed Therapy

Inpatient LIFE Care

Outpatient Palliative Care at Nursing Home

Outpatient Palliative Care (Clinic or Home)

0% 0%

"1st Steps" LIFE Care Planning

Disease-Specific ACP

"Advanced Steps" ACP
(LIFE Care Directive to Physicians)

BEREAVEMENT

DEATH

LIFE Care Planning

"Advanced Steps" ACP
(LIFE Care Directive to Physicians)
First Steps ACP Interview Tool: Adults with Chronic Illness
(Meeting with individual and agent)

Note to Facilitator: Information in blue boxes is for Facilitators only and not intended to be read out loud.

This interview is for individuals with an existing chronic illness who have selected a healthcare agent or is with an individual who may be willing to take this role. The goals of this planning session are to:

1) Promote understanding of the role of the healthcare agent
2) Explore understanding of the individual's medical condition
3) Discuss the three decisions for First Steps planning
4) Complete an advance directive as appropriate

1. Assess the motivation, knowledge, and beliefs of the individual

“Hello. My name is __________, I am an Advance Care Planning Facilitator. I help individuals with chronic illness and their families learn how to plan for future healthcare decisions. This often takes more time than people expect. I will start with a few questions.”

“Tell me what brings you here today?”

“You may have received information about advance care planning. Tell me what you understand about this type of planning.”

2. Provide the following information ONLY for clarification of ACP or AD as needed. For example:

Advance Care Planning

“Advance care planning is for all adults. It is thinking and talking about future healthcare decisions if you had a sudden event, like a car accident or illness, and could not make your own decisions. A person close to you would need to make choices for you. We call this person a healthcare agent. This conversation will help your agent understand your goals and values. This will help him or her to make decisions for you, if needed.”

Advance Directive

“It’s important to write down your goals, values, and preferences. There are many ways to do this. We recommend that you use a document called an advance directive. This allows you to choose a person who can make healthcare decisions for you. This person will only make choices if you cannot make them for yourself.”

“These are new ideas for many people, so I want to make sure I was clear. Can you tell me what you now understand about advance care planning?”

“What fears or concerns, if any, do you have about planning?”

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TEXAS MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST) [TXMOSTCoalition2-26-16]

<table>
<thead>
<tr>
<th>First Name:</th>
<th>Last Name:</th>
<th>Follow this MOST and patient preferences first, then contact a physician. Any section not completed implies full treatment for that section and does not invalidate the form. Send this MOST with the patient for all transfers between treatment sites. Comfort care and dignity will be provided to all patients.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>Date Form Prepared:</td>
<td></td>
</tr>
</tbody>
</table>

A

PHYSICIAN RESUSCITATION ORDER: If patient does not have a pulse and is not breathing:

- [ ] Attempt Resuscitation (CPR) Place tube in the windpipe, electrical shocks to the chest, chest compression, and IV tubes for fluids/medications.
- [ ] Do Not Attempt Resuscitation/Allow Natural death (DNAR/AND) Provide physical comfort, emotional, and respectful spiritual support to patient and family. [ ] Out-Of-Hospital-Do-Not-Resuscitate Form completed

If patient is not in cardiopulmonary arrest, follow orders found in Sections B and C.

B

MEDICAL INTERVENTION SCOPE: If patient is unstable, has pulse and is breathing:

- [ ] FULL INTERVENTIONS: Transfer to a hospital, and if necessary to ICU. Use comfort and selective measures, and may add medically appropriate ICU interventions like, but not limited to, intubation/ventilator support, ICU-only medications, and dialysis.
- [ ] SELECTIVE INTERVENTIONS: If necessary, transfer to a hospital. In addition to comfort measures, may add interventions like intravenous antibiotics, non-invasive breathing support (BiPAP/CPAP), and fluid resuscitation.
- [ ] COMFORT INTERVENTIONS ONLY: Avoid hospitalization unless needed to provide comfort care. Focus on symptom control, dignity, and allowing gentle, natural death should it occur. Use comfort interventions like oral, subcutaneous, or intravenous medications (e.g., opioids), comfort foods/liquids, oxygen, and emotional/spiritual support.

ADDITIONAL ORDERS:

C

MEDICALLY ASSISTED NUTRITION/HYDRATION

Offer nutrition and hydration by mouth at all intervention levels if feasible.

- [ ] No medically assisted nutrition.
- [ ] Unless medically contra-indicated*, defined trial of medically assisted nutrition.

Length of trial ____________ Goal ________________

- [ ] Long-term medically assisted nutrition.

*In some circumstances including, but not limited to, heart, lung, liver or kidney failure, assisted nutrition or hydration may increase suffering or hasten death, and is therefore medically contra-indicated.

DOCUMENTATION OF DISCUSSION AND SIGNATURES:

<table>
<thead>
<tr>
<th>Discussed with:</th>
<th>Rationale for these orders:</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] Patient (Patient has capacity)</td>
<td>(Choose all that apply)</td>
</tr>
<tr>
<td>[ ] Health Care Agent or Decision Maker:</td>
<td>[ ] Living Will (Directive to Physicians and Family or Surrogates)</td>
</tr>
<tr>
<td>[ ] Court Appointed Guardian</td>
<td>[ ] Medical Power of Attorney</td>
</tr>
<tr>
<td>[ ] Others in Attendance:</td>
<td>[ ] Other:</td>
</tr>
</tbody>
</table>

Relationship, Name

<table>
<thead>
<tr>
<th>Physician Signature: My signature certifies both the order and preferences above and the basis for them.</th>
</tr>
</thead>
</table>

Physician Signature: Print Physician Name: Date: Phone Number: 

<table>
<thead>
<tr>
<th>Patient or Patient's Surrogate Signature:</th>
</tr>
</thead>
</table>

Patient or Surrogate Signature: Print Patient or Surrogate's Name, if signing: Date: Phone Number: 

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCARDED

Organization or Facility Identifier:
Is Legislation Really Imperative to Implement a POLST Paradigm?

- Texas Statutes regarding Advance Directive documents don’t specify use of any particular Living Will or Directive to Physicians document.

- A person’s living will can be written on a napkin as long as it meets legal requirement for two witnesses or notarization.

- Nothing in the Texas Advance Directive Statutes prevents implementation of a Directive to Physicians which incorporates all the elements of a MOST / POLST including physician (PCP) attestation that the patient’s chosen preferences for life-sustaining treatment are appropriate given the patient’s clinical situation.
Key Features of the LIFE Care Directive to Physicians

• **Goal-Defined Time-Limited Trial for medically-assisted breathing**
  - BiPAP (yes / no; goal of treatment)
  - Mechanical Ventilation (yes / no; goal of treatment)

• **Goal-Defined Time-Limited Trial for Medically-Assisted Nutrition (feeding tubes, artificial nutrition)**
  - No medically-assisted nutrition
  - *Short-term trial* of medically-assisted nutrition during rehabilitation stay (for example 21 days)
  - *Long-term* medically-assisted nutrition
  - *Escape Clause* (I, or if I am incapacitated, my MPOA or surrogate, may decide to stop medically-assisted nutrition if my condition changes such that the burdens of treatment outweigh the benefits and it is no longer in my best interests)
Key Elements of the LIFE Care Directive to Physicians

• Empowers patient choice for individuals with life-limiting illness
  - DNR ( Allow Natural Death) – yes / no
  - Goal-Defined Time-Limited Trials
    • Medically-assisted breathing
    • Medically-assisted nutrition (short-term, long-term, use of the “Escape Clause”)

• Unlike the MOST – POLST, it is not a physicians order, but it only becomes effective following a Physician Endorsement by the patient’s PCP which serves to acknowledge the patient’s preferences for life-sustaining treatments and certify that the patient’s condition is such that it is appropriate for these treatment preferences to be honored effective immediately.
Advanced Steps Directive to Physicians for persons with a life-limiting chronic illness and/or advanced age.

This is a legal document known as an Advance Directive. It is designed to help you communicate your wishes about medical treatment at a time in the future when you may be unable to make your wishes known because of illness or injury. These wishes are usually based on personal values. In particular, you may want to consider what burdens or hardships of treatment you would be willing to accept for a particular amount of benefit obtained if you were seriously ill. Texas Health and Safety Code 166.032 (c), 166.033, 166.036, 166.039, 166.046, 166.088

Name: ___________________________  Phone: ___________________________  Date of Birth: ___________________________

Address: ___________________________  City: ___________________________  State: ___________________________  Zip: ___________________________

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A  CARDIOPULMONARY (CPR) RESUSCITATION: I have no pulse and am not breathing.

☐ Attempt Resuscitation (FULL) Tube in the windpipe, electrical shocks to the chest, chest compression, and IV tubes for fluids/medications.

☐ Do Not Resuscitate (DNR) Allow Natural Death (AND) Health care professionals should remember that a DNR order does not necessarily mean that the patient has automatically chosen to forgo the treatments outlined in sections B, C, & D once they arrive at the hospital or emergency department.

☐ Out of Hospital DNR completed

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B  MEDICALLY ASSISTED BREATHING: I have a pulse but am having difficulty breathing, or I am not breathing.

☐ Intubation and mechanical ventilation

Length of trial: ________  Goal: ________

☐ Noninvasive ventilation (e.g. BiPAP®)

Length of trial: ________  Goal: ________

☐ No medically-assisted breathing (DNI)*

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C  MEDICAL INTERVENTION SCOPE: I have a pulse and I am breathing but my medical condition is worsening.

Use appropriate interventions for the scope of treatment preferences noted below. If this section is not completed, then provide full interventions.

☐ FULL INTERVENTIONS: Transfer to a hospital and, if necessary, to ICU*. Use comfort and intermediate measures, and may add medically appropriate ICU* interventions such as, but not limited to, intubation/ventilator support, ICU* only medications, and dialysis.

☐ INTERMEDIATE INTERVENTIONS: If necessary, transfer to a hospital. In addition to comfort measures, may add selected interventions such as non-invasive breathing support (BiPAP/CPAP®) (see section B), fluid resuscitation, antibiotics, and blood transfusions. Generally avoid transfer to ICU*

☐ COMFORT INTERVENTIONS ONLY: Avoid hospitalization unless needed to provide comfort care. Focus on symptom control, dignity, and allowing gentle, natural death should it occur. Comfort interventions include oral, subcutaneous, or intravenous medications (e.g., opioids), tube feeding and oxygen. Always provide emotional and respectful spiritual support for patient and family.

Additional orders: ___________________________

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D  ARTIFICIALLY ADMINISTERED NUTRITION AND HYDRATION: I am unable to take nutrition or hydration by mouth.

Offer nutrition and hydration by mouth at all intervention levels, if feasible.

☐ Long-term artificially administered nutrition and hydration.

☐ Defined trial of artificially administered nutrition and hydration. Unless medically contraindicated. In some circumstances, including but not limited to heart, lung, liver, or kidney failure, assisted nutrition or hydration may increase suffering and hasten death.

Length of trial: ________  Goal: ________

☐ (initially) ________  (if I am incapacitated my MPOA* or surrogate may decide to stop artificially administered nutrition and hydration if my condition changes such that the burden of treatment outweighs the benefits, and it is no longer in my best interest. HSC §166.046

☐ No artificially administered nutrition and hydration: i.e. feeding tube or parenteral nutrition

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E  DOCUMENTED CONVERSATION: Note - This form should not be completed without the assistance of a trained facilitator. Refer to Section E on back.

☐ Direct conversation with person who has decision-making capacity. HSC §166.039

☐ Direct conversation with Health Care agent (legally-appointed by MPOA* form or court appointment). Attending physician’s statement required.

☐ Direct conversation with Legal Nurse of Kin/surrogate decision-maker for incapacitated patient. Attending physician’s statement required.

☐ Additional attachments completed.

MPOA*surrogate name/phone contact: ___________________________  Relationship to patient: ___________________________

Facilitator (Print Name/Sign): ___________________________  Date: ___________________________

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F  Witness #1

Signature: ___________________________  Print Name: ___________________________  Date: ___________________________

Address: ___________________________

Witness #2

Signature: ___________________________  Print Name: ___________________________  Date: ___________________________

Address: ___________________________

Notary Public State of Texas

State of Texas, County of ___________________________

This instrument was acknowledged before me on ___________________________  (Notary’s signature)

Notary’s Printed Name: ___________________________  My commission expires: ___________________________

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G  Physician’s Statement:

I am the primary care and/or attending physician for ___________________________  and, in my opinion, the patient’s expressed treatment preferences are appropriate to the clinical condition. I recommend that health care professionals acting in the outpatient setting or in the hospital honor the patient’s stated treatment preferences.

Physician’s Signature: ___________________________  Date: ___________________________

Physician’s Printed Name: ___________________________  License #: ___________________________

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Revision date: 2/14/17
**Review Prognosis**  In the setting of a life-threatening chronic disease or terminal illness, the patient and family often want to understand prognosis. Thus, it is important to clarify the likely course of the patient’s illness and prognosis before a meaningful decision can be made regarding code status. Unfortunately, many providers may avoid giving “bad news”.

**ACP CPR Discussion – Key Points**  Cardiopulmonary Resuscitation is an aggressive medical intervention and needs to be discussed as such. But rather than emphasizing the physically violent nature of the procedure (the “You don’t want us to break all your ribs do you?” approach), it is better to educate the patient and family about the odds of survival and return to health after CPR.
Medically-Assisted Breathing

- BiPAP – often used as a comfort measure
- Intubation and Mechanical Ventilation
  - An option for treating patients with pneumonia or congestive heart failure with acute respiratory failure
  - Patients may opt for a time-limited trial of intubation and mechanical ventilation even though they wish not to receive cardiopulmonary resuscitation (CPR) in the event of cardiac arrest
Artificially-administered nutrition and hydration must be provided unless, based on reasonable medical judgement, providing artificially-administered nutrition and hydration would:

1. Hasten the patient’s death

2. Be medically contraindicated such that provision of the treatment seriously exacerbates life-threatening medical problems not outweighed by the benefit of the provision of the treatment
Artificially-administered nutrition and hydration must be provided unless, based on reasonable medical judgement, providing artificially-administered nutrition and hydration would:

3. Result in substantial irremediable physical pain not outweighed by the benefit of the provision of the treatment.

4. Be medically ineffective in prolonging life

OR
Artificially-administered nutrition and hydration must be provided unless, based on reasonable medical judgement, providing artificially-administered nutrition and hydration would:

5. Be contrary to the patient’s or surrogate’s clearly documented desire not to receive artificially administered nutrition and hydration

In Other Words:
The Advanced Steps Directive to Physicians facilitated discussion focusing on Section D (Medically-Assisted Nutrition) is Critically Important
MEDICAL RED JACKET

This jacket should accompany you when seeking medical treatment.
Contents of Medical Red Jacket

ITEMS INCLUDED IN THIS JACKET: (Please Check all Included)

- Living Will
- Medical Power of Attorney
- Out of Hospital DNR
- MOST - Medical Order for Scope of Treatment
- Problem List
- Medication List
Vital Role of LIFE Care Directive to Physicians

- Patients with decompensated cirrhosis awaiting liver transplantation
- Patients with stage 4 cancer receiving disease-directed therapy (XRT or chemotherapy)
- Patients with end-stage renal disease on maintenance dialysis
- Nursing home patients with advancing dementia
Advance Care Planning is a Means to a Better End

• “...one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with the patient’s and families’ wishes, and reasonably consistent with clinical, cultural, and ethical standards.”

Making Sure Your Voice is Heard
GRMC LIFE Care Planning
Moving End-of-Life Care Decisions from the ICU to the Kitchen Table where they Belong

‡ Institute of Medicine’s definition of “A Good Death”
First Steps ACP Interview Tool: Adults with Chronic Illness
(Meeting with individual and agent)

Note to Facilitator: Information in blue boxes is for Facilitators only and not intended to be read out loud.

This interview is for individuals with an existing chronic illness who have selected a healthcare agent or is with an individual who may be willing to take this role. The goals of this planning session are to:

1) Promote understanding of the role of the healthcare agent
2) Explore understanding of the individual’s medical condition
3) Discuss the three decisions for First Steps planning
4) Complete an advance directive as appropriate

1. Assess the motivation, knowledge, and beliefs of the individual

   “Hello. My name is _____________. I am an Advance Care Planning Facilitator. I help individuals with chronic illness and their families learn how to plan for future healthcare decisions. This often takes more time than people expect. I will start with a few questions.”

   “Tell me what brings you here today?”

   “You may have received information about advance care planning. Tell me what you understand about this type of planning.”

2. Provide the following information ONLY for clarification of ACP or AD as needed. For example:

   **Advance Care Planning**
   
   “Advance care planning is for all adults. It is thinking and talking about future healthcare decisions if you had a sudden event, like a car accident or illness, and could not make your own decisions. A person close to you would need to make choices for you. We call this person a healthcare agent. This conversation will help your agent understand your goals and values. This will help him or her to make decisions for you, if needed.”

   **Advance Directive**

   “It’s important to write down your goals, values, and preferences. There are many ways to do this. We recommend that you use a document called an advance directive. This allows you to choose a person who can make healthcare decisions for you. This person will only make choices if you cannot make them for yourself.”

   “These are new ideas for many people, so I want to make sure I was clear. Can you tell me what you now understand about advance care planning?”

   “What fears or concerns, if any, do you have about planning?”

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